



Feedback Summary: Challenges Accessing Medical Care for CYP with SEND: January 2025

Parents of children and young people (CYP) with SEND have shared raw, honest feedback about the barriers they face when accessing A&E, X-ray departments, Minor Injuries Units, and children's wards. These stories highlight a lack of understanding, dismissive attitudes, and inconsistent support, which lead to traumatic experiences for children and families alike.

We propose gathering additional feedback from parent carers and engaging with PALS to review complaints data from families accessing these services. This will help identify recurring issues and drive meaningful improvements.

Key Issues

1. Poor Understanding, Communication, and Inconsistent Support

“Communication and understanding from receptionists and frontline staff is so hit-and-miss. You never know what you're going to get. Some staff are great, but others just don't get it. And when it's bad, it's awful.”

- Parents report that staff often lack training in understanding SEND needs, leading to poor communication and support.
- Families feel ignored or dismissed when advocating for their child's needs, increasing stress in already difficult situations.
- **Example:** “When I asked if they could call us when the department was quiet, they outright refused. I had to make two trips—first to check if it was calm enough, then go back to get my child. It's ridiculous that parents have to do this.”

2. Invisible Disabilities and Poor Interception

“They totally don’t seem to understand how much pain ND children will put up with just to avoid the trauma of interacting with medical staff.”

- Poor interoception means many CYP with SEND don’t recognise or express pain in a typical way. Staff often misunderstand this and dismiss their discomfort.
- **Example:** “My daughter walked around for two days with a broken finger after being refused adjustments at Minor Injuries. She just couldn’t face going back after the first experience.”

3. Trauma in A&E and X-Ray Departments

“A junior doctor touched my child without warning her. Then he tried to put in a line while she was screaming and almost vomiting with fear. When I intervened, he told me I was a bad mother. Now she has a needle phobia and needs CBT just to have her vaccinations.”

Families shared repeated examples of distressing interactions with medical staff, including:

- No reasonable adjustments like quiet spaces or allowing parents to stay during procedures.
- Dismissive attitudes and lack of empathy from staff.
- **Quote:** “When the paramedics are saying A&E isn’t safe and suggesting keeping her in the ambulance, you know something’s wrong.”

4. Barriers in Children’s Wards

“When we arrived, no one had any idea what a sunflower lanyard was, and no one asked if there was anything they could do to help. It felt like her SEND didn’t matter at all.”

Families report:

- No preparation or guidance for hospital stays, such as hospital passports or clear expectations.
- A lack of awareness of sensory needs and visible identifiers like sunflower lanyards.

5. Care Plans Are Ignored

- Despite the effort to create detailed care plans, families find they are often ignored or unavailable in the system when needed.
- **Example:** A parent shared how their child's care plan stated she could wait in the car to reduce anxiety, but staff insisted she sit in the crowded waiting area. This led to multiple attempts to abscond, putting her in danger.
- **Quote:** "If CAMHS go to the trouble of writing a plan, it should actually mean something when we arrive at A&E."

6. Dismissive Attitudes and Rigid Systems

"When I asked if they could call us when the department was quiet, they outright refused. It's not a hard adjustment, but it would have saved us so much stress."

- Families often encounter rigid policies that deny basic adjustments, like waiting outside or in quieter spaces.
- Staff frequently make parents feel like they're being "difficult" for advocating for their child's needs.

Parent-Reported Experiences

1. Dismissive Staff:

- "A consultant in the hand clinic told me, 'She's not in that much pain. It's just her autism making her act out.' Then they X-rayed her thumb and found it was fractured."

2. Care Plans Not Followed:

- "We had to explain her needs over and over because the staff didn't know what a care plan was. It made everything worse for my son."

3. Rigid Policies:

- "A&E refused to let them wait in the car, even though it was in their care plan. They ended up running out of the department twice because they were so overwhelmed."

4. Trauma from Procedures:

- "A doctor put in a line without explaining it to her first. Now she has such severe anxiety about needles that we're doing CBT to help her cope with vaccinations."

Suggestions for Action

1. OxPCF to collate More Feedback

- Gather further input from parent carers to build a clear picture of recurring issues

2. Engage with PALS

- Review complaints data from families of CYP with SEND to identify problem areas and drive improvements.

3. Staff Training

- Train staff, from receptionists to medical professionals, on:
 - Autism and sensory needs.
 - Poor interoception and how ND children experience and express pain differently.
 - Handling invisible disabilities with empathy and flexibility.

4. Practical Adjustments

- Introduce quiet spaces and flexible policies like allowing CYP with SEND to wait outside.
- Make hospital passports and care plans mandatory tools for supporting families.

5. Improved Communication and Accountability

- Ensure care plans are accessible, followed, and respected by staff.
- Create clear feedback processes so families feel heard and supported.

Conclusion

“Families shouldn’t have to fight every step of the way to get their child the care they need.”

Parents’ feedback makes it clear that medical settings are often unprepared to support CYP with SEND, leading to unnecessary trauma and distress. By improving training, implementing practical adjustments, and ensuring care plans are followed, we can create a safer, more supportive system for SEND families.