contact a family
for families with disabled children

Strengthening Parent Carer Participation
Making Your Case

• Welcome to this Contact a Family Webinar

• If there is a technical hitch, please do bear with us

• Those of you joining by pc, laptop, tablet or smart phone should now be able to see this introduction slide
Timing & Questions

• As there are so many attendees, it is not practical for verbal questions to be taken, therefore you will all remain ‘muted’ throughout.

• If at any point you have questions, please use the question icon on your GoToWebinar tool bar on your screen.

• This will allow you to type your question in to the text box and submit this to the Webinar administrator.

• We will select as many relevant questions to answer as time allows, if similar questions are received we will condense these where possible.
Q&A Session

• Further relevant questions, not covered in the time allowed, will be answered and posted on the Contact a Family website along with the recording of this Webinar and any handouts, details of which will be circulated next week.

• At the end of the Webinar a short questionnaire will launch, please take the time to complete this as this will assist with future online training events.
Let us begin with introductions

Hi.
I am Barbara Wilson, a CAF Associate based in east London.
I am joined by Kulwinder Bola, Chair of Luton PCF and Co-chair of the Eastern Region.

Thanks to Ruth who is working behind the scenes and to Gail for hosting us today.
Making Your Case is about your Forum getting, and presenting, a strong case to influence things for the better.
What we will cover

• Why **evidence** is important
• **Principles** of gathering evidence
• National and local **sources of information**
• **How to** record key information from parents
• **Different ways** of carrying out research
• **Presenting your findings**

We have examples from Luton PCF and **Positive Parents** in Havering in how they have influenced policy and provision in their areas.
Follow up

• Please **share examples of good practice** with your adviser and within your regional network meetings.

• As we will not be able to cover everything in the hour we will have **handouts on jargon busting, a checklist & good practice**.

• Please use the material in this webinar to help your forum plan how you can evidence your work in 2016.
Why is evidence important?(1)

“We need reliable evidence to inform tough decisions and support service improvements, efficiency and better outcomes for people using services and their carers”

SCIE
WWW.SCIE.ORG.UK
Why is evidence important?(2)

- Local Authorities & Clinical Commissioning Groups make decisions using evidence - with a focus on outcomes
- It is good practice for forums to provide parent representatives with facts and figures so they can accurately represent the forum in strategic meetings and give them more confidence in what they are saying.
- Having an evidence based approach also helps give local authorities confidence in you as a forum.
- In Luton it has been helpful to know our baseline – how many families live in the area, what are their backgrounds and the ages of the children or young people and how many have signed up to our Forum.
Here is our membership shown in an Infographic format

Making your Case
LPCF REPORT

Member's Children and Young People by SEND

Members by Ethnicity
Recording the ethnicity of our members has enabled the LPCF to be seen as an organisation which has clear ethnic representation of the local population. Our diverse membership has been pivotal in getting the organisation invited to a range of strategic level meetings across Education and Health. We are fast being seen as an organisation to be linked with, when developing or evaluating service use.

The chart above shows the six most commonly reported SEND amongst LPCF member's children/young people.

Member's Children and Young People by Age

Holding data on the child/young person's age has enabled us to alert the LA to the needs of the families around transition. It has contributed to ensuring services are being developed accordingly, taking the child/young person's age and needs into account. This data has also enabled the LPCF to think about organising/taking workshops to help families to better understand and plan for transition from a parent's perspective.
What is research?

**Research**

The *systematic* investigation into, and study of, materials and sources, **in order to establish facts** and reach new conclusions.

**Similar words**

Investigation # Testing # Analysis # Fact Finding # Examination # Scrutiny

The Oxford Modern English Dictionary definition.
Key Principles (1)

Ethical issues and codes of conduct to adhere to when carrying out research

- The first being **informed consent** – so you must be transparent in your purpose. People should be **fully informed** about how their views and experiences will be used.
- **Right to decline** to participate – with no consequences
- The person knows **who to contact**
- Ask for **permission** to use images or quotes
Key Principles (2)

• Maintain Confidentiality – de-personalise the summary/report
• Integrity – Honesty and openness about where your information, views and or issues come from and how many parents it relates to.
• Are there any conflicts of interest for those carrying out research or reporting on the research?
• How will you feedback to parents about the outcome of discussions/surveys?
Positive Parents influencing outcomes in Health

In the last 2 years PP have been having quarterly meetings with the Clinical Commissioning Group and other providers. These meetings are open access, have a Question Time format and are chaired by Healthwatch.

Positive Parents keep the Action Plan up to date using a traffic light system.

One positive change
Hospital in-patient care. Carers now have a proper recliner by the bedside if they need to stay overnight.
Language to look out for

You may hear → This is what it means

• Dataset  ✓ All of the information gathered during a survey which needs to be analysed

• Demographics ✓ Studies of a population based on factors such as age, race, sex, economic status, level of education, income level and employment

• Indices of deprivation ✓ A measure of the level of deprivation in an area

• JSNA ✓ Joint Strategic Needs Assessment, a tool used by LA and CCG to monitor the health and well being of their population
Where to find information (1)

• Use the Office of National Statistics (ONS) [http://www.ons.gov.uk/ons/index.html](http://www.ons.gov.uk/ons/index.html)

• Check your LA or Clinical Commissioning Group’s websites. They have to produce a Joint Strategic Needs Assessment (JSNA). This shows statistical information about the numbers of disabled children and children with SEND.

• The Short Breaks Statement shows the level of need for families in the area and the range of provision and amount of provision.
Where to find information (2)

• **National Charities** such as Contact a Family, Council for Disabled Children, Mencap and Scope produce research reports outlining **key issues for families** – you can use this kind of evidence to back up your case.

• **Legislation and Regulations.** National Quality Standards can also help you reflect on what’s happening at a local level and identifying areas for improvement or gaps in provision.

• Talk to your local **Healthwatch.** They often have Information Officers, produce regular newsletters and have a good overview of issues. Send them a copy of the CAF/NNPCF briefing **Healthwatch and PCFs.**
Where to find information (3)

- Check out other like minded support groups or voluntary organisations in your area for their Impact or Annual Reports – there may be information included that is of interest or relevant to your issues
- Keep linked into NNPCF and your region for news about key issues in other areas
- Keep your own membership database up to date

Top Tip

Always remember to quote your sources of information
## Using Information

### What to do

- **Know where** to find the information you need
- **Double check for accuracy**
- Use individual circumstances to create **powerful case studies** with lessons **for all** to avoid **anecdotal** trap
- Think about **pan disability** and across the **0-25 age range**

### Ways

- Co production
- Consultation
- Quantitative – numbers
- Qualitative – experience

### Top Tip

**Always feedback.**

Families **need to know if any action** has happened as a result of what they shared
Know the Difference

Using research to help you to make your case can help. But you need to know when to use which approach:

**Qualitative or Quantitative**

**Qualitative research** is exploratory, and it is used when we don’t know what to expect. It’s also used to gain a deeper understanding of the problem at hand, for example ‘Why do so few colleges offer a good range of courses for students with SEND?’

**Methods used:** Interviews, face to face, focus groups, video recording, and observations

**Quantitative research** is much more conclusive it tries to measure how common a problem might be. For example *How many SEND children are known to their GP as well as known to their community paediatrician?*

**Methods used:** Survey – by phone, online (email attachment or interactive) and Audits
You will have regular contact with parents either **formally** in meetings, conferences and events or **informally** through social media, coffee mornings, workshops, training days, phone calls or face to face contact through forum activity or meeting people through school activities.

1) **Recording the issues parents raise and their experiences** is important in helping to provide evidence to back up your views.

2) It helps you **to reflect on** what you’ve heard and think about whether the views you raise are backed up by parents actual experiences.

3) It provides a **bank of evidence** so you can be more transparent and open in discussions with the local authority.
Recording Issues (2)

- **Minutes of meetings** – if one parent raises an issue in a meeting – ask for a **show of hands** from others who have the same or similar experience – count and record the number.

- **Use flipchart** in meetings to have smaller group discussions and record issues in this way - type up and save.

- **Reports** from Conferences and events

- **Issues or feedback** from training or workshops
• Create an **Issues Log** to record individual issues raised by parents. Then you can count up how many parents have the same issue.

**The Advisers** have an example of a log using Excel for you to use. Or find free software on [https://www.google.com/sheets/about](https://www.google.com/sheets/about)

• **Post on social media** and see how many parents respond.

• Create a **texting service** and ask parents to **text Yes** if they have experienced a specific issue.
Research methods (1)

• Post questions for your parent carers to answer on social media – Facebook group, twitter, your website, text messaging

• Collaborate with colleagues in the council, education, health or voluntary sector when they need to consult with parent carers or co-produce on a service/strategy – the earlier the better

• Consider combining forces with other forums to work with a researcher on a particular issue if it needs to be more in depth. Example What Works for Us Report- 4 forums and other partners (June 2014)
We know that often the return rate on surveys can be low. Parent carers find **face to face** or **telephone contact** a better way to engage. Some Forums offer vouchers to the first 10 or 20 respondents.

Use **every opportunity** to talk about the important issues for your parent carers- **capture any themes emerging**.

**Top Tip**

**Share these themes** at your next meeting-decide if it needs follow up. **Who needs to know about this issue?**

**Who can act on it?**
Designing a Survey

Imagine it as a funnel

Start out broad then narrow it down. Avoid order bias. Do not give away the answer you would like in your question.

Use clear language and the right tone.

Keep the length in mind.

Ensure confidentiality.

Decide if it needs to be kept anonymous.

Top Tip

You need to start out with a clear understanding of what you are trying to achieve.

Adapted from D. Gardner.
Further help

Ask other forums what surveys they have done?
Is there a **good survey you can adapt** so you do not have to re-invent the wheel?

**Kent Parent Carer Forum** have a **click on** section on their website for parent carers to complete interactive surveys – currently have 13 open across a whole range of topics.

http://kentparentcarerforum.co.uk/home.aspx

Dr T Burgess at the University of Leeds has written a guide for **non researchers** on how to design a survey:

http://iss.leeds.ac.uk/downloads/top2.pdf
The importance of how you describe issues

Social Model of Disability
Presenting your case (1)

• Always think about your audience – what do they know already – what are their interests?
• Keep it simple and powerful - highlight key points
• Verbally - rehearse what you want to say with another parent carer
• Written – one page, or if it is a more detailed, longer paper have a short summary.
Visual information helps most people digest facts.

- People are **30 times more likely** to read something with images than **just a text alone**.

- **Infographics** are good for **data, maps, timelines and comparisons**. Aim to have more images and less text. Use a free software package such as: [www.piktochart.com](http://www.piktochart.com) or [www.easel.ly](http://www.easel.ly)

Using **Infographics** was straightforward and quick. Another method is **to create something** using publisher or similar software – by finding images from clip art or your own photo collection **or** you could **pay for** print /design expertise.

Our next slide is an excellent example of using **Infographics** taken from the CAF **Counting the Cost 2014 Report**.
Good example of Infographics

SURVEY RESULTS

Going without

83% of families with disabled children say they are going without.

I go without food on a daily basis. I make a £30 shop last two weeks. If there is no money left for electricity then there's no electricity.

In winter having little or no heating makes Yasmin's muscle spasms worse, which is extremely painful for her.

THE NUMBER OF FAMILIES GOING WITHOUT FOOD AND HEATING HAS DOUBLED:

31% going without food
16.5% 2012
14% 2010

33% going without heating
21.5% 2012
16% 2008

AND A THIRD OF THOSE GOING WITHOUT FOOD AND HEATING ARE DOING SO MORE THAN ONCE A MONTH
Presenting your case (3)

• Focus on any solutions and options as well as highlighting the issues

• Fill out detailed surveys such as the SEND Survey for the Department of Education—ask questions if you do not have the information you need - can this be done in partnership?

➢ Our recent experience in Luton
Presenting your case (4)

Avoid

• Presenting inaccurate information
• Exaggerating numbers because of an agenda
• Only asking leading or biased questions
• Being overly emotive
• Not declaring any conflicts of interest
• Using the situation to lobby on your own behalf
• Failing to feedback
Positive Parents influencing service provision

3 years ago PP realised that Short Breaks money was not reaching families so after talking to parent carers they identified that there were few family leisure activities on offer in the large country park.

They negotiated with the council to spend some of the Short Breaks grant on a range of accessible bikes after researching other schemes and highlighting health benefits.

They worked in partnership with the council and the park team to add this range of eight differently adapted vehicles to the regular fleet of bikes two years ago.

Now everyone can enjoy the great outdoors.
ACTION BREEDS CONFIDENCE & COURAGE.
Questions?
• Thank you for attending with us today

• A short questionnaire will launch at the end of this webinar

• Please take the time to complete this it will help us plan future online training events including other topics you would like to see

• The recording of this Webinar, presentation and questions will be on the parent participation Resources page of Contact a Family’s website next week – an email confirming this will be sent to you once this is available