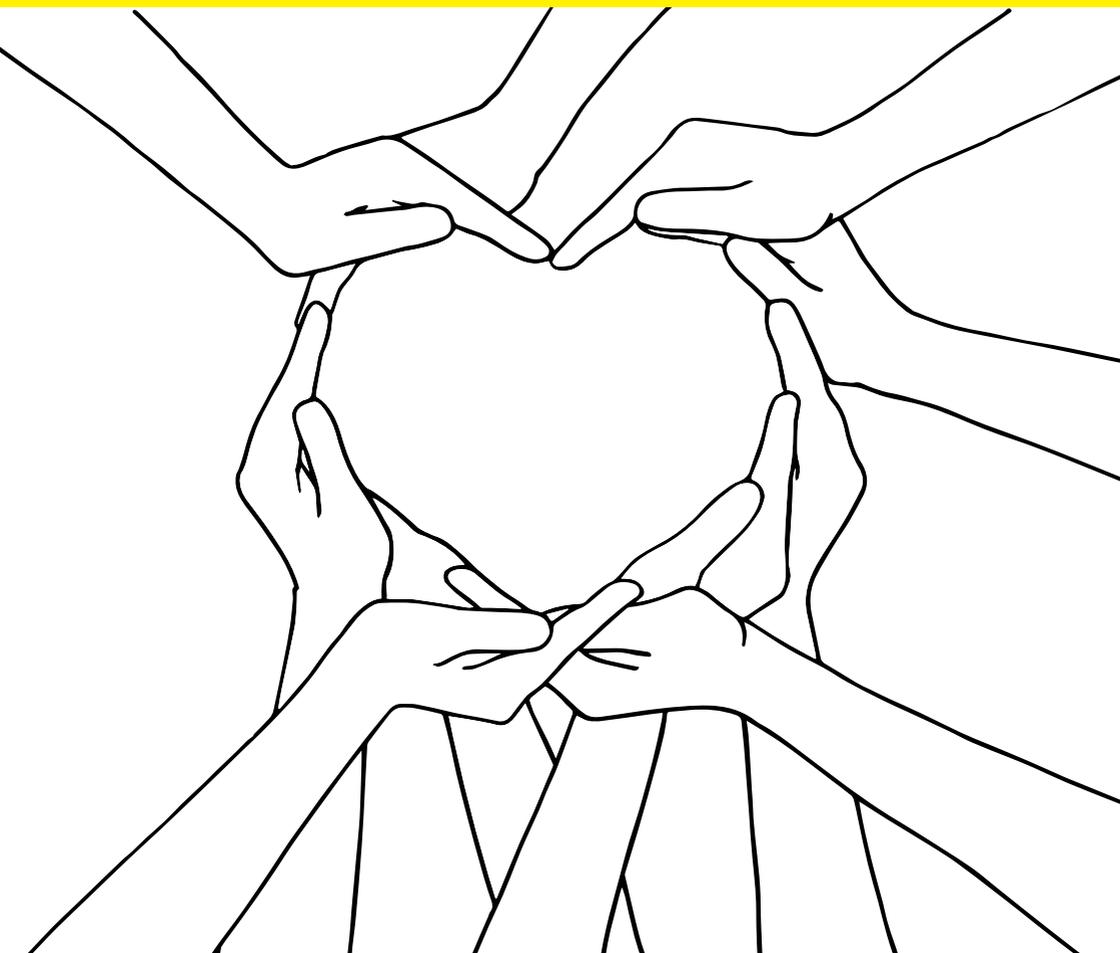


Working Alongside Parents

Guidance for health, education and social care practitioners



Introduction

Guidance for health, education and social care practitioners

Supporting parents and carers of children with special educational needs and disabilities (SEND) requires empathy, understanding, and close collaboration between health, education and social care practitioners. These families often face challenges that are unique to their child's needs.

Practitioners who approach their role with respect and willingness to learn from the family's experiences will be more successful in providing meaningful support to deliver the best possible outcomes for everyone involved.

Getting things right first time and building trusted relationships is also easier and can make things less costly for the services involved.

This guide has been developed by NHS Cheshire and Merseyside - Cheshire East Place, Cheshire East Parent Carer Forum and disability charity Contact. They worked alongside parent carers in Cheshire East to ensure the guide offers practical advice, supported by real-life experiences, to help practitioners work more effectively with families of children with SEND.



Listen

Emotional support for parents - acknowledge the emotional load

Raising children can be emotionally challenging for parents, especially when their child has complex needs. Providing not just practical but also emotional support is critical.

What parents and carers told us:

“At times, it feels like I’m juggling so many roles – parent, carer, therapist, advocate. Just having someone acknowledge that helps”



“When I feel genuinely listened to I feel better”



“Please ask me how I want to be addressed rather than automatically calling me ‘Mum’ or ‘Dad’”



“Give me the time to explain my worries and how things are impacting my family”



“My child can often be upset in an unfamiliar setting so if I tell you I feel an appointment would be easier without my child present or at home, please listen and try to accommodate this”



Practical tip:
Take a moment in meetings to ask parents how they are doing. Simple check-ins like, “Is there anything you need?” can make a big difference.

Understand

Educating without overwhelming - provide information in manageable steps

Families are often given large amounts of information at once, which can be overwhelming, particularly when navigating a new diagnosis or multiple disabilities. Practitioners should provide clear, structured guidance on key next steps.

What parents and carers told us:



"I am the expert on my child; please recognise me as an equal in decisions relating to their education or care"

"If I am upset or irritated with the system please don't take it personally"

"This process can be overwhelming with many different appointments and different practitioners involved so please recognise this"

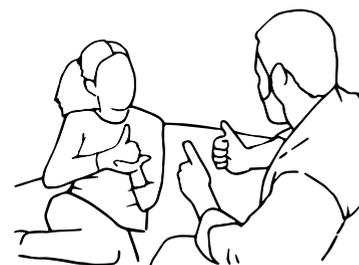
"Sometimes I have too much information to process, so summarising the 'top 3' priorities at the end of meetings or appointments is really helpful"



"In the early days, I was handed a huge pile of leaflets. It was too much to handle all at once. What I really needed was guidance on the first steps"

"Showing you have tried to put yourself in my shoes and you care really helps"

"Help me understand what support is available for my child's future, not just their immediate needs"



"If my child is non-verbal or has a communication disability, please ensure they are included in discussions in an accessible way"

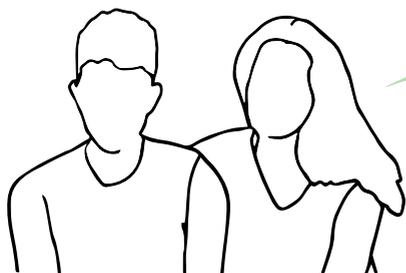
Practical tip:
Provide information gradually and in an accessible format (e.g. written, visual, or video), offering follow-up meetings to address questions.

Collaborate

Listen to the parents

Parents know their child better than anyone. They are experts on their child's needs, triggers, and strengths through to their learning styles, even if they are not 'professionals'. It is essential that practitioners create an environment where parents feel heard and respected.

What parents and carers told us:



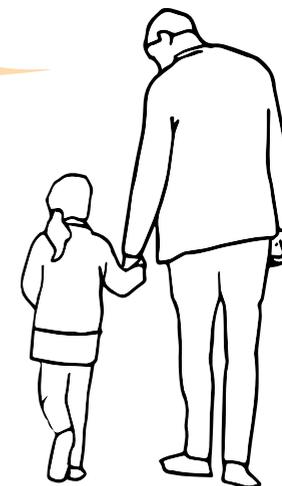
"I felt like we were being dismissed by some practitioners, as though our insight wasn't important. It's exhausting having to fight for my child when it feels like practitioners are not listening"

"Recognising that I have expertise as part of the team around my child makes me feel valued and engaged"



"It really helps if all involved practitioners talk to each other and share information with my agreement"

"Please work with me to make reasonable adjustments which may improve the outcome of appointments e.g. could a meeting take place at home or virtually, could you provide a picture of yourself and the venue in advance if my child hasn't been to see you before? Consider if your venue has appropriate facilities e.g. hoist facilities or stairs as well as lifts? Is there a quiet room we can wait in instead of a large busy waiting room?"



Practical tip:

During meetings or consultations, reflect on what parents share with statements like, "That's really helpful, thank you for sharing. We will take that into account." Encourage families to complete a personal/patient passport and share with the practitioners they work with.

Communicate

Keep lines of communication open

Many families deal with multiple services simultaneously and effective communication is crucial to ensure no details are overlooked. Doing what you say you will, managing expectations and keeping promises can help reduce unnecessary extra stress.

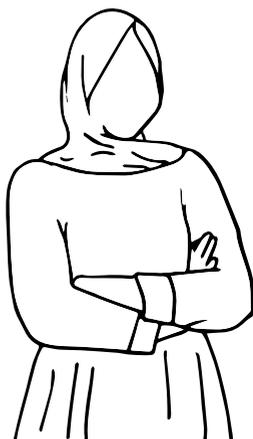
What parents and carers told us:



"There's often a lack of communication between different practitioners and often it feels like I'm passed from pillar to post. Sometimes it feels like I'm the only person expected to understand the full picture of my child's needs"

"Keep me updated on where we up to with referrals and the waiting list"

"Signpost me as soon as possible to organisations which can help, whilst we wait for support"



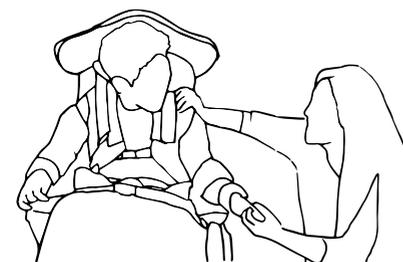
"Your letters can cause us anxiety, so please use clear, positive language and be kind"

"Always explain next steps, timescales and keep promises"

"Please copy me into all letters and emails"



"My child uses assistive technology or requires alternative communication methods, ensure this is respected in all interactions."



Practical tip:
Use a system that ensures all practitioners involved in a child's care can communicate easily and frequently, with the parents included in all updates.

Be flexible

Avoid one-size-fits-all solutions

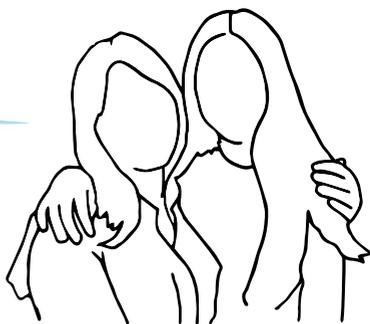
Every person is unique, and what works for one may not work for another. A tailored approach is necessary in all settings, whether it is education, health or social care.

What parents and carers told us:



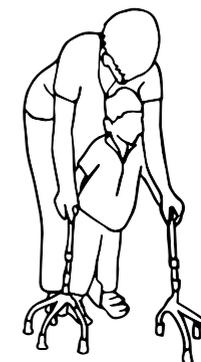
“People assume that because my son is able to communicate verbally, he doesn’t need much help. But he struggles with sensory overload, and social situations can be a nightmare”

“My child masks how they are really feeling at school but has huge meltdowns at home. Please believe me when I tell you how hard things are”



“My daughter needs routine, and sudden changes can be distressing. Just a little flexibility would make all the difference”

“I need practitioners who adapt to my child’s needs, not force my child to adapt to the system”



“My child needs an accessible changing place, so I get anxious attending long appointments in case she needs toileting and there’s nowhere safe or suitable”

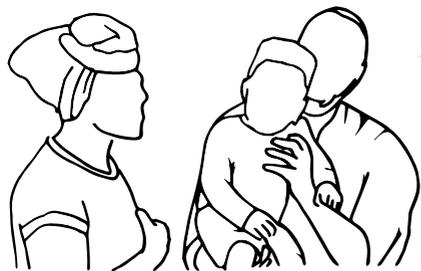
Practical tip: Always consult parents when devising support plans and ask questions like, “What works for you at home?” Regularly review and adjust strategies as the child’s needs evolve.

Respect family dynamics and cultural backgrounds

Understand each families situation

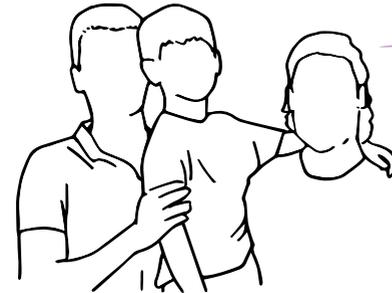
Every family is different, and cultural values or family's dynamics can impact how they approach their child's disability. Practitioners should avoid making assumptions about what is best for the child without understanding the family's unique circumstances.

What parents and carers told us:



"In our community, there's a lot of stigma around disability. It's tough to balance our cultural values with what my son needs"

"My child has a blended family, and decisions involve more than one household. Please respect that"



"We speak multiple languages at home, which affects my child's development please don't assume delays are just because of bilingualism"

"Please don't judge our parenting because it looks different from what you expect. We are doing what works for our family"



Practical tip:

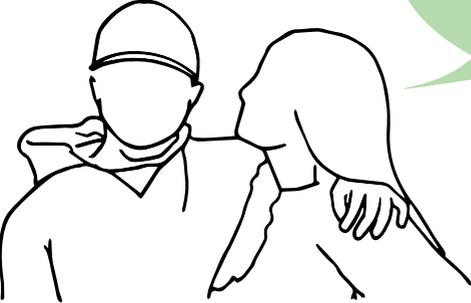
Ask questions like, "What is important to your family?". Tailor your approach accordingly, ensuring you provide culturally sensitive care and support.

Encouraging independence while acknowledging needs

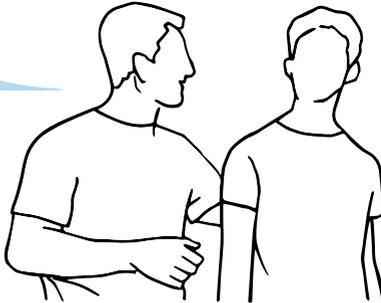
Help parents plan for the future

Parents are often concerned about their child's future, especially around independence and long-term care. While encouraging independence is important, it needs to be balanced with their unique support needs.

What parents and carers told us:



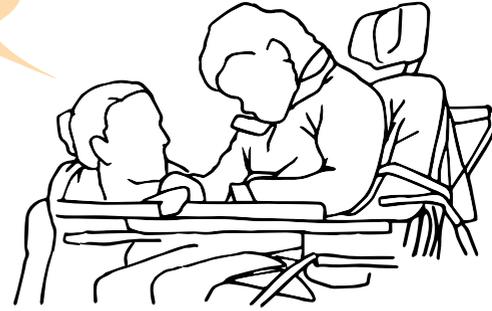
"It's a constant worry – will my child be okay when I'm no longer here? It's about finding the balance between helping them gain independence and making sure they're supported"



"My child wants independence, but they still need a lot of support. It's not one or the other"



"It would help if education practitioners looked beyond academic success—life skills matter too"



"We need long-term solutions, not just short-term fixes"

Practical tip:
Work with parents to develop realistic goals, focusing on life skills that encourage autonomy as far as possible, while ensuring support networks are in place for the future.

Support

Helping parents navigate services - be their advocate in the system

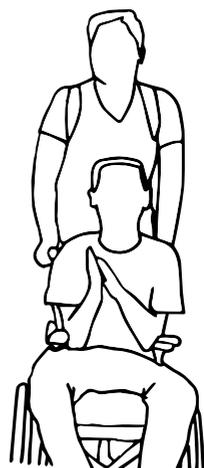
Navigating healthcare, education, and social care systems can be overwhelming for families. As a practitioner, helping parents access services and advocating for timely intervention can be a lifeline.

What parents and carers told us:



"It feels like we're constantly battling with paperwork, waiting lists, and appointments. Having someone to guide us or push for faster access is invaluable"

"I often feel like I need a law degree to understand my child's rights"



"Sometimes I don't know what to ask for because I don't even know what's available"

"It's exhausting fighting the system. Please stand with us, not against us"



Practical tip:
Offer guidance on navigating the system, assist with paperwork, provide signposting to local and national support services and advocate on behalf of families for quicker and appropriate service access.

Conclusion

Collaboration with parents of children who have special educational needs and disabilities is about partnership, respect, and open communication. By listening, personalising support, providing emotional care and helping families navigate complex systems, practitioners can make a real difference. Every parent's experience is unique, but aiming to build trusted relationships and working alongside them will help ensure the best outcomes for children and young people.

There are some videos which provide more insight from parents on Contact's website, along with lots of other useful information to practitioners.

<https://contact.org.uk/practitioners/advice/>



[Useful videos from Contact](#)



[Link to Contact's guide for GPs on making practices more welcoming](#)

Your feedback, suggestions, and personal experiences are incredibly valuable to us. They help us improve future versions of this leaflet and ensure it's as helpful and relevant as possible.

Please get in touch at: enquiries@cheshireandmerseyside.nhs.uk



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contact
*For families
with disabled children*