

October 2014

2013 to  
2014

# Participation and Engagement

  
**family voice**  
peterborough  
*together improving services*  
*for children and young people with disabilities and additional needs*

Face 2 Face  
Parents supporting parents  
of disabled children

Scope to...  


**healthwatch**  
Peterborough

Louise and Maxine  
Family Voice Peterborough  
2013 to 2014

## Participation/ Engagement September 2013 to September 2014

### Headlines

173 parents in total have been involved some level via face to face meetings/ events

113 professionals have been involved at some level via face to face meetings events

139 respondents have taken surveys via survey monkey – the breakdown of parents/ professionals is not possible due to either surveys being completed anonymously or respondents self-reporting as both parent/ professional

Parents have self-reported being members/ attendees at PDDCS, PADSG, LM, NAS, AHG and Face2Face

Children's/ Young people disabilities have been reported by parents as including Autistic Spectrum Disorders, Learning Disabilities, Tourette's, Mental Health Disorders, Cerebral Palsy, Sensory Impairment, Down Syndrome, Complex Health Needs and Genetic Disorders

Involvement from fathers is much lower than involvement from mothers

Reported age of children ranges from 2 to 22

Methods used include open meetings, a conference, focus groups, social media discussions, online surveys and parent representation

Evidence is both qualitative and quantitative

Co-production on; EHC plan template, Local Offer (e-form, page content, voluntary sector inclusion and information leaflets), Communications work plan, personal budgets policy, 0 to 25 group

Participation in; EHC processes, EH&WB strategy group, Carers Service Procurement

## **INTRODUCTION**

This report focuses on participation and engagement rather than on SEND, although the two are over the course of the past year synonymous with one another due to the reforms that have been taking place in the same time period. The report encapsulates work between November 2013 and September 1<sup>st</sup> 2014. The end date has been chosen as it marks a point in time when much of the work mentioned in this report has led up to. The 1<sup>st</sup> September 2014 is the date at which the legislation around SEND in particular came in to affect.

Much work has taken place not just with Family Voice Peterborough (Designated Parent Carer Forum for Peterborough) but also with organisations such as Healthwatch Peterborough (HWP) and the National Autistic Society Peterborough and District Branch (HWP). This report has been put together jointly by Family Voice Peterborough (FVP) and Face to Face Peterborough – Scope (F2F) who have also worked closely to ensure wider parent carer involvement.

Some of the data presented in the body of this report and also photographic evidence will go towards demonstrating the increased and cross representative parent carer involvement in work around the SEND reforms in Peterborough. The report will explore some of the history behind parent participation, the methodologies utilised, the approach taken by FVP and what has taken place in the past year.

There is also an on-going “culture shift” in terms of parent participation which has called for a real change in working practices with the Local Authority which it is hoped will have a wider impact on more general participation; this shift was slow in the beginning and has gathered momentum in the build-up to the 1<sup>st</sup> September.

## **PARTICIPATION/ ENGAGEMENT PRINCIPLES**

### ***Defining parent carer participation***

*The purpose of participation is to ensure better outcomes for families of disabled children and to improve services for all users. It is about the involvement of parents with a wide range of professionals and local service managers in the planning stages of service delivery. It is underpinned by the following principles:*

- 1. User involvement should be central to policy making, and the design and delivery of services at a local, regional and national level*
- 2. Parent carer participation is acknowledged as mutually beneficial to service planners and service users*
- 3. Parent carer participation currently still needs support both financially and developmentally at a national, regional and local level*
- 4. Local authorities will continue to consult with and involve parent carers in service development and delivery*

### ***Three key elements for effective parent participation are:***

- Information – providing information to parents about service development and their opportunities to influence.*
- Consultation – getting feedback from parents about their experience of services to inform further development, and offering options about a new service or a change in services, usually on a limited range of choices.*
- Participation – giving parents a significant voice in the design of a new service and the development of a service over time.*

“Towards a more ordinary life.... A report on the progress of parent carer participation and the development of short breaks: 2008 – 2011” pp23 to 26 Together for Disabled Children July 2011 v0.1

Participation is often defined as ladder. Parents are viewed as having little influence at the bottom of the ladder and being empowered and co-producers at the top of the ladder.

*“Consultation is often mistaken for participation, but it is part of the whole process of participation. Participation is about parents playing a full part in the decision-making process and is usually a continuous exercise. This requires practitioners to create the right environment for this to happen....”* (Contact a Family and Council for Disabled Children 2004. Parent participation: improving services for disabled children Professionals’ Guide)

More recently extra elements have been added to the ladder principle as defined above; these include “no engagement” at the very bottom and “co-production” at the very top. Co-

production is about being involved in the discussions where ideas are developed together, then designing what needs to happen, and doing the work together.

### ***Participation Methods***

Some of the prescribed methods for enabling parent participation are as follows, we have utilised these as well as social media and online surveys.

#### Conferences

Conferences where specific themes are discussed are used to facilitate parents having their voices heard. These are led by the board of trustees who have strategic support from lead members of their local children's services. Conferences are public meetings where parents and professionals come together to discuss the themes on the agenda. As these are big public meetings they are not suitable for children to be in attendance.

#### Task and Finish Groups

A group is set up to look at a specific theme and has a start and finish date; these groups can be made up of parents and professionals.

#### Meetings

Parents are invited to regular meetings to discuss their experiences of specific services. These meetings can be small, big, private or public. People often refer to such meetings as forums. Such meetings require a chair with good facilitation skills. It may be possible for parents to have their children with them depending on the topic under discussion and whether all in attendance are agreeable.

#### Focus Groups

Similar to task and finish group in that a specific area or service is discussed (focus) on. Focus groups are made up of people who use, are involved in, a specific service. It may be possible for parents to have their children with them depending on the topic under discussion and whether all in attendance are agreeable.

#### Research/ Consultation

This can take many forms and often incorporates some of the methods already mentioned.

#### Parent Representation

Parents attend task and finish groups, conferences and meetings on behalf of other parents and represent their views.

## **METHOD**

Working in partnership with Face2Face Scope and other organisations as detailed in specific reports FVP have utilised the following participation methods;

- 4 online surveys delivered via survey monkey
- 1 annual conference
- 2 open meetings
- 2 LO/ EHC focus Groups
- 7 SEND Strategies focus groups
- Social Media discussions

FVP have provided parent representation in the following work streams and boards;

- LO/ EHC/ PB Workstreams
- EH&WB
- SEND
- CFJCB
- CCG Care Design Groups
- 0 to 25 Service
- Carers Partnership Board

FVP working in partnership with Face2Face, Healthwatch Peterborough and on occasion NAS Peterborough and District have enabled parent carers to take part in work on all of the topics listed below;

- SEN strategy
- Local Offer
- EHC plans/ process
- SEND awareness
- CAF use
- Participation and Engagement
- Neurodevelopment Health
- EH&WB strategy input
- Carers Tender Procurement
- Personal Budget
- Preparing for adulthood

## **PARTICIPANTS**

### **LO/EHC Focus Groups**

Focus group session 1 had 12 parents including 1 dad in attendance. They represented a range of disabilities/ additional needs; Autistic Spectrum Disorders, Mental Health Issues, Visual Impairment and Learning Disabilities.

Focus group session 2 had 8 participants in attendance. They represented the following disabilities/ additional needs; Autistic Spectrum Disorders, Learning Disabilities, Tourette's, Mental Health Disorders and Cerebral Palsy.

All the trustees took part either during session 1 or 2; there are 5 female and 1 male trustee and their children and young people have the following disabilities/ additional needs; visual impairment, PMLD, mental health issues, speech and language delay, autistic spectrum disorders and developmental delay. One trustee was also representing Face 2 Face Peterborough (Scope) in a professional capacity.

### **LO Open Meetings**

57 parents attended the day workshop and 25 parents attended the evening workshop. Of the parents who attended several self-reported membership on the following parent groups locally NAS, Face 2 Face, Peterborough and District Deaf Children's Society (PDDCS), Peterborough and Area Downs Syndrome Group (PADSG), Little Miracles (LM). Parents who attended were also known to FVP either through the parent's forum database or through online Facebook chat rooms overseen by FVP.

Around 60 professionals attended an event on 21<sup>st</sup> November

### **Strategies Focus Groups**

12 Parent cares (11 women and 1 man) from across Peterborough who have CYP with a variety of disabilities and additional needs. 7 parent reps took it in turns to run the sessions.

### **Conference**

59 parents/ carers/ Grandparents attended the conference

53 attendees were professionals/ representatives from across the LA or 3<sup>rd</sup> Sector.

5 trustees were able to attend and run the conference.

### **Surveys**

There were 139 responses across the four surveys and of these at least 5 people responded to both awareness surveys, it is not possible to tell in anyone else took more than one survey as the workshop and CAF surveys were completed anonymously. If you assume that the 24 who took the CAF survey and 9 who took the workshop survey also took the awareness surveys there are still 49 unique respondents. The awareness surveys and workshop survey were completed by parents/ interested professionals and the CAF survey was completed by parents only. From those who responded to the awareness survey and workshop survey 73 out of a possible 115 completed the section. It is not possible to establish a full breakdown of parents/ professionals as some respondents selected more than one category to define themselves.

## **EVIDENCE**

### **Quantitative**

- Surveys
  1. SEND Reforms Awareness
  2. Common Assessment Framework Knowledge
  3. SEND Reform Groups
  4. SEND Reforms Awareness August

The data from the surveys has been shared with PCC and has been used to inform some of the decisions within the LO and EHC work groups.

- feedback form data

At all meetings, events, conferences attendees are asked to complete feedback forms which contain rating scales, closed and open ended questions. The sort of data captured relates from understanding of a topic through to details relating to SEND of any CYP.
- numbers of attendees at face to face meetings/ events

FVP also have a register for face to face meetings and events and record how many attendees there are, whether they are parents/ carers and/or professionals and whether they are male or female.

### **Qualitative**

- Case studies

Parents present feedback through providing a snapshot of their experiences in writing and FVP have utilised video as well to share experiences of being a parent rep <http://www.youtube.com/user/FamilyVoicePeterboro>

*“I really enjoyed the opportunity to attend the SEND reforms meeting, but found the allotted time to be a bit short (I attended the evening session). There were lots of questions raised and as I am new to this experience (daughter having been recently diagnosed), the more I learned, the more questions I found I had. I heard lots of parent’s worries that the current level of services some people were receiving under the current situation would be lowered or cut under the new policy. Not knowing much about currently available resources myself, the Send reform seems a good idea, if implemented correctly. It is imperative that the new guidelines are co-authored by parents of, AND by differently-abled children, not just by the heads of departments who may have no experience dealing with day to day life with disability. There must also be no ONE SIZE FITS ALL, as every child, family situation and disability are different.*

*I got confused by all the MUST’s, and SHOULD’s, and think that should be clearer. Didn’t really understand all that.*

*In our experience, the primary school my daughter attended did nothing to help her as she did not have a “statement”, at the time I did not know what that was... All I could do was keep asking more questions of more people until I finally stumbled on to the right*

*path (FVP). Now, in Secondary school, she is getting some help, but she could really excel in school and her social life with some more specialized services. For example: social skills classes: How to read her peers non-verbal cues and understand sarcasm, How to stick up for herself and her ideas in a diplomatic way and a scribe at school would be so helpful, because though my daughter is very intelligent, her writing is of a year 3-4 student. Often it is illegible, yet the information is in her brain, she needs help getting it to the page. She is bored by some of her classes in year 8 because she is not learning anything new; they don't realize how much she already knows! It is very frustrating for her!*

*I just want the best life she could achieve. If the teachers could read her writing, they would know she is bright enough to be challenged more, and **SHOULD** be! If she could understand what her peers were communicating, she could have more friends, maybe be invited to a birthday party every now and again... These are just normal things most parents take for granted that their child will have in life...*

*I am also concerned about the "Academy" status of her school?! I did not take in all the info on this, but feel sure I heard that some schools, but perhaps not academies were to be effected by the changes."*

*"Working in the Pop Up Shop gave me great satisfaction and I'm glad I had the opportunity to have an impact on so many families. It wasn't just about giving them information on the SEND Reforms - although this was very important but it was giving families hope that we are there for support whether that is through listening, signposting or simply just being there. There is nothing worse than the feeling of isolation and loneliness. Together is better!"*

- Written views on EHC plans and processes, LO content pages, open ended survey question responses

Parents/ carers have provided statements/ comments/ views on various aspects of the work relating to the reforms; a report was produced that relied very much on written views around the EHC work (*EHC Plans Report*, August 2014, FVP).

A particularly useful tool in this area has been Facebook as parents/ carers can be presented with information and then have the time to read the information and post responses when it is convenient to them, this overcomes some of the barriers associated with face to face meetings like childcare, time and lack of confidence.

*"We had various people around the table Social Worker, Neurodevelopmental manager, parent partnership officer, SEN Manager, educational psychologist, SENCO, myself and my husband.*

*The purpose of the meeting was thoroughly explained to us and we were happy to be involved in the process. We liked that the 1st part of it was all about our son and his story so far so we wouldn't have to keep explaining it. We also liked that we were actively involved and our son was at the centre of it rather than people reading reports to make decisions. Ours was very much around education rather than Health or Social Care but we didn't mind as education seems to have taken priority at the moment. The experience was a very positive one and a*

*great way to break down barriers between parents and professionals because they made sure that we were happy with what had been discussed.”*

- Written monthly reports which include completed parent rep feedback forms  
Throughout the work relating to the reforms a written monthly update report has been written that contains copies of the parent rep reports, statements/ comments from parents/ carers.

## **ENGAGEMENT**

### **Pop Up Shop**

The pop-up shop ran for six weeks during which time a rota of support was established which included early years practitioners, Face 2 Face, SEND Partnership, Healthwatch Peterborough and Carers Trust.

- Over five parent carers benefitted from direct contact with the SEND Partnership Officer
- One parent carer was supported on a specific health matter by the Designated Clinical Officer.
- Over 50 parent carers had their details recorded to be kept informed

### **Carers Events**

Parent representatives have manned information stands at various carers events run by the adults carers team. These stands enable other agencies, professionals and parent carers unknown to Family Voice Peterborough to become informed about support available to parent carers, the SEND Reforms and activities and events open to families with children and young people with disabilities/ additional needs.

## **PHOTOGRAPHIC/ VIDEO DATA**

Over the past year work has also been started to gather more data by way of taking photographs at meetings, conferences and focus groups and interviewing stakeholders and videoing the presentations at the annual conference the forum holds. The use of video is a fairly new idea and the footage taken so far has been uploaded to YouTube with the presentations from the annual conference receiving the most hits.

<http://www.youtube.com/user/FamilyVoicePeterboro>



## **Comments/ Feedback**

Adrian Chapman (AD for Communities and Targeted Services.)

*“Family Voice Peterborough have been integral to the design, development and delivery of the SEND reforms. I have been amazed by the enthusiasm, passion and commitment shown by parents, trustees and paid staff from FVP, which has led to an honest, open and effective partnership being formed between them and other public sector agencies. This partnership really does set the benchmark for how we should do business as a city going forwards.”*

Jonathan Lewis (Assistant Director – Education, Corporate Property and Children’s Resources / Children’s Services Peterborough City Council)

*“Working with Family Voice has provided the perfect opportunity for the cultural change that will ensure we can provide an open environment and moving forward in jointly shaping services. We have been challenged and supported and this can only help improve outcomes for Children in Peterborough.”*

Dr Venkat Reddy (Lead Clinician, Community Child Health Services, CPFT, SEND Champion)

*"Family Voice Peterborough provides fantastic platform for Families to influence the commissioning, provision and redesign of Education, Health and Social Care services for children and young people in Peterborough.*

*I am impressed with the commitment and professionalism of the representatives and value their role very highly"*

Tanya Smith (Parent Rep/ Volunteer)

*“Family Voice Peterborough have been inspiring to me as a parent forum not only engaging with parent carers regarding the latest SEND reform updates and making them feel involved and informed in the whole decision making process but also listening personally to any issues or concerns raised and taking them forward in a positive manner to the local authority. They collate this information in various ways through the workshops, training, social media, the pop up shop, focus groups, conferences and any other events we attend.*

*I thoroughly enjoy being part of Family Voice Peterborough as they have empowered me as a parent to engage with other professionals and co-produce any support plan needed for our children to fully reach their potential regarding education, health and social care system.*

*I feel very confident in signposting other parent/carers to the relevant agencies depending on what issues they are facing to take their matter forward in a positive manner.*

*As a Parent Representative I have felt very much appreciated and feel I play a crucial part in co-producing services with the Local Authority. This has been proven through drawing up a formidable Education, Health and Care plan along with the Co-ordinated plan to support our children and young people.”*

Mandi Rennie (Trustee/ Treasurer)

*“On the first Tuesday of every month, I run a breakfast club, where parents come along to Van Hage in Eye, and we all have breakfast, paid for by FVP. This is usually very well attended, with around 10 parents attending each month. We discuss the Local offer, and the SEND reforms locally, as well as our experiences of the EHC process. After breakfast, everyone knows they will need to fill in a feedback form, or look at and comment about draft versions of SEND policies, to see how it looks to parents who will have to use them. It is a popular and productive way to engage parents.*

*On the second Tuesday of every month, I run a children's behaviour discussion group, at Costa Coffee in Bretton Centre, where we discuss various things that are behaviour related, such as fussy eating, tantrums, stealing, sibling rivalry, bed-wetting and such. These topics are all basic behaviours in children that parents feel they may need advice and guidance on. After holding a couple of these groups, i feel it is more a parenting issue as opposed to a diagnosis symptom issue in the majority of cases. For example, a parent said her children will only eat sweet foods, and she was putting syrup on mashed potatoes to ensure they were eaten. i said it was not the ideal solution, and she informed me her husband usually has a whole jar of syrup on his mash! and there was the reason her children did it- they had learned it from their father. This group is not so well attended, although the meetings are usually animated and very busy. The parents find them productive. I feel they would be better attended if parents felt they were getting something for free, like at breakfast club.*

*I also hold a discussion and support group around adolescent mental health issues, also at Costa in Bretton. This is supposed to be for parent carers of young people with mental health issues, such as self-harming, psychosis, eating disorders, body image issues etc, which is not so well attended, except by parents of autistic children I feel this demonstrates these parents have a need and feel this is the chat group for them. There may be cause to look at how this group is marketed and how other parent carers can be encouraged to attend. This would also benefit from offering 'something free' to attendees, who invariably say they find it useful.*

*The breakfast club regularly sees around 10-15 parents attending each month, the children's behaviour group has seen an average of 4 parents attending, and the mental health group attracts around 4 parents each month. I feel that these groups could be better advertised and also offer a freebie to parents to get more attendees, who could find them useful and informative.”*

Vanessa Perry (Volunteer Office Administrator)

*“Over the past year I have attended a few groups to give me more of an understanding of the SEND reforms as a parent and as a volunteer to take other parent/carers to the next level of their understanding but also to help record their views to help towards our Peterborough*

*Local Offer. I was part of the Pop Up shop in the town centre where I felt a great help as parents came in for advise, signposting and understanding. By doing these things gave me a greater understanding of the new reforms and made me realise I knew more than I thought I did. In turn this gave me more confidence as a parent.*

*I often attend the Breakfast Club to discuss issues that are 'on topic' as well as the Coffee Morning set up by Mandi Rennie. Where we usually have a good old rant about things that are on our minds and try and help other attendees with their issues: discussing ways to enable them to make positive steps forward.*

*But my skills have been put to best use in the office. Where I have done an overhaul of the members database filing and organising the general filing to enable the trustees to locate all their information easier.*

*At the moment I am updating the electronic member database and adding more new members weekly. As well as this I have been entrusted to oversee the tickets and passes (inc monitoring of the same). A job I am really enjoying."*

Dafne Stoelhorst

*" I have only just been involved but what I have seen so far is a lot of dedication to making sure carers are the voice of their children. Meeting people and getting information you normally would not have easy access too, but which are vital for making sure your child(ren) get the support they so need"*

Carol Eastwood Barber

*"A parents voice is vital if peterborough is to provide the excetional services that our children deserve. It has been a privilege to be involved with many working group and to have a voice that has been heard."*

Teresa Frobisher

*"I have really enjoyed being involved with family voice, i feel its very important parents voices are heard too help make services better for our children and give them the support they need, i'm seeing the difference this is making with the send reforms"*

## **ANALYSIS**

Over the year between September 2013 to 2014 reports have been produced detailing the monthly progress in Peterborough in relation to the SEND reforms, feedback has been gathered at open meetings, focus groups and the annual conference, the use of YouTube has begun and a Pop Up shop was run by parent reps.

All the activities mentioned above have produced both qualitative and quantitative data from parent carers on a variety of topics and can demonstrate a wide representation of parent carer views; disabilities/ additional needs of children and young people which have been self-reported by parent carers range from sensory impairments through to physical impairments and complex health needs and groups accessed by parent carers are from disability specific support groups through to peer to peer support groups.

The use of on-line surveys has proved very useful for overcoming barriers such as child-care, time as evidenced by the number of responses across just four surveys. There has also been an increase in using Facebook to gather feedback on documents which also enables wider participation and has helped overcome the barriers just mentioned; one of the issues around use of Facebook in this way has been around the difficulty in explaining complex issues.

Far more parent carers have been engaged in work locally around services for children and young people with disabilities/ additional needs than has perhaps been realised and the process of pulling all the data together has shown this. Representation is more widespread than realised and more parents want to become increasingly involved rather than just informed.