

Report highlights huge problems faced by parents of children with autism

14 March 2016

Parents of children with Autism Spectrum Disorder (ASD) face severe challenges in accessing adequate services, according to a survey of hundreds of parents in the United Kingdom.

Just 11 per cent of [parents](#) felt that the NHS professionals they encountered understood their concerns about the behaviour and healthcare challenges of their child. The majority, 70 per cent, felt that their child's symptoms were attributed to ASD and seen as something to "get on with", rather than being worthy of further investigation and treatment.

Respondents to the survey identified diet and nutrition issues as a major cause for concern, yet just one per cent of parents were able to access services in this area and have their problem resolved. The vast majority, 77 per cent, did not. This is despite the fact that many parents reported health and behavioural progress in their child following dietary changes. Similar patterns were identified in relation to services for gut problems, behavioural challenges, sleep difficulties, and toileting issues.

One parent said: "My son has had multiple physical problems: chronic constipation, self-harming, food intolerances, epilepsy. Yet it is only the epilepsy which has been taken seriously (although the treatment has been ineffective to date). All his other issues have been dismissed as 'just autism' and there has been a reluctance to offer any kind of investigation or treatment."

The survey, carried out by the charity Treating Autism during 2014, forms the basis of a report, authored by Professor Jane Wills, based at the School of Geography, Queen Mary University of London. There are more than 600,000 people living with ASD in the UK today, and it is estimated to cost the UK in the region of £32 billion every year in lost earnings, care and support for all those involved.

Professor Wills said: "This report highlights the scale of the challenges faced by children with ASD and their families. It is frequently a battle for parents to access good quality health support for their children. There is an urgent need for new thinking and a much more holistic approach by those who are training health professionals and designing services for children and families."

Anita Kugelstadt, Chair of Trustees from Treating Autism said: "Treating Autism argues that this report highlights how a new outlook is necessary to address these ongoing serious challenges—diagnostic overshadowing as just one example—which significantly reduce quality of life for people with ASD, limit their potential, place great emotional stress and financial strain on the families, and in the long term put a greater financial burden on the tax payer. With a willingness to investigate symptoms thoroughly and pursue accurate diagnoses, and then explore safe and low-cost treatments when appropriate, quality of life for our children could be improved dramatically."

Survey participants were asked about the challenges faced by their children. Respondents were given a list of 22 problems, such as anxiety, erratic behaviour, and obsessive speech, and asked to identify the total number affecting their child. The number of problems faced ranged from a low of five to as many as 22, with 73 per cent of parents selecting 16 or more of the options listed. Respondents added their own comments which documented the severity of the problems they faced.

One parent said: "Will not chew or swallow solid foods at the age of almost 5 years, has to be liquidised but will chew anything wooden, metal or plastic." Another said: "Spinning round objects has moved on to smacking one hand on top of the other and biting his hand or fingers to the point where his skin is now leathery as it hasn't had a chance to heal."

While a number of parents spoke positively about individual NHS professionals, a majority of 61 percent reported that there was no understanding of their concerns about the issues facing their child. A majority of respondents, 70 per cent, reported that they had been told that physical symptoms were due to autism, and as such, the implication was that they did not warrant further investigation.

Provided by Queen Mary, University of London

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