



Our Voice Parents' Conference June 23 Report

Summary

Our first face-to-face conference since 2019 had around 70 parents and carers attending.

Verbal feedback on the event was very positive, and this was confirmed by the evaluation forms that we received. Parents welcomed the chance to talk to key professionals in the panel session, discuss individual issues in one-to-one sessions and attend the Mental Health workshop.

As always, the organisation of the conference is very time-consuming for a small organisation such as Our Voice, partly because of the sheer numbers involved, with more than 30 professionals having a role. However, the event offers an unparalleled opportunity for coproduction and has a huge impact in terms of opening up discussions between parent-carers and professionals, and so we feel it is an extremely worthwhile exercise.

The constraints of our venue meant that we had to limit numbers and we were only able to hold one workshop (rather than 4 at our last face-to-face conference) and a more limited number of 1:1s with a maximum of 66 slots in the 1 ½ hour session compared to 156 at our last face-to-face event. Despite this, the format of the event was successful overall, and people generally felt that the 2-hour slot for the Q&A session was about right when combined with the opportunity to ask questions via post-it notes. Obtaining some questions in advance, and tailoring them effectively, made the session more productive for parents and we were able to get answers to a broad range of questions relevant to a wide audience.

Summary of event feedback

Based on verbal and written feedback received:

100% found the event useful overall.

92% rated the Q&A session as good, very good or excellent

93% rated the mental health workshop as good, very good or excellent

80% rated their one-to-ones as good, very good or excellent.

Key quotes:

The event was so very well organised. Thank you for all the hard work that went into it. The coordinators were excellent in ensuring people got to ask their questions and also provide information themselves from their experience of being in the system. Thank you so much and I look forward to next year's event!

Thank you for hosting this event - it makes us feel not alone, and know/signpost where we can get help

'I made more progress in the 30 minutes of my two one-to-one sessions than I have done in over 6 months of emails and phone calls'

Key themes from the event

There were a number of themes that recurred, and it was clear that some parents are frustrated by their experiences with the system.

- Frustrations with annual reviews not being carried out in a timely fashion and the knock-on effect this has
- Frustration that some schools are not inclusive of children with SEND and that they are not held to account in this respect.
- Transition to some services at age 18 can still be problematic and parents feel that they are sent around in circles when trying to resolve problems
- Waiting times for services are a source of frustration – particularly for CAMHS and diagnosis.



- Poor communication from some services continues to be a significant source of frustration and often erodes trust and confidence.

Recommendations

- We propose holding termly ‘mini’ parents’ conferences’ focusing on specific service areas so that we can explore issues in more depth, head off potential problems, and allow for more one-to-ones (especially for those areas where demand outstripped capacity, especially CAMHS, OT, SEN Services, Speech and Language and JSDC) and hold related workshops. We are currently setting up meetings to discuss these with professionals from the areas that we propose are involved in our initial sessions, which are:
 - Social care/JSDC/Short Breaks
 - Health and therapies
 - SEN Services
- The tabletop exercise at our Mental Health workshop opened up some interesting avenues to explore further the particular barriers that can make it difficult for our young people to access services and some ideas on how these might be overcome using a multi-disciplinary approach. We are setting up follow-up discussions to look at the feasibility of a project to address these issues.
- As communication is an ongoing issue, we recommend that services give focus to this area including setting expectations (setting out steps and timescales at the outset and being clear when parents can expect to receive a response), ensuring that cover is in place for absence and alternative contacts are clearly communicated when this is the case, and ensuring that escalation systems are transparent and this information is accessible to parents.

Contents

Summary	1
Summary of event feedback.....	1
Key quotes:.....	1
Key themes from the event	1
Recommendations	2
Feedback	3
Overall	3
Q&A Panel Session	3
Workshop on supporting your child’s mental health	4
One-to-one sessions.....	4
Venue	4
Mental Health Workshop Analysis	5
Appendix – comments from parents	8

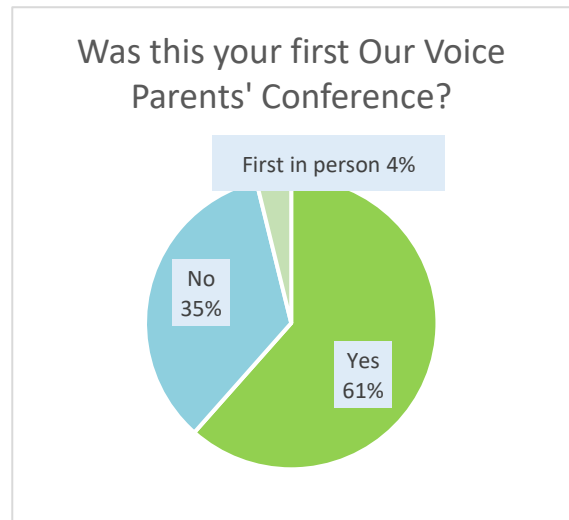
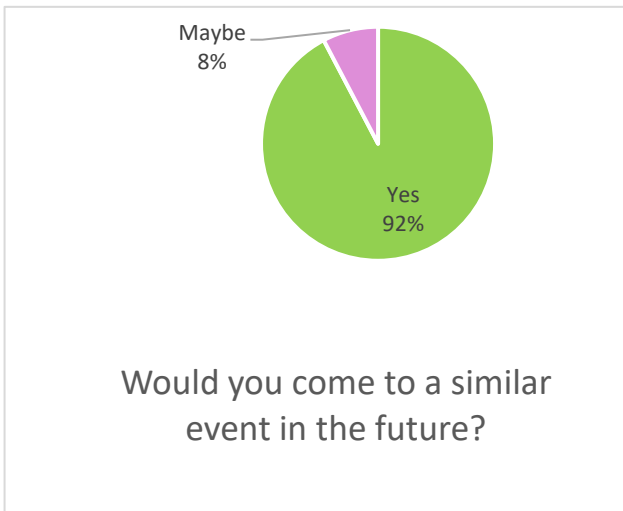
Feedback

We received a total of 26 completed feedback forms (on paper at the event or online in the following week).

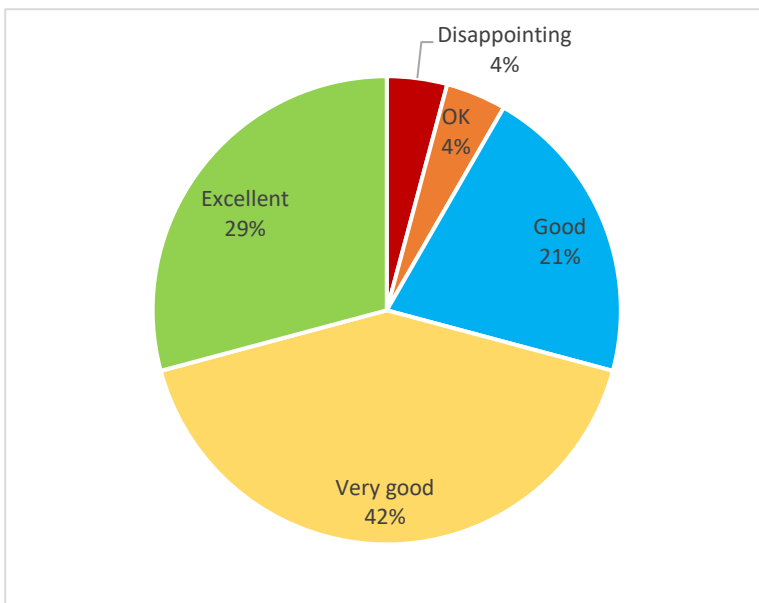
Overall

Parents were asked to say whether they found the event useful and informative. Of the 25 people who responded to this question 100% gave a positive response to this question, with several adding comments to say how useful it was and express their thanks.

61% of attendees had not attended the conference before. The large majority said that they would come to a similar event in the future.



Q&A Panel session



This session worked well and was generally well-received. Obtaining some questions in advance enabled us to manage the session more effectively, but we were still able to allow plenty of time for live questions as well as gathering more via post-it notes. We had two hours for the session and comments suggest that this was about right.

25 feedback forms were received, with 29% rating the session as excellent and 42% as very good and 21% as good.

From the comments, it appears that the one person who rated the session as disappointing was expressing their sense of frustration at dealing with the system overall, rather than specifically with the event.

Workshop on supporting your child’s mental health



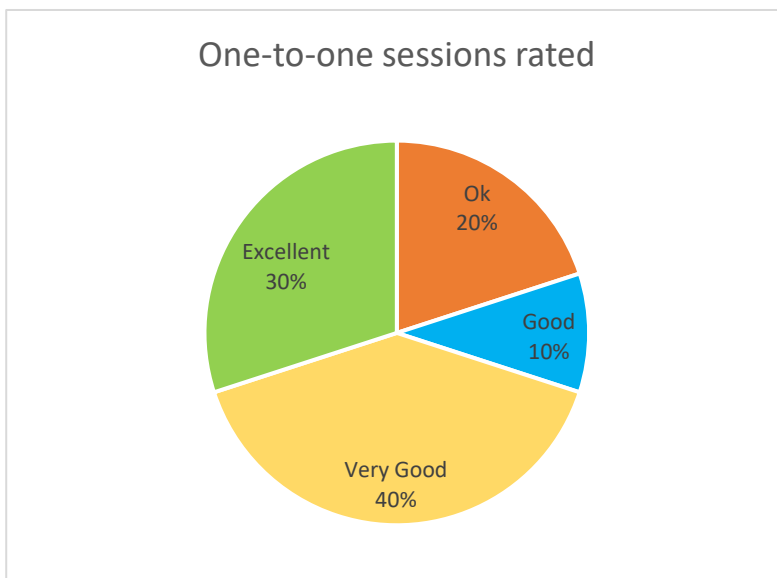
20 feedback forms were received with 70% rating the session as excellent or very good and a further 23% as good.

Although we didn’t specially ask for comments on the workshop ,one participant said ‘Great participation - everyone seemed comfortable to share. Great to feel so many organisations are working towards a common goal’.

One-to-one sessions

Generally, the feedback (both written and verbal) on one-to-one sessions was very positive.

We know from past experience that parents particularly value this session, and we were particularly pleased to be able to offer so many slots this time and that we were able to cover such a wide range of services. One parent commented: *‘I made more progress in the 30 minutes of my two one-to-one sessions than I have done in over 6 months of emails and phone calls’*



We received 11 feedback forms relating to the one-to-one sessions, with 70% rating these as excellent or very good.

One parent felt that they did not have enough time in their one-to-one with transport (still rated as 4).

Regarding their one-to-one with physio, one parent commented *‘He was very helpful in providing useful information and took time to listen to my concerns regarding supporting my child’*.

Venue

Everyone who answered this question said that they liked the venue.



Mental Health Workshop analysis

How do we better support the mental health of children with SEND who are already some of the most vulnerable to having poor mental health?

For our conference workshop, we thought carefully about which topic would be most useful to our families and Mental Health for our children and young people was the area our families requested the most.

We know there is a national crisis for all children and adolescents, but this workshop highlighted that our CYP with SEND are disproportionately impacted. They are already at higher risk of poor mental health, and this is compounded by inadequate and inappropriate support from statutory and community services.

Community Services in Enfield offering early intervention support for Mental Health

We invited 5 services from the community who are supporting mental health for all CYP in Enfield well:

- NCL Waiting Room
- Wellbeing Connect Services
- EPC (Every Parent and Child) – My Time Counselling Service
- MIND Parent Support Programme
- Mental Health Support Teams in schools

*SEND specific support offered by these organisations:

- NCL Waiting room - Signposting to the Local Offer
- My Time Counselling for those with mild SEND and no learning disabilities
- MYME attends special schools
- MIND has an 8-week programme for parents of CYP without PTSD or moderate to severe learning disabilities, who are on the CAMHS waiting list

Why do CYP with SEND need specialist mental health support?

I. *They are more vulnerable due to many factors:

- Anxiety in autistic CYP and those with a learning disability, even in normal circumstances
- Complex communication needs
- Unsupportive and challenging environment (including sensory challenges)
- Health issues
- Many of our CYP/families are suffering trauma with compromised coping abilities
- Lack of meaningful activities and opportunities for relationships/friendships

All of the above were exacerbated during covid with increased school absence, increased anxiety, lack of routine, reduced activities etc.

Firstly, the identification of mental health issues in our CYP is concerning due to:

- Diagnostic overshadowing, where the deterioration in mental health (expressed in behaviour change) is misunderstood or misdiagnosed as an expression of the child's learning difficulty/disability
- When this poor mental health is overlooked or incorrectly explained, it can and often leads to crisis and possibly admission into tier 4 services

II. They are poorly supported with insufficient therapeutic and social care services:

- Crisis prevention for SEND is undervalued by Government, under resourced and underfunded



- Not enough staff in CAMHS for all children – long waiting lists and recruitment is challenging
- Parental perception is that the additional skills and knowledge needed to successfully support CYP with SEND are lacking so that they are discharged quickly without effective or meaningful treatment
- Pre-CAMHS support/early intervention for CYP without SEND does exist, but very little for SEND (see above *)
- Mental Health support is being developed in schools for children without SEND and for those with less complex difficulty/educational needs

Tabletop Exercise

We heard from a few organisations looking at what they can offer. Early intervention for CYP with SEND is challenging for both CAMHS and for the early support services.

So the workshop focused on being creative, asking its participants :

1. How can we help our children and young people as well as their families as a whole, more?
2. We can discuss what else they may be able to do to support our children with SEND
3. We can also discuss ideas about what would help your child – even if they sound unrealistic – to see if any of these ideas might be things that we could work together to help our families
4. What are the barriers now?
5. What could be put in place to adapt existing services so that they are fully accessible for children and young people with additional needs?
6. What new ideas could be introduced to provide support in a more timely way?

Thoughts, ideas, and suggestions gathered from table discussions including parent carers and service providers

Parent support – training and support for parents/carers:

Trained Parent Buddies

Transition and mental health and well-being support

Train parents in skills and strategies to help them /their children

Via school or MH online workshops re how to manage/meet your own child's needs

Early prevention – help parents before things reach crisis

Creating a network community to share skills knowledge and experience

Offer group therapy for parent carers – as above can also network and share skills/knowledge (not alone)

More emphasis on transition support

Training for staff – MH teams and schools and SEN

To better understand the needs of SEND children and young people and how to best support – knowing types of triggers and what would help – exploring how to identify these triggers and how to support them and reduce anxieties

Communication – more training to support professional's ability to communicate to children and young people – e.g. trained in basic Makaton, Talking Mats etc. by SALT – “train the trainer” approach, and have other “experts” doing the same in schools and across services

Planning ahead –



Offer of CBT (Cognitive Behavioural Therapy) whilst waiting for CAMHS – more accessible – can do in groups of parents and groups of like ability children?

Training for services as to what other services are available... e.g. GP reception or 111 staff not automatically referring parents to go to A&E if having a mental health crisis.

CAMHS and other services to make more short training or information videos available

MH and WB leads/champions in schools/all educational settings for those with SEND (not just the SENCo)

More schools offering and having staff trained in Emotional Literacy Support Assistant (ELSA)

Improved processes and training around Transitions

More support for children and young people

Similar training for parents/professionals as for children and young people – (just adapted)

More support for siblings

Improved support for Transitions

Social care and more activities and community support

Promotion and development of places or ways for children and young people to meet and more leisure activities in general developed to meet their needs, on a group basis but also 1-1 friendships

More activities where parents/carers can attend as well as children and young people can attend together

More respite for parents

Despite efforts around Local Offer – making it easier for people to find activities available locally

Improved support for Transitions

Coproduction; parent carers, services and schools working together

Schools need to work on effective collaboration with parents, so they are able to input

Parents and school should review every 6 months

Integrated joined up working.

When supporting a child with complex needs, there must be a multidisciplinary team to include mental health, SaLTs, OTs, EPs, so that the factors mentioned above *, do not prevent effective identification of mental health issues and good/appropriate support planning is formulated with the right expertise

Less patronizing and jargony explanations

Recommendation

Following our conference workshop, we recommend that Our Voice representatives and an MDT of senior professionals with decision-making authority work together in order to explore trialling one or two of the concepts/ideas above with one or two willing parents/carers, young people and associated services, to develop case studies and review and evaluate impacts and outcomes.



Appendix – comments from parents

General comments

The event was so very well organised. Thank you for all the hard work that went into it. The coordinators were excellent in ensuring people got to ask their questions and also provide information themselves from their experience of being in the system. Thank you so much and I look forward to next year's event!

Thank you for hosting this event - it makes us feel not alone, and know/signpost where we can get help

The event was detailed and allowed lots of Q&A

The event was well structured and there was a fair time for Q&A. The event met my needs and was very helpful to my needs.

MH Workshop - great participation - everyone seemed comfortable to share. Great to feel so many organisations are working towards a common goal.

It was a nice event. It is nice professional is there find the chance to talk, thanks

Look forward to receiving resource pack and answer from panel on other questions raised. Thanks Our Voice

Very well organised. Thank you to everyone for facilitating Meet the SEND Heads Conference

I enjoyed the event and learned many new things

Thank you. It has been very helpful. It was nice to ask questions and understand the support

I really appreciated this kind of event for parents. Thanks

Well done Our Voice team! Thank you for arranging the conference.

Fantastic - thank you so much.

Negatives

Once again lots of talking but the services are still inadequate and are getting worse. Talk is cheap and nothing changes. The whole system is not fit for purpose. I've been in this system for over x years with x children and all services have been destroyed by your education system - it is a joke! (note: numbers removed from quote to ensure anonymity)

What else would you like to have seen at the event?

Break-out session for parents with children of similar age with relevant professional support to talk through challenges and support available

Additional coffee break. Microphone v. helpful.

Perhaps a little more time for Q&A with the panel as a lot of parents/carers had questions that they wanted to ask but were prevented due to time limits.

Perhaps helping parents/carers with their personal referral forms or guidance for these - still at this stage.

It's been the same year on year with no real changes happening.

It was nice helpful, very welcome, but we need more help and information about Adult service. Thank you

A maximum of 1 or 2 questions for each person that wished to speak