



## Working Together Well Management Group – 12<sup>th</sup> April 2022

**'Have your Say' on SEND**

You are invited to Parent and Carer Engagement Events focusing on co-production and how your voice can influence the SEND offering in Birmingham. There is a choice of online or in person, with more events planned for February and March 2022.





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### Feedback Report:

### Parent Carer 'Have your say' Engagement Events

*December 2021 – March 2022*



## 1. Introduction

1.1 Findings from the SEND Local Area inspection report identified the following areas of weakness which are grouped together as a priority for development and improvement under the auspices of the SEND Accelerated Progress plan (APP) Objective 3 Working Together Well Management Group (WTWMG):

- Co-production not embedded in the local area
- Parental engagement is weak
- A great deal of parental dissatisfaction
- A Local offer not used by parents as a means of SEND communication

1.2 A number of tasks and actions have been identified as a priority for Birmingham in order to start the process of addressing the above deficits. These include development and delivery of:

- A co-production framework
- A SEND partnership agreement
- A communication and engagement strategy
- Review and improvement of the SEND Local Offer website

1.3 In addition to the above tasks named within the APP, an additional piece of co-production mapping work was commissioned by the SEND Local Area Partnership in October 2021 which has subsequently been included in the above project deliverables.

1.4 In October 2021 the practical task began to address the issues sitting behind the inspection letter headline findings which can best be summarised as:

- A lack of shared understanding within the SEND system (and amongst the SEND Local Area Partnership) about what co-production means
- A lack of ownership and commitment to co-production as a valued approach to delivering SEND support and services
- Weak representation of parent's carers and young people in planning and decision-making structures
- A lack of meaningful engagement opportunities for families (parent carers and young people) which result in tangible and transparent improvement.
- Families not being kept updated about service changes and improvements and how to make the best of this.
- A Local Offer which parent carers and young people did not feel met their needs.

1.5 As part of the practical approach to tackle the above weaknesses and objectives and to build the foundations of co-production working, a number of activities and initiatives commenced in October 2021 (under the auspices of Objective 3). In the first instance this prioritised the SEND Local Area Partnership in collaboration with the local Parent Carer Forum (PVF) working together to develop:

- A Shared understanding of what co-production means
- A working definition for Birmingham SEND co-production
- A set of guiding principles to underpin co-productive relationships



- 1.6 In the spirit of modelling good co-productive working, the next practical task to follow on from and further develop the above work has been the delivery of a comprehensive parent carer engagement initiative across Birmingham which has taken place between December 2021 and March 2022.
- 1.7 The parent carer engagement work has been happening in parallel with a number of other tasks sitting under the APP Objective 3 and most specifically
- The larger scale mapping of co-production initiatives referred to in 1.3 above. This work has involved larger scale engagement with stakeholders across the whole local area SEND system of support including public, community and voluntary sector organisations, young people parents and carers and specifically focusses on identification and exploration of examples of SEND support in co-commissioning, co-design, co-delivery and co-assessment and how such examples can be grown and further developed. This work will be reported on separately to the WTWMG in May 2022.
  - Task & Finish groups drawn from across the SEND system of support and including collaborations with the Parent Carer Forum (PCF) to deliver a youth participation strategy; parent carer engagement plan and network of co-production champions.
  - A specific Task & Finish group will draw together the findings, suggestions, and recommendations of the current parent carer engagement initiative as well as the commissioned activity outlined above in order to develop and deliver the co-production framework.
- 1.8 Going forward, once all the key tasks of Objective 3 are completed, the groundwork is established for the Birmingham journey forward to strengthen and further develop partnership relationships and to work with an approach and a framework that is jointly understood, owned and implemented across the SEND system of support.

## 2. Purpose of Report:

- 2.1 The report provides feedback from a series of 8 parent carer engagement workshops titled 'Have your say' held between December 2021 and March 2022. The report has been compiled by the SEND Improvement team co-production officer in collaboration with the SEND Improvement Team Communications and Engagement Lead who co-designed and co-delivered the work programme alongside colleagues from Birmingham Parent Carer Forum (PCF). The work programme was supported in its delivery by colleagues from across the Education Health and Care family of services who acted as co-facilitators within workshop sessions.

The aim of this report is to:

- Provide an overview of the engagement process and system learning from this
- Provide a summary of key messages and issues from parents and carers
- Seek WTWMG agreement to utilise report findings to further develop the co-production framework
- Offer next step recommendations



### 3. Methodology/Process:

- 3.1 The planning, preparation, promotion, and delivery of the engagement work programme commenced in October 2021 and was originally planned as a series of face-to-face workshops happening across the city throughout December 2021. The onset of the Covid-19 variant Omicron and associated government restrictions meant that final plans were altered and stalled in late December which resulted in delayed delivery of workshops as well as a reduction in planned face to face sessions due to the associated restrictions.
- 3.2 Planning and development of the sessions was carried out in close collaboration with colleagues from the Birmingham Parent Carer Forum (PCF) and drew on learning and key messages arising from previous parent carer engagement events held in the city.

To this end, the following principles were agreed:

- Dates, location, and timings of events should specifically take account of parent carer feedback and advice to provide assurance of the following:
    - opportunities for working parents and carers to attend
    - opportunities for parents and carers to attend during the school day when childcare may not be necessary/less problematic
    - opportunities for parents and carers to attend both central and neighbourhood settings preferably with available bus routes
    - opportunities for both face to face and online engagement
  - Promotion and publicity of the workshops should have the largest possible reach to parent and carers of children and young people with EHCPs within schools and all other SEND learning and support services and across Health and Care settings and community settings. Agreed circulation and distribution lines via whole system communication methods including the PCF and other parent carer network mailing lists; schools and health intranet and noticeboard; cascade email circulation across the Local Area SEND Partnership network; SEND Local Offer and other known and reliable parent social media messaging platforms as well as the partnership (NHS, Children's Trust and City Council) social media channels.
- 3.3 The approach underpinning this work programme sought to address the key issues relating to Objective 3 tasks (outlined in 1.4 above) using the SEND Code of Practice principles aligned with a number of respected and credible approaches to this work.

This included key learning and resources from the Council for Disabled Children; Contact (for families with disabled children) NHS Collation for Collaborative Care and the associated Making an Impact programme and Think Local Act Personal Framework (TLAP) in support of greater engagement, involvement, participation, and co-production with families. In essence, the approach was one of 'strengths and value based' to facilitate discussion with parents and carers about the things that mattered most to them in relation to SEND support for their child/young person and the journey of improvement in Birmingham.

In brief, the summary values of TLAP:

- People are citizens first
- Everyone is equal



- People have choice and control over their care and support
- It's important for everyone to feel they are part of their community
- When services talk to people, they talk about what matters to them, what they are good at and what they want to do.

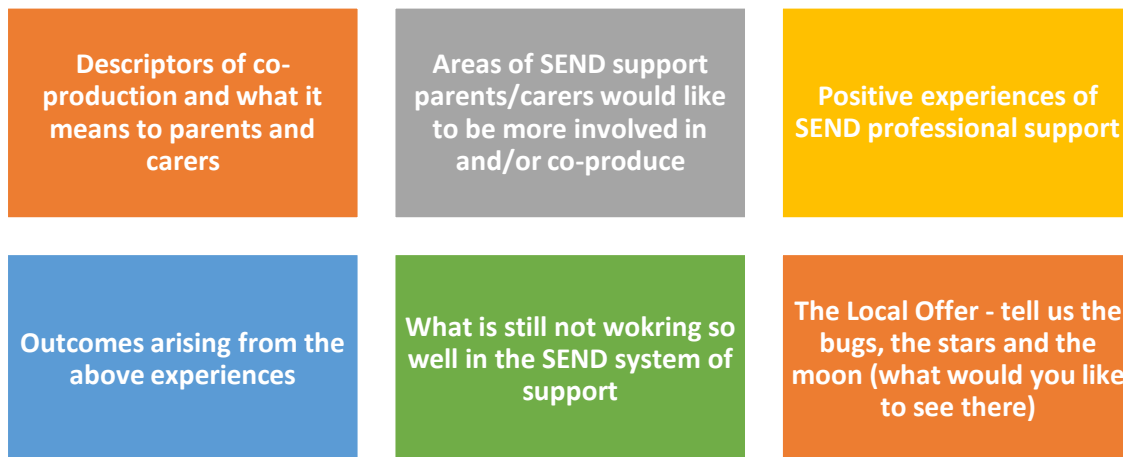
***"... effective participation should lead to a better fit between families' needs and the services provided, higher satisfaction with services, reduced costs (as long-term benefits emerge) and better value for money"***

(SEND Code of Practice 1.11-1.12)

3.4 The aims and objectives of the parent carer engagement workshops were to:

- Update Parents and Carers on the SEND Improvement journey so far
- Share and further develop the draft co-production framework toolkit including definition of co-production, guiding principles for co-production working
- Hear about next step suggestions to develop co-production working
- Road test the Local Offer & identify further ways of improving
- Expand the SEND parent carer network

3.5 The process to achieve the above was largely delivered through facilitated round table discussion groups which captured responses and feedback from parents and carers when asked to talk about what matters most to them in relation to the following:



3.6 Notes of parent carer contributions were taken by facilitators during online and face to face discussion groups and these were subsequently transcribed and now form the basis of a master feedback of comments and experiences and suggestions contained in Appendix 1 below. This body of work reflecting the views and lived experience of just under 100 parents and carers is summarised by the author(s) within the feedback messages and next step recommendations contained hereafter in this report. It is anticipated that the raw material contained within Appendix 1 as well as the key messages and next step recommendations outlined within this report will be utilised to best effect to further develop core tasks both within Objective 3 but also other APP Objectives and most particularly in order to inform the SEND strategy going forward.


3.7 An online feedback survey was promoted and made available to parents and carers at the end of every workshop session and completed forms were used to make changes and improvements in the engagement workshops as the programme progressed. Comments taken from the surveys are utilised later in this report and attributed as such.





4.2 **Opportunities for future SEND co-production** formed part of the next step considerations which parents and carers were invited to discuss. Building on the responses illustrated in 4.1 above (which identified a range of behaviours, values and attitudes, practices, and processes), the following opportunities to strengthen SEND co-production in practice are summarised in the list below.

**Parent Carer identified opportunities for future SEND co-production**

	<p>Education Health and Care planning – important to involve parents and carers from the outset. Parent centred planning.</p>
<p><b>What areas of SEND support for your child/ family would you like to be more involved in or see more co-production of?</b></p>	<p>Form filling for all SEND help and support – involve parents in working documents to change things</p> <p>Involvement of parents at Annual Reviews</p> <p>Would like more support in deprived areas of the city</p> <p>A central hub of SEND support</p>
<p><b>What areas of SEND support do you think should be co-produced?</b></p>	<p>Communication between the council and families – if parents can't get to speak to SENAR then schools and other professionals can't either, so everybody's time is wasted – this needs to be improved</p> <p>Transition and Forward planning to prepare for adulthood</p> <p>Communications systems for parents and carers within health services in NHS</p> <p>SENAR – making it more parent friendly</p> <p>Community links</p> <p>Post diagnosis pathways and support – don't diagnose and dump</p> <p>Holidays/short breaks</p> <p>Peer support networks</p> <p>Funding and personal budgets</p> <p>Choosing where my child's education takes place</p> <p>Making parent support more consistent across all schools</p> <p>A SEND code of conduct for all those involved</p> <p>Bridging the gap with the 3<sup>rd</sup> sector</p> <p>Jargon busting council and SEND information and communication for families</p>



4.3 **Learning from and building on positive examples of SEND practice and support** was a key part of the strengths -based approach used to plan and deliver this series of parent carer engagement workshops. The approach is rooted in basic social work theory and practice that emphasises citizen self-determination and strengths and is underpinned by a philosophy that views individuals and communities as resourceful and resilient in the face of adversity. It is citizen led and has a focus on future outcomes and strengths that unite people and practice. The approach works well and is complimentary to the Think Local Act Personal (TLAP) framework to achieve person centred and personalised care and is compliant with the recommended best practice approaches described in the SEND Code of Practice 2015. Building on these approaches, the workshop sessions provided opportunities for parents and carers to consider and share any experiences of SEND professional practice that they judged to be good and furthermore to identify and share any positive impact and/or outcomes this produced for them.

4.4 **Some Common themes** emerged from the parents and carers who cited examples of positive SEND practice they had experienced, and their responses have been grouped together under the following three areas of SEND support:

**?** *“Thinking about a positive/good experience involving you/your family and a SEND professional – what did they do?”*

**Communication:**

Involved in conversations from the start	Gave good advice and offered professional experience	Good communication and honest advice
Gave good tips for dealing with my daughter's anxiety	Helped me to understand my child	Raised awareness amongst other pupils about my child's needs - intolerance of noise as a symptom of ASD
She was a go-between with me and the SEN officer	Answered all my questions	The professional fed back
She escalated my concerns	She challenged school in a meeting to make sure the meeting included my child's health needs	School puts all SEND information into their newsletter





**SEND Processes:**

Identified early developmental issues in child and acted upon them which resulted in early referral	Paediatrician for ASD nursery age child	She made things happen [Deputy Head-Teacher]
She helped get everyone together. They worked with us, rather than did things to us	Took holistic view of the child. We came up with a common goal and plan	Signposted me to a service and other professionals who helped
Had a named professional (HV, HOY, Support Worker)	Teacher adjusted in classroom environment that took account of my child's needs	Inclusion for my child
Received the plan on time	Took the EHCP seriously and did what it said in it	Good referrals, early recognition and ownership by professionals

**Attitudes, Values & Behaviours**

Listened, made me feel at ease, understood	Responsive (to mine and my child's needs - school teacher)	Professional and dedicated - gave me time
I felt believed and my view validated - made me feel that my child was important to them	Good communication: <i>used plain language, not jargon, broke things down so I understood</i>	A positive approach taken which found ways to work around the barriers - problem solving
Treated my child with respect and dignity as if it was one of theirs	Remembered my previous call, what it was about, and followed things up by email and copied me in	Parents need to be involved at every stage of the process. Including what support is being put in place.
Knowledgable, experienced and up to date - know the system	Parents and children treated as individuals, respected and consulted	See child's behaviour as communication rather than just as challenging behaviour - looked behind for its meaning



**Direct parent / carer quotes:**



**Good Communication**  
*'Kept me informed'*  
*'Responded to my email within the hour!'*  
*'Followed things up with a phone call'*  
*'She kept me updated'*

**Attitudes and Behaviours**  
*'She was always positive – if she didn't know the answer, she came back to me when she had found out'*  
*'They get my daughter'*  
*'Didn't treated me like I was neurotic, or I didn't matter'*  
*'Made me feel safe to send my child to school for the 6 hours a day she needed to be there'*  
*'She was persistent, listened and communicated well.'*

**SEND Processes**  
*'They took the EHCP seriously and did what it said in it'*  
*'Had the same person supporting me from early years until she (daughter) started school'*  
*'The Paediatrician attended school meeting to challenge school and advocate for support'*

4.5 The range of experiences cited in 4.4 above were further explored in discussion with parents and carers by invited reflections on how they felt at the time as a result of their positive lived experience of SEND support. The responses below provide clear examples of positive outcomes that can be achieved for families when they receive the right SEND support, and the simple cause and effect happens. Taken as a whole, these may be the basis to develop quality indicators for co-production and inclusive practice.

**Outcomes arising from positive experiences of SEND support**

**?** *"Thinking about the positive experience of SEND professional support you experienced, what one word best describes how you felt?"*

Relief	Hopeful	Cared For	Advocated for	Grateful	Clarity	At the centre of what is going on
Respected	Believed	Validated	Recognised	Trust	Reassured	Empathy
Supported by professional	Included	Heard	Talked to, not at	Valued	Cried with happiness	Empowered
Listened to	Supported [by school]	Understood Understanding	Involved	Like a family	Emotional	Heard
	Safe	Trusted	Positive	High Expectations	Appreciated	



4.6 **Summary Issues of concern** and identification of areas of SEND support that are still not working so well for families was a natural element of the engagement workshop process and as such did not have any prescriptive methodology or task assigned to it – the discussion was robust and free-flowing by parents and carers throughout the eight workshops and the following summary reflects the key points made.

**Communication:**

Phones aren't answered, no reply to emails and no call backs	Talk to parent/carers from outset about child's development. Make an early referral	Supply Parentlink number on all communications and offer case worker mobile when/where appropriate or possible
Don't know who to contact or where to go next – there is a lack of proper sign-posting	We are not kept updated on healthcare and assessments and what is happening when.	During the pandemic we felt totally abandoned
Lack of ongoing communications regarding child's progress - No regular updates about child's progress in school from any professional	Have to repeat child's and family story to numerous professionals on many occasions. Never spoken to the same person twice at SENAR.	Not involved in early conversations
There is too much jargon and use of acronyms or professional dialogue	Parents feel isolated and need signposting to peer support and support services	Have to explain ourselves several times and told we can leave if we don't like the service.



**SEND Processes**

Parents/carers not included in or invited to EHCP or ongoing meetings about their child/ren's development - and then update.	EHCP information – out of date/irrelevant/not including parents or carers/poor quality	Lack of flexibility about timing of Annual Reviews and other meetings for those with caring responsibilities
Need better information and guidance about what to expect and how to prepare for meetings	CYP fall off a cliff edge at 16+ - Poor and late transition planning	Lack of available options for 16+ - Offer wider choice of opportunities including apprenticeships
SENAR staff don't have good local knowledge of schools and services - Families want a named person to help navigate the system	Unacceptable waiting times for assessments. Child losing educational support because of delays – BCC employ external contractor to reduce the backlog?	Lack of reasonable adjustments in public service spaces – BCC need to produce guidance on this and publicise it
Lack of equipment and delays for equipment for – by the time children receive some equipment they have outgrown it or their need has changed.	Lack of advice about CYP milestones e.g. what happens at puberty when children have specific needs and disabilities	Lack of support whilst awaiting and after diagnosis – need interim advice, information and support

**Attitude, Values & Behaviours**

Lack of recognition for parental/carer knowledge and experience in caring for their child.	Treat parents and carers as equal partners in a partnership relationship – culture is still one of 'done to, not done with'	Withholding information in relation to diagnosis and issues relating to disability - tell us how it is...
Take responsibility when mistakes are made. Honesty, transparency, no fudging, no pretending and apologise when things go wrong	Parents/carers are not genuinely understood or supported on the journeyLack of regard for working parents/carers commitments and availability	P/C lack of awareness about diagnostic conditions and impact on education
P/C not treated as equal partners in partnership relationships – 'Done to, not with	Treat people as individuals – 'Don't call me Mum' – Develop some code of conduct about SEND values and behaviours	





***We are 'talked about, not talked to' 'We are diagnosed and dumped'***

***'Feels like banging on closed doors and nobody answers'***

***'No-one has spoken to me although I was promised a meeting in December. Communication between partners is poor – conversations are not happening between partners about children.'***

4.7 **Road-test of the improved Local Offer and suggestions for further improvement** was carried out with parents and carers through guided discussion and viewing of the online platform with feedback summarised under the three categories of Bugs Stars Moon...

**Parents and Carers told us...**

**What was a 'Bug' [problem] for parents?**



- Not knowing about the Local Offer
- People should know about the Local Offer and use it but don't
- The Local Offer isn't user friendly
- Difficult to navigate
- Pathways and parent journey impossible to follow
- Parents want to know more about the LO and think it's a good platform to find information and support from
- Its tricky to find documents about for e.g EHCP and Transition
- Jargon-Terminology not accesible to everybody
- Referral forms not on site (short breaks)
- No contact details – could these be moved higher on pages - Services to include how to access, who can refer, thresholds, what to do if you have a problem
- Once you find pages it can be good but it can be hard to find the pages or documents.
- Use Shropshire as good example

**'Star' [what parents like]**



- The Local Offer site is looking better
- Local Offer looks great!
- Its improved! Its far clearer than Local offer sites in other areas
- Newer site is much better for when looking for schools. Birmingham site seemed clearer than neighbouring authorities in terms of what schools and provisions were available but did not explain what the TYPES of provision were (one step back).
- Search is working better



'Moon' [what parents would like to see on the site]



- Have a co-produced Frequently Asked Questions page on Local Offer
- Promote the Local Offer -big promotion not just intranet in schools etc
- Also reach people before their SEND journey
- Include flow-charts and graphics and less text -Flowchart or how services are linked and contact details needed
- Make it jargon-free - could have an index?
- Road-test/walk through and make changes live with young people and parents
- Local offer needs to be a virtual advocate/support to navigate the system
- Timescale for each service – e.g waiting lists
- Put criteria for services on the LO so parents know whether that is for them
- Need to start with the parent experience – why are they coming to the Local Offer and then map a parent journey to produce flow charts for the site
- Family friendly site
- What social care and funding is available
- Virtual hand holding
- A specific area for Young People on the LO/microsite
- A LO APP for young people
- Promote/advertise the Local Offer in schools (Request Heads to send LO link directly to pupils and parents) ; colleges; health settings ; local media ' Birmingham Live' – think BIG – publicity campaign!
- More mobile friendly version of LO
- A summary template of LO for ease/speed of access
- New name 'SEND Local Offer'?*
- Localised into geographical areas – interactive map*
- Market it – publicise it; put on social media platforms like FB/Instagram etc*
- Explain the site-User guide for the site
- Webinars on personal care
- Work with schools and parent groups to cascade the local offer developments
- Put feedback form on home page – higher up
- Get MPs to promote it for surgeries
- Could be nice to have a paper information pack. – map the customer journey
- What is classed as primary need? Parents won't necessarily have identified a primary need.*
- A portal would be helpful (multi agency) difficult to track which services you are referred to where in process etc etc
- 'At a glance' booklet on everything send – pathway following diagnosis Use flow-charts



## 5. Feedback – Engagement programme process

5.1 The table below illustrates the range of opportunities for engagement which were made available to parents and carers over a four-month period between December 2021 and March 2022.

5.2 **Table 1: Engagement Programme**

Engagement session	Location	Time of day	Method of engagement	Parent/Carer Eventbrite sign-up	Parent Carer Attendance
15.12.21	Virtual	Weekday Evening 6.00-8.00pm	Teams Ms	65	15
22.01.22	Virtual	Weekend Morning 10.00-12.00pm	Teams Ms	55	17
27.01.22	Virtual	Weekday Afternoon 1.00-3.00pm	Teams Ms	48	15
15.02.2022	Central Birmingham Carrs Lane Conference Centre	Weekday Morning 10.00-12.00pm	Face to face workshop	52	15
01.03.2022	Virtual	Weekday Morning 10.00-12.00pm	Teams Ms	13	7
01.03.2022	Virtual	Weekday Evening 6.00-8.00pm	Teams Ms	18	12
08.03.2022	West Birmingham Billesley Ark community centre	Weekday Midday 12.00-2.00pm	Face to face workshop	16	6
08.03.2022	North Birmingham Wilson Stuart Special school	Weekday Evening 6.00-8.00pm	Face to face workshop	17	6
				<b>Total = 314</b>	<b>Total = 93</b>

5.3 Of particular relevance illustrated within table 4.2 above is the striking disparity between numbers of those showing interest and intention to attend the event and those actually attending – just under 25%.



5.4 After each workshop session, the author(s) and facilitators reflected on the range of possible reasons for the relatively low turn-out despite the extensive efforts to maximise parental carer participation by mounting an extensive and widespread event promotion across the whole SEND system and beyond; offering workshop variation in relation to times of day and week; inclusion of weekend and geographical location etc. The reflective learning includes the following noteworthy points:

**Low turn - out isn't unusual in Birmingham**

PCF advise that citizen 'turn-out' per se is low across the city and not confined to SEND parent carer events.

Families are disenchanted with historical SEND systemic failure and its going to take time for them to be convinced their opinion matters.

SEND families may turn out in higher numbers if its about themed information that directly supports their individual circumstances rather than more 'being asked for views'.

**Arrival of Covid-19 Omicron variant**

Workshop dates coincided with Government restrictions for Omicron in December 2021. This brought renewed caution, risks and actual illness for SEND families.

Some families sent late apologies as children tested positive for Covid.

Priorities shifted for families due to Omicron

Planned face to face workshops had to move online - this may have excluded those parents and carers without access to home computers and/or those with limited IT literacy and/or confidence to use in public spaces.

The extended period of running the workshops (over 4 months due to Omicron) may have led to decreased appetite for event promotion by stakeholders and sign-up by parent carers.

**Eventbrite**

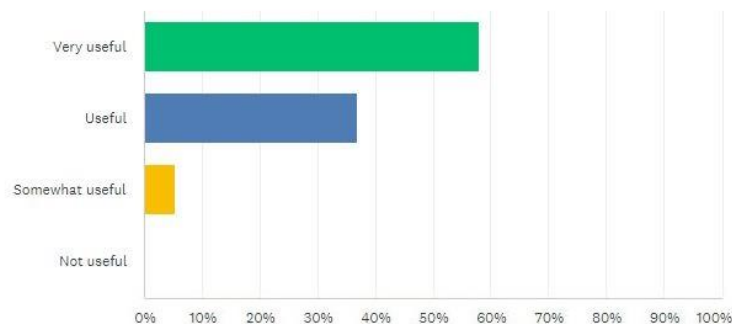
Although a reliable and successful ticketing and event platform, the ease of registration and 'non-fee paying' nature of the event may have meant a higher no-show as limited incentive.

5.5 Feedback from parents and carers who attended the workshop sessions was wholly positive, helpful and informative for future events, shown here in quantitative and qualitative feedback.

**How useful did you find this meeting? [19 Responses]**

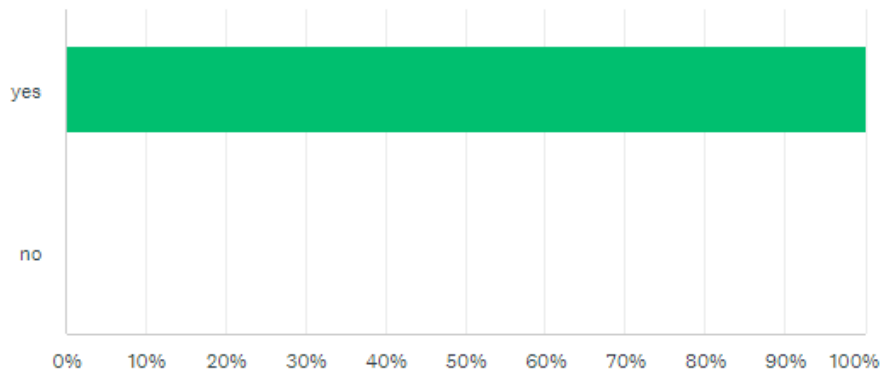
How useful did you find this meeting?

Answered: 19 Skipped: 0





Was the meeting a good use of time? [19 Responses]



What did you like about the meeting?

*'Small group meant we could all input but there was no pressure, it was good to hear acknowledgment of the gaps and issues and that changes are being made, I also like the fact that you asked for positives not just negatives'*

*'I was truly and really heard'*

*'Not only did you tell me where I could find information help and support but your asking for feedback which is very important that you value users feedback to improve services'.*

*'Opportunity for all to share their views, done in an open and honest way, criticism / feedback dealt with very constructively and supportively'*

*'The way everyone had a chance to speak'*



What could make it even better?

*'Sending out the questions you would like to ask us in advance so we can reflect upon them'*

*'More officers spoke about their roles'*



**Future  
Considerations**

Size doesn't always matter. These workshops have produced a quality detailed bank of information and evidence from the lived experience of 90+SEND families and make recommendations for SEND improvement planning going forward - it achieved this through a combination of workshop approach and active input of a significant number of interested and involved parents and carers freely sharing their time and experience.

Experiential engagement events are labour and time intensive and require facilitators skilled and experienced in participation and engagement. They are not consultation sessions or routine Q&A and as such they also require support from across the EHC support network and dedicated time for planning and delivery co-productively.

Parent Carer Forum (PCF) collaboration was essential to the credibility and successful delivery of this work programme - this created a significant drain on PCF limited resources and availability for other key areas of work and support and parent carer time is voluntary given.

The nature of such facilitated workshops means a planned programme is developed and advertised in advance to families (so they know and agree to what they are attending). This does not lend itself to spontaneous guest appearances or changes to the programme that attendees may not have expected or wanted.

Contingency planning for disruption and airing of grievances by individuals is a common feature of any public workshop event but most especially so in the SEND system that is Birmingham. Clear boundaries are required to establish safety and purpose for ALL parents and carers and it is important to plan for the majority as well as the minority. Having representatives from the SENAR service available to deal with issues was helpful but should not be routinely required going forward, as culture changes take place and embed.

Public workshop events are not an appropriate platform for parent carer individual grievances or concerns to be raised and/or be responded to and this series of workshops made that message clear in its promotional messages. Nevertheless, this occurred and going forward it may be helpful for a different and BAU approach to be put in place to support parents and carers to air routine concerns to SEND service providers on a regular basis and as part of customer satisfaction strategies.

Parent carer attendance and participation at such events is a voluntary activity for a cohort of citizens who have considerable pressure and constraints on their time caring for some of our most vulnerable children and young people with SEND and complex health needs; managing busy households and competing priorities within the work and wider family and community environment. Acknowledgement of this must be considered in relation to the provision of real or 'in-kind' symbolic gestures/incentives.

Despite the Covid restrictions on face-to-face meeting, attendance rates identified above do not suggest major variations (except for the very last sessions) between preference for online and/or face to face and in conversation with parents and carers it would seem that the choice of either is what is important but a preference for evenings was verbalised by many?

Venues in different geographical locations and settings does not appear to have mattered or meant an increased attendance at sessions. On the contrary, both the school and community centre location generated the lowest turn-out despite the greatest of promotion and publicity across the whole special school's forum and network for the evening event at Wilson Stuart school.



## 6. Next step recommendations

6.1 This report to be shared with all members of the WTWMG for consideration and next step actions.

6.2 The WTWMG commit to using the key messages and feedback in this report to directly improve SEND services and support and further inform current work objectives and tasks across all 4 APP objectives

6.3 The summary feedback and key messages contained within Section 4 of this report are:

- Embedded within the co-production framework
- Utilised to update the SEND local offer
- Incorporated within culture and behaviour objectives and other priorities to be developed within the SEND and Inclusion strategies
- Taken as information to incorporate into SEND improvement workforce development and training plan
- Incorporated into the co-production mapping recommendations and next step actions

6.4 Key messages contained within section 5 of the report are used as information to inform planning and delivery of future parent and carer initiatives.

6.5 The SROs of Objective 3 to thank all parents and carers who took part in these events and assure them that their input will influence SEND improvement. Also, to send them a copy of any reports created as a result and express appreciation for their time, particularly given the domestic demands that many live with.

6.6 Actions that have occurred or are planned as a result of these engagement workshops to be shared with SEND parent carer networks via 'You said, We are doing' feedback on the SEND local offer.

## Appendix overleaf



## Appendix 1

'Have your say' – parent carer workshops - December 2021 – March 2022

*All feedback comments from facilitator notes and notes made on day on flip-charts*

*Different colours/fonts represent feedback different events*

### Exercise 1 – Co pro values & Behaviours

Positive experiences highlighted from the following SEND professional network: PAUSE  
Mental health support for YP; Parent Link; SENCOs' Teaching Assistants; Teachers; Deputy  
Head; Parent Link

Q1. Thinking about a positive/good experience involving your child/family and including a  
SEND professional.....

Words given by parents and carers to describe their feelings because of the positive  
experience:

- Empowered
- Listened to
- Supported (by school)
- Understood/understanding
- Relief
- Grateful
- Believed
- Reassured
- Hopeful
- Relief
- Clarity
- Validated
- Empathy
- Cared for
- At the centre of what is going on
- Recognised
- Supported by professional
- Advocated for
- Respected
- Trust
- Included
- Heard
- Talked to not Talked at
- Valued



- Cried with happiness
- Involved
- Like a family
- Emotional
- HEARD
- Safe
- Trusted
- Child was safe
- Surprised
- Positive
- Supported
- Appreciated
- Proud – good things happen with high expectations
- Listened to and genuinely understood

**Q2: What things did the professional do to contribute to this feeling?**

- Listened
- Adjusted (schoolteacher) within classroom environment that took account of child's needs and promoted inclusion for parents' child
- Made me feel at ease
- Supportive
- Responsive (to mine and my child's needs- school teacher)
- Raised awareness amongst other pupils about my child's needs – intolerance of noise as a symptom of ASD
- Included
- Professional
- Dedicated
- Understood
- Gave good advice and offered experience
- Answered all my questions
- Helped me to understand my child
- Took time – met with me
- I felt believed and my view validated
- They worked with us, rather than did things to us
- Gave me time
- We came up with a common plan and goal
- She made things happen (Deputy Head-teacher)
- She helped get everyone together
- Signposted me to a service and other professionals who helped
- Gave good tips for dealing with my daughter's anxiety
- Named professional (HV, HOY, Support Worker)
- Relationship with parent AND child



- Professional provided information
- Good communication
- Know family at a personal level
- A positive approach taken – problem solving
- Staff came across as wanting to include my child, not exclude – trying to find flexible ways to make things work
- Made me feel that my child was important to them
- Treated my child with respect and dignity as if it was one of theirs
- Found ways to work around the barriers
- Listened to me
- Valued my view as parent who knows my child best
- Problem solving approach not problem creating approach
- They understood my child's behaviour as communication, rather than just as challenging behaviour – looked behind it for its meaning
- Proper and thorough assessment taking in all aspects of the child's world
- Used plain language – not jargon or professional language – broke things down into language I understood
- Made reasonable adjustments in school for my child
- Child's needs and wants were recognised
- Had a named individual to speak to
- Kept me informed
- They get my daughter
- Didn't treated me like I was neurotic, or I didn't matter
- Gave daughter tremendous SENCO support when she needed it then backed off when she improved and didn't need that amount of support
- Took the EHCP seriously and did what it said in it
- Was a whole team thing and it included me (the parent) – child was then happy to go to school?
- Made me feel safe to send my child to school for the 6 hours a day she needed to be there
- She was persistent, listened and communicated well. She was always positive – if she didn't know the answer, she came back to me when she had found out
- The professional fed back
- Took responsibility/personal involvement
- Showed understanding
- NEAT Bus Driver – goes extra mile, talks to my child, always on time, communicates, aware of child's needs and asks questions
- Pro active
- Action rather than words
- Challenged the system
- Consistency/continuity
- Took holistic view of the child
- Knowledgeable / up to date



- Signposting
- Experienced/know the system
- Being talked to, not about
- Were calming
- Had the same person supporting me from Early Years through to starting school
- Good communication and honest advice
- She kept me updated with texts
- She put wheels in motion
- Received the plan on time
- She was a go-between with me and the SEN Officer
- She challenged school in a meeting to make sure the meeting included my child's health needs
- Responded to my email within the hour!
- Supported me at a time when anxieties in the family about my daughter were very high
- Remembered that I had phoned the service previously and acknowledged my previous call and what it was about and followed things up by email and copied me into that email.
- She escalated my concerns
- Followed things up with a phone call
- Student used to go to theatre company which led to paid employment **encouraged young person to share talent.**
- Good experience with Early Years Intervention Service – led to early referrals and had continuity of a person for support. **Good communication, texts, emails providing information, confidence and assurance, someone looking across the whole picture for child. Supported transition. Involved parent in feedback sessions. Went extra mile**
- Positive experience with Parent Link. Often have to leave a message but team has **responded within an hour**, if not have responded that day. Spoke to a team member who remembered previous contact. Parent Link member of staff emailed the professionals that needed to be involved and escalated to head of service copied parent/carer in throughout. Rang on mobile to follow up. **Didn't feel that there was a hierarchy, worker felt on same level.**
- Paediatrician **attended school meeting to challenge school and advocate for support.** Professional who had listened and taken on board. Made time to attend meeting. Flip side is that parent view wasn't listened to and need professional to advocate. Parent view and expertise should be enough.
- Being at meetings as a parent/carer can be very isolating. Parents need to be involved at every stage of the process. Including what support is being put in place.
- *Being done do not done with*
- *Nothing about us without us*
- Schools puts all SEND information into their newsletter
- Professional honesty, step by step help
- People who care and share best practice



- Buy in and accountability
- Involved in conversations from the start
- Parents and children treated as individuals, respected and consulted
- Understand that parents are the experts and include them in the whole journey
- Be Empowered workshops are very good for parents who are new to the system
- Good referrals and early recognition by professionals
- Sent information home in child's school bag
- Rearranged EHCP meeting so parent could attend today's workshop
- Identified early developmental issues in child and acted upon them which resulted in early referral to Paediatrician for ASD for nursery age child

### Feedback - Parental/Carer Issues:

- During pandemic felt abandoned
- Positive school experience described above fell apart once child transitioned to secondary school
- Son got lost in the system during the pandemic
- Parent support groups are limited by being in school term time and during working hours- no good for working parents
- Long wait for diagnosis and underwent mediation with SENDIASS
- Answer the phone to us (SENAR)
- Acknowledge our emails – Reply to our emails (SENAR)
- Work with professionals who are helping my child – who have a close relationship with them
- Not being 'heard' or 'listened to' by health and primary school staff meant a 2-year delay between Y4 & Y6 and result meant critical support wasn't providing during child's developmental milestones during this period.
- A lack of proper signposting from professionals (in primary schools / health visiting etc) results in parents being passed from pillar to post and unnecessary delays for children.
- Poor communication when EHCP's are being developed (not including parent) results in poor quality Draft EHCPs – involve parents and carers in the assessment process
- Incorrect telephone numbers/contact details for signposting to for e.g. parent line causes parental frustration and delay – need gold standard signposting
- Waiting times between sessions once treatment and support is finally provided – worsened during pandemic
- Would like choice of online and face to face support
- SENCOs need to make more effort to pull all services in to a person centred plan
- There has to be a joined up pro-active approach from professionals
- EHCPs are too complicated – have to be accessible to everyone, not just people who are involved in the system/understand the process
- Lack of support post diagnosis (ASD)
- Information for YP post diagnosis





- Feels like banging on closed doors and being in a dark void
- Support fell away when child turned 5 and entered reception year
- Not receiving updates from professionals working in school (Multi agency not just school staff)
- *No support through 2/3 year wait for diagnosis*
- *School blocking appointments and excluding parents from 'professionals' meetings where the parent was representing professionals who could not attend*
- *Not getting a 360 degree view of a child*
- *Not being flexible and creating blocks – e.g. making a child wear a PE kit which meant he then became a school refuser.*
- *How can parents release funds from their EHCPs to pay for services required that NHS / BCC can't provide?*
- *Not included in EHCP planning, never told about support services or advice (e.g. SENDIASS/Local Offer)*
- *Schools don't know where to send parents/carers for advice*
- Lost paperwork, not treated respectfully, not said sorry, put phone down on me, happened more than once
- Still making same mistakes – problems with transport no changes on EHCP reviews schools and SENAR don't follow up
- Transition not working children to adults, changes in social worker, trying to get something in place since July. Whole spectrum 0-25 – what happens when they become adults
- No one has spoken to me though I was promised a meeting in December  
Communication between partners poor. Conversations are not happening between partners about children.
- EHCPs not updated
- BCC staff must not use the pandemic as an excuse for anything
- Parent link worker phone line not being answered (text is not an acceptable response, parent wanted phone call)
- Kids with Plans already – ongoing terrible experience of annual reviews
- Communication out to parents is still terrible
- Quick wins just aren't being done: answering phone, being realistic with parents, being honest (even if bad news), being accessible, having named SENAR staff
- Inconsistency of family experience in SENAR and going through process is so bad
- Some examples of real incompetence
- Cultural / issues in how parents are being treated : not as equals, being silenced, agreement not sought, being 'done to' and no accessible routes to challenge
- Schools / systems still work via diagnosis not need
- SENAR employing new staff who do not know the Birmingham system or available services
- EHCP's not being implemented
- The Covid Pandemic is being used as an excuse for a poor SENAR service



- 2 year Waiting time for ASD assessment - If BCC employed a private company it would clear the backlog.
- Children with ASD are losing education because of delays in assessment and associated lack of special school places.
- Not answering the phone; not returning email messages is poor practice – BCC could learn from primary care where GP surgeries have same day call back service to patients – don't always need answers just need to be kept updated.
- Maintain contact with parents via monthly zoom calls
- Assessment criteria is inadequate
- Principle officers (SENAR) should be attending meetings
- It's still about 'doing to- not with' parents within Education – BCC Education could learn from NHS colleagues
- Arrange meetings and times to talk at 'parent -convenient' times – stop 'cold- calls' – parents work too!
- Have never spoken to the same person twice at SENAR – no continuity and repetition of our story
- **Educate me.** If you want to get the best of me so I can get the best of you educate me. I am not an educational specialist, don't expect me know instantly.
- **Jargon busting**, making things accessible. Think of different ways of engaging with me needs to be more tailored. Too many acronyms. Consider EAL for parents/carers
- **Parents and professionals Makaton training sessions** – could this be replicated
- **Wider range of webinars needed**
- Need to take into account of time that is convenient that for parents as well as for them. **Prearrange times for meetings. Mutual respect and understanding for availability**
- Co-production is about being supported in a timely manner at parents' pace and need as well as our child
- Having to explain yourself several times
- Can't afford equipment or services you are signposted to
- Lack of help 16-18
- Long waiting list for Autism diagnosis
- Passing the buck, not listening
- Transition issues with continuing medication and equipment
- No help once ECHP ends at 18 (but the law says it's 25?)
- Have to go through waiting lists twice when children are removed by the service which decides that they don't need support. Parents have to start the journey again when the problem reoccurs
- No reasonable adjustments e.g. lights and music in a waiting room
- Information sharing is poor, don't know what information is available and where it is stored
- Vicious cycle of no diagnosis, no support – but that just adds to waiting lists. Need more help without a diagnosis



- No support for mediation, meetings moved to be last minute and there is no preparation or guidance.
- Parents told they can 'leave' if they don't like the service
- Need direct links to Special Heads Forum and to share information on Class DoJo (parent app).
- Very difficult to work out where help can be found (diagnosed and dumped)
- Need a booklet on everything SEND – support, advice resources
- Need booklet that is print as well as online for parents who aren't online
- Parents need to be involved in school placements – schools think parents don't know about education
- No support during COVID – all services and short breaks were withdrawn. This has led to long term Mental Health problems.
- Victim blaming
- House adaptations take 5-6 years
- Early intervention is key – nursery staff need to be better trained
- Access to SLT is too difficult
- Funding is awful – took 3 years to get the right wheelchair
- All equipment and adaptations take far too long
- Parents asked to leave an EHCP meeting and told they know nothing about education
- Professionals don't come to EHCP meetings
- Support for mental health and physio has disappeared
- Targets not monitored
- Too much door knocking – parents should be given all sources of support and advice, not have to go looking for them
- Not all families access CHCs
- SENDIAS & SENAR pass us from pillar to post
- SENDIAS offered me limited support and didn't prepare me properly for mediation
- Treat us with respect - don't call me 'Mum' - call me by my name
- Treat me as a n individual
- Out of date EHCPs
- 'fights' by parents all the time to get things done
- Victim blaming in the system
- Support drops off at transition
- Poor experience of wheelchair services – waiting too long and by the time received the child has outgrown
- Parent lifting child in/out of bed and no hoist available

### Parents want / ideas

- Monthly zoom catch up with the PO for their child to catch up on progress – SENAR proactive
- Each PO with a phone number so parent can contact them
- The phone to be picked up in SENAR
- To be treated with respect as that will help them trust the professional
- Professionals throughout system to be honest with parents – no fudging, no pretending and saying sorry and taking responsibility for mistakes made



- Parents want milestone advice – i.e. what is coming up next in their child's life or education. E.g. changes like puberty can affect physical conditions and medication. Need advice from someone who is one step ahead. Home to School Transport, Medical needs and equipment changes.
- Registered carers need support and education
- Children involved in the Commonwealth Games
- Inclusive plans
- Support and respect for what parents are doing
- Schools should be better at linking parents to support services
- Parent networks sharing tips and advice
- Need more help with transition
- Better signposting
- Better co-ordination across the whole system
- Feel neglected and discriminated against
- Be empowered type workshops
- Accompany me to meetings
- Plan meetings around parents
- Workshops/webinars/ leaflets on the range of behaviours/ issues etc associated with diagnosed conditions for e.g ASD/ADHD so that parents can properly support child at home
- Use a range of methods to communicate with us including paper/information leaflets- we don't all have computers
- Reduce acronyms and jargon
- Acknowledge that different parents are at different stages of the EHCP journey and experience will vary – some have very young children and just entering then system and some more mature and extended experience over years and young people moving out of the system
- SEND leaders to utilise parents' skills – recognise that there is a significant bank of lived AND professional experience across the parent carer community network for e.g GPs, nurses, therapists

## Exercise 2 Defining Co-production

Q1: Thinking about the shared definition of co-production.....

What words best describe how you would feel if you were more involved in your child's SEND journey?

- Move to action
- Trust
- Ensure the legal requirements of EHCPs are fulfilled
- Long wait for diagnosis and underwent mediation with SENDIASS
- Answer the phone to us (SENAR)
- Acknowledge our emails – Reply to our emails (SENAR)



- Work with professionals who are helping my child – who have a close relationship with them
- Communicate
- Spokes of a wheel
- Integration
- Partnership & equal
- Together
- Involved
- In the process and all the way through the process
- **Child centred**
- **Co ordination**
- **Action**
- **Look at the wording about 'decisions' in Ofsted definition on B'ham Letter**
- Not everyone knew the term
- Action not just talking
- Building together as a partnership
- Leading to decisions/change
- Including children more
- Communication, listening leading to action
- *Empowered*
- *As if my voice counted*
- *Clear understandable language*
- *Being aware for parents out there*
- *Sharing – Being Informed*
- *Going private – ensuring services are available*
- *Listening*
- *Find practical solutions – e.g., school example*
- *Involvement of EHCP Communication.*
- *Not chasing everybody*
- *Adhere to the Code of Practice*
- *Think about developing a code of conduct*
- *Transparency*
- *Open conversations*
- *Accountability*
  
- *Feedback from conversations and meetings*
- **Equal partner**
- **Ask me**

Connected = feels 'done to' – not active enough a word

Respected = you can be respected *and* ignored

Empowered = doesn't result in change necessarily



All professionals need to join up – it is not for parents to fill the gaps

**Q2: What areas of SEND support for your child/ family would you like to be more involved in/co-produce?**

- Involved at annual review but then know nothing about what's happening with their child in school, OT/SALT, Ed Psych. CAT visits etc. Needs too much chasing. Parents not copied into reports from education assessments but happens automatically for hospital appts. Families seeking private support due to lack of info; **want to be more involved and seen as partner year round**
- Would like more support in deprived areas, less charities and support services available in area one parent lived in (?)
- **EHCP plans and processes**
- **Form filling**
- *A central hub*
- *Communication between the council and families – if parents can't get to speak to SENAR then schools and other professionals can't either, so everybody's time is wasted – this needs to be improved*
- *EHCP's – parents involved in working documents to change things*
- **Transition**
- **Forward planning – PFA skills**
- **Comms in NHS**
- **Developing independent living**
- **SENAR – making it more parent friendly**
- **Community links**
- **Post diagnosis – don't diagnose and dump**
- **Holidays/short breaks**
- **Peer support networks**
- **Funding**
- **Choosing where my child's education takes place**
- **Making parent support more consistent across all schools**
- **Person Centred Planning**
- **Bridging the gap with the 3<sup>rd</sup> sector**
- **Jargon busting**
- *Co-production is about being supported in a timely manner at parents' pace and need as well as our child*

Areas people would like to see more co-production

- Involved at annual review but then know nothing about what's happening with their child in school, OT/SALT, Ed Psych. CAT visits etc. Needs too much chasing. Parents not copied into reports from education assessments but happens automatically for



hospital appts. Families seeking private support due to lack of info; **want to be more involved and seen as partner year round**

- Would like more support in deprived areas, less charities and support services available in area one parent lived in (?)
- *Raise awareness of Co-Production and importance to involve with Parents/Carers from the outset.*
- *Support worker didn't know about services – at school. E.g., Stick.*
- *Improve communication.*
- *Culture change. "Parents need to be recognised as part of the whole team" otherwise "cannot see the whole picture" – welcome as equals around the table. Move beyond frameworks of knowledge and power.*
- *Training.*
- *Code of conduct... being told about it*
- *Problem solving not problem creating intent*
- *I'd have access to an advocate if I needed help explaining my child's needs*
- *I'd understand what range of services are available*
- *I'd be seen by the school as central / key for them to be able to support my child well*
- *Schools would not be scared of listening to me, involving me, even when it's difficult*
- *Reasonable adjustments*
- *Co-produce in EHCP at working document stage. Code of practice being followed. Advocacy – individualising approach*
- *Comms / Advocacy*
- *Involving Parents when they want to be*
- *Value parents' views*
- *Include parents in EHCP meetings*
- *Training sessions for parents to increase awareness and understanding of child's diagnosis and specific needs e.g., ASD/ Makaton*
- *Communication on parents' terms*
- *Remembering who the customer is*
- *Attending meetings*
- *Signposting and guidance*

### Exercise 3: Review Local Offer

Parents and Carers told us their

What was a Bug (problem) for them?

- Not knowing about the Local Offer
- People should know about the Local Offer and use it but don't
- The Local Offer isn't user friendly
- Difficult to navigate
- Pathways and parent journey impossible to follow
- **Only 1-2 parents knew about the Local Offer**



- Parents want to know more about the LO and think it's a good platform to find information and support from
- *Didn't know it was there – would have been ideal if I'd known about it*
- *It's not user friendly – you have to do a lot of clicking to find what you want*
- *Translation tab isn't obvious*
- Jargon
- It's tricky to find documents about for e.g EHCP and Transition
- referral forms not on site (short breaks)
- No contact details – could these be moved higher on pages - Services to include how to access, who can refer, thresholds, what to do if you have a problem
- Once you find pages it can be good, but it can be hard to find the pages or documents.
- Too corporate
- Terminology not accessible to everybody
- Use Shropshire as good example

#### Star (what parents like):

- The Local Offer site is looking better
- Local Offer looks great!
- Its improved! Its far clearer than Local offer sites in other areas
- Search is working better
- Newer site is much better for when looking for schools. Birmingham site seemed clearer than neighbouring authorities in terms of what schools and provisions were available but did not explain what the TYPES of provision were (one step back).

#### Moon (what parents would like to see on the site)

- Have a co-produced Frequently Asked Questions page on Local Offer
- Promote the Local Offer -big promotion not just intranet in schools etc
- Also reach people before their SEND journey
- Include flow-charts and graphics and less text
- Make it jargon-free
- Road-test/walk through and make changes live with young people and parents
- Local offer needs to be a virtual advocate/support to navigate the system
- Timescale for each service – e.g waiting lists
- Put criteria for services on the LO so parents know whether that is for them
- Need to start with the parent experience – why are they coming to the Local Offer and then map a parent journey to produce flow charts for the site
- Family friendly site
- What social care and funding is available
- Virtual hand holding
- A specific area for Young People on the LO/microsite





- A LO APP for young people
- Promote/advertise the Local Offer in schools (Request Heads to send LO link directly to pupils and parents); colleges; health settings; local media 'Birmingham Live' – think BIG – publicity campaign!
- More mobile friendly version of LO
- A summary template of LO for ease/speed of access
- Have a live chat facility on LO
- *New name 'SEND Local Offer'?*
- *Logo?*
- *Localised into geographical areas – interactive map*
- *Market it – publicise it; put on social media platforms like FB/Instagram etc*
- Explain the site
- Use plain language
- Webinars on personal care
- User guide for the site
- Work with schools and parent groups to cascade the local offer developments
- Put feedback form on home page – higher up
- Get MPs to promote it for surgeries
- *Jargon is annoying – could have an index?*
- *Flowchart or how services are linked, and contact details needed*
- *Could be nice to have a paper information pack. – map the customer journey*
- *A portal would be helpful (multi agency) difficult to track which services you are referred to where in process etc etc*
- Explain types of provision
- *What is classed as primary need? Parents won't necessarily have identified a primary need.*
- *'At a glance' booklet on everything send – pathway following diagnosis Use flow-charts*
- *Use Shropshire as exemplar*

It would be great to know where parents can turn to/ who to ask if they feel that their child need these services, but school are not willing to use them as they cost them money or they have purchased a limited package of their services and they have used up their allocated hours. Speaking from our experience we have a list of DRs, OT, Speech therapists, STICK team, to name a few saying our child desperately needs access to those services but school refuse to allow access due to their budgetary and resource constraints, despite having previously agreed that our child would be allowed to access these. It's very difficult for parents to then see what they can do apart from applying for an ECHCP/ speaking to SENDIASS. If there were links to other options, it would be helpful to know if there is anything else we can do- or a route map as to how to access these services?

