



## Factsheet 12

# Communication and children with CHARGE syndrome

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It is generally accepted that development of both receptive and expressive communication skills is delayed at least in some areas, in children with CHARGE syndrome (Brown, 2005; Peltokorpi and Huttunen, 2008; Rowland, 2008; Thelin, Steele and King, 2008).

There are two aspects of communication development that research has shown are likely to pose particular problems.

- **Symbolisation.** The ability to use abstract symbols is regarded by many as very difficult for children with CHARGE syndrome who have a combined vision and hearing impairment (Bruce, 2005; Siegel and Wetherby, 2006; Thelin, *et al.* 2008).
- **Intentional communication** is another area that can be difficult. This is the awareness and knowledge that "my actions or signs can get you to do or share something". For example, pointing at a cup will encourage someone to get the cup or talk about the cup.

### Communication partners

Children with CHARGE strongly rely on communication partners who are able to respond sensitively in a way that is meaningful to them. This will support the child to develop a secure and trusting relationship with those partners.

The experience of trusting or expecting that you will receive a response from the other – that you can influence someone else's behaviour, intentionally – has a fundamental impact on the development of communicative ability (Nafstad and Rodbroe, 1999).



### Executive function difficulties

Nicholas (2005) identified neurological difficulties within the area of executive functioning that may also affect communication. As a result of this, the child with CHARGE may have specific problems predicting the influence of the things they do, and the influence that they might have on others. Consequently, there may be a delay in a reaction from the child but this does not necessarily mean that they do not 'want' to communicate.

This view is supported by Brown (2005) who explained that many children with CHARGE need extended time to process information. They often develop techniques to establish a firm physical, emotional, perceptual, and cognitive 'base' each time before they can respond. It is important to establish a good relationship with



the child in order to recognise and adapt to these ways of regulating and processing information.

Routines and a certain degree of predictability may help children establish such a safe 'base'.

## Communication modes

All modes of communication may be appropriate for children with CHARGE. Introducing different communication modes (especially including those with a concrete component such as symbolic object systems, pictures, or picture symbols) is usually helpful so that they can eventually make a choice of their preferred modes. These may be different for reception and expression (Brown, 2005). Inclusion of a concrete component such as symbolic object systems, pictures, or picture symbols is often beneficial and may help overcome executive function difficulties.

Hart (2006), discussing communication development in children with special needs, explains there is a risk with practitioners who have a strong focus on language acquisition and augmentative communication systems. There is a danger that this approach may lead to skipping the steps by which interaction, the relationship and trust between communication partners is built.

That is not to say that all formal modes of communication should be disregarded.

## Focussing on the fundamentals

There is a growing sense in deafblind education for communication partners to perceive the world from a deafblind perspective. When the aim is simply to connect to the other person, about any topic that may be of interest to them rather than to lead them to our own predestined goals, the outcome will be infinitely more exciting! We can do this by focussing more on the fundamental communicative processes, like negotiating about meaning, and taking the other person's perspective.

It is essential to create conditions for good communication by:

- organising the world by providing a safe physical and social environment
- creating interesting situations that will motivate both communication partners
- providing enough one-to-one time
- allowing the child to take initiatives and bring their own ideas into the conversation.

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## GLOSSARY

**Executive function:** a set of mental processes that helps connect past experience with present action. Used to perform activities such as planning, organising, strategising, paying attention to and remembering details, and managing time and space.

## REFERENCES

- Brown, D. (2005) CHARGE syndrome "behaviors": Challenges or adaptations? *American Journal of Medical Genetics*. 133A, pp. 268–272.
- Bruce, S.M. (2005) The impact of congenital deafblindness on the struggle to symbolism. *International Journal of Disability, Development and Education*. 52, pp. 233–251.
- Hart, P. (2006) Using Imitation with Congenitally Deafblind Adults: Establishing Meaningful Communication Partnerships. *Infant and Child Development*. 15, pp. 263–274.
- Hartshorne, T.S., Hefner, M.A., Davenport, S.L.H. and Thelin, J.W. (2011) *CHARGE syndrome*. Abingdon, Oxfordshire: Plural Publishing.
- Peltokorpi, S. and Huttunen, K. (2008) Communication in the early stage of language development in children with CHARGE syndrome. *The British Journal of Visual Impairment*. 26 (1), pp. 24–49.
- Nafstad, A. and Rodbroe, I. (1999) *Co-creating communication*. Oslo: Forlaget-Nord Press.
- Nicholas, J. (2005) Can specific deficits in Executive functioning explain the behavioural characteristics of CHARGE syndrome? *American Journal of Medical Genetics*. 133A, pp. 300–305.
- Rowland, C. (2008) *The communication matrix*. Retrieved May 28, 2013 from the Communication Matrix website: <http://www.communicationmatrix.org>
- Siegel, E. and Wetherby, A. (2006) Nonsymbolic communication. In M.E. Snell and F. Brown (Eds.), *Instruction of students with severe disabilities*. (pp. 405–446). Baltimore, MD: Paul H. Brookes.
- Thelin, J.W., Steele, N.K. and King, E.A. (2008) *CHARGE syndrome: Developing communication in children with multi-sensory deficits* [Webinar Powerpoint slides]. Retrieved 28 May, 2013 from <http://www.asha.org/eweb/OLSDynamicPage.aspx?Webcode=olsdetails&title=CHARGE>