

Special Needs Group evaluation

Introduction

The following citation is taken from page 34 "Together from the Start – Practical Guidance for professionals working with disabled children (birth to third birthday) and their families" which has been produced by the Department for Education and Skills and the Department of Health.

"Parent support groups, where families with young disabled children have the opportunity to meet with each other and exchange experiences, are an important source of mutual support and information. They also provide one means to overcome the isolation that many families feel when disability has been diagnosed. Service providers should actively encourage the development of such groups at local level and do whatever they can to make it possible for all parents to attend. It is important that ... the families decide the nature and format of meetings."

As a result of messages such of this, one of the original targets that faced the Sure Start Torquay programme was:

"Improve the quality of life for parents and children with severe/profound disabilities."

To this end the programme employed a Portage and Inclusion Link Worker (PIW) with a remit to focus on this target and supporting parents with special needs or raising children with special needs.

As well as delivering a portage service and visiting families experiencing these needs, the worker also developed a support group for these families. This group brings together families with special needs for mutual support and the opportunity to share experiences. The group also receives regular visits from other agencies and professionals to deliver talks on relevant topics. For example the group has been visited by:

- a Speech and Language Therapist to explain their role and how they can be accessed
- Relate to discuss how to maintain mental and emotional health when living with the stress of a disability

The group is also used as a forum to identify gaps in service provision so that the relevant agencies can be made aware of them.

This evaluation looks at barriers these parents did face, how Sure Start has helped them and what barriers they still experience.

Methodology

Evaluation work in the programme has been focussed on surveys via questionnaires. However these have increasingly been found to have a poor response rate, even when an incentive is offered. For this research a new approach was decided upon. To keep with the comfortable feeling of the actual group it was decided the best way to investigate their opinion was through an informal focus group.

This was held during one session of Sure Start Torquay's Special Needs Group which is held regularly, in a central location.

These parents were asked questions on a variety of topic areas. Rather than the traditional approach of recording and transcribing the discussion, something the researchers felt would intimidate the parents, an open discussion was had around the topic and notes recorded on flipchart paper. Concurrence with the recorded notes was asked for frequently, to ensure what was being written accurately reflected the parents' feelings. These notes were then written up and are discussed below. The focus group was not recorded, as is traditional with this method; rather the PIW took notes of the discussion on flipchart sheets. Each note recorded by the PIW was agreed with the group, ensuring it was their opinion being reflected by what was written.

A discussion of this methodology and the experience of the PIW will be produced in a further report.

Results

Below is a verbatim transcription of the notes taken and agreed during the focus group. The italicised comments are the questions posed to the group by the PIW. The following comments are those made by the parents attending the focus group.

"What services did you access before Sure Start?"

- 1) John Parks – but no parent support
- 2) Mayfield

John Parks offer phone support on request – medical support.

There was a Downs syndrome support group but it was for the children rather than parents.

No groups for cerebral palsy.

OT through Social Services.

"I had a social worker but she was useless."

- No follow up or contact support
- Social worker allocated not much seems to happen

If the problems aren't as big you seem to get overlooked.

"it doesn't meet the criteria."

“What services did you access after Sure Start?”

Information given e.g. holiday club, playgroup

Dad’s club is good.

Enjoyed outings.

“I enjoy the informality, meeting other adults particularly because I am a single parent.”

Special needs support group particularly helpful.

Much more aware of what else is happening through SS staff and other parents.

The speakers to the group have been very useful.

It’s good to get things “off your chest”.

Emotional support is good – talking to others who understand.

“I found out about benefits that I could apply for”.

“What barriers did you experience before Sure Start?”

Don’t meet the criteria.

Parent identified a need but wasn’t able to find a service that was willing to fund appropriate help.

Left on your own – are they going to ring? – what should I do now?

Didn’t feel that we got adequate explanations.

Benefits – very difficult to sort it out.

Knowing which agency to go to and what you are entitled to.

“What has Sure Start done for you?”

Has been helpful in providing some of this information.

Finding out about local amenities.

Doing things with others.

Provided emotional support

Home visit is useful, to see a friendly face someone to talk to. Feel you can phone them up.

Good to have someone to talk to who understands (empathises

not negative – need to speak positively

“What barriers to attending Sure Start’s special needs group do you feel exist?”

Barrier - People think it will be serious – negative – focussing on disability.

“How can the barriers be overcome?”

Follow up phone calls – would be contact without pressure.

Special needs group – informal drop in and informative more formal sessions (coffee morning)

Can we invite people who live outside Torquay?

“What have you gained from attending the group?”

Friendship.

A sense of humour.

Information.

Places to go – with others.

Shared experience, others here understand.

Emotional support.

No stigma, non judgemental.

Reach figures

The PIW keeps a register of attending families and to date ten different families have attended. Not all families have registered and are therefore not reflected in contact figures for the programme. The table below details the reach figures for attendance at the special needs group for the six month period September to March.

Table 1: Attendance at Special Needs Group

Date	Families	Carers	Children
9 th Sept	2	3	1
23 rd Sept	3	4	1
7 th Oct	3	4	1
22 nd Oct	1	1	1
4 th Nov	4	4	2
18 th Nov	4	5	3
2 nd Dec	3	4	3
13 th Jan	4	5	2
27 th Jan	4	4	1
24 th Feb	4	4	1
10 th Mar	3	3	0
Average	3.18	3.72	1.45

At present the programme has 871 children registered within area. Of this 871, only 13 children under the age of five are reported as having a special need of some description.

Discussion

Four main themes of discussion were formed by the group:

- 1) Before Sure Start
- 2) Now that Sure Start is here
- 3) Barriers to services that have been experienced
- 4) How has life improved

These areas and the comments made within them will be discussed below.

Before Sure Start

There appeared to be a general consensus amongst the participants that if your child's problems were severe enough, you could get support. However if your child's problems fell outside the inclusion criteria there was very little available to you.

“If the problems aren't as big you seem to get overlooked.”

Even when your child did meet the criteria there was little for the parents, much of the support was naturally aimed at the children.

Now that Sure Start is here

The overwhelming impression is that the parents thoroughly appreciate the support and opportunities they have had access to as a result of Sure Start Torquay's presence.

“Good to have someone to talk to who understands (empathises).”

The PIW has a child of her own with additional needs. Her empathy with the group's situation was very important to them and this is reflected by the above comment made and agreed by the parents. They valued an opportunity to share their concerns and to have services in part aimed at their needs as well as their children's.

Barriers

From the discussion there appeared to be three main barriers for parents of children with special needs. Firstly a lack of information, both in respect of a provision of availability of services and with regards to professionals keeping families informed.

“Left on your own – are they going to ring? – what should I do now?”

“Didn't feel that we got adequate explanations.”

“Knowing which agency to go to and what you are entitled to.”

This issue was very important to the group. It is understandable that anybody who felt they were not being given sufficient information or support by a relevant agency would feel disempowered and disillusioned. The parents that participated in this group strongly felt they were frequently passed from pillar to post and there was a general experience that the information they were occasionally supplied with was lacking.

Secondly the issue of meeting the criteria for special needs support.

“Don’t meet the criteria.”

This was again a recurring feature of the discussion. Parents of children that met the criteria for special needs find themselves able to access and receiving an disproportionate amount of support to those who maybe just “fall short”.

Finally, the participants in this focus group felt there was a lack of support to develop resources when a need had been identified.

How has life improved

The most prevalent feeling with the group was that as a result of the Special Needs Group, they now have a wealth of peer support.

“Friendship.”

“Shared experience – others here understand.”

The group has enabled them to meet people who share their difficulties and given them the forum to access the mutual support this shared experience can facilitate. In turn this has empowered the family and made the parents happier. It is worth noting that although average attendance figures are quoted in the Reach Figures section, this does reflect an average. Families do not attend each session, fortnight to fortnight. Rather, different parents will attend when they are able, making the group fluid.

This piece of research has looked almost exclusively at how the Special Needs Group has helped the parents, which is in keeping with the group’s aim of being to provide parent-to-parent support. It seems sensible to assume that more supported and happier parents will lead to happier children with better outcomes but none of this is evidenced here. There is a low attendance by children as many attend daycare or school. Future research with the Special Needs service should look into evidencing the outcomes the children experience as a result of the support that their parents receive, as well as looking at ways their needs can be provided for.

Conclusions and Recommendations

The group has shown itself to be valuable to the parents attending. Although a slightly relaxed approach to the programme's boundaries has been taken by this group, largely it still remains a service restricted by Sure Start's limits on age and area. Due to the relatively low number of children with special needs in the area (13 out of 871), it would be more cost-effective for the running of a group such as this to expand these restrictions and open the group to a wider population. There is the potential to expand the boundaries so that more parents are able to access this service.

- *Recommendation:* The PIW should approach the portage service and other professionals to discuss the possibility of expanding the boundaries to the whole of Torquay and increasing the frequency of the group from fortnightly to weekly.
- *Recommendation:* A rota of visiting professionals and speakers could be planned but it needs to be stressed here that not every week will see a professional in attendance – on occasion the group should be allowed an informal meeting where they can offer each other mutual support.
- *Recommendation:* If this is found to be successful the model could be taken to other areas within Torbay (such as Paignton and Brixham).

At present the group is largely aimed at supporting the parents (with an average of 3.7 parents attending fortnightly compared to 1.5 children). This means there still remains a gap with direct group support for the children that the group is concerned with.

- *Recommendation:* Investigate the potential for additional support services aimed at delivering to the children directly, e.g. special needs Stay & Play.

Marketing of services available at present is insufficient and would benefit from improvement. This has been shown by the group's reporting of the lack of awareness of available resources, something the Sure Start group has sought to rectify, but an area that remains a continuing need and not the sole responsibility of Sure Start.

- *Recommendation:* More will be done to seek the opinions and input of the group's attendees, to ensure that information is being marketed in a manner most suitable to their needs.
- *Recommendation:* Other service providers should take on board any future findings with respect to marketing and in light of the poor information sharing situation evidenced by this report, seek to ensure their practice becomes more parent friendly.