Eating issues, eating disorders and autism

Dr Judith Gould

Problems with eating often begin very early on with some babies struggling to latch on and suck the breast properly to children having real problems with textures, food fads and pica. Those early experiences may affect the long term possibility of developing an eating disorder.

Lorna Wing and I developed the Diagnostic Interview for Social and Communication Disorders (DISCO) which not only enables the clinician to make a diagnosis of an ASD but more importantly describes the skills and difficulties experienced by the person. As part of the assessment we can identify any difficulties the person has regarding all sensory issues. The difficulties experienced with textures and tastes of food are an important aspect to consider. For some children, just the sight or smell of certain foods can make them nauseous. I remember one lad I worked with who would gag if he smelt or even saw butter. It always fascinates me how some individuals on the spectrum have very precise taste recognition. You wouldn’t think it was possible to tell the difference between a McDonald’s chip and a Burger King chip, but they can! Dealing with food fads early can potentially prevent the development of eating disorders at a later time.

When a child is refusing to eat a certain food or food type, it’s important to work with the refusal whilst trying to make changes. It’s important that we do not impose our wants onto a child. You have to work with the child not against him or her. Food fads in individuals with an ASD are very common. It always amazes me how some people can live on a very limited diet and survive. Of course if a child is totally refusing to eat you may have to resort to extreme physical interventions such as tube-feeding, but otherwise it’s important to start with what the individual’s needs are and work from there.

It’s also essential to unpick why a person is refusing to eat in the first place. For example, I knew one boy who refused to eat at school, and it turned out that he wasn’t eating because there was simply too much choice at dinner time and it overwhelmed him. By reducing the choice to just two options, it would have removed the stress of lunchtime for him and his eating issues would have been understood.”

Some individuals with autism struggle to identify when they are hungry. Donna Williams, an individual on the spectrum, first drew this to my attention. She never felt hungry so she relied on visual prompts to remind her to eat. We need to know far more about interpreting why people with an ASD react to sensations differently. This is very complex.

“The reasons for eating disorders in autism are different from those experienced in the neurotypical population. With autism it’s often more about obsessions with calorie counting or exercise than it is about body image. There is also an element of control involved too, as controlling their intake of food is the ultimate control when the rest of the world seems so unpredictable. It’s so important to understand the reasons behind behaviours in order to treat them effectively. However, I believe that it’s essential that you start with the autism; identify how that affects the individual and you’ll be able to meet their needs and reduce their anxiety. In fact, understanding anxiety is the key to understanding how eating disorders occur in autism.

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These behaviours and obsessions around food can often provide these individuals with routines and structure to help them manage their anxiety. If you help them to manage their anxiety effectively then you’ll often see that their coping strategies, such as controlling their food rigidly, will start to improve."

Dr Judith Gould has worked in the field of autism for 40 years. Together with Lorna Wing, she coined the phrase “autism spectrum” which has revolutionised how autism is viewed. She is the Director of the Lorna Wing Centre for Autism in South London.

Judith is shortlisted for the Autism Professionals Awards 2013 Lifetime Achievement Award, sponsored by The Huntercombe Group. Winners will be announced at a prestigious awards dinner held on the first night of The National Autistic Society’s Professional Conference on Tuesday 5 March 2013 in Harrogate. For more information about the conference or to purchase tickets for the awards dinner, visit: www.autism.org.uk/conferences/professional2013.

You may be interested in our NAS information sheets on dietary management for children and young people: