



Family childcare stories

Adam

Adam is 11 years old, he has an older brother who is 12 and a sister who is two. Adam has CHARGE Syndrome and after he was born, he spent the first six months of his life in Great Ormond Street Hospital.



Babies with CHARGE Syndrome are often born with life-threatening health conditions, including complex heart defects and breathing problems. Most children have hearing loss, loss of vision, difficulty swallowing and with balance, and have delayed development and communication.

The importance of play for Adam

When Adam came home he had a gastro feeding tube, and life became very difficult for Adam's mum, Lydia who also had a healthy, active 18 month old boy, Ethan at home. Ethan was already attending pre-school a few days a week but most of this "free" time for Lydia was spent at hospital and medical appointments for Adam. Despite his physical condition, Adam's parents felt strongly that he needed to be playing with other children and in an environment where he would be developing alongside other children.

Getting the right childcare

His parents found a local authority funded special needs nursery but this had a nine month waiting list and they felt that in the life of a baby this was too long. So they approached their old childminder who had cared for Ethan when he was a baby. Despite this childminder having had no previous experience of caring for children with complex needs, she had what Lydia describes as a "can do" attitude as well as being very loving and caring. She was prepared to learn from Lydia about feeding and communicating with him. Her positive attitude and willingness to learn alongside Adam and his parents really smoothed the way for the whole family and helped normalise life for them all.



Inclusive childcare for Ethan and Adam

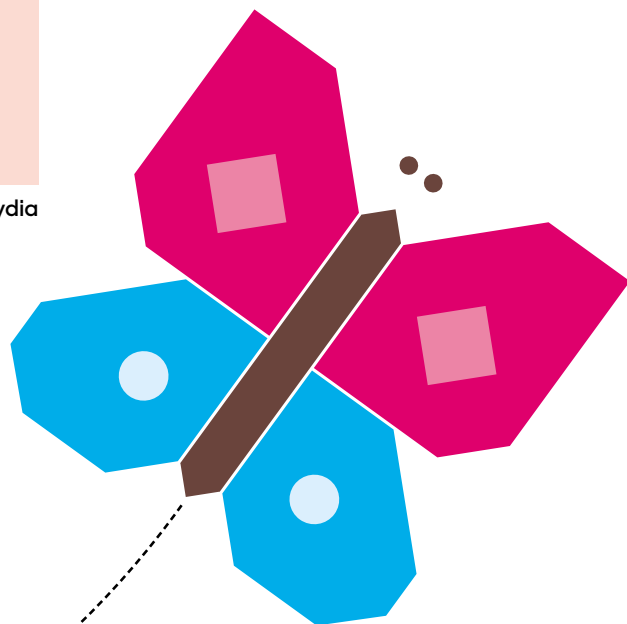
The family also used a local play-scheme during the holidays. This has been hugely useful as both Adam and his brother have been able to attend together and when funding has permitted, they have been able to secure one to one support for Adam. The family has been able to use direct payments to pay for after school activities, for support when Lydia and Adam have medical appointments as well as for a SENSE holiday play-scheme.

"If you can't find a childminder with experience of caring for children with complex needs - find one with a positive attitude who is willing to learn with the family."

Adam's mum Lydia

Advice from Lydia

- Find a childminder or nursery with a "can do" attitude, they make all the difference and normalise life.
- A good childcarer can help you deal with all the emotional adjustments and practical issues of juggling a young family, including a child with a disability.
- Find inclusive after school and holiday care where all your children can attend at the same time.
- Transport is often a major problem, so you may need to tackle this with your council.



For further information about childcare and family services visit:
www.familyandchildcaretrust.org