Background

CEN hosted a Family Information Event in partnership with education colleagues in Glasgow, Family Fund and Kindred in February 2014. The aim was to offer families the opportunity to hear about support, advice, grants and information that might be available to them.

The event was promoted to families by the schools in Glasgow supporting children with complex and exceptional needs and a big thank you to Andrea MacBeath, Head Teacher, Kelbourne Park Primary School for hosting this first event. 36 family members attended; a mix of mums, dads and grandparents who came with diverse backgrounds and experiences.

The event involved short presentations from Dawn Moss, Lead Clinician NMCN CEN; Salena Begley, Family Fund and Veronica Warrington, Kindred followed by discussion with parents whilst sharing the tea and cakes kindly provided by Kelbourne Park Primary School. Members of the local Community Children’s Nursing Team also supported the event.

Comments from families about their experience

A key aim for CEN for the event was to hear about families experiences about the support they receive and ideas for improving services. Here are some of the comments that families wanted to share:

- “Why is it so hard? Why are there so many barriers? Why do I have to fight for everything?”
- “Nobody listens to me. I feel punished for having a child with a disability.”
- “The doctor called my child an ‘enigma’, that wasn’t helpful.”
- “Finding out information can be difficult.
- “The doctor called my child an ‘enigma’, that wasn’t helpful.”
- “Why is it so hard? Why are there so many barriers? Why do I have to fight for everything?”
- “Nobody listens to me. I feel punished for having a child with a disability.”
Feedback from families about the event

15 family members completed the evaluation form and rated the event on average 4.4 out of 5 (1 = not useful, 5 = very useful).

80% had not heard about CEN or Kindred before today’s event. 90% had heard about Family Fund.

These were the comments from families about the event:

“My son has ‘complex learning difficulties’; it would be good to get information on this and educate other professionals to help them understand issues we/they have to deal with.”

“Very informative day, a meeting earlier in the day a meeting earlier in the day would be helpful as I’m clock watching to go collect kids from school.”

“Good to see organisations come together at one event as it is often difficult for parents to access services or find information.”

“I had heard of family fund but didn’t know much about it. I didn’t know what sort of help I could get but now know they help with a wide range of things.”

“CEN need to offer contact details other than email or the website as everyone does not have internet access.”

“Very useful and pleasure to meet new parents, would be useful to have these types of events more often.”

“Would be good to have a couple of reps with each organisation.”

“More days like this would be ideal.”

“Helpful event, would like more information on other help available.”
The families told us that they would like more information about the following topics:

- Autism
- Behaviour management (suggestions from 2 parents)
- Places to take children and activities
- Incontinence, what products are available (suggestion from 2 parents)
- Communication (suggestion from 2 parents)
- Role of occupational therapist
- Social work
- What help is available when your child moves to secondary school
- What help is available when your child moves to adult services
- Role of social worker and help that can be provided (suggestion from 2 parents)
- Respite care

Conclusion

This was a successful event with positive feedback from everyone involved. Salena Begley, Family Fund and Veronica Warrington, Kindred highlighted that they had provided information and advice to many families who had not previously heard about their services. For CEN we were able to identify 17 new families who wanted to be involved with CEN and to receive information in the future from the network.

Future plans

The families who attended expressed interest in a further event and so a date has been arranged for Monday 16th June at 1pm. The event will be hosted by Mary Cloughley, Headteacher, Hampden Primary School, Glasgow.

The aim for CEN is to translate this model of family engagement within other areas across Scotland.