



Factsheet 18

Social and emotional development in children and young people with CHARGE syndrome

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Many children and young people with CHARGE syndrome will experience difficulties with their social and emotional development and need support to overcome these issues.

According to Hartshorne and Salem-Hartshorne (2011), social and emotional development is:

“A term used to describe growing children's ability to form close, secure relationships and to use their emotions productively in interactions with others.” (p. 205)

This will require the development of social skills (e.g. initiating and responding in social interactions, turn-taking, sharing, supporting and engaging) and also regulation of his or her emotional state.

What are the issues relating to individuals with CHARGE?

THE PEOPLE AROUND THEM

Parents – attachment/bonding is the first stage of social and emotional development. To develop secure bonding it needs both the parents and the child to take part in reciprocal interaction where each gives and receives. Reda and Hartshorne (2008) explored the issue of early attachment and bonding of young children with CHARGE with their parents and also the impact that this had on parental stress. They found that almost half of the 25 families they worked with had difficulty with forming a normal attachment: Having a child with CHARGE syndrome is likely to be a challenging experience for parents. Early interventionalists should be alert to parenting stress and problems with attachment and bonding as they provide support for these families. (p. 9)



The wider family – will need support to increase their understanding and give them confidence in engaging successfully with the child with CHARGE, as well as providing support to the immediate family.

Friendships – are often difficult for children/young people with CHARGE. We know that children with CHARGE are very often interested in socialising but they have great difficulty in developing friendships with their peers (e.g. Souriau *et al.* 2005; Hartshorne *et al.* 2007).

This is likely to be partly due to the child's sensory impairments that can, for example, result in the child having difficulty picking up on non-verbal cues and missing the social nuances. Their behaviour may not



always be acceptable to their peers who do not always know how to respond/engage.

The use of 'Circle of friends' and structured play activities can support the child with CHARGE and his or her peers to develop positive and enjoyable relationships.

UNDERSTANDING SOCIAL INTERACTIONS – DEVELOPING SOCIAL SKILLS

Individuals with CHARGE often experience difficulty in initiating and responding in social interactions, turn-taking, sharing, supporting and engaging. These difficulties are likely to be linked to the child's sensory impairments, sensory integration difficulties, executive function difficulties and lack of experience and understanding of important concepts (e.g. what is 'communication'; what is a 'friend').

As well as ensuring that the child has a firm understanding of some of the underlying concepts that support the development of social skills, these skills will often need to be taught in a structured way – including lots of opportunities to participate in turn-taking games, the use of role play (including the use of figures to help overcome some of the executive function difficulties) and social stories to practice how to engage in different situations.

EMOTIONAL REGULATION

Emotional regulation is what the child is able to do to regulate his or her emotional state. Many children and young people with CHARGE do seem to have difficulty controlling their emotions and may experience huge emotional swings. There are currently no studies of emotional regulation in CHARGE but perhaps these difficulties are linked in part to executive function difficulties that affect the individual's ability to monitor their thoughts and actions and to anticipate outcomes and adapt to changing situations (Hartshorne *et al.* 2007).

These difficulties may also be linked to their sensory integration issues that can result in a poor proprioceptive sense and lack of awareness of self. The poor feedback may mean that the child or young person is less aware of their own emotional state or how they are affecting the emotional state of others (e.g. making their friends happy, frustrated, sad etc.), and may also create an apparent lack of empathy in others.

Some strategies and activities that can be used to support the child or young person to learn to regulate their emotional state more effectively include:

- ensuring secure relationships with key people

- consistent routines and environments, especially for those children at an earlier developmental level
- identifying strategies that help raise arousal levels or calm when needed
- developing an understanding of their own emotions, perhaps starting with 'happy/sad' – for example, pointing out when a friend has fallen over and is sad etc, as well as focussing on their own emotions
- using a chart of 1–10 about how I feel, with 1 being happy and 10 being really angry/upset
- pet therapy – for some children at an earlier developmental level having a pet can be very calming and for the others having something to nurture can be very positive
- developing a concept of self and a positive self-image
- having a safe place to go to (e.g. a quiet corner or a bean bag) with a favourite object/book/music.

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GLOSSARY

Executive function: the cognitive process that regulates an individual's ability to organise thoughts and activities, prioritise tasks, manage time efficiently, and make decisions.

Proprioception: the unconscious perception of movement and spatial orientation arising from the information received from the tendons, joints and ligaments.

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