



**Notes of the meeting held Wednesday 25<sup>th</sup> November  
At the Fisherman's Cot, Bickleigh**

Present: 7 parents, Debbie Wheeler (Parent Partnership Service), Eleanor Scott-Wilson (IPS, Parent Partnership Service), Hil Rundle (Further Response Manager, Eastern), Steve West (Further Response Manager, Eastern), Nicky Ruane (Development Worker, Parent Carers' Voice)

Apologies: Apologies were received from 2 parents

**1. Welcome, introductions and apologies**

John welcomed everyone to the meeting as Chair and then everyone introduced themselves.

**2. Boobs and Black Tights – Miriam Guard**

After introducing herself Miriam began by explaining that all young people have difficulties at puberty; add to that a learning disability, autism or other difficulty and the problems are compounded. Her experiences have shown her that although not all of these young people are on the autistic spectrum most of the strategies used for those on the spectrum would work for most if not all young people. This was because the strategies employed break things down to the very basics.

When dealing with any challenging or difficult behaviours she felt that it was important to follow the four Cs – Communicate, be Clear, remain Calm and be Consistent.

Communication

This is crucial, especially during the teenage years.

Her son only understands sexual development from his (male) point of view as she felt, because he couldn't understand the concept of relationships, it would be dangerous for him to know that women are involved.

She then explained that he also has no concept of the stages or process of growing up. Although he could recognise photos of himself when he was a small child he cannot relate this to other people and has no idea that a small child will grow into an adult and not remain a child forever. We tend to make assumptions about a young persons level of understanding and in many instances we may assume that they understand more than they do.

There followed a discussion about how some people find it more difficult to discuss things, especially topics such as sex and puberty, but how essential that was.

Be Clear

Miriam stressed the importance of being clear in what you were saying. Remember that many young people may have difficulty in processing the information that is

given to them. Instructions need to be short and clear, and not too many given at the same time. Give time for the young person to process each instruction before moving on to the next.

### Stay Calm

Not always easy, especially in times of high stress, but losing control and shouting or screaming back will rarely resolve the problem. Miriam suggested that whenever possible you should try to add some humour to lighten the situation rather than getting angry.

### Be Consistent

If you make a rule, stick to it!

When setting rules it is important to think about whether the rule will transfer to different situations. What is acceptable in your bathroom at home may not be acceptable in the toilets at school or in someone else's bathroom.

### Other points to think about

If the young person has 'lost the plot' the best thing to do is to back off until they have calmed down.

During puberty problems tend to be around sex and aggression. We need to remember that children with additional needs tend to miss out on the information that they would traditionally have learnt from their peers 'behind the bike shed', so we must make certain that they have been given the information they need.

There followed discussions about problems that parents had encountered, how to help girls and the need for young people to understand about private places and how to keep young people safe.

For those with limited communication Widgit symbols are available for everything.

There then followed a question and answer session and Miriam left suggestions for some books that parents might find useful.

Useful reading:

Making Sense of Sex by Sarah Attwood

The Challenging Behaviour Foundation has various resources

[www.thecbf.org.uk](http://www.thecbf.org.uk)

Jessica Kingsley publishers have a catalogue that contains information on many books that may be of help. Their online catalogue can be viewed at:

<http://www.jkp.com/catalogue/>

## **3. Other information/ updates**

### Direct payments

New guidance has been issued for those families who use direct payments with strict time limits for the submission of tracker forms. Nicky stressed the importance of families ensuring that they completed their returns promptly and that if they were having any difficulty in doing so that they ask for help. Tracker forms are now to be sent to County Hall rather than to the Direct Payment worker.

### Future information days

Nicky said that they were looking at what parents might feel would be useful as training or as a future information day and asked parents for suggestions.

It was suggested that a day looking at some of the less well understood conditions such as dyslexia and dyspraxia might be popular, along with information about visualised learning.

Exclusions was another suggestion as there still seem to be issues in some schools some parents are still unaware of the rules around excluding a child with additional needs.

This led on to a discussion around issues in school with Debbie answering questions from parents.

### Integrated Children's Services update

Steve West and Hil Rundle updated the meeting as to the recent changes within Children's Services.

They are co-managing Exeter, East and Mid Devon to ensure an equality of service across the area. Parents will be informed of any changes that might impact upon them.

When asked about CAMHS Steve said that unfortunately CAPA (Choice and Partnership Approach) has been suspended due to the enormous increase in referrals and budgetary restraints.

Learning Disability nursing assessment clinics are up and running. Previously young people needing and assessment would sit on a list until they could be offered an appointment but now they are being offered a clinic appointment and this is helping to reduce the wait time.

Parents who feel that an LD intervention might be helpful for matters such as complex behaviours, sleep, continence, diet, puberty etc can write to:

Anne Marie Skinner,  
Single Agency Referrals,  
One Capital Court,  
Unit 1a Bittern Rd,  
Sowton Industrial Estate,  
Exeter  
EX2 7FW

The referral will then be passed on to the team and if it is felt appropriate the parent will be contacted about an appointment.

## **4. AOB**

There being no other business John thanked everyone for attending.