

Case study: *supporting siblings of children with a disability*

Article 23 of the UNCRC is clear that children with a disability have the right to live a full and decent life with dignity and independence, and to play an active part in the community. It requires governments to do all they can to provide support for children with a disability. However, it is also important to recognise the rights of siblings of children with a disability. Their lives can be profoundly affected by their sibling and they may face their own challenges and difficulties. Siblings of children with a disability may need extra support and attention to ensure their voices are heard and their needs are met, as this case study illustrates:

Our family consists of mum, dad, two boys (10 and 13) and a dog. In many ways we are fortunate but every aspect of our lives (from the house we live in to the light bulbs we use) is dictated by our eldest son's autism and, to a lesser extent, hearing loss. As adults, we can forgo such things as a social life, family holidays, regular sleep but our youngest owes no such duty to surrender the things that others may take for granted. As parents, you try and be even handed but the cards just haven't been dealt that way – it's the eldest who holds the trump cards and the youngest who suffers as a consequence of the compromises needed to get us through everyday life.

Doing anything, going anywhere requires almost military planning and contingencies for when it all goes off the rails – spontaneity is not an option. A friend of our youngest coming over to play (a comparatively recent progression) requires all sorts of explanations to parents and the friend about some of the more unusual behaviours and their background. Although these have been generally well-received and expose way more personal family information than the norm but you get used to having your family's lives open to scrutiny – we have no secrets any more.

These are choices we, as adults, have made in order to support our eldest child but our youngest had no choice. No choice but to try and sleep when 'Santa Claus is Coming to Town' is played endlessly on a toy keyboard in the night, no choice when we cut short our last attempt at a family holiday a few years ago – no choice in having his life planned around his brother's and it being a matter for the scrutiny of strangers.

One night, a few years ago I heard our youngest crying in his room and found him kneeling on his bed, his face in his forearm and pressed to the wall. All attempts to console him or discover the reason just led to ever more anguished, body-wracking sobs before he eventually turned to me and wailed 'I don't know.' At that point I knew all right and realised that, until that point, I hadn't appreciated just how big the impact was.

We learned that you have to ask questions to which there are no right or wrong answers, to listen without judgement and to answer any question with complete openness and honesty. It's scary and the future's uncertain for them too.