

News

Risk of “stranger danger” to people with Williams Syndrome needs better understanding, researchers say

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Bev Smith and son Dylan Mckimm

The risks of “stranger danger” to children and adults with the genetic disorder Williams Syndrome should be better understood to improve their personal safety, according to new research from Durham University.

The researchers have called for increased awareness and better intervention techniques to educate teachers, health professionals and young people with the disorder about the risks posed by strangers.

The Durham-led study, prompted by parents’ concerns about appropriate interactions with unfamiliar people, found that the majority of children with Williams Syndrome showed a lack of awareness of stranger danger.

Williams Syndrome is a rare neuro-developmental genetic disorder affecting about one in 18,000 people. There are approximately 3,500 people in the UK who have the disorder.

Children and adults with Williams Syndrome can suffer from physical health issues, such as heart problems, as well as mild to moderate learning difficulties and high anxiety.

A particular trait of the disorder is that those with Williams Syndrome are often good talkers, although they might not understand everything they talk about, and very outgoing and friendly towards other people, increasing the risks to them from strangers.

The Durham researchers showed short films about raising awareness of stranger danger to 16 young people with Williams Syndrome, aged eight to 17 years, then scored them according to their responses to a series of follow up questions about the films they had seen.

They found that on average, 73 per cent of the answers given by the young people with Williams Syndrome did not show appropriate knowledge and awareness of interactions with unfamiliar adults. This compared to an average 40 per cent of the responses given by a younger group of typically developing children who were also tested.

One film showed a man asking a young boy to help him find his dog in a playground. Typical responses from children with Williams Syndrome were that the boy in the film should help the man find his dog.

Those who showed less awareness of stranger danger were also those who were reported by parents as experiencing more difficulties with peer relationships and had less adequate social skills.

The research, funded by the British Academy, is published in the [Journal of Intellectual Disability Research](#).

Lead author Dr Debbie Riby, in the [Department of Psychology](#), at Durham University, said that adults with Williams Syndrome were just as vulnerable as children to the risks posed by strangers.

She said: “A classic feature of the disorder, across all age groups, is that children and adults tend to be very verbose and they can have a propensity to approach unfamiliar people.

“Our study has shown that the majority of children with Williams Syndrome who we tested had low awareness of the risks posed by strangers, which increases their vulnerability.

This vulnerability is particularly evident when you consider the full Williams Syndrome profile – outgoing personalities, talkative in nature, a tendency to approach unfamiliar people, but reduced intellectual capacity to understand an interaction, when combined place an individual with Williams syndrome in a vulnerable situation.

“The aim of our research would be to ultimately develop a social skills training programme, looking at social interactions and possibly delivered by teachers, to raise awareness of social communication issues in people with Williams Syndrome.

“If people with Williams Syndrome who would benefit from social skills training could be identified in childhood, it could mean they will be less prone to struggling with appropriate social interactions by the time they reach adulthood. This may increase their daily living skills and reduce vulnerability.”

Dr Riby, who also heads up the North East Williams Syndrome Research Group, added that any existing social skills interventions and training programmes that may currently be used with individuals who, for example have autism, would need to be evaluated to see if they fit the needs of individuals with Williams Syndrome.

She said that future investigations of social behaviours associated with Williams Syndrome were also needed to consider how best to feed the recent findings into social skills training.

Lizzie Hurst, CEO of the Williams Syndrome Foundation, said: “It is vital that people supporting Williams Syndrome children and adults are aware of their social vulnerability.

“Williams Syndrome adults are at particular risk as there is a presumption, based on their misleadingly good linguistic skills, that they can take care of themselves. The adults are often not afforded the same protection extended to children, which in fact they still need.”

Case Study 1 – Bev Smith and Dylan Mckimm

Dylan Mckimm, 13, lives in Spennymoor, County Durham, with his mother Bev Smith, 38, and stepfather Brian Smith, 41.

A pupil at The Oaks Secondary School, in Spennymoor, Dylan displays the typical outgoing personality of people with Williams Syndrome.

Mum Bev said: “He’s always been overfriendly growing up and whenever he sees someone walk past our house he runs to the front door and shouts hello to them.

“He’ll even shout hello to people he doesn’t know. He loves the attention, but when people don’t respond, which sometimes they don’t, he can get very upset.

“It can also affect his routines. Dylan likes to see one of our neighbours from his window every morning and he won’t get ready for school or have breakfast until he has, which can be quite difficult.

“To help with this, we have a support worker who comes in on a morning who sets a routine for him and once he’s ready, then we open his blinds.”

Bev said she had concerns about giving Dylan more freedom as he gets older, but that more awareness of Williams Syndrome and its traits would help.

She added: “The more awareness there is of the disorder and things like the increased sociability that comes with it, the better.

“People might think there’s something wrong with Dylan, but they don’t know what it is. If they had more awareness, they might take a different approach.”

Case study 2 – Judy and Chris Steel

Judy Steel, 60, and her son Chris, 39, live in Bingley, West Yorkshire.

Chris, an actor with Mind the Gap, a specialist professional theatre company for people with learning disabilities, has Williams Syndrome, which means he is very outgoing and friendly towards other people.

While saying that she wouldn’t want her son to change, Judy admits that Chris’s lack of awareness has caused problems when he meets unfamiliar people.

Judy said: “It was a real issue when he was growing up. We lived next to a park and he used to take his bike. One particular time somebody walked up to him and started chatting to him, then threatened him and stole his watch.

“And about three years ago when he was in town having his lunch, someone started chatting to him about football because he was wearing a Liverpool shirt. The next thing you know his mate said ‘I need to ring my mum, but I need a mobile phone. Can I borrow yours?’ Chris gave it to him and he didn’t get it back.

“It’s that sort of thing. They don’t see the danger in a situation and they don’t have the social tact to say just a minute that’s mine. I can’t lend it to you.

“Within the Williams Syndrome group of people this problem is well known, but not within the general public.

“I think there should be more awareness, especially in schools and places of education and even work places. If people are aware and know about the problem then that’s half the battle.”