



## Early Learning and Community Childcare Hubs parent case study

### What does good quality look like for parents with disabled children in the early years?

*'I have found accessing childcare for my son, to straight forward and positive experience. He was admitted without hesitation to our local private nursery via the hub, which was the first childcare provider that I approached. I have found the staff to be helpful and willing to learn about my son's additional needs. Robbie needs to be fed through a gastrostomy tube so when he started at nursery the staff all received the relevant training from a local community nurse. As a result, I have full confidence in their ability to provide safe and good quality childcare for Robbie.'*

#### Top tips

Things to remember about supporting parents of children with SEND:

- The early years are the toughest time for parents. They are often in a very vulnerable place, stressed, depressed or grieving for their child's future and what is to come. Coming to terms with a child's condition or disability is incredibly hard.
- Parents are emotionally on a roller coaster. Parents are asking if it is their fault, feel guilt, anger, desperation and deep, deep sadness.
- This is also the time they need to be making decisions and often they have no knowledge of SEN, no experience of children with SEN before .
- Leaving a disabled child is harder – good quality care is the main barrier. And often parents feel they are compromising on their child's care, so there is also a heightened sense of guilt.
- For parents with children with SEND you cannot separate education and childcare. These are one and the same thing because as a parent you know your child needs help as soon as possible and as intensively as possible.
- Something else people forget is that you cannot share pickups, play-dates after school or exchange childcare. We cannot share babysitting, sleepovers and other childcare arrangements in the way you can with children who do not have SEND.
- Parents will often have very clear views about their child's needs. It is imperative that childcare settings offer open communication and co-operation with parents.

#### Context

Contact a Family, is the UK charity for families with disabled children and young people - what the condition, whatever the needs, wherever they live. Contact a Family have partnered with 4Children on the Early Learning and Community Childcare Hubs programme for the last three years.

In this case study is written by Stacey Lewis, mum to daughter May, who was born with severe brain damage. She writes here about what good quality early learning and childcare means to her. She hopes her experiences will help the Hub improve their practice for other children with SEND.

“It was completely unexpected and, as parents, we were lost. We had no idea how to access services or help her in any way. It was a very difficult time. I had no idea that accessing nursery would be our greatest challenge. People assume that May’s disabilities are a constant challenge in our lives, but the reality is that it is the complex systems we encounter and reluctance to work with her and us that is the most difficult.

“We contacted over fifty childcare providers and only three would even show us around their facilities. It was demoralising to know so many doors were being shut in my daughter’s face and she wasn’t even one-year old yet. One nursery, even insisted we have a Statement of special educational needs before they’d agree to meet us. Statements have now been replaced by Education, health and care (EHC) plans but this is still happening.

“The wonderful thing is that, despite the difficulties I and friends had in getting our children into nursery, once there, the nurseries loved working with them. Personally, May attending nursery was completely transformative for both her and us. Even today, I would attribute the stimulation and socialisation she learnt at nursery to her ease in the wider world and comfort with primary school. The most essential thing they did was teach her to eat with a spoon, which is no small thing! If they hadn’t, she would be tube fed today. This one small thing helps save the NHS thousands over her life.

“This one incredible act illustrates the difference between a parent left to their own devices and one where they work alongside professionals. I am educated to post-graduate level, but I’d never had a baby – let alone a disabled one – and I didn’t know the first thing about teething, weaning, even nursery rhymes! I feel very grateful that I had access to their experience and training.

“The staff in the nursery were everything I’d hoped: patient, caring, thrilled at her accomplishments even when they didn’t tick any box on the developmental chart. They were careful to keep me informed of her needs and progress. They worked with the OT and physio assigned to her and not only didn’t mind doing her stretches, etc, but constantly asked what more they could do to help her. Their dedication was such a relief after months on my own when she was a baby.

And, I had been very isolated – on my own with a disabled baby to whom I adored but had no idea what to do with. Once in nursery, I had access to their input and I was able to return to work – a financial, social and mental health imperative. Weeks before my return date we still hadn’t found May a place. So, nursery saved my sanity and also financially as I was able to earn a salary.

But, it wasn’t just us. The staff, parents and children loved having her. Parents would tell me their children would come home singing songs about my daughter. They ran to her when she came in through the doors, brought her over toys and turned them on when she couldn’t do it herself.

And the staff just adored her. Many of the people involved in her care went on to work with disabled children on a permanent basis in schools, as special needs nannies or SEND coordinators. That has been one of the most positive aspects because I know it was the direct experience of working with May that inspired them to continue down this path. If the nursery hadn’t taken that risk, would they have ever worked with a child like her and gone one to help all those future children? Probably not.

This illustration summarises what’s important to me and other parents like me.

# What's important to me?



OPEN COMMUNICATION



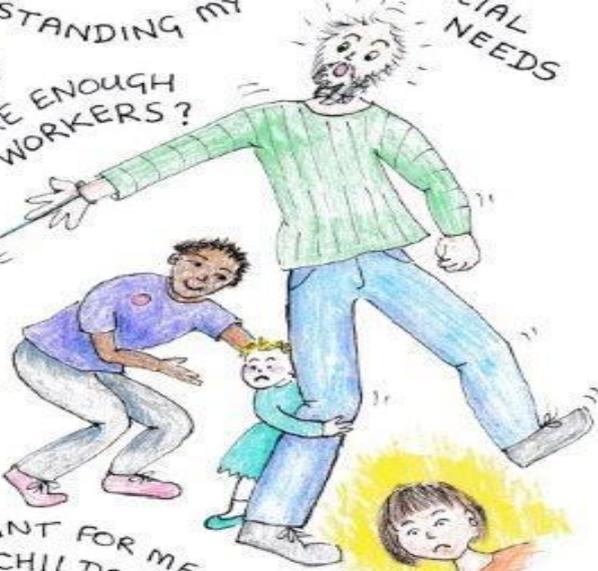
WILL MY BABIES BE OKAY?

UNDERSTANDING MY CHILD'S SPECIAL NEEDS  
ARE THERE ENOUGH WORKERS?

THE PROVIDER SHOULD ADAPT TO THE INDIVIDUAL NEEDS OF THE CHILD...  
CAN THEY DO THAT?



SAFETY!



IT'S IMPORTANT FOR ME TO KNOW MY CHILDREN ARE SUPPORTED, CONTENT AND HAPPY IN THE SETTING

