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## NEWS RELEASE

# OPENING THE DOOR

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### HEALTH PROFESSIONALS URGED TO 'OPEN THE DOOR' TO FAMILIES TOUCHED BY AUTISM

Support from health professionals for families in the U.K. whose lives are affected by autism and Asperger syndrome, is revealed as "frighteningly inadequate" in a National Autistic Society (NAS) survey '**Opening the Door**' launched today (May 4th) at the House of Commons.

The survey reveals that **65% of parents** questioned had to see three or more professionals before getting a firm diagnosis for their child, with an astonishing **40% of parents** waiting more than three years to gain a diagnosis - **10%** of them waiting 10 years or more.

One parent's comment succinctly expresses their frustration and concern: "**The period leading up to diagnosis and receiving a diagnosis was a totally traumatic experience for all the family. It was a long drawn out process and we found that the number of professionals we came into contact with did not have sufficient experience or knowledge of autistic spectrum disorders.**"

The NAS calls for increased awareness of autistic spectrum conditions among front line health professionals - GPs and Health Visitors - and the adoption of a number of basic good practice measures, such as the administration of The Checklist for Autism in Toddlers (CHAT) to all children at the 18 month check. The CHAT has been demonstrated to be a useful initial screening instrument to alert professionals that a full diagnostic assessment is needed. It is designed for GPs and Health Visitors, and is completed in just five to ten minutes, but must be followed up promptly if there are signs of autism.

more.....



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Early diagnosis '**opens the door**' to a brighter future for people with autism and Asperger syndrome who often struggle in education and adult life. The survey demonstrates that in a significant number of cases it has been a difficult and convoluted process to obtain that diagnosis and an accurate assessment of how the disability will affect the lives of the person and their family.

Parents surveyed cited a variety of sources (friends, professionals, the media) as the route by which they first became aware of autistic spectrum conditions. It was striking that GPs and Health Visitors were rarely mentioned. This suggests a worrying lack of knowledge of autistic spectrum conditions, which affects more than 500,000 people in the U.K., among the very professionals parents of young children see on a regular basis.

**"Diagnosis had to be pushed for. My GP was reluctant to refer me and said I was worrying about nothing. I saw him at least six separate times to express my concerns about my son before he would refer me."** ....quote from the parent of a seven-year-old boy.

The problem does not relate solely to the parents of young children, but also to adults. Lack of diagnosis, in adulthood, often occurs when the disability is at the more able end of the autistic spectrum, including Asperger syndrome. But whatever the age of diagnosis - whether the person is two or twenty years-old - the right type of help can make a great difference to their future. Proper assessment can help secure services and support that could improve their lives in tangible and practical ways. People with autism and Asperger syndrome need specialised pre-school help and education, respite care or support in finding employment and benefits they have a right to, including mobility allowances.

*ENDS.*

#### **Notes to news editors:**

1. Summary of findings attached. If you require a free copy of the report please contact the press office (details below). Members of the general public can obtain copies for £5 from the NAS Publications Department, Telephone: 0171-903 3595.
2. Journalists are invited to the launch at the House of Commons, IPU Room at 11.30am – 2.00pm. Refreshments provided. For security reasons, please ring the NAS Press Office to confirm your attendance.
3. Autism Awareness Week 1999 runs from May 1 - May 8.
4. CHAT is available from University of Cambridge, Department of Experimental Psychology, Downing Street, Cambridge CB2 3EB. Tel: 01223 333550

For further information contact the Press Office, The National Autistic Society (NAS), 393 City Road, London, EC1V 1NG. Telephone 0171-903 3593. Email: [Press@nas.org.uk](mailto:Press@nas.org.uk)

Website: [www.oneworld.org/autism\\_uk/](http://www.oneworld.org/autism_uk/)

# OPENING THE DOOR

## SUMMARY OF MAIN FINDINGS

\* 65% of parents sought help within six months of first having concerns about their son or daughter. On average, parents in the survey sought help between 3 and 6 months of their first having concerns.

\* Over 40% of parents had to wait more than three years to get a diagnosis. 15% had to wait between 5 and 9 years and 10% had to wait ten or more years.

\* Frontline health professionals appear to have little knowledge or awareness of autistic spectrum disorders. Nearly two-thirds (62%) of parents went to their GP or Health visitor for help when they were first concerned.

\* 65% saw three or more professionals before they got a firm diagnosis. 25% saw five professionals or more.

\* Multiple diagnoses were often given to parents. Over time the diagnosis often changed from a general and incomplete diagnosis to a more specific diagnosis on the autistic spectrum.

\* 45% of parents stated that the disability was explained inadequately or not at all at the time of diagnosis. 81% stated that there was either no assessment of severity or a vague assessment of severity given at the time of diagnosis.

\* 45% of parents were dissatisfied to some degree with the diagnostic process with 20% being very dissatisfied.

\* 45% of parents reported they were not given any advice about where to go for help/support/counselling or further explanation after they had received the diagnosis.

\* 50% of parents reported that the support they received at the time of diagnosis was inadequate.

*Footnote: This report was based on the answers of 294 members of the NAS to a postal questionnaire. All these members are parents with one response received from a parent who is also a partner of a person with Asperger syndrome.*