Improving the management of children with learning disability and autism spectrum disorder when they attend hospital

I. Vaz
Department of Paediatrics, South Warwickshire Foundation Trust, Warwick, UK

Accepted for publication 7 June 2010

Health professionals are likely to encounter persons with learning disability and autism spectrum disorder (ASD) at sometime in their career. Approximately, 2% of patients on a general practitioner’s register are expected to have learning disability (NHS National Patient Safety Agency 2004). It is estimated that 26% of people with learning disability are admitted to hospital every year, compared with 14% of the general population (MENCAP 1998). Specific data for children are not available. Children with learning disability have reduced ability to understand new and complex information (DOH 2001). They may have limited language skills, may not be able to report their symptoms and concerns, and their distress may manifest as challenging behaviour. Health care services have a legal duty to provide appropriate level of support to patients who have learning disability (MENCAP 2004).

The prevalence of ASD is estimated to be approximately 1% in the child population (Baird et al. 2006). They have varying levels of verbal and intellectual abilities and may have special needs unique and very specific to the individual (Morton-Cooper 2004). They can find attending hospital particularly upsetting (Deudney 2005). There is some overlap in the difficulties children with learning disability and those with ASD experience. Medical and nursing staff have to adapt their approach to children with a learning disability and ASD to be able to assess and manage them appropriately.

Children with ASD often find the experience of going into a medical setting frightening because of their inability to cope with a change in their routine and problems in comprehending what is happening to them and around them. They find attending accident and emergency (A&E) departments particularly anxiety-provoking because of the sudden nature of the clinical event, the unpredictable waiting time on arrival, which is dependant on triage priority, and the sensory overload from noise, lights and crowded busy waiting rooms even in child centred areas within the A&E department. The need to undergo a number of urgent investigations and treatment can also exacerbate anxiety. They may get overwhelmed with anxiety and become withdrawn or have behavioural outbursts making clinical examination and investigation a challenge. Hand flapping, rocking or other repetitive body movements sometimes seen in children on the autism spectrum can be due to anxiety, and a coping mechanism in a stressful environment (Howlin 1998; May 2005). Staff can help to reduce these children’s anxiety by ignoring unwanted behaviour, complimenting cooperative behaviour and dealing with them in a calm and reassuring manner. A survey conducted among our A&E staff, which included doctors and nurses, indicated that the majority (83%) had a reasonable understanding of the general features of ASD. However, a significant proportion (50%) did not realize that sensory overload that often occurs in an A&E setting could exacerbate their behavioural problems (Vaz 2009). This could be because they do not encounter children with ASD frequently.

There are a number of measures that the health professionals can take to ensure a successful health encounter with these...
children. They need to be aware that many children with learning disability and ASD are able to understand visually presented information and modelling or imitation better than verbal explanation. Where possible, using objects and equipment to ‘act out’ the intervention on the carer or a model before carrying it out on the patient can increase the chances of gaining their cooperation. The use of pictures or photographs to show what will happen is also helpful. Children on the autism spectrum may have difficulties interpreting facial expressions and gestures. It is important to speak in simple language and break down the actions needed in short steps (Hudson 2006). Direct requests help to avoid misunderstanding from literal interpretation of speech often seen in persons on the autism spectrum. They may get upset if they are asked too many questions or their personal space is entered. Explanation and warning must be given before getting close or touching for physical examinations, investigations and treatment. Distraction with conversation on topics of their special interest, toys or objects they like, and singing or counting can be useful in reducing anxiety in a medical setting.

Parents and carers always have a key role in trying to get cooperation from children. This role is even more pivotal in children with learning disability and ASD (Bradley et al. 2002; Autism Steering Committee NSLIJ 2004) as they know best their child’s specific sensitivities, their usual mode of communication and the sort of rewards that generally produce the desired behaviour. A brief conversation with the parent or carer prior to seeing the child could make the clinical encounter successful. Parents and carers often prepare their children for a planned medical encounter in different ways (Jones 2006) including using photographs, pictures, symbols and social stories (Gray et al. 2002). Social stories are a short description of a particular situation, event or activity that includes specific information about what to expect and why and the framework for appropriate behaviour (National Autistic Society 2008). Even a seemingly trivial request made by a parent should not be ignored because it may make the difference between having a positive or negative encounter (Davis & Goldband-Schunick 2002). Paediatric nurses may also be able to help in understanding and meeting the needs of these children in parts of the hospital not staffed by children’s nurses.

Health-care staff in a hospital setting may lack training and skills in understanding the symptoms in people with learning disability, and the parents and carers have a key role in interpreting their behaviour (MENCAP 2007). Parents or carers usually inform the staff that their child is on the autism spectrum or has a learning disability. From the outset the staff need to work with them on how best to deal with their child. It has also been suggested that a system is put in place for identifying on the medical records, those individuals, who have a learning disability (MENCAP 2004). This would alert staff to modify their approach where necessary and deal with them appropriately.

Waiting is one of the most difficult tasks for children with ASD and learning disability. Some may prefer the choice of a first or last appointment of the day. However, the time for assessment is unpredictable in a busy A&E department and the anxiety caused by waiting and the break from usual routine can provoke a behavioural disturbance particularly in children on the autism spectrum. Consideration should be given to seeing them first irrespective of the clinical priority assigned at triage. If waiting is inevitable, the parent or carer should stay with the child in a quiet area, where there is minimal sensory stimulation, using strategies they usually deploy to occupy the person during waiting times. If clinically appropriate, there should be flexibility in allowing the child the option of waiting with the parent outside the medical environment until it is time for assessment (Autism Steering Committee NSLIJ 2004). Limiting the number of staff involved in treating the child also helps them to understand what is happening to them and the role of the care provider (Deudney 2005). Staff also need to recognize that more time is generally required for assessing symptoms in people with learning disability (MENCAP 2004; Bradley and Lofchy 2005).

There is often frequent turnover of staff, particularly trainee doctors in hospitals. They have many priorities for training and there are limitations by way of time and resources available. Nevertheless there should be opportunities during the doctors training and professional development to increase their awareness regarding the special needs of children with learning disability and ASD and how best to address them so that they can deliver optimum health care to them. Relevant information and educational material that is easily accessible should be available on the hospital intranet (Autism Steering Committee NSLIJ 2004; Deudney 2005; Shropshire County PCT 2006). The memory of a distressing experience in a medical setting can have a detrimental effect on subsequent attendances.

Many children are understandably apprehensive about attending hospital. Those with learning disability and ASD may find it particularly anxiety-provoking. Creating awareness of their special needs among health professionals can minimize the anxiety these children experience, resulting in a more positive encounter for everyone.

References

Bradley, E. A. & the Psychiatry Residency Year 1 Intellectual Disabilities Psychiatry Curriculum Planning Committee, University of Toronto (2002) *Guidelines for managing the client with intellectual disability in the emergency room*.
MENCAP (2007) Death by Indifference, Following up the treat me right! Report, MENCAP.