Teaching sex education to children with learning disabilities

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Teaching sex education to children is challenging at the best of times. But when those young people also have learning disabilities, many health professionals could be forgiven for shying away from even attempting it. But not the team of children's learning disability nurses at Leeds PCT, who have developed a teaching pack on puberty and sexuality in children with learning disabilities.

Developing the role: background

Addressing sexuality is just one aspect of their role. The team, led by Nicci Isaac and including Stephen Simpson, Cherie Marriott, Jill Cavasi and Julie Sutton, also look at:

- Sleep
- Continence
- Behaviour issues
- Epilepsy

The nurses visit schools, children's homes and parents' homes, conduct assessments and prepare health action plans which could result in follow-on work for the team or a referral.

Over the past five years, all team members have contributed to the development of the teaching pack - Puberty and sexuality for children with a learning disability.

The impetus came after several referrals relating to sexualised behaviours in children with learning disabilities.

The team started to look at what sex and relationships education these children were receiving at their schools and discovered that it was patchy – and in some cases non-existent.

Overcoming fears and misconceptions

Stephen says this was partly because of misconceptions. 'People don't think that children with a learning disability will have those relationships,’ he explains.

'‘It was almost like a taboo subject and it was almost brushed under the carpet’

'There's a fear that after teaching sex education they'll all go out and do it. Almost the opposite is the case.'
'Children with learning disabilities are more at risk of sexual abuse, so they need to have that information,' he says.

Another hindrance was that teachers were unsure of how to approach the subject. 'I don’t think the teachers really knew where to start. It was almost like a taboo subject and it was almost brushed under the carpet,' he says.

But there is evidence that the education is badly needed. According to the youth offending team in Leeds, 40% of adolescents who commit a sexual offence have a learning difficulty.

In addition, children generally pick up a lot of their sex education from peers in the playground but children with communication difficulties largely miss out on that.

**A series of workshops**

When developing the pack, the team primarily looked at children with a severe learning disability, but the resource covers all levels of ability.

Rather than developing it completely from scratch, the team combined best practice into an easy to deliver series of 12 workshops which can be done successively or in isolation.

The first session looks at helping children develop a sexual identity and covers the concept of a life cycle: that babies grow into toddlers, who then become teens, adults, and older adults.

Stephen explains that many of the children get all of their personal care done for them, and may have never looked in a mirror. 'Some of them might not even know if they are a boy or a girl.'

Other topics include:

- Body changes
- Public and private parts and places
- Consent and assertiveness
- Personal hygiene
- Menstruation
- Wet dreams
- Male and female masturbation.

Stephen explains: 'A lot of the issues are to do with public and private places.'

Each session is followed by homework, which parents can use to explore their views and reinforce the messages for the child.

Parents may not have considered, for example, that changing an older child in the living room is not appropriate.

**Benefits**
One boy who particularly benefited from this part of the programme is John, a 14 year-old boy with significant learning disabilities who attended a special school.

John had two anti-social behaviour orders for exposing himself to young children in the community.

He had not received any sex education and assessment revealed that he had only rudimentary knowledge of his body and puberty.

The children's learning disability nursing team delivered the workshop to John's class.

He learned the appropriateness of private and public places, along with the consequences of his actions, and the number of incidents reduced.

**Resources**

A variety of resources are contained in the pack, including clothes for role-play, pictures, videos and anatomically correct dolls. It even has an opening song to signal that the session has started.

The pack is intended to be self-explanatory for professionals.

Nurses from the team have delivered the teaching over a 12-week period to a number of schools, but they hope to scale down their own role and that school nurses and teachers will carry on the teaching.

They have also had interest from social services staff in children's homes and from parents. Stephen emphasises the importance of reinforcing the messages over and over, after each session and when the entire course is completed.

The popularity of the resource means that ten copies will soon be available for hire from the public health resource centre in Leeds.

**Opportunities for children, professionals and parents**

There will be opportunities for children and professionals to feedback comments to the nursing team, so the pack can be developed further.

There have been many requests to purchase the pack, so the nurses are looking into copyright issues.

And the Department of Health has announced that the pack could be useful for all children in primary schools.

Stephen feels the success of the pack is due to the ease of delivery and the fact that everything is in one place. 'There are good resources out there but they don't deal with everything together,' he explains.
'A lot people think that children with learning disabilities are asexual, that they don't have any sexual worth'

‘And it can be used to teach children of a variety of ages, from nine to 18 years, and at different levels of ability.

Stephen has worked with children and adults with learning disabilities and epilepsy for many years, and qualified as a nurse nine years ago.

But working on this project has brought some surprises. 'It's still surprising that in this day and age, children with learning disabilities do not have the equality that their mainstream peers have.

‘And some of the beliefs of parents, carers and teachers about this subject - that they shouldn't have this education - that has been a bit surprising,' he said.

He believes people hold this viewpoint for a variety of reasons. For children with severe learning disabilities, this may be because they will never have sex.

'A lot of people think that children with learning disabilities are almost seen as asexual, that they don't have any sexual worth,' he said.

But nurses in the team explain that the teaching pack is not just about intercourse. In fact, the subject isn’t even mentioned until Session 11.

And he says parents are afraid that the education will increase sexual activity. So, before they run the workshops, parents can attend a meeting to find out what will be discussed.

When they hear about the other topics, parents are keen about the education. Nobody gets offended by the personal hygiene session, and they think discussing public and private places is a good idea.

'When you talk through some of these issues and that it's not purely about intercourse, the parents get on board,' he says.

Stephen concludes: ‘Our whole objective is to get a standard of sex education that will be equal to mainstream peers. We hope that if there is a resource out there, there's almost no excuse not to use it.'

Puberty and sexuality for children with learning disabilities - the main principles:

- Children with learning disabilities have a sexual identity and need equality with mainstream peers
- Sex education for children with learning disabilities is non-existent in some places, despite the fact that they are more vulnerable to abuse
- Sex education needs to be delivered in a way that is appropriate to the disabled child's communication needs
- Anyone can deliver this education, but school nurses and teachers in particular have a key role in ensuring that this teaching happens
- Sex education needs to be continually reinforced by professionals and parents or carers