

Notes from SEND Workshop

25th March, 10:30am – 12pm

Carers Trust, St Ives

Attendees

Parents: 6

Professionals: Jane Ryder-Richardson, Teresa Grady

Facilitators: Lenja Bell and Jane Ryder-Richardson

Background

The aim of the workshop was capture the views of parents to shape what services Cambridgeshire County Council will plan for, how and where they should be delivered and what outcomes are wanted. The County Council wants to understand what is most important to parents at home, in their community, and from health and education settings.

Parents were asked to look at four stages along a journey:

- Early concerns – when you first realised something was not right about your child's development or you knew your child had a difficulty
- Assessment or diagnosis
- When support was provided for you or your child
- What do you (or might you) want for the future?

We looked at what was *Not Helpful* and *Helpful*.

Parent Feedback

Parent feedback was captured on a sticky wall as written below.

Early Concerns

Not Helpful:

- Ostracised by other parents
- Services not integrated e.g. paediatrician and physio
- Schools vary – support vs. no support

Helpful:

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- At school, supportive Head and SENCo, pro-active and hands on, fantastic inclusion worker who introduced me to a parent support group
- Heard via family member about Contact-a-Family who introduced me to another parent who advised me to start getting a statement for my daughter

Key Elements:

- Need better communication between professionals, and between professionals and parents
- Need more support – a designated person
- Need contact with someone in a similar situation

Assessment or Diagnosis

Not Helpful:

- Excluded from infant unit when son was under 5, no interest in helping since he was under 5
- No package of support (a few years ago), *would be Early Support now*
- Feel alone, need someone to listen, never had commitment from somebody
- Schools required 'autism' diagnosis, a paperwork exercise
- Never felt believed by school, different behaviour at school than at home (very difficult at home)
- Label e.g. diagnosis too important, parent description is important
- Health put negative limits on what could be achieved
- Had to go for a statement without support of school

Helpful: nothing listed

Key Elements: nothing listed

Support Provided

Not Helpful:

- After meeting with professionals to discuss support, overheard being called a 'drama queen', felt like I was battling all alone
- Need groups for cognitive-able children

Helpful:

- Great midwife re: speech concerns
- Local support group e.g. Welcome 2 Our World
- Disabilities Nurse and Aspergers Team involvement
- Early Bird Course – met parents, brought together husband and wife

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- Croft for family therapy

Key Elements: none listed

Future Needs

- Want child to be happy, to have experiences in life that she enjoys, need to be proactive to achieve this
- Need someone with interest and passion to help / support
- Need a teen version of Early Birds
- Social workers don't know always know about benefits, etc.
- Feel we've dropped through the net

Key Elements:

- None listed

General

- Need more inclusive attitude
- Need more creative approach
- Need culture change / change in attitude
- Never know what a child can achieve, no limits
- If child excluded from school, shouldn't get letter restricting their time outside of the home
- Joined pot of money for children (health, education and social care)
- Institutions look after themselves
- Idea – use Facebook as an active resource between parents and professionals
- Idea – broker parents to support each other

Key Elements:

- Contact with someone in similar situation e.g. coffee mornings
- Access to courses
- Holistic approach to family, including siblings