

## April 4<sup>th</sup> 2012– ‘Involving Children in research’ working group.

This was the first meeting held by PenCRU to discuss and brain storm how we can go about setting up a ‘Children’s Faculty’. This is something that we have been thinking about since the unit was first established in 2008. We carry out research about children and would like to give them the opportunity to have a voice in what we research, and how we design and carry out our projects. We have been concentrating on establishing our Family Faculty and how we work with them; we have an established group of 200 members and have built up good working relations. This has put us in a good and trusted position to meet the challenge of setting up a ‘Children’s Faculty’ which we hope will work in a similar way. Inevitably there are some challenges to be faced and we decided it would be best to ask our Family Faculty members if they could help us think about how we could go about setting up this group. The Family Faculty and their children (with additional needs and siblings) were invited, along with relevant professionals and members of the research team.

There were 20 people in attendance; nine of these were children of mixed age (6-15) and mixed abilities. The families who attended were members of the PenCRU Family Faculty. There were three members of the PenCRU team. No other professionals were able to attend although did express an interest in the group.

We had an informal welcome with drinks and snacks to start.

We started the meeting with an ‘icebreaker’; everyone introduced themselves and the animal they would most like to be. We then gave a brief introduction about PenCRU; although the parents were aware of our work we thought it was important to give the children an idea about what we do.

An introduction of the purpose of the meeting followed – a ‘Children’s Faculty’, to involve children in the work we do. We had written on the whiteboard the main objectives of the meeting in a What, Why, How format. We used these three headings as points for discussion, we wrote down the main points of issues raised and comments on a flip chart; please see notes below.

What is a Children’s faculty?

Why have a Children’s Faculty?

How to go about setting one up?

There was plenty of discussion from parents and children although for some it was hard to participate in this part of the meeting. This was due to a lack of expertise within the PenCRU team in regards to communication with children with very complex communication difficulties. This is something we need to address and think about when we have future meetings.

We were concerned that the children did not get much opportunity to speak as their parents/carers were understandably more confident; however we felt that for this first meeting it was necessary for the parents to be there so the children could get to know us.

**Action:** One parent mention Dame Hannah Rogers’s speech and language department offer training, we will look into this and other possibilities.

The discussion was quite lengthy and some of the children were getting restless so we switched tasks and asked the group to design a leaflet that we will use to give out to new members. This proved to be very popular and we had some excellent designs. We will use these design ideas to produce two different leaflets for different abilities. It was

suggested that we need to use symbols such as Maketon, PECS etc in any leaflet designed for children with additional needs. We have copied these designs and returned the originals to the children.

**Action:** we need to look into whether it is necessary to purchase software for one of these communication aids and discuss which one would be the most widely understood. Possibly have a doodle vote with group or Family faculty and go with one most used?

We had lunch, possibly it would have been best to book a different room so people could break out.

After lunch we discussed some of the challenges and practicalities, who and how to recruit new members, the best way to keep children informed; see notes for more detail.

We discussed the idea of holding a competition to name this group and design a logo; this seemed to be well received. We discussed meeting again in the summer holidays, for this meeting we hope to have some help from members in planning. We would also like to encourage children to attend without their parents, although of course would leave this to each individual family's discretion.

We asked each family to complete a feedback form about the meeting,

We asked:

- Was this type of meeting useful
- Was the info presented easy/hard to understand
- Length of meeting too long/short
- Could you play active part in the discussion yes/no
- Were activities easy/hard
- Suggestions for future meetings
- Any other comments

Below are the comments that were made:

*'perhaps a 'arty' decision task for kids that makes them talk or express in art; music in background for lunch'*

*'more arty things. Well done'*

*'possibly use the facilities of school (sensory room/playground) to intersperse activities that very disabled children can do with the main objectives of the meeting'*

*'perhaps some games or we could go for a walk and talk about what we do. Very good'*

*'more games for kids to get involved in more'*

*Small group discussions; sensory area; games; pictures/symbols on agenda. Go somewhere else for lunch'*

*'Worthwhile and useful'*

*'the presentation was great and clear to understand'*

There were also two comments that the meeting should have been two hours instead of three

Each child received a £10 amazon voucher as an acknowledgement of their time and the parents' travel/childcare expenses were paid and parents were also acknowledged for their time as per the usual PenCRU policy. The cost of

holding this meeting totalled £426.15 (refreshments £105; childcare/travel expense £146.15; acknowledgement of parents time £100; children vouchers £90). We need to bear in mind the time and the costs for setting up this group.

This was a great start to setting up a Children's Faculty' and we have much work to do. We were prepared for a 'messy' meeting; however you need to start from somewhere.

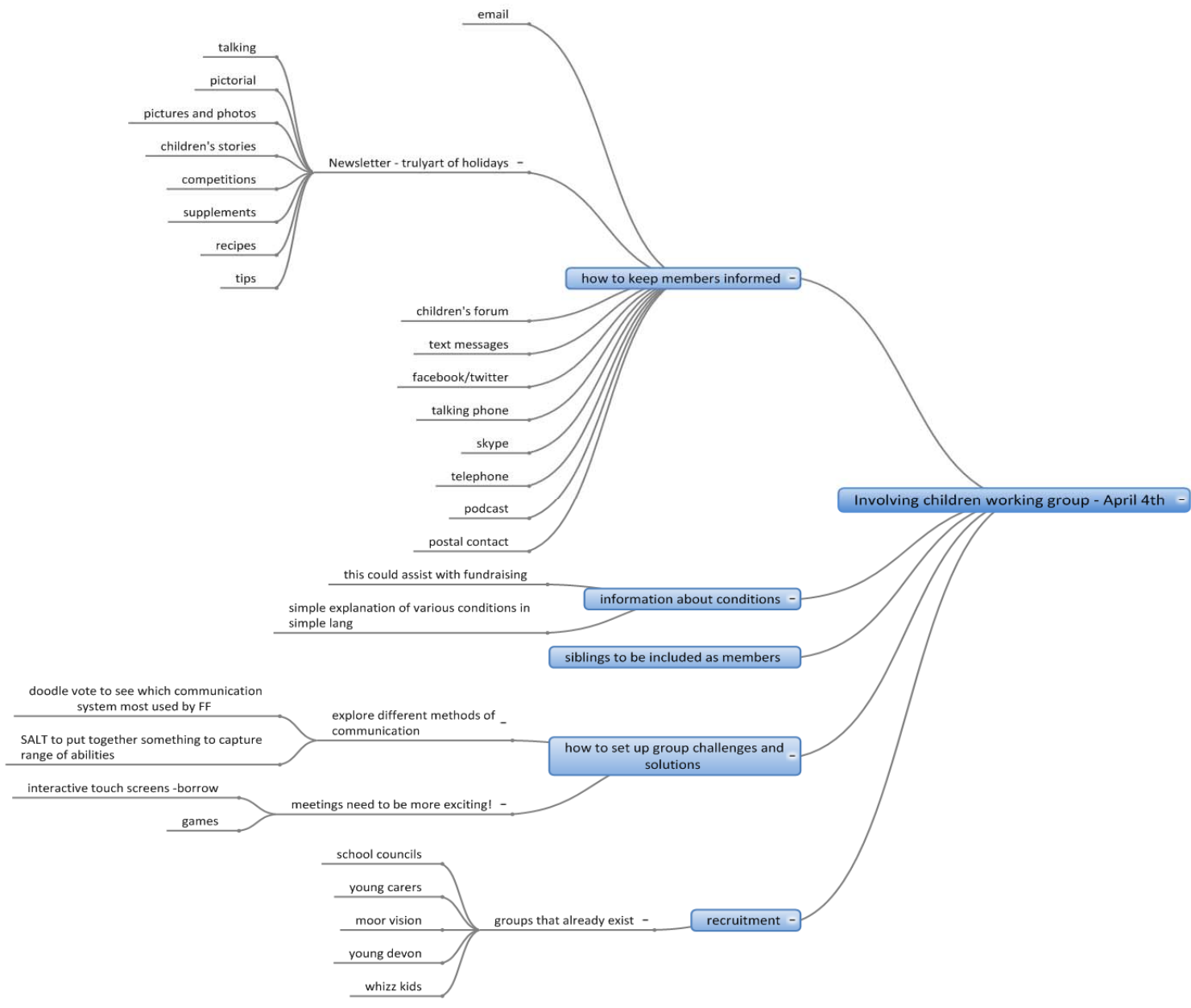
### **Actions:**

- Send an email to the Family Faculty to feedback about this meeting; tell them in general way what/how the Children's Faculty will work and invite them to tell their children and encourage them to sign up! Also announce the competition for naming the group and designing their logo.
- We were sent a link by one of the parents attending to a software package for creating 'accessible' newsletters: <http://www.news-2-you.co.uk> this was interesting and we need to explore if there are other packages out there and decide if this is something we need to look into purchasing.
- Take the designs for the leaflets the children did and design two leaflets for different abilities
- Think/plan for first meeting in August launching group; ask current members if they would like to get involved in the planning

### **Lessons learned and thoughts for next meeting**

- More activities and games – we need to spend some time thinking of games that can be used productively
- Less or shortened blocks of talking
- We need to ensure that children get a chance to input their ideas at meetings, whether this is achieved by encouraging them to attend without their parents or by being more mindful of giving them opportunities to talk
- We need to think about some training for the PenCRU team to build confidence in different methods of communication
- Moving location within the meeting, i.e. somewhere separate for lunch, having some or all of the meeting outside

# Notes from meeting



## email sent to children who attended:

Hello,

Thank you so much for coming to our meeting last week to help us think about how to create a 'Children's Faculty', we really enjoyed meeting you and hearing what you had to say.

### The meeting

The main points that we talked about were:



- **What** is a 'Children's Faculty'
- **Why** we would like to set up a 'Children's Faculty'
- **How** shall we set up a 'Children's Faculty'

We will write up all your comments and send them to you in the next couple of weeks; please tell us if we have got it right or not!

### The Leaflets

We are thrilled with your leaflet designs, they are brilliant! We will send them back to you very soon. We will take your ideas and use them to help us design two different leaflets for different abilities.



### The Competition

We also talked about having a competition to find a name and design a logo for the 'Children's Faculty'; we would like to offer this to all the children of our Family Faculty.

### PenCRU Children's group

Thank you for signing up to be the first, founding members of the group. We would like to meet you all again and hope we can have a meeting in the summer holidays. We would love it if you would help us plan and run this meeting, let us know if you would like to help.

We are really excited about working with you; please get in touch with us if you have any questions.