Visual symbols in healthcare settings for children with learning disabilities and autism spectrum disorder

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Abstract

Children with learning disabilities (LD) and autism spectrum disorder (ASD) get anxious while attending healthcare settings as it is not part of their usual routine. They often understand visual symbols better than speech. Many of these children are accustomed to using symbols at school and at home to support their verbal understanding. A list of commonly conducted physical examinations, medical investigations and treatment procedures was compiled by the author with the help of parent support groups for ASD and Down’s syndrome. In total, 150 visual symbols were developed for use in healthcare settings in consultation with parents, special needs teachers and a software company. Overall, 50 health professionals from 12 clinical areas in the hospital and community were consulted for their views on introducing symbols in healthcare settings. All had experienced difficulties in gaining cooperation from this group of children and strongly endorsed the use of symbols. They suggested using symbols in clinics and sending visual symbols home before the appointments to improve the children’s understanding and cooperation.

Key words: Learning disability ■ Autism spectrum disorder ■ Visual symbols ■ Healthcare settings ■ Children

Attending a healthcare setting can be a daunting experience for most people, and this is especially true for many children with learning disabilities (LD) or autism spectrum disorder (ASD). About 1% of children in the UK are thought to have ASD (Baird et al, 2006). There are about 3–4 people with a severe learning disability for every 1000 people in the UK (NHS National Patient Safety Agency, 2004). It is estimated that 26% of patients with LD are admitted to hospital, compared to 14% of the general population (Mencap, 1998), and they are likely to find clinical assessments and treatment procedures particularly stressful. Their behaviour and communication skills may deteriorate in healthcare settings (Hudson, 2006), which can present a challenge to health professionals.

Many children with ASD or LD are able to understand visually presented information better than verbal explanations (Hudson, 2006). Simple line diagrams can be drawn to represent medical investigations and treatment procedures, helping these children understand what to expect when spending time in a healthcare setting.

Visual symbols for healthcare settings were developed by the author with the help of parents, teachers, health professionals and a software company and were used for children with LD and ASD attending a ‘special school’ (a school catering for children with LD, ASD and other special needs) clinic to help them understand what was going to happen and provide guidance on how to respond to the situation. These children were accustomed to using visual symbols at school and at home to help them understand activities they needed to cooperate with.

A survey was undertaken among health professionals providing care for children in the hospital and community clinics. The aim was to consider the use of visual symbols to aid communication with children who have LD and ASD. The results of the survey indicated that there was enthusiasm for using visual symbols in healthcare settings. The visual symbols have the potential for increasing these children’s understanding and cooperation when they attend hospital or other healthcare settings.

Background

Various cultures around the world have been using pictographs to convey ideas for thousands of years and well before any language had developed. Today visual symbols are commonplace in everyday life situations—for example, road signs, disabled parking places, laundry instructions on garments and recycling materials. Children with LD and ASD are often able to better understand information when verbal explanations are enhanced with visual cues (Hudson, 2006). Their understanding of speech may deteriorate when they are in an unfamiliar place, such as a healthcare setting, as it is not part of their usual routine. In these situations, visual symbols could be used in conjunction with verbal instructions to enhance understanding, easing the anxiety.

Many children with LD/ASD have been introduced to the use of visual symbols at school and at home to support their understanding of their daily routine and help them make choices between activities. Parents and teachers have found them beneficial in those settings. However, there are no readily available symbols that are applicable for use in healthcare settings, as far as the author is aware.
Aims
The aim was to develop a variety of clinically appropriate visual symbols for use by parents and health professionals in different clinical settings and to evaluate their appropriateness and feasibility for use in those settings.

Ethical issues
The hospital management and Caldicott Guardian were informed of this plan to develop visual symbols for use in healthcare settings and supported it. It was classified as service development and ethical approval was considered unnecessary. The visual symbols with clinical themes were developed for use in an existing weekly paediatric clinic in a special school. Visual symbols have been routinely used in the classroom in this school for a number of years to indicate children’s daily timetable of activities.
Method
A list was compiled of physical examinations, medical investigations and treatment procedures that are commonly carried out in children. This was done in consultation with parents from two parent support groups for ASD and Down’s syndrome, special needs teachers and nursing and allied health professionals working in the area. A software company (Widgit Software) helped develop these symbols to convey each concept or idea in a simple way using line drawings. Overall, 150 symbols were developed to represent medical examinations, clinical procedures and treatments that are commonly carried out in children. Two formats were developed—event timeline (symbols arranged in a strip to show sequence of expected events) and key fob (symbols attached to a key fob for easy portability). Examples are shown in Figures 1, 2, 3 and 4. In addition, some symbols were also developed to represent different health professions. This was to ensure the children understood the roles of the different members of staff and recognised them and were also used as signposts for the clinic door or treatment area. Some symbols were designed to convey instructions, such as ‘wait’ or ‘play’, for when there was an interval between different members of staff and recognised them and were also used as signposts for the clinic door or treatment area. Some symbols were designed to convey instructions, such as ‘wait’ or ‘play’, for when there was an interval between activities such as applying local anaesthetic cream and a blood test or between doing an X-ray in the accident and emergency (A&E) department and plaster application. ‘Well done’, ‘goodbye’ and ‘finished’ symbols were also produced to indicate the end of the clinical encounter.

Event timeline symbols were used on 20 consecutive children with LD and ASD attending a special school clinic. The children were already familiar with using symbols in the event timeline format in the classroom for their daily timetables. With the help of parents, they were shown the relevant symbol along with the verbal instruction before an activity was undertaken, for example, checking weight, measuring height, listening to chest, checking tendon reflexes. All parents found them easy to use and strongly endorsed their use. They also suggested that they should receive the symbols before the appointment to prepare their child in advance. Below are some responses from parents:

‘I think this is a really good idea and will help children understand what is going on’.

‘I think this is a fantastic idea. Well done for doing this. It will help all the children it is aimed at so much’.

‘This would help so many parents whose children need to use the hospital and will stop the children from being so frightened’.

‘I think this is a good idea for all children’.

‘It would put their mind at rest and not get upset’.

The views of 50 professionals in a district general hospital and the community child health service were sought on the proposed introduction of symbols in these settings for children with LD and ASD. The informal qualitative survey sought the views of the professionals seeing children in the hospital and the community, using a brief questionnaire. Each professional was asked:

- If they had experienced difficulties in obtaining the cooperation of children with ASD and LD during clinical encounters
- Whether they thought visual symbols in addition to verbal instructions would help increase understanding in this group of children
- Whether they would use symbols in their clinical practice if the symbols were made available
- Which of the two formats (event timeline or key fob) they would prefer to use in their clinics.

The professionals included doctors, learning disability nurses, audiologists, paediatric nurses, diabetes nurses, asthma nurses, phlebotomists, physiotherapists, occupational therapists, speech and language therapists, dieticians, orthoptists, radiographers and special needs teachers.

Results
All 50 of the professionals who were consulted had experienced difficulties in obtaining cooperation in children with LD and ASD in their clinical practice. All felt that the relevant visual symbols would help to increase the understanding of verbal explanation given in clinical settings. They were keen to have access to visual symbols to help explain the tests and treatments to these children before and during their appointment. All preferred the event timeline format for use in clinics. However, 40 professionals indicated that the key fob would be useful to carry with them while working away from their usual clinical area. They also suggested that older children and teenagers might prefer it. Comments included:

‘Excellent idea’.

‘Visual prompts are useful for us all’.

‘Generally a good idea to use visual symbols’.

‘Fantastic set, useful for children and adults with special needs/disabilities and for those who have English as second language’.

Discussion
ASD affects 1% of children (Baird et al, 2006). Most paediatric nurses will encounter these children in a hospital or community setting at some time in their career. LD nurses will obviously encounter them more often. Many of these children have difficulties in communication and experience high levels of anxiety, especially in unfamiliar surroundings, and while being engaged in activities outside their normal routine (Vaz, 2010). Overall, 2% of patients on a general practitioner’s list may have a learning disability (National Patient Safety Agency, 2004). They have reduced ability to understand new and complex information. The Mencap report, Treat Me Right (2004), highlighted the need for accessible information for people with LD.

Nurses have a pivotal role in this context. They are often the first point of contact in the GP surgery; A&E department, clinic and ward. They often accompany children with LD or ASD to other departments where examinations and treatments are undertaken. Nurses have more contact with
these children than any other health professional and it is therefore important that they make these encounters as stress free and productive as possible.

Visual symbols help children to understand examinations, investigations and treatments. While the verbal explanations are only available at the time they are being given, the visual symbols can be looked at repeatedly to reinforce what has been said, especially for those with poor auditory memory and difficulties remembering and retaining more than one piece of information at a time. As the activities are being completed, the relevant symbols can be removed from the event strip, to which they are attached with Velcro, to make the next activity visible. There is scope for adding symbols on to the event strip to represent rewards or ‘well done’. This can help to reinforce cooperative behaviour and achieve continuing cooperation from the child.

During a clinical encounter the child with LD or ASD may not understand that the perceived unpleasant experience in the healthcare setting will end at some stage. The event timelines clarify to these children that the procedure will not go on indefinitely and there is a ‘finished’, ‘goodbye’ or ‘home’ symbol at the end of the timeline. Although these symbols were developed mainly for children, they have the potential for use in adults with language and communication difficulties and those who do not speak the local language.

Minimal training in the use of visual symbols is required, which can be incorporated into the general induction and training of nurses who will be working with these children.

Limitations
This survey has a number of limitations, particularly the fact that the visual symbols were used in a small sample of children attending paediatric clinics in one special school, who were already familiar with the use of symbols in the classroom and at home. This study will be extended to a larger random sample of children attending the hospital and community clinics.

Conclusion
This survey indicates that professionals do experience difficulties in gaining cooperation from children with LD and ASD in healthcare settings. Visual symbols can be created to represent common medical investigations and treatment procedures to make it easier for these children to understand and prepare for the experience.

The author’s experience indicates that there is a willingness and enthusiasm among parents and professionals to use visual symbols to prepare children for clinic appointments, examinations, investigations and treatment procedures.

Nurses have an important role in ensuring that this vulnerable group of children have a positive and successful outcome following a healthcare visit. The successful use of visual symbols in everyday use in our environment is well established. This survey suggests the same could be achieved in healthcare settings.

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Conflict of interest: none


KEY POINTS

- Most nurses working with children will encounter some children with learning disabilities and autism spectrum disorder in the course of their professional lives
- In healthcare settings these encounters can be stressful for the children and challenging for the professionals involved
- Visual symbols can be made to represent medical examinations and treatment procedures to make it easier for these children to understand what to expect
- The use of visual symbols with the involvement of the parent or carer could help to make the unfamiliar encounters less stressful for these children and more productive for health professionals
- Nurses can have a pivotal role in the use of visual symbols to improve child-centred care in this vulnerable group

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