

Families search for truth among autism treatments

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HEALTH EDITOR

BETWEEN the sensory gym and the psychologist, the occupational therapist and the speech therapist, Belinda Taylor and her sons attend up to 15 appointments a week.

Christopher, 14, has tried fish oils, probiotics, elimination diets and massage therapies alongside regular medications in an attempt to manage his autism. His 10-year-old brother, Zachary, who has the related Asperger's syndrome, is enrolled in rugby league, after a recommendation contact sport might help his social development.

"I've networked, I've researched and I've advocated. I do it because the more I do now, the less they'll need later," said Mrs Taylor, referring to the belief that early treatment may improve her sons' development. Her main source of information is other parents, through support groups and Facebook communities.

The first Australian audit of the treatments given to children with autism shows the typical child uses between five and nine different therapies in a year –

many of them expensive and scientifically unproven.

Mark Carter, from the Special Education Centre at Macquarie University, said 60 per cent of the 80 families polled in one of twin research projects used complementary or alternative medicines, with no solid evidence of their effectiveness.

Associate Professor Carter said it was of concern that the federal

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government funded techniques such as sensory integration therapy – based on a hypothesis that the brains of children with autism misinterpret information from their senses – via the occupational therapy component of its Helping Children with Autism support package.

Meanwhile, he said, children were not getting enough of intensive behavioural and educational therapies proven to make a difference. "There's no

slam-dunk interventions," he said, "but we have interventions with strong evidence and those with no evidence at all."

About 30 per cent of children were fed a gluten- or casein-free diet, or both, said Associate Professor Carter, who presented his latest online survey last week at the Autism Spectrum Australia Research Forum. "That costs \$30 to \$120 a week, plus 10 to 20 hours buying and preparing foods. It's a big imposte on families."

Trevor Clark, the director of education and research at autism service provider Aspect, said some families believe they should try "all and every treatment".

"Some of the interventions are marketed very cleverly. They feed on families' vulnerability, and some are very expensive," he said.

Leslie Embersits, the director of Mindd Foundation, which promotes alternative therapies for developmental problems in children, said it was legitimate for parents to follow other families' advice. The government's research agenda was "locked in the behavioural paradigm", she said, and funds should be directed towards studies of nutritional treatments.



Many appointments, one goal ... Belinda Taylor with her sons Christopher, 14, and Zachary, 10. Photo: Kylie Pitt