contact a family
for families with disabled children

Strengthening Parent Carer Participation
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.

• I will select as many relevant questions to answer as time allows, if similar questions are received I 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, 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
Reach out a Little Further  
‘Building an inclusive and credible forum’

Training Facilitator: Lorraine Pattison  (Associate Consultant)  
Parent Co-facilitators: Steph Sherratt & Jacqui Byland
Before we begin the webinar let us first introduce ourselves:-

hello
Introduction

This webinar is intended to support forums across the country to ‘Reach out a little Further’.

- Support you to build an inclusive and credible forum
- Promote wider participation by reaching out to those families who are often labelled ‘Hard to Reach’

Duration of the session: 1hr
What we hope you take away from this webinar?

- ‘Partnerships & Networking’ and Inclusive practices
- The ‘Emotional Psychology’ that prevents people from joining their local forum.
- The ‘Practical Barriers’ faced by families.
- Strategies to remove those barriers, to promote wider participation.
- Equality & Diversity
- Marketing & Promotion
It is recognised that forums across the country are at various stages in their structure and development.

Whilst some forums are well established, with wider family members, others are recruiting new members and some are beginning again for a variety of reasons.

Whatever stage your forum is at, we hope this webinar will help you to become an inclusive and credible forum.
Inclusive practice is an approach to enable and empower all parents and carers to access and contribute to the forum, feel valued, listened to, respected and acknowledged
Protected Characteristics

- Age
- Disability
- Race
- Sex
- Gender reassignment
- Sexual orientation
- Pregnancy or maternity
- Religion or belief
Inclusive Practice

• Forums must not discriminate against people or treat them unfairly on the basis of these protected characteristics (Direct Discrimination)

• Forums must not do something which will have a worse impact on someone because of a protected characteristic (Indirect Discrimination)

• You must not treat someone less favourably because they have complained about discrimination (victimisation)

• You must not behave abusively or disrespectfully towards someone with a protected characteristic or tolerate this from any other forum member (harassment)
Inclusive Practice

- You must challenge negative comments and stereotypes within your steering group, wider membership and in any other arena
- Good Practice Develop and Equality and Diversity Policy and make sure you let your committee, members, staff, parent representatives know about it
- Develop a code of conduct so everyone is clear on the behaviour that is expected and put on training for members
- You must make reasonable adjustments for disabled people to access your service
- Forums should also be taking positive action to identify groups not yet represented, plan and take action to reach out to these groups
Diversity relates to differences in:

- Culture and/or language
- Gender and transgender
- Appearance
- Lifestyle
- Sexual orientation – Lesbian, Gay, Bi-sexual, heterosexual
- Social and economic circumstances
- Family structure
- Abilities, e.g. physical, social, creative, intellectual
- Values and beliefs.
Barriers for Parent Carers

- Working parents who cannot attend events
- Parents who had a negative experience of a group
- Parents who speak English as an additional language
- Parents new to the country who have little experience of culture
- Grandparents – legal guardians who don’t respond to fliers advertising to parents or feel it wouldn’t be appropriate for them.
- Parents with low self-esteem and self-confidence
- Single parents – mums or dads

- Dads- no direct mention of
- Parents with no extended family members
- Parents who feel they have little to contribute to a group
- Young Parents / Teenage
- Parents in mainstream settings
- Disabled Parents
- Parents who home school their children
When we make reference to the wider family, we do not mean only mum and dad, it is meant as an inclusive term which includes grandparents, foster parents, adoptive parents or anyone with parental responsibility caring for a child with special educational needs and/or disabilities.
Inclusive practice in forums provides opportunities for all cultures and diverse groups of people to access support, feel welcome, develop new friendships and find out what help is available for their family. Feeling welcome and included helps build and strengthen peer relationships, and promotes and understanding of diversity and respect.
There are no strangers here; Only friends you haven't yet met.

William Butler Yeats
• Be mindful about the “people like people like us” theory – and only attracting people with the same views and interests as you – this is particularly key for leaders

• It’s important to involve people with different views, interests and ideas – this keeps the forum fresh and builds inclusivity.
We need to recognise that although some individuals have physical, cultural and psychological differences, which affect their everyday lives. Some elements of society or other people’s reactions to these differences contribute and dis-engage people further, making them less confident to come along to new events. That maybe the physical environment, organisational and / or attitudinal barriers.

It is these barriers that result in people being excluded or labelled:-

‘Hard to Reach’

Lets us now look at the range of emotions people go through when dealing with changes in their life.
What makes it ‘Hard to Reach’?

- Accessibility
- Poor communication and advertising.
- Never enough time/warning given
- Social media feeds their needs (do they?)
- Not having extended family members
- Not using your allies/networks (professionals, local sources, charities, organisations)

Emotional and Psychological Barriers

- Not identifying with other members (BME)
- Mis-trust / stigma
- Special needs themselves
- Helplessness, hopelessness, sense of complete isolation ‘feeling no-one else is like them’
- Depression/Denial/Guilt/
- Acknowledgement/low morale (of child with disability)
- Wording?? Misleading/off-putting not drawing people in eg workshops offering ‘parenting programmes’ ‘come and get your voice heard’
Forum Leadership Style

• The Style and approach of forum leaders is vital to the inclusive development of the forum

• You need to create a trusting and nurturing forum that people want to be part of

• how do other people perceive your forum – what unconscious messages do people pick up on and how does this impact on public perception of the forum
‘Practical Barriers’

- Some parent, carers and wider family members are not in the usual ‘networks’ who you target.
- They can’t get to the venue, low income, no car, no bus service
- They cannot make the date or time – venue or meeting isn’t accessible – they need interpreters, ramps lifts, speech to text reporting
- Food doesn’t meet their cultural needs – halal, vegan,
- The agenda does not suit -It does not fit with their life at that time (e.g. survey on wheelchair services)
- They don’t want to be amongst a certain group or won’t go to certain towns, villages and areas
- Suffer fatigue from a particular subject (eg LA constantly asking for views on short breaks and not delivering on feedback/solutions)
- They have a large number of professionals involved with their child and constantly at meetings and appointments and the advertising material does not hook them.
- Even exhausted parents would come to events but some need a ‘HOOK’ to get them there in the first place, then its up to you to ensure they see the value of coming along
Some parent carers will be ‘Hard to Reach’ if:-

What you are offering does not appeal to them, they don’t see the value of, or how it will benefit them or their family. Whilst you have experience of how these families are feeling:

The key is to step outside yourself, walk a mile in their shoes, re-evaluate and reflect upon what your aim is, think about the world they live in, see it through their eyes right now.

REMEMBER YOU’VE BEEN THERE- YOU KNOW WHAT YOU CAN OFFER - THEY DON’T.
Remove the Barriers

Insanity: doing the same thing over and over again and expecting different results.

Albert Einstein

http://www.brainyquote.com/quotes/quotes/a/alberteins133991
Introducing Steph & Jacqui

Sharing what they did in Bolton to widen participation and their membership following an area of improvement they identified as a priority for them.
Striving for a voice, choice and equal opportunity for families of Disabled children aged 0-25 years

Bolton Parent Carer Consortium

Striving for a voice, choice and equality of opportunity 0-25 years

Bolton Parent Carers Consortium

February 2016
Who we are...

- In May 2014 life started with seven voluntary sector groups who met to develop a constituted group Called BPCC consortium.

- ZACS, Breaking Barriers, Greenfold parents group, Day trippers, COG, Imag1ine, Shorai Conflict and Prevention, BAAS, Parent representatives on Task and Finish Groups (Full members)


- Rumworth SEN School (Partners)
• We currently have open and closed steering group meetings
• We have a number of sub groups one of the being Seldom heard Families. This sub group meets approx. every month and then reports back to the steering group.
• We have a small budget to cover the costs of our priority areas from the Main Government grant.
How this sub group came about

• In 2014/15 BPCC applied for a discretionary grant to achieve this aim.

To assess ways to promote BPCC and support to families, who may be seldom heard (hard to reach in communities where English isn’t their first language). To break down a communication barrier.

• We worked with an Asian family who helped us to forge links with Bolton Council of Mosques, (BCoM in turn link to the 24 Mosques in Bolton). We met regularly at BCoM to become familiar with the local community and in April 2015 organised an “Open Day” inviting the local community, Mosque leaders and local providers having a small market place.
What’s happened in Bolton?

• The discretionary grant was used to translate an A4 double sided leaflet advertising the Open Day -one side English and one side in Urdu and this was sent to all the primary and secondary schools in Bolton who had Asian Families and given out to all the Mosques via BCoM. We also translated and printed the BPCC leaflet and our SEND brochure into Urdu.

• Our leaflet has been distributed via the BCoM manager to every Mosque in Bolton.

• The grant was also used to offer a Workshop to our BCPP members and parent carers aimed at us all having a better understanding other minorities. We looked at Myths surrounding a variety of cultures based on Bolton's population and used a local firm to deliver this workshop.
What we learnt from year one...

• That we have to go at some one’s else pace, so the open day had to be within the Easter holidays as that when we would attract the local community.
• To offer local cuisine which was made by the male elders at BCoM.
• That we can’t reach everyone at the same time and year two we would prioritise based on Bolton population.
Year two

• We forged links with ACIS - Achievement, Cohesion and Integration Service
• ACIS is the first point of contact for families coming into Bolton i.e.
  • Refugee status in a refugee camp
  • Asylum seekers
  • EU Country Migrants
  • EU secondary Migrants
  • Migrants from outside the EU using a Visa
• It has been a fascinating journey to date to get an insight into what a family experiences upon arrival in Bolton.
Year two

- After the meeting with ACIS we almost went back to basics, looking at how a family might access the internet, use our website as a starting point
- Now Use google translate – not brilliant but a starting point
- Re designing the home page to have a button to press to locate our leaflets etc. in different languages
- We looked into the priority languages in Bolton and have recently translated out leaflet and SEND brochure into four more languages
- We designed a basic A4 poster to sign post families about education and this then formed a discussion about what next
• We have very recently linked with BRASS - Befriending Refugees and Asylum Seekers and plans are in place to further this opportunity.

• We have re looked at who is “seldom heard “ and this has created questions to answer and from that.

• We realised that any family can be “seldom heard” because you don’t know what you don’t know, we will continue to look at creative ways to engage and in 2016 that will be through Health and Social Care.
First Steps

• Understand your current membership via your database
• What information do you capture in your database – is it just names and addresses/email addresses or do you have a specific database and membership form which captures postcode, date of birth of child, disability or additional need of the child or young person, age of the main carer, ethnicity?
• There is an example of a membership form as a handout with this webinar
First Steps

Which diverse groups are living in your community

• Your local authority must produce information about the local population and a Joint Strategic Needs Assessment with the CCG (Clinical Commissioning Group)
• They must also produce a Short Breaks Statement which outlines the following:
  • the range of services provided
  • any criteria by which eligibility for those services will be assessed
  • how the range of services is designed to meet the needs of parent carers in their area

• Office for National Statistics has a range of information and you can compare find out about regional trends here:
• You can talk to your local authority to find out more
• Look at your database and find out which groups are missing
Building Partnerships

You don’t have to do it all yourselves!

- Local Authority and CCG Leads – what doors can they open for you?
- Lead Officer for the Portage team
- **Voluntary Sector networks in your area**
- LA Out Reach (LIST) teams out in the community
- Lead in the SENDIASS team - (Local Offer Webpages)
- Lead Officer in Families Information Service – (Local Offer Webpages)
- Children Centres – Managers and Family Support Officers
- Early Years - Local Preschools, Nurseries, Leisure Centres, Health Centres
- Local Short Break Providers
- Child Development Centres
- Hospital Clinics and GP Surgeries
- Local Shops – specialist shops such as those for equipment, specialist food shops such as Polish Supermarkets, Chinese Supermarkets
- Community Networks and Community Centres or village halls
- Churches, Mosques, Temples, other religious or community based centres
Lincolnshire Parent and Carer Council sent their forum leaflet, a survey and reply paid envelope to all schools in their area with help from the local authority school carrier service – they had over 2000 replies for parents and carers who all became members.

Other forums attend school parent evenings and open days with information stands and a team of forum ambassadors who actively promote the forum and capture key issues faced by families.

- How does your forum get information to Parent/Carers in Special, Mainstream or Independent Schools and colleges?
There's a way to do it better - find it.

Thomas A. Edison
Communication is more than words, it is the exchange of thoughts, feelings, information and ideas between people. Spoken language is just one method people communicate by, it is by no means the only one. Fundamental to your marketing and promotional materials is getting the message across.

People need to understand fully what's on offer, what’s in it for them, what's involved, what's expected of them if anything, how they will fit in.
Marketing and Promotion

- Not all parent carers want or can be involved to any great extent
- Ensure there are a variety of ways for parents to contribute – Some parents will need to get to know you, like you and trust you before they may be willing to commit to anything more than attending an event or receiving a newsletter
- Find out how other forums promote themselves and their activities, Look at other forums websites and make sure you keep yours up to date
  - Have more than one way for parents to join, and communicate with you
  - Use symbols to show people you are inclusive
  - and that your forum is also for them
Parents attention may not be grabbed by headlines such as:-

- Help us Shape and Influence services
- Parent Participation- come have your voice heard
- Join a Strategic committee – get involved

They are more likely to respond to phrases that appeal to them personally, such as:

- does your child have additional needs
- are you getting the support and help you need?
- help us to make a difference
- Meet other parents
- Develop new skills and increase your job chances
- Learn about services and support available
The language we use can be that essential difference to getting a clear message across and improving participation and attendance.

Ask people who don’t know anything about you to look through your information in draft form before publishing it.

Everyone smiles in the same language.
Hooks

Just one these hooks could be the MAX CARD. Offers discounts at family attractions.

Some forums use them to attract new members linking this up with the disability register or as a stand alone offer.

http://www.mymaxcard.co.uk/
The S19 principles are designed to support participation, offer greater choice and control and promote collaboration between education, health and social care. Further more to support high quality of provision to meet the needs of children and young people with SEND.

Forums need to think about how they involve their wider membership in the development of the forum so they are also respecting

- Views, wishes and feelings of wider families
- Promote participation in whatever form that supports choice and control
- Encourage collaboration in order to contribute to making a difference

Some thoughts to link with Marketing and Promotion

Forums need to think about how they involve their wider membership in the development of the forum so they are also respecting

- Views, wishes and feelings of wider families
- Promote participation in whatever form that supports choice and control
- Encourage collaboration in order to contribute to making a difference
Other Forum Successes

• Brighton and Hove meet regularly with the Lesbian, Gay, Bi-sexual and Transgender switchboard and one of the parent reps on PaCC Steering Group is a representative of the LGBT communities. They plan to do some more targeted outreach in the future.
Bradford Bangladeshi Community

- We spent a good 18 months in linking in and working with leaders in the Bangladeshi community in order to be able to hold an event at their community centre. For Bradford, the Bangladeshi community have many families with multiple children with disabilities and also children with many health needs.

We used our existing links with Barnardo's who already were working with the Bangladeshi Community Association. Through them we were introduced to their committee members who realised that we could help support and gather the voices of many of their families in order to improve and influence the services they received. Quite a number of families had no services or very few. We were able to hold a Chill, chat and chew event at their community centre and have not looked back, increasing members, gaining trust and being able to feed the views of those families to necessary services that can support them.
More Successes

- Slough Take laptop to event and encourage people to sign up to Disability Register and help them set up an email address if they don’t know how. Use translators to reach BME groups.

- Gloucestershire Use a mobile projector to meet groups in their own community buildings to tell them about the forum.
More Successes

• South Glos – dedicated person to support and train volunteers and tailor roles to their interests and talents, no matter how long they can commit for or how little time they can offer to ensure.

• Cornwall – uses Facebook to reach parents across this rural county – asking support groups to consult with their members and feed back to the forum.

• Islington put on a film night for Dads which has been really successful in attracting new dads and enabling them to get involved.
“The tide has gone out and has left a million starfish on a beach. They are slowly dying under the heat of the sun. A little girl is walking along this beautiful sandy beach. As she walks, she picks up a starfish and throws it into the sea. Then she picks up another one and another one, throwing each into the sea. An old man comes up to her and says; “What are you doing, little girl? There are millions of starfish out there, dying. You cannot make a difference.” The girl kneels down, picks up a starfish, throws it in the water and says, “It made a difference to that one!”

Individuals cannot necessarily change the world. BUT “YOU CAN make a difference” and collectively as a group you can influence change for the better.
If we did all the things we are capable of, we would literally astound ourselves.

Thomas A. Edison

http://www.brainyquote.com/quotes/quotes/a/alber Eins133991
## Positive Action

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<th>What you do now</th>
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Training is fundamental to the future success of any group. It is good practice to ‘up-skill’ other members of the steering group or wider forum, so they are skilled and prepared to take over a role in the event of another parent moving on.

Forum Leaders need to adopt a Community Development approach. Coaching and Mentoring others is a model that ensures everyone has the appropriate underpinning knowledge that can be put into practice.

The publication opposite produced by Contact a Family entitled ‘Parent Carer forum Handbook’ is a really good resource to assist all forums in not only set up, communication, marketing and social media.

http://www.cafamily.org.uk

It has helpful sections to assist in managing changes and planning for the future.

See pages 62-65 handbook for more in-depth guidance.
Coming together is a beginning; keeping together is progress; working together is success.

*Henry Ford*
Thank You

- 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