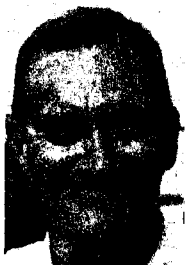


Minding the Difference: talking to individuals about their condition of CHARGE syndrome

Gail Deuce and David Brown (2010)



Gail Deuce



David Brown

There are so many challenges for any family that has a child with CHARGE Syndrome. With the passing of time we have been hearing about a problem that an increasing number of parents are facing as their children grow and mature – when, and how, and why should you talk to your child with CHARGE about the syndrome? We are usually asked about this at a time when the parents are already feeling that they have got this complicated task wrong, often after their child has become upset at some sudden revelation of their own difference or of some limitation in their abilities. Recent examples of this include a 12 year old girl who became upset at the sudden awareness that her two sisters did not wear hearing aids like she did; a teenager who showed great anger and then a long period of depression after being told that he would never be able to drive a car; and a 5 year old who refused to wear both glasses and hearing aids as soon as he entered school because he saw that none of his peers were wearing them.

For families whose child with CHARGE has little or no language this is clearly an even more imponderable situation.

Investigation

In response to requests from parents we decided that this issue needed some investigation, and we based this on structured interviews to find out what families felt about this issue, what they had done and what had worked.

The interviews were undertaken either by telephone, email or face-to-face contact, using a series of structured questions. The questions asked focussed on discovering the importance of sharing information about CHARGE, what information to share, and how to share it.

The nine families all had a family member with a medical diagnosis of CHARGE (ages ranging from 14-32 years). Because of limited time and resources we included only parents whose children had a good level of language in our group of interviewees, nine families in total from three different countries (the United Kingdom, New Zealand, and the United States).

Findings

Eight of the nine families asked had chosen to speak to their child about having CHARGE. The remaining family had chosen not to although they had spoken about some of the anomalies without reference to the

overall condition. Their reason for this was that their child identifies himself with the deaf community and it was felt that to talk to him directly about CHARGE would adversely affect his self-identity.

The eight families who had talked to their child about having CHARGE felt it was important to do so for a number of reasons. All of these families reported that the affected child had noticed that s/he was different and was asking "Why?"; it was accepted that the child is likely to face many challenges and difficulties and it was felt that it is sometimes helpful to have a reason why. All the families commented that it is important for the individual to know about CHARGE to help him/her understand and accept what s/he can do, to recognise what his or her limitations are, and also to understand why s/he might find it hard to do those things that their siblings and friends often seem able to do much more easily.

All the families reported that sharing information is an ongoing process that is often a response to the child asking questions or bringing up an issue that needs to be talked through. Information had been offered when it was felt to be appropriate and this was dependent on their child's maturity and

capacity to understand. The need for lots of repetition was raised, with time for the child to absorb it and internalise it. Information tended to be shared through informal conversation that included other immediate family members and often occurred around the dining table during a meal. It was felt to be important to include siblings and other close family members so that the child felt their condition was accepted. One family reported that the older brother and sister had accepted the diagnosis but would not allow it to be used as an excuse! Only one family had involved anyone from outside their immediate family to share information, that being a counsellor at school who was involved because of friendship difficulties.

The families who had shared all felt that it is important to be honest and open.

For example, "Will my hearing get better?" - "No"; "Will my hearing get worse?" - "Possibly, like your mum and dad aging, but it could be worse". Families felt they shared all relevant information, but that sometimes they were not very explicit, usually when it was concerning information that perhaps was more difficult to share. It was interesting to note that the issue of infertility or not being able to drive a car were issues that were frequently identified, although not by every family. The need to maintain a sense of humour was also highlighted, as well as being sensible and

realistic, but at the same time not overcompensating and assuming that CHARGE can be 'blamed' for everything.

Very little advice or support had been made available to families in relation to sharing with their child about CHARGE and all the families reported that they had to commit to discovering much of the information themselves. Families highlighted the need for access to appropriate professionals that they would maintain links with over time. They also commented that they would like regular access to professionals who had an in-depth knowledge of CHARGE, and that all professionals involved with their child should have at least some understanding of CHARGE. One family suggested it might be helpful to set up a group for teenagers with CHARGE where they could meet socially and have an opportunity to talk. It was recognised that there would be a need for the involvement of a skilled person to mediate, provide information etc. as needed.

Discussion

The majority of families questioned felt it is important to share with their child about CHARGE as it helped with the development of self-identity and explained

why their child is as they are. As one family said: 'The more informed he is, the less taboo there is around who he is'.

It needs to be recognised that what is right for one child may not be right for another; the family that had chosen not to share had done so because their child identifies himself as a part of the deaf community and it was felt that his self-identity could be adversely affected.

So much of this issue also seems to be tied up with how the family themselves is feeling about CHARGE and all that it entails (for example, their own feelings about infertility, and the possibility of not being able to have grandchildren). It seems that this needs to be discussed and explored by the adults before issues can be discussed and explained to the child. Two of the individuals with CHARGE involved in the study had told their mothers and fathers that it was they as parents that had the 'hang ups' about CHARGE which did not affect the individuals themselves - they were more focussed on what they needed!

A theme was identified that emerged throughout the answers given to the questions asked. It is not an emphasis on the clinical condition that is so important, but rather to focus on what the implications are

Information tended to be shared through informal conversation that included other immediate family members and often occurred around the dining table during a meal

for everyday living, and how these challenges can be tackled. The individuals with CHARGE were not really interested in hearing about CHARGE as a medical condition, but they did want to talk about and explore the adaptations that helped them.

For parents to be able to share information about CHARGE effectively and fully with their child clearly depends on the parents themselves being well-informed.

Parents need to be provided with clear information on CHARGE on an ongoing basis, and kept up-to-date about new information as it emerges. This might be offered in a number of ways through:

- involved medical professionals
- other involved professionals
- family support groups

- conferences
- information leaflets
- the internet
- research papers and other published articles

There is a need for professionals to increase their knowledge and understanding of CHARGE, and in particular the practical implications of this condition, to ensure they are in a position to help equip parents to share with their child when they feel it is appropriate. This whole process relies on parents having the knowledge themselves to be able to share it with their child.

This sharing of information is part of the whole process of developing self-advocacy and self-determination in the individual with CHARGE. Although this study

was restricted to discussing the subject matter with families of an individual who had a good level of language, this is appropriate for the whole population of individuals with CHARGE in relation to self-advocacy and self-determination, enabling the person to take control as far as they are able to do so. For example:

- Your eyes hurt in bright sunlight: wear a peaked hat and/or sunglasses
- Supporting and encouraging to wear cochlear implant processor
- Learning not to pull out the gastrostomy tube

We recognise some people will continue to need a high level of support, but they can still make real choices and exert some control if we enable them to do so.

Editorial *(continued from page 3)*

equality for deafblind persons, which would be the envy of many countries. The Canadian organization, CDBA, announces an Intervenor Competency framework established to address the need for a standardized knowledge and skill set for Intervenor working with individuals with congenital deafblindness. This could be very useful to other organizations which employ Intervenor, contact persons and interpreter guides. We welcome a report from Japan. Akemi, whom some of us met at ADBN in Aalborg, describes how deafblind theatrical performers contributed positively towards awareness of their disability during commemorative events in Osaka.

Articles of a more technical nature include an extensive article by Dr. Rowland (USA) describing an on-line assessment tool for early communicators who are deafblind, and an exploration from Karen Wickham (Australia) into the world of mental illness within

the deafblind community. Gail Deuce and David Brown return to the magazine with an interesting study describing the results of conversations with families and individuals about their CHARGE syndrome condition.

I was fortunate to have attended the 8th ADBN Conference in Aalborg, Denmark in late September 2010. Of the excellent plenary sessions, we are featuring four stories about important relationships, family and otherwise, which affect the lives of deafblind people. Included are Femke's connection with her social worker; Linn's relationship as the daughter; Sabine's reflections as the sister, and Annette's personal insight as a contact person. These very personal stories are very powerful.

I encourage members and professionals who read this magazine to come to Brazil in late September 2011 to attend the 15th Dbl World Conference in Sao Paulo. Check out the conference

website for more details on the Call for Papers. Expect to have a wonderful experience in Sao Paulo, both intellectually and socially. Vula's introductory article 'Sao Paulo Welcomes the World' is a good primer.

Congratulations to Sense Scotland for their flagship centre, TouchBase, receiving recognition as a UNESCO Creative City of Music arts and music venue.

I mentioned in my last editorial that Dbl was considering converting the magazine's current print format to being primarily web based. Readers should not despair any further about the loss of the print magazine. The Board recently decided to continue with the current print magazine format and add a web-based version later.

Finally thanks for the compliments for the previous edition and the overwhelming contributions for this edition. Keep them coming!

Stan Munroe