

Notes and views from Autism Workshop

30th April, 10:30am – 12pm

Bar Hill Tesco Community Room, Bar Hill, Cambridge

Attendees

Parents: 14

Professionals: Jane Ryder-Richardson, Teresa Grady

Facilitators: Jackie King, Lenja Bell, Jane Ryder-Richardson, Teresa Grady

Overview

Workshop Objective: What makes good autism provision and support for your child?

The aim of the workshop was capture the views of parents of children and young people with Autism 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 has helped parents the most:

- at home
- in their community,
- with life skills
- in school

Parents were asked to look at the four different areas above in groups. They discussed and listed what was *Needed* and what was *Working*.

Parent Feedback

Parent feedback was captured on flipchart paper and cards posted on the sticky wall as written below:

Home

Needed:

- Good information ASAP much earlier on (*this was mentioned several times*) – need more than a few books/leaflets from Paediatrician and then being sent away. Need a comprehensive information pack on: Education, Health, Social Care, SCIP, Benefits
- A buddy scheme.
- Uncomplicated and simplified forms (*this was mentioned several times*) to access: support, benefits, carer funding etc....
- More expert signposting – wanted more information to understand about behaviour.

- More knowledge.
- More choice for family and child – need to be creative and responsive to family needs.
- Information needs to be available for young carers and young parents support groups need to be easily available.
- Aspire Programme – Romsey Mill, a family worker has been cut from budget.

Working:

- Support at home via short breaks such as CAMPlay, Sunshine Club, Community Support – *this was noted several times by parents.*
- Early Bird Course (*this was highlighted several times*). The TA came too. Needs to be done more often and repeated for older children up until adulthood.
- Sibling Support – from EY's to teens, centre 33, Papworth Trust – *this was mentioned several times.*
- Family Worker – to support with ever changing scenarios
- Children's Disabilities Nurse to work with family at home and child in school, acts as a co-ordinator
- Positive Parenting – learning to focus on good behaviour (ABA techniques)
- Learnt to help child cope in social situations, develop independence and life skills through ABA
- Early Years Team – looked for the positive, suggested befriender to take child out to activities.
- University 'Big Sibs' – student befrienders
- Using strategies learnt, relearning autism friendly approaches.
- Shared understanding within the family
- Support triggered by social care not via short breaks.
- Involvement with Aspire Programme – Romsey Mill.
- Home is built around the child, this in turn supports positive behaviour.
- Occupational Therapy
- Joining SCIP database – schools/pinpoint need to be more aware
- Using a visual timetable in all settings – although this is not always followed by all areas of child's life
- Portage – led activities to help with speech and language difficulties.
- Meeting other parents asap – making a support network
- Family Therapy at the Croft – changed my whole family for the better, gave us coping strategies.

Community

Needed:

- A mentor.
- More places needed to go where it's ok for your child to be themselves.
- A countywide befriending scheme available for all
- Consistency. Support depends on where you live
- Feeling isolated and unsupported. Support for this

Working:

- Support groups (*mentioned several times*): Little Miracles – Soham/Ely/Peterborough: happy children, parents with similar issues supported, events organised – outings, speakers
Welcome to our World
March Pegs – for parents and children, parent led.
Pinpoint
VCS
Autism Anglia
NAS
Homestart
- Short Breaks funding (*listed several times*)
- SCIP – information on activities (*mentioned several times*)
- Facebook communities/ groups (*mentioned several times*)
- Aspire Youth Club at Romsey Mill (*mentioned several times*)
- Early Support
- Mencap befriending scheme.
- Social Events – prevent isolation
- Disabled groups such as swimming, multi-sports, garden centre
- Jane Tuck sib group
- Children's centres – information sharing, advice/support, young children happy to play with similar peers in relaxed and open environment, help in understanding next steps.
- Able to pursue own interests with support, often 1:1: horse-riding, scouts, swimming, jump club
- Meeting other parents at school in the right placement
- Local community – friends and neighbours
- Being able to share concerns and talk about difficulties
- GP
- Staff awareness training
- Awareness Assemblies – school
- Awareness in the media – e.g. 'The Curious Incident of the Dog in the Night'

Life Skills

Needed:

- Life /functional skills training (*mentioned several times*) e.g. support needed to implement - young person to be given responsibly around the home e.g. specific task. Money, travel, cooking, benefits, friends/relationships. Need a youth club to promote life skills. Needed in all schools.
- Good quality EHC Plans. (*mentioned several times*) Schools need to recognise yp strengths and abilities and build on these to lead to work. The info. needs to go into the EHC Plan (if one is given post 16). Need one person profile and multiagency meetings for shared understanding of yp's needs. *Raise Aspirations*
- More variety of work experience (*mentioned several times*) not all young people like gardening, cooking or art. There's also an assumption that the YP will do that for the rest of their lives. Look at other countries for good examples and need more local companies on board. Need more initiative by local businesses and self-employment.
- Shops to display 'help' card, somewhere to go if you are in trouble.
- Awareness. Worried about how other people will interact with my child.
- A whole development package. Can't find examples of – assertiveness training for child, managing anxiety, supporting mental health, internet training, sex education and relationships.
- More Lego clubs.
- A co-ordinator to 'tell you what you need to do' for the whole family.
- PFA – need information on benefits, housing, and advocacy. This information needs to be easy to understand and given EARLY.
- Give choices - young person and parents are not listened to.
- Better trained staff and a dedicated SEND department.
- Specialist equipment for mainstream.

Working:

- Special Schools teach life skills (this needs to happen in mainstream too).
- Reinforcement for skills learned at clubs to use at home.
- Therapy paid for by county council
- IDEAL course – Impington

School

Needed:

- TA's that are trained in autism. The right person for the child. *(listed several times)*
- A class teacher who is trained and sympathetic to child's needs. The responsibility must be the teachers, not the TA's. *(listed several times)*
- Schools that are proactive. Don't wait until the problems escalate e.g. think ahead to manage anxiety and don't wait for things to break down before support/ interventions are put in place. *(Mentioned several times)*
- Accountability/ monitoring of bullying. Peer and teacher understanding. Deal with low level bullying – the child may not be aware of it. *(listed several times)*
- Shared training and information – parents, governors and professionals working with child together. *(listed several times)* E.g. Cambridge Communication.
- Listen – schools listening to parents, especially the SENCO. No empty promises, need action and regular follow ups not just at annual review. The statement needs to be adhered to.
- SENCO's that are not teaching, that have time to do job.
- Strong and transparent systems to be in place for communication and feedback to parent in which they are fully involved and consequences when not adhered to. Direct feedback to head teacher/governors – pay scale (performance management or SENCO has to go to training).
- Follow up on parent questionnaires.
- Believe the parent is the expert and know that all children with autism are not the same.
- Teach social skills. Realise that communication can be a problem.
- Peer ambassadors in school.
- Sessions on general SEND.
- Consistency, flexible arrangements, choice of support.
- Kite Marking – accreditation.
- Choice of placement.
- Security of provision – not being fearful that it is going to be taken away.
- Less stressful annual reviews.
- A co-ordinator.
- Lifelong support
- Awareness
- Choice and flexibly – people, training, flexi-schooling, after and before school settings.

Working:

- Specialist teaching service.
- Statement/ EHC Plan

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- Early Support.
- Portage helped assisted place at nursery school
- Special school and specialist placements.