



Exeter Parent Carers' Voice
Notes from the meeting held on Tuesday 1st July 2008 – Cowick Barton, Exeter

Present:

3 parents

Nicky Ruane Development Worker

Apologies:

Apologies were received from 2 parents

1. Welcome, introductions and apologies for absence

Margaret welcomed everyone to the meeting.

2. Exeter Forum – plans for the future

Margaret began by explaining where the forum is now and what the difficulties are in attending meetings. Many parents and carers work and many more are involved with other groups and have limited time to participate.

Evening meetings were discussed, but there is still not sufficient support for this idea to make it viable.

There followed a discussion around how to promote the forum. Currently dates are advertised in the DISCplus newsletter and through the generic forums. The Children's Centres have in the past had details of meetings, but as a rule Children with identified needs tend to be directed to Honeylands which has its own support group for families. Links have been made to this group, but parents from it tend not to attend meetings although several sign up to receive information. It was agreed to start to circulate the meeting details to SENCOs in Exeter schools in the autumn

The group discussed the possibility of doing an article about PCV for the Express and Echo.

They also discussed the possibility of a coffee morning as a way in for new parents as it was still felt that new parents can find it off-putting to come to formal meetings. It was asked why the air and share meetings had ceased. Nicky explained that support for them had dwindled and so they had been abandoned. Many parents move on from the forums into employment, training, and other things. This was felt to be a success, and it needs to be recognised that the forums will be continually changing and that the parents attending will come and go. Once their initial problems have been sorted they tend to move on to training and then look towards work opportunities, and then will only come back to the forum if they encounter further difficulties.

Speakers for future meetings

Ideas were discussed for inviting speakers to attend the meeting and talk to parents. Some of the ideas put forward were:

- Sexual Health and keeping safe with specific sessions for both girls and boys
- Mental Capacity Act and the issues around consent
- Parenting beyond the grave - wills and trusts
- Annual reviews
- Members of the Joint Agency Service to explain what their role is
- Post 16 provision – Connexions
- Leisure provision for teenagers with special needs in school holidays

It was agreed that Nicky would arrange for speakers from the suggestions and list would be reviewed to meet families needs/requests.

Changing Places Toilets

Asda had agreed to pilot the Changing Places Toilets in their stores but have now said that they will not be doing so as there is no demand. It was questioned who was consulted as it was felt that the people for whom it would be beneficial had not been consulted.

It was suggested that families who felt strongly about this could email the CEO of the company to challenge this decision.

Play Park

Money is rolling in. Miriam hopes the initial build will commence in September. Details of the project can be found at www.theplaypark.co.uk

Miriam discussed the plans for the park, including the signing which will allow it to be fully accessible by all. There are currently some areas in which she is still in negotiation with the City Council. One is over the need for a changing places toilet that is suitable for changing adults/teenagers, and the other problem is over the funding of a pathway from the car park and designated parking spaces for wheelchairs. It is hoped that these matters will be resolved at a site meeting later in the month.

Nicky agreed to contact Ian Cowe to stress the importance of resolving these matters from the point of view of parents in the Exeter area.

It is hoped that it will be opened by December.

3. Conversation Days

There have now been two rounds of events for parents/carers looking at services for children with additional needs in Devon. The next event for the Exeter area will be taking place on Tuesday 23rd September at the Gypsy Hill Hotel from 10.00 – 2.00. Lunch will be provided. Parents will be invited to give their opinions about children's services and hear plans for the future.

Some of the subjects that will be covered include:

- Where we are with the Carers breaks programme
- Education! Education! Education! What's news?

- . Transport and leisure activities – what do we know? What can we do better?

A final agenda will be sent out to all those who express an interest in attending nearer the time.

If you would like to book a place, or any more information on this event please call Beryl Perrin or Phillipa Braund on 01392 382047 or email beryl.perrin@devon.co.uk

4. Any Other Business and locality issues to take forward to the County Forum

Inclusion in schools

When staff shortages happen disabled children often seem to be the first to suffer. Concern has been raised by one family that where their child should have regular small group sessions in school with a specially trained teacher this always seems to be the first thing to be cut when other staff are away through sickness or other reasons.

It was felt that families needed to be reasonable about situations. Where it occurs without warning and is for a short period of time there may be little the school can do due to the specialist nature of the provision. If the school know about the situation in advance and it is likely to last for some time, such as long term sickness or maternity leave, then steps should be taken to ensure the needs of that particular group of children are met. If families experience problems they should initially take it up with the SENCo or the Head Teacher to resolve the matter.

Transition protocol – who funds work experience placements for children with high level needs?

When they go on work placement who is responsible for that child? One parent had to fund a carer to go with her son on work placement because school did not have sufficient staff to release on to accompany the child. Using their Direct Payments they have to pay someone to accompany him rather than the school supplying him. Who is liable? What is the situation for young people with additional needs in mainstream schools?

Date of next meeting: **Tuesday 16th September**
Speaker: **Clare Cox on the Mental Capacity Act**

* * * * *

Nicky Ruane,
Parent Carers' Voice, Exeter CVS, King William Street, Exeter, EX4 6PD

Telephone: 01392 201572
nicky.ruane@exetercvs.org.uk