to take blood) and can lessen the likelihood of the person taking blood getting hit by a flailing arm or leg.

Providing a distraction during blood taking may help to reduce anxiety e.g. an iPad, favourite toy or game, iPod and headphones, an activity book involving having to find objects, singing, engage the person in a conversation about something they are passionate about.

Medication

Local anaesthetics (e.g. creams such as 'Emla' cream) can be used to numb the skin and reduce pain before blood is taken. Ethyl chloride is an alternative to anaesthetic cream; it acts as local pain relief when sprayed onto the skin. It has no anaesthetic properties, but rather works as a vapo-coolant. A thin film of liquid is sprayed onto the skin, which makes the skin cold and less sensitive as the liquid evaporates.

Who Can Help?

Some families arrange for the Community Nurse to visit their child at school to carry out a desensitisation programme. Other parents have found the services of a play worker or play therapist useful. Talk to your local hospital or GP about this. A play worker can visit your child at home and go through the process of giving a blood sample with them. Your local Community Learning Disability Team (CLDT) can be a good source of advice. CLDTs usually have clinical psychologists and Learning Disability Nurses who can work with adults with learning disabilities around needle phobia.

Can the blood taking be combined with another procedure to make it less stressful?

If a person is having an operation, ask the anaesthetist at the pre-op session about the possibility of taking a blood sample whilst they are anaesthetised.

A Final Note

These tips may help someone you care for or support to find it easier to give blood samples. They are not a magic wand that can be waved with instant success. For some people, just getting them to a point where they feel comfortable with the setting and staff, where blood may eventually be taken, can be a lengthy process in itself. This is before you even reach the stage of the person being happy to undergo the full procedure, if ever. Realistically speaking, we know there are going to be some children and adults who will always struggle with giving blood whatever measures are put in place to help them.

Autism Characteristics in Children with Down's syndrome in England and Wales

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Previous research to date

Only a few decades ago, medical textbooks reported that Down's syndrome and autism rarely occurred together. However, case studies describing autism traits in people with Down's syndrome became more common in the 1990s and within another 10 years, systematic investigations of autism spectrum disorder (ASD) in Down's syndrome were being published in academic journals. Initially, the focus was on challenging behaviour, but more recently other aspects of development in children with Down's syndrome and autism have been considered. Despite this, there is still a lot to learn about the dual diagnosis of Down's syndrome and ASD. To help progress our understanding, the Down's Syndrome Association (DSA) linked up with the Institute of Psychiatry, King's College London to conduct the largest scale evaluation of autism characteristics in Down's syndrome to date.

The research study

The aims of the study were to increase awareness of the possible co-occurrence of Down's syndrome and ASD and improve knowledge of how autism presents in children with Down's syndrome. We started by writing to around 1,400 members of the DSA asking some questions about autism characteristics and behavioural problems and were very pleased to receive around 500 responses. This gave us great insight, but in order to find out more we visited 50 children across England and Wales and asked their parents and teachers for more information. The questions considered the children's behaviour in more detail (at home and school), as well as parent wellbeing. The visits allowed us to spend some time with the children and to observe any autism characteristics.

How common is ASD in children with Down's syndrome?

The initial survey indicated that 38% of the children (all aged between 6 and 15 years at the time) showed significant autism traits. This is much higher than previous studies, which suggest up to 15-20% of individuals with Down's syndrome screen positive for ASD.

There are several reasons why we think our figure was higher. Firstly, ours was not a diagnostic study and so we were not able to confirm the presence or absence of autism in those children who met the threshold for ASD on the parental screening questionnaire. Secondly, the survey was entitled 'Differences among children with Down's syndrome' and so it is likely that parents who saw their child's behaviour as different to that of "typical" Down's syndrome behaviour were more likely to get in touch. Thirdly, understanding and awareness of the dual diagnosis has improved in recent years. Therefore,

parents might be more aware of ASD characteristics and that children with Down's syndrome can have these problems. Finally, our sample was at least twice the size of those in previous studies and the geographical spread was much wider. The small scale of previous studies may have affected the profile of people who responded.

Given that autism is very common in children with intellectual disability, with rates reported at around 40%, it should not be surprising that the proportion of children with Down's syndrome screening positive for ASD is also high. However, the expectation set by early medical textbooks is that Down's syndrome actually reduces the risk of having ASD. The fact that Down's syndrome is diagnosed very early in an infant's life might play a part in low rates of the dual diagnosis. Thus, once the diagnosis of Down's syndrome is made there is no need for doctors to seek other explanations for why the child is not following a typical developmental pattern. In other words, nobody is looking for other conditions. However, if a child with Down's syndrome also has an additional disorder, such as autism, this diagnosis can be very helpful in ensuring access to dedicated support (e.g. autism specialist schools).

Is ASD more common in boys with Down's syndrome?

Many research studies have shown that ASD is more common in boys, with rates reported at around four times higher than in females. Although previous research into ASD in Down's syndrome has not reported a gender difference, we found that boys were around twice as likely to meet the ASD screening threshold than girls. We think that the big sample helped us to identify this gender difference. However, the difference is not as pronounced as typically seen in ASD. Why we find this gender difference is unclear – it could be that Down's syndrome somehow protects boys from ASD or it amplifies the risk in girls.

Is the profile of ASD characteristics the same in children with Down's syndrome?

The survey questions allowed us to consider the profile of autism characteristics in children with Down's syndrome who met the threshold for ASD compared with the profile typically seen in people with ASD only. The comparison showed that there are several characteristics (including offering comfort, social smiling and eye gaze) that are better developed in children with Down's syndrome who screen positive for ASD compared with people with ASD only. On the other hand, the children with Down's syndrome and ASD tend to have more severe compulsions and rituals.

Meeting the children allowed us to conduct standardized assessments of ASD traits as would be done by clinical professionals and to explore which items were most helpful in identifying ASD. Out of the 40 questions on the screening questionnaire, 15 were particularly effective. This implies that a shorter questionnaire might be more appropriate when screening for ASD in Down's syndrome, and would certainly be quicker and easier to administer.

Are there behavioural differences?

When the behaviour of the children with Down's syndrome who met the threshold for ASD was compared with that of other children with Down's syndrome, there were higher rates of emotional symptoms, conduct problems, hyperactivity and peer problems in the first group. Levels of conduct problems and hyperactivity in the Down's syndrome and ASD group were just as high as in an ASD only group. In contrast, they showed fewer emotional problems than the ASD only group.

Parents also reported that children with Down's syndrome and ASD tended to have more communication and social relating difficulties (although they often had good eye contact), as well as being more self-absorbed and teacher reports echoed these findings. However, teachers tended to describe more anxiety and disruptive behaviours at school. It might be that context plays a part in how anxious or disruptive children are, or it could be that the interpretation of behaviour differs between parents and teachers.

Adaptive behaviour skills, including communication, daily living skills and social skills, were also assessed in the children we visited. Although levels of communication and socialisation difficulties in children with Down's syndrome and ASD were similar to those reported for children with ASD alone, the pattern of these difficulties often differed. For example, the children with Down's syndrome were more likely to approach others, but they had a more limited vocabulary than children with ASD only. They also tended to have poorer daily living skills i.e. in self care, and domestic tasks etc.

Impact on the family

Several studies have shown that having a child with ASD can be stressful and affect parental wellbeing. On the other hand, stress levels in parents of children with Down's syndrome are reported to be no higher than those of other parents. There is a risk that the pressures of raising a child with Down's syndrome and ASD go undetected, given that the formal dual diagnosis is rare. In the second phase of this study, parents were asked to report on their stress, wellbeing and perceived support. The parents of children with Down's syndrome and ASD reported a higher level of stress than those with Down's syndrome only. It seems that the often challenging behaviours of children with Down's syndrome and ASD may contribute to stress levels. Lack of perceived support may also have an impact although to a lesser extent.

Implications of the research

Hopefully the research will go some way in improving clinical awareness of the co-occurrence of Down's syndrome and ASD. The more detailed breakdown of the specific autism characteristics in children with Down's syndrome should be particularly helpful to clinicians.

The research also showed that the questions typically used to screen for ASD are appropriate to use with children with Down's syndrome, but that the development of a shorter screening questionnaire could be useful in identifying children who may be at risk of autism. However, confirmation of an ASD diagnosis still requires a detailed clinical assessment by professionals with expertise in developmental disorders.

The information on challenging behaviour in this group, as well as the stress reported by parents, indicates that existing services for families with children with autism might be helpful. For children with ASD, early interventions have been shown to be effective in improving adaptive behaviour, language and social communication. In addition, research shows that equipping parents with the skills to manage their children's behaviour can lead to reduced stress and improved relationships.

See the Down's Syndrome Association's blog on Dual Diagnosis ASC/DS https://dualdiagnosisascds.wordpress.com/