Changes in the field of autism

Dr Glenys Jones from the University of Birmingham reflects on changes in the field of autism over the past 30 years.

Whilst the needs of an individual with autism may change over time, it’s also likely that the understanding of the professionals who work with that individual will also develop. In recent years the awareness and knowledge of autism has grown rapidly and nobody knows that better than Dr Glenys Jones.

Glenys has worked in the field of autism for over 30 years and currently works in the Autism Centre for Education and Research (ACER) at the University of Birmingham. Here, she shares how the understanding of and attitudes towards autism have changed over the past three decades.

"I first became involved in autism in 1981 when I trained as an educational psychologist at Nottingham University. It was there I met Professor Elizabeth Newson who was very involved in the field of autism and ran weekly assessment clinics. I was very impressed at her skill and ability to engage parents in the process and at the very helpful and positive reports she wrote for them.

"This was in stark contrast to the experience of many parents of children with disabilities who I’d met in previous research work. Often parents had been excluded from having good written reports and their opinions were seen to be of less value than those of the professionals.

"In the early days we only looked at autism from the outside. It was only in the mid 90s that the perspective of people with autism took hold and this has had an increasing influence in what we do today. Autism literature has also changed substantially from the 80s. The books that were around then largely focussed on what people thought autism was, rather than focussing on how individuals with autism might be supported. In 1987, Patricia Howlin and Michael Rutter released the book Treatment of children with autism. This was one of the first that looked at how to work with and support children with autism. There were also very few biographies of people with autism. Emergence - labelled autistic by Temple Grandin was the first I read. Now in 2013, we are overwhelmed with books, journals, DVDs and websites. Although, in the 80s we knew that people like Temple could write about their condition, these were not used to inform our work. However, today much of the wisdom behind the strategies used are now underpinned by the views of people with autism, and that’s been a real sea change. Their insights and perspective have also led to a shift from a sole focus on deficits and gaps to one in which strengths and interests are also promoted.

"I later worked with Elizabeth Newson again on a project jointly funded by the Department for Education and the Department of Health, which explored the provision and interventions for both children and adults with autism in England and Wales. I was amazed at the differences in what was offered to very similar individuals and families which largely depended on where they lived and who had been involved in the assessment. This was because in the early days good
practice was locked into schools and adult services with very limited ways of disseminating ideas. The growth of courses and conferences as well as training programmes and online courses has led to information being shared and discussed and a growing consensus on what is deemed to be effective.

"Following my work with Elizabeth Newson I developed a passion to share the knowledge I'd gained from talking to professionals and parents and from filming children in different types of settings. I took up a post at the University of Birmingham which combined opportunities to do research with developing materials and resources for accredited training programmes on autism.

"One of the projects I worked on was the Inclusion Development Programme (IDP) commissioned by the National Strategies. This free, web-based training resource was a real catalyst for change, because it shared the knowledge, understanding and good practice in mainstream schools. There's been a real growth in the understanding of autism in both special and mainstream schools, alongside a growing number of children being identified and diagnosed with autism in both sectors. In the 80s, most autism specific schools had been developed by The National Autistic Society or by local autistic societies, but now there are many more autism specific bases and units within local authority schools.

"It is so important for staff in services and schools to have at least a basic awareness of autism. Individuals are then more likely to be understood and supported, rather than criticised and sanctioned.

"In 2007 the Department for Children, Schools and Families set up the Autism Education Trust (AET) to collate and disseminate key information on the education of children and young people with autism in England. I led the first Survey the AET commissioned into what key stakeholders considered to be the main challenges in educational provision which was published on the AET website in 2008.

"I'm currently a member of the AET Programme Board. In collaboration with children and adults with autism, parents, carers and autism practitioners, the ACER team developed a three tier training programme to be delivered through AET training hubs across England. A Competency Framework and a set of National Autism Standards for professionals working in education was also produced to audit the skills and knowledge of staff.

"Going forward, I’d like to see much more support for adults on the autism spectrum. The knowledge and skills developed by staff in schools and by parents and carers need to be maintained and built upon into their adult lives. We must have a lifelong perspective, giving individuals life skills and enhancing their emotional wellbeing, as well as working on their academic skills."

For more information on the ACER accredited courses visit
http://www.birmingham.ac.uk/research/activity/education/acer/courses/index.aspx

For access to the IDP and for more information on the AET training programme visit
www.autismeducationtrust.org.uk

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