

What words come to mind when you describe your experiences with Children's Community Services?



What would make the biggest difference to you, your child and your family in the way that children's community services are currently run?

OT - three referrals no response

Joined up communication

more staff

Effective communication

Joined up thinking

Having staff! Unfortunately not enough to provide the service that is required just to meet needs.

For our SALT to include social communication needs.

Familiar staff that you can build trust on and know your family.

Communicated to us , if possible provide updates

What would make the biggest difference to you, your child and your family in the way that children's community services are currently run?

Access when needed in a timely manner or support on how to work with parents whilst they are on the long waiting list

Effective communication

Holistic approach

earlier intervention, self service support, whilst ypu wait support, post service support

Services working more closely with schools

Access to mental health support pre CAMHS

Would be helpful if the appointments could be better coordinated.

Visit different services on the same day in the same place

Understanding of older children, including teenagers

What would make the biggest difference to you, your child and your family in the way that children's community services are currently run?

Partnership with families

Community services coming into our community rather than having to travel for an hour to access children's services

not operating in silos, working together across services

Genuine early help
Less judgement
Fewer barriers
Don't gatekeep knowledge and information
More staff
Stop requiring parenting courses for access

alternative ways to make assessments to meet tsunami of need

Listening to parents and young people.

Not being abandoned if you don't meet the criteria for a pathway.

with limited workforce all SALTs OTs etc should be trainers and adopt a train the trainer model

Increased capacity - needs are often different from time of referral so by the time provision is offered it is no longer suitable. Particularly relevant/common for SALT and OT.

What would make the biggest difference to you, your child and your family in the way that children's community services are currently run?

Not enough staff. Joined up approach remove barriers.
Listen to families first and foremost.

Cumbria has no OT support at all for sensory issues, yet it is a huge issue. Sensory training and understanding needs to be a priority especially since covid.

Understanding the community offer

Shorter wait times, support on pathways whilst waiting, not just a call to check in. Clear information on how to get on a pathway. Schools better informed to identify and support

Focus on support before diagnosis while waiting or instead

More help & services for communication needs rather than just the physical difficulties with pronouncing words. Parents are being given OT appts over the phone which is just wasting time as child needs to be seen in person.

Early intervention and triage service with other strands

Having these options close by not having to travel into cities

Knowing what the different services are commissioned to deliver. Better service monitoring and held to account.
Cultural shift. Clear referral processes.

What would make the biggest difference to you, your child and your family in the way that children's community services are currently run?

Greater trust and communication with families

Post Diagnosis support for cyp

Smooth transition to adulthood, especially where medication is needed.

Services knowing what other services are offering

Showing empathy for families with their disabled ones.

More consistency . So many staff changes

More availability of provision in schools - but properly and appropriate, not just poorly trained or non experienced support staff

If support is not available, explain why and what other support can be accessed. Not just linking to out of date charities and expired websites

help to navigate the system

What would make the biggest difference to you, your child and your family in the way that children's community services are currently run?

should look at parents as well as other professionals to support SALTs etc

One stop shop

School being more aware on how to identify and support so diagnosis not dragged out because they are academically capable but struggle in other ways. Or mask

Remove barriers

More community based appointments such as at schools

use a train the trainer model

Need sensory trained OT's in our area

Communication between different services, not being told that 'it's not commissioned' therefore being forgotten about. That doesn't remove the need from the child!

Supporting with transportation for some that are struggling with buses.

What would make the biggest difference to you, your child and your family in the way that children's community services are currently run?

More holistic approach

More timely mental health support

Not enough availability of support for long term chronically ill child in Isles of Scilly

The NHS to continue to collaborate with the County Councils and PCFs so all working together

Genuine joint planning and commissioning - ics's schools and LAs must plan and commission together.

Parents view of paramount importance

Understand the barriers. Many parents of children with additional needs have their own needs. The admin and organisation required to make and meet appointments requires more than my executive functioning can always manage.

NHS SL Therapists in schools, interventions should align with education. Often their priorities are NHS based but don't support the education

Support whilst waiting

What would make the biggest difference to you, your child and your family in the way that children's community services are currently run?

joined up approach with all services including child's education

Training on partnership with families

Wait times, support during those times. Respect the parent carer role and what they submit in information terms

Lower threshold needed for acceptance to autism referral

Support for parents to deliver interventions, therapy etc and cost of equipment (especially Ot)

Sure start centres

Early intervention

We have a great relationship with our NHS colleagues but lots of staff left & changed role with ICB changes

Access to support outside school

What would make the biggest difference to you, your child and your family in the way that children's community services are currently run?

Work with parent carer forums to co-produce services

Occupational therapy does not seem to be available to us in Isles of Scilly

need to know what is available while waiting

Simpler process of referral by professionals for ASD diagnosis

qualitative data - what impact are these waits having

The families we represent need to know what is out there. There is no proactive offer, but many many barriers to access. Separating MH from other services builds in hidden waits that mean the lived experience of navigating is even worse

Speech and language is going to be needed more and more due to the issues with covid and the amount of CYP with different types of social anxiety, selective mutism and so on. Teams need to work together eg CAMHS and SALT at the same time

mental health not included

Mental health offer, especially for those with SEND and the trend to reject if a cyp has a neuro condition

What would make the biggest difference to you, your child and your family in the way that children's community services are currently run?

waiting times between initial and subsequent appointments are so long with no contact in between.

Huge impact on behaviour

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

Yes for SALT. I would expect Mental Health to be high

Camhs . The service is on its knees

feel that waiting lists are longer

Waits in Cheshire east are longer and often you wait on one list and then another and then another

I thought that there would be more people on waiting lists
tbh

yes for SALT, huge need

Mental health, access to CAMHS is our biggest issue

Need data on intervals between appointments - targets for first appointment following referral are ok. What about 2nd appt?

Lack of trained staff available for appointments OT therapy not fit for purpose for most children with Sensory processing

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

staff shortages is a big issue.

I wonder how much of this data is falsified

Needs data on whether community services are delivering services in EHCPs

Access to camhs is a real issue in our area. Mental health support for those who are autistic is near impossible to gain

Depends on the area and the commissioned offer, sensory or etc

access to mental health support, where do parent sgo for help while on waiting lists

Yes. It's a service that is already stretched and unable to recruit means it's very reflective of our needs in Herts - the list is getting longer each day!

Staffing issues - not enough staff

Camhs waits, urgent referrals can be over two months for help,, long waits on ASD and adhd assessments, SALT and OT also long waits

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

Yes, although not having MH / ASC etc waiting times included muddies the picture as families are referred from one list to another list meaning hidden waits in the lived experience that aren't captured here

Mebtal health offer and ease of access especially as those with SEND not seen as meeting criteria, especially if neuro

Waiting lists seem longer from what families tell us. CAMHS, SALT etc

Yes 100% but CAMHS is definitely by far the biggest waiting list in our area. I agree with the comment about time between appointments, over a year in some situations in between! For a 6/7yr old child that is a huge part of their life so far

Data doesn't necessarily tell the story of families who don't meet a high threshold

Staff turnover

Waiting on a list for triage first is not the same as total waiting from referral to being seen by a professional

Finite services being spread thinner and thinner.

qualitative data - what impact are these waits having and what interventions/support is available

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

Services commissioned to support Camhs have now closed their waiting lists due to high number of referrals

Data seems to allow commissioners to think it's working No qualitative info about whether it works and what the outcomes are

Waiting lists for therapy impact in terms of increased need with Mental Health issues

Information and communication about the process is lacking Access, services, pathways and referral routes change every 6 months meaning information is absent or out of date No one knows what should happen, let alone what is happening for the child

Doesn't reflect how long families are able to access services

Long gaps in service when staff often go off sick (stressed) for long periods, then leave, needing to start again with new staff.

Doesn't reflect the areas are competing for staff. We boarder lots of areas and lose staff to higher paying neighbours

Post 18 services and transitions

Essex PCF have a great booklet on caring for you neurodiverse child and Cambs and Peterborough are being funded by ICS to develop

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

No smooth warm handover for those in transition at 16/18/19

This doesn't cover when you are supposed to be receiving a service, but resources are so stretched that instead of monthly appointments, we have had to wait 9 months for a next appointment.

It would be helpful to have a definition of what services are included in this

Yes. too long but following a pilot scheme a new intervention has started in Herts with the Family Centres and PHN offering the Early Support sessions and Early Adventurers to highlight and pick up families being identified with SCLN

Difficulties separating children who have speech & lang difficulties with EASL. Some parents seem to get "fobbed off"

Share where you are up to and also our local NHS partners

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

An offer to dip into when child signed off

Difference between successful education or not

My son had intensive therapy for years and years, ensure there is joined up working with Schools so that they can daily/weekly therapy with them

My child had intensive support to help with speech sounds and this was a big investment in time but made a massive impact

Answering on behalf of membership, not me Early intervention would be amazing, but it simply doesn't happen without informed parents knowing how to access it

Impact on emotional well being

Early intervention needs to be followed up to check that it has been carried out and been successful. This has not been done for us and intervention was totally disregarded by school!

Early intervention made a huge difference in becoming a confident communicator.

early regular intervention is vital

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

Locally Chattertime sessions at children's centres that are open to all under 5's are useful so parents who have concerns can attend to ask questions without going through referral

Can I point out that Dyslexia is an educational diagnosis not a medical one and is too often not included in language and literacy issues

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.

It took 3 years to gain speech and language support for my non verbal son. My other son also non verbal had SALT from 6 months and the difference it has made in progress is substantial. Now i have to keep refusing to be discharged

Our salt have a phone line for parents and a fact file with tips for parents

Any issues are addressed earlier meaning it improves the quality of their home lives, family relationships and education.

My child's speech and language always made a leap when he'd been away for a weekend, or done something different. There is an argument for funding activities and short breaks

Importance of therapist involving school and the family and clearly communicating with both

Can prevent the trauma of forcing parents to "parent" in ways that don't work for their child

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

My 7yr old has selective mutism. She has struggled since she started nursery at 1yr old. Nursery got SALT involved and it was pushed to 'see what happens at school'. What's the point of early intervention if it doesn't actually happen fully?

Being seen outside of health settings eg in school so less time out of school/nurseryHelpline between therapy interventions when you have been left to eork on something

It's an early flag for other co comorbid issues

Early intervention stops escalation into other over stretched services.

Salt attached to teams, LD, cystic fibrosis etc

It enabled giving the appropriate support at thd right time for great results.

End thresholds. Allow families to access graduated support appropriate to their needs - some will need a little others a lot.

It is essential to fully involve families, and help them understand the system, so they can complement any SALT in the home effectively

Can be life changing for parent and child to build positive child-lead interactions that will stand them in good stead for navigating trickier times later on. But this was on a pilot 9 years ago

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

A new intervention has started in Herts with the Family Centres and PHN offering the Early Support sessions and Early Adventurers to highlight and pick up families being identified with SCLN

One of the biggest impacts of being at an ICAN nursery was support for parents and carers. I had never had that before .

Make clear that best practice for local rollouts will involve the local PCFs, and will add value and make the job so much easier. We are here to help find solutions, not make problems

Early intervention can improve the ability for a child to read and understand not only writing but also non spoken language. My daughter was advised during her process to be reviewed but secondary school have left her 3 years

End the signed off from service idea. No gatekeeping.

True co production. Not just heres what we want to do, sign it off so we can say its co produced

I believe early intervention, if it had been carried out, would have assisted in earlier identification of ASD

Get NNPCF representatives involved from the start nationally and local PCFs locally. PCFs should be part of the discussions about what the problems are and finding the solutions, not consulting later on

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

Work in partnership with us

By working in co production directly with forums

Coproduction.

Continue to share with us and seek input. Today has been helpful

Definitely have a meeting with the PCF's

Making it clear that projects you role out locally need to involve PCF

Involve NNPCF both nationally and regionally as much as possible

Working with us and listening.

coproduction with NNPCF and individual PCFs

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

Ensuring ICBs are aware you working with us

Communication, communication, communication

Most here are representing 100s of families

Provide the statistical data that confirms the voices of forums

We would love to be able to work closer as at the moment our raising of concerns ends with service providers and commissioners

Make sure that local providers and commissioners co-produce with PCFs

I know for Durham - co production with these services is lacking... (not for want for trying from the PCF said)

Ensuring forums are sufficiently funded to do this work.

ICB working with PCF's

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

Showing willingness.

Ensuring your team has a seat on local ICB's

Make sure this is on the ICB agenda

Clear communication between your team and local commissioners

Possibly questionnaires to use with our members might be helpful in gaining further insight, or some other way to collect more direct experiences from families.

Reaching all communities

Need to raise this agenda with health and well-being boards as they don't seem to realise this is under their remit

Forums are very solution focussed and have a wealth of intelligence to support this.

Forums would benefit from health funding to do this kind of work

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

Make sure it makes a difference. We can ask parents and carers for their lived experiences and ideas, but we also need to be able to show them that it is worth their (very precious!) time

Push what real co production requires and involves

Regular updates as well that can be published to parents that are frustrated with the system

Remember that coproduction isn't always necessarily a formal thing, if you are producing a handout to give to parents, ask us as forums before publishing it or even better, produce with us. It can just be a quick email/phone call etc

Realise the urgency. A year in a young child's life is an enormous length of time