

## **Life skills for the most needy**

**Autistic students can make astounding progress with the correct diagnosis and teaching. Mary Hampshire reports**

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Mary Timperley is frank about what she expects of her autistic son. "Some autistic kids are really bright. But James is never going to be the next Einstein," she says.

James, aged 19, cannot speak. He attends the further education department at Robert Ogden School, Thurnscoe, South Yorkshire, run by the National Autistic Society (NAS), a charity that runs schools, further education provision, referral services, employment schemes and residential homes.

Mrs Timperley, who lives in Sheffield, explains: "James has learned life skills such as preparing food and meeting people. He has also discovered how to communicate using symbols. Now he can make decisions for himself. He says 'yes' and 'no' by nodding, and he comes on nights out with us and our friends. That's progress," she says, proudly.

The severity of autism spectrum disorders varies enormously. Individuals are categorised as having autism or, at the higher end of the spectrum, Asperger's syndrome. Diagnosis is the key to accessing education but provision is very patchy. According to a recent NAS report: Ignored or Ineligible: The Reality for Adults with Autism Spectrum Disorders, too many people are diagnosed late in life - if at all.

"The provision is just not there," says Ann Taylor, senior residential service co-ordinator of Autism Initiatives, Liverpool, which specialises in residential care for adults with Asperger's syndrome and autism. The charity, which was established 30 years ago, has 94 adults in 34 homes and takes referrals nationally. It also has a school for 4 to 19-year-olds.

"This is much more the case for adults with Asperger's syndrome than autism: 80 per cent are referred to us in their late twenties, thirties or forties," says Ms Taylor. "Their parents have struggled for years not knowing what was wrong. Once they get a diagnosis, they often face a fight for funding from their local authority. Part of the problem is that this client group is mistakenly seen as too able to warrant help."

Mark Eames, head of post-16 at Robert Ogden School, says: "Things are improving but we have had parents who have taken their local authority to court."

The NAS report found that only 43 per cent of adults with autism were diagnosed before the age of five, despite having urgent needs. About 18 per cent of this group were not diagnosed until 16 or beyond. Longer delays were experienced by those with Asperger's syndrome: 46 per cent were not diagnosed until they were over 16.

A third of parents said that their son or daughter had suffered mental health problems including depression, a nervous breakdown and suicidal thoughts. This figure increased to 50 per cent where diagnosis was after the age of 30. Many adults with autism spectrum disorders remain invisible. Most live at home with ageing parents. The survey found, for example, that 49 per cent of adults with Asperger's syndrome live with their parents.

The NAS is calling on the Government to issue national guidance covering education, social, employment and health services. Its recommendations include a national protocol for the screening of autism spectrum disorders; training for all teachers working with this client group; training for psychiatrists and primary care practitioners; needs-led assessments by social services and, in conjunction with local health authorities, a much wider range of services.

James is one of the lucky ones. He was diagnosed at the age of five and his local authority has funded his schooling. "I just can't imagine how we would have coped without the right help," says Mrs Timperley. "When James was younger, he couldn't use a knife and fork. It was difficult taking him out in public. He was obsessed with escalators. He would want to keep going up and down them. He used to run off. At the hairdressers he once stripped naked to shake off the hair. "Since he's got specialist help he's come on tremendously. He likes computers, playing board games and enjoys walking and swimming. Before, he was interested in absolutely nothing."

Despite the depressing picture painted by the NAS report, existing services provide a beacon of hope, illuminating what can be achieved. For example, the Robert Ogden's FE department, which has 24 staff, including an educational psychologist and three speech therapists, takes about 30 students a year. Most stay three years. Many have come up through its school which offers day, boarding and residential placements.

"Students vary enormously," says Mr Eames, "from some who are like toddlers to very able teenagers who can hold down part-time jobs and may complete ASDAN (Award Scheme Development and Accreditation Network) modules such as English, maths, science, design and technology and information technology or GCSEs. "But all the students need a very structured, low-arousal environment, otherwise they become very anxious and challenging."

The classrooms are gently lit and painted in magnolia. Teachers only use white paper. Students have portrait photographs on their desks so they know their

places. Teachers address students in simplified sentences. "It might sound abrupt but we use keywords. It takes less time for the student to process the information," says Mr Eames. "We'll say: 'James, sit,' instead of, 'Please sit down James.'" Students are taught the Picture Exchange Communication System (PECS) in which symbols are used to develop verbal skills and understanding.

The curriculum is tailored to individual needs and includes key skills such as literacy, information technology and personal skills. The emphasis is on independence skills, accredited to OCR (Oxford and Cambridge RSA Examinations) National Skills Profile.

Modules focus on communication, number skills, personal skills, the community and home management, and include subjects such as responding in a group, indicating needs and preferences, understanding giving and receiving, awareness of sensible behaviour, preparing food, using shops, identifying basic personal needs, exploring and using community facilities.

"We had one lad who wouldn't do anything unless he was told to," says senior teacher Jon Mount. "But now he can put his tray down, pick up a knife and fork and scrape his plate afterwards. It took us a whole year for him to learn that but it's a tremendous achievement."

James Timperley is due to complete his further education at Robert Ogden soon and his family nervously wonder what the future holds. "I'd like to see him attend a day centre and continue his learning because he's come on so much," says Mrs Timperley. "Just because society knows about these conditions does not mean it understands them," says Ms Taylor. "But there is hope. We know that with the right support, people with Asperger's syndrome and autism can move on dramatically with their lives."