

An introduction to the NHSE CYP Community
Services Team

**National Network of Parent Carer Forums –
Summary of Menti Responses from
Participants**

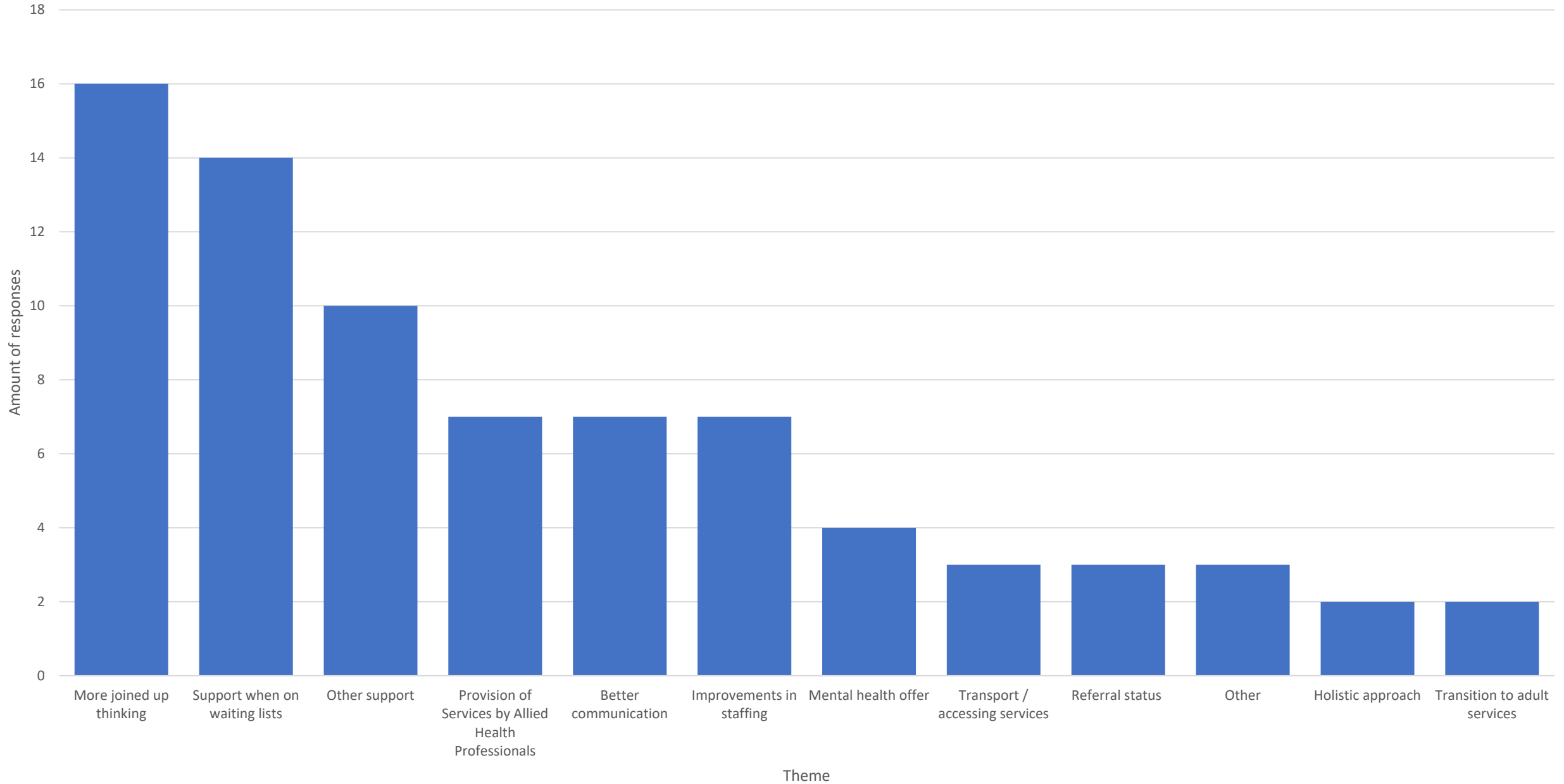
Tuesday 31 January 2023

Responses from Menti.com following conference session with NNPCF on 31.01.22

Presentation statistics:

- 229 votes in total
- 37 participants
- Responses were gathered 'live' in the session
- Attendees were asked to respond to 5 questions on Menti.com throughout the session
- NNPCF is the independent national voice of parent carer forums, consisting of 152 local parent carer forums across England
- Attendees were representatives of local parent carer forums, all with lived experience themselves of caring for a child with disabilities

Responses by theme of what would make the biggest difference in the way that CYP Community Services are Run



Responses by theme in what would make the biggest difference to the way CYP CHS are run

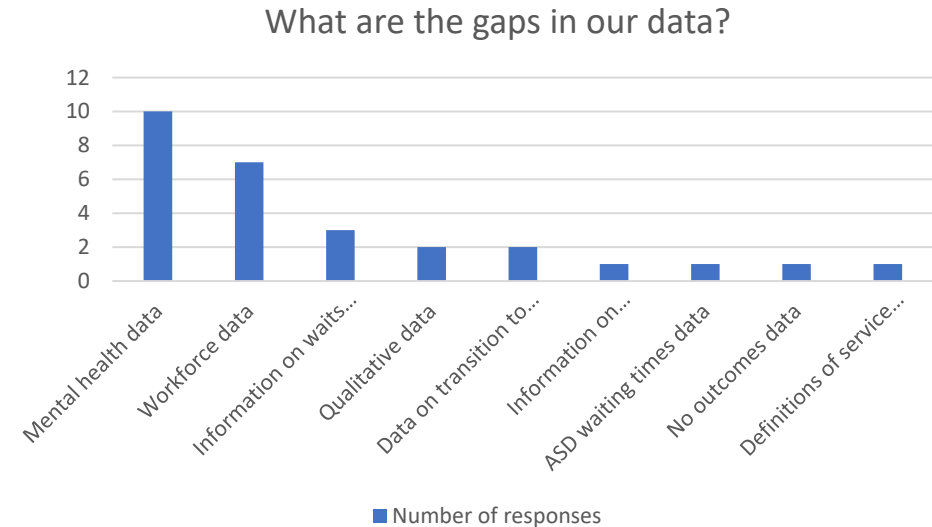
Theme	No of Responses	Suggestions and Examples
More joined up thinking	16	<ul style="list-style-type: none"> Closer working between services and schools Properly trained support staff in schools One stop shops Partnership with families Not working in siloes Sure start centres
Support when on waiting lists	14	<ul style="list-style-type: none"> Support whilst on waiting list Support in timely manner with earlier intervention Better appointment coordination New ways to assess need Needs often different from time of referral to time of intervention so services no longer suitable Impact of waits Knowledge of what support is available whilst waiting
Other support	10	<ul style="list-style-type: none"> Support after being seen Not being 'abandoned' if you don't meet referral criteria Post diagnosis support Support to navigate system Removing barriers Support outside of school
Provision of Services by Allied Health Professionals	7	<ul style="list-style-type: none"> For SaLT to include social communication needs OT offer in some areas poor Sensory trained OT provision More support to be delivered in person rather than virtually Acuity of need greater due to Covid

Responses by theme in what would make the biggest difference to the way CYP CHS are run

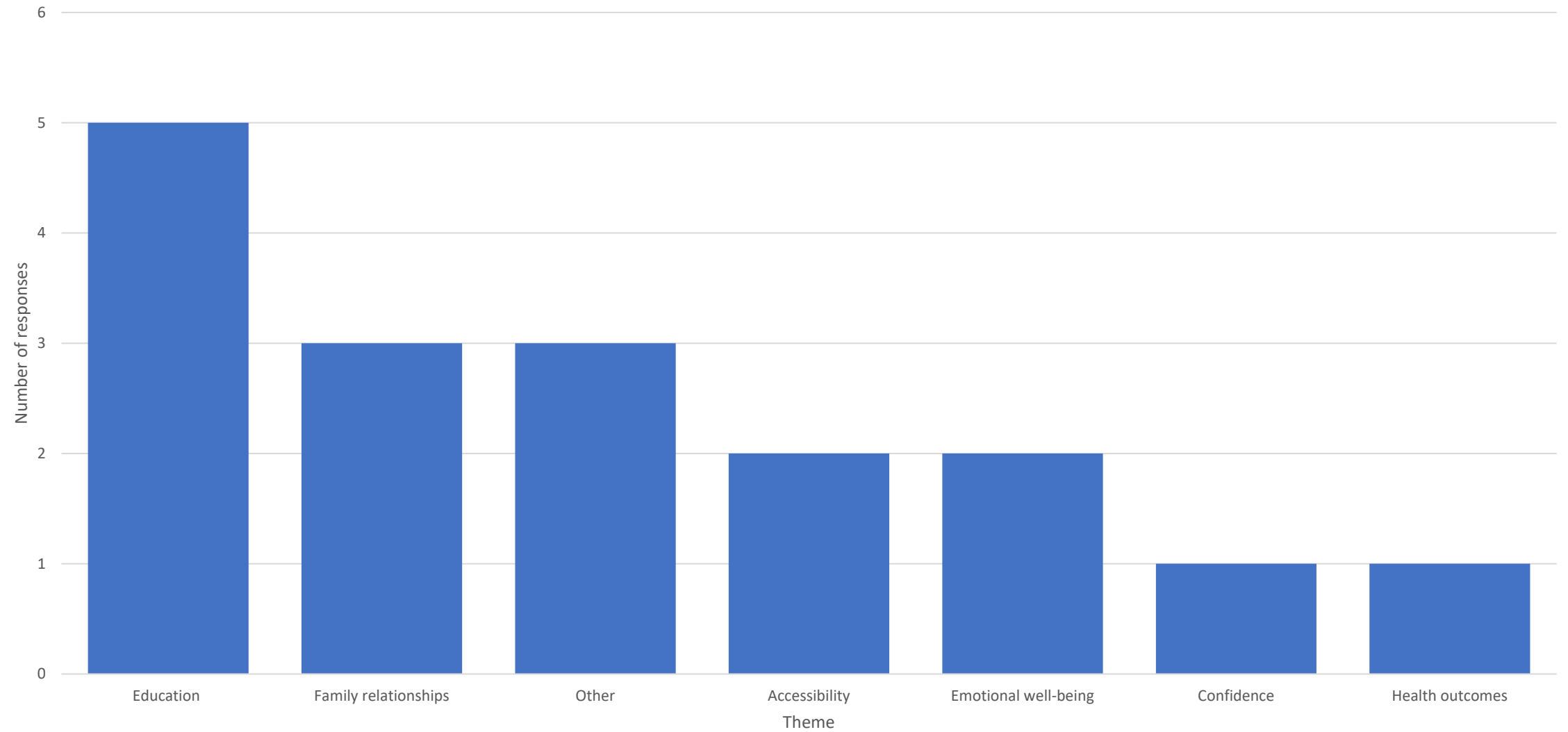
Theme	No of Responses	Suggestions and Examples
Better communication	7	<ul style="list-style-type: none"> Joined up communication Effective communication To receive updates Listening to parents and young people Trust Empathy
Improvements in staffing	7	<ul style="list-style-type: none"> Understaffed services Continuity of care so families can build better relationships Adoption of 'train the trainer' model to meet workforce shortages Consistency
Mental health offer	4	<ul style="list-style-type: none"> Access to mental health pre CAMHS More timely support
Transport / accessing services	3	<ul style="list-style-type: none"> Mental health not included in community services
Referral status	3	<ul style="list-style-type: none"> Accessibility of services Poor bus routes
Other	3	<ul style="list-style-type: none"> Services in communities rather than in cities Clearer referral processes
Holistic approach	2	<ul style="list-style-type: none"> Less judgement, fewer barriers, removing requirement for parenting courses for access Knowing what services are commissioned to deliver Impact on behaviour
Transition to adult services	2	<ul style="list-style-type: none"> Understanding of older children, including teenagers

Does our data reflect your experiences of accessing children's community services? For you, what are the biggest gaps in our current data?

Yes	Number of responses
Reflect SaLT waiting lists	2
Reflects growing waiting lists and staffing shortages	1
No	Number of responses
Feel waiting lists are longer	6
Feel this data is inaccurate	1
Lived experience not reflected	2



Benefits of early intervention from Speech and Language Therapy

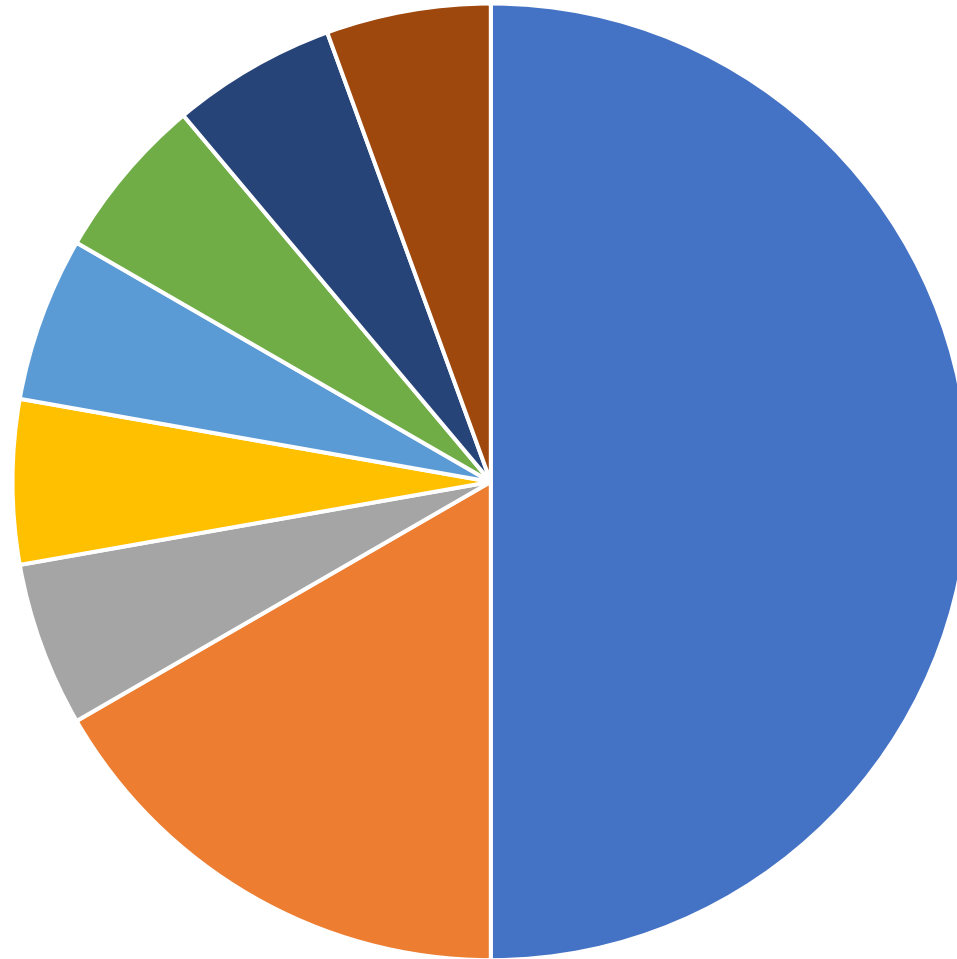


If your child uses speech and language therapy services, are there any insights that you can offer about the benefits of early intervention?

Theme	Number of responses	Example responses
Education	5	<p>Difference between successful education and not'</p> <p>'Ensure there is joined up working with schools'</p> <p>'Getting support early especially in conjunction with schools is key. At the moment schools cannot get support and so children suffer as schools aren't skilled'</p> <p>'Ability to read'</p>
Family relationships	3	<p>It can prevent trauma of forcing parents to "parent" in ways that dont work for their child'</p> <p>'Support for parents and carers that they might not have had before'</p>
Other	3	<p>Early regular intervention is vital'</p> <p>'It took 3 years to gain speech and language support for my non verbal son. My other son is also non verbal and had SaLT from 6 months and the difference it has made in progress is substantial. Now I have to keep refusing to be discharged'</p> <p>'Stops escalation into other overstretched services'</p>
Accessibility	2	<p>Early intervention would be amazing, but doesn't happen without informed parents knowing how to access it'</p>
Emotional well-being	2	<p>Impact on emotional wellbeing'</p>
Confidence	1	<p>Made a huge difference in becoming a confident communicator'</p>
Health outcomes	1	<p>It is an early flag for other health issues'</p>

How can we support you and amplify your network's voices at a national level?

Responses



- Work in partnership and coproduce
- Provide statistical data that confirms voices of forums
- Clear communication
- Make sure it makes a difference and a good use of parents / carers time
- Make sure part of ICB agenda
- Ensuring forums are funded to do work
- Regular updates that can be published with parents
- Realise urgency