



Factsheet 16

Educational needs and educational support for the children and young people with CHARGE syndrome

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Children and young people with CHARGE syndrome are likely to be educated in a wide variety of educational settings – from mainstream schools (possibly with specialist resource bases) to schools for children with severe learning difficulties.

Although the choice of educational provision for a child will be influenced by what is available within the child's local authority, the main driving force must be clear identification of the child's educational needs and how these are to be met.

The heterogeneous nature of CHARGE means that each child will require an individualised educational provision.

Despite the heterogeneous nature of CHARGE there do appear to be some common features. This is supported by Majors (2011) who explains that learners do present a similar personality and learning characteristics. This indicates that it should be possible to generalise about the educational needs of a learner with CHARGE whilst maintaining respect for the individuality of each child.

The first step must be to identify the issues that are present and formulate an effective response. Most children with CHARGE will have combined visual and hearing impairments and are therefore recognised as deafblind/multi-sensory impaired (MSI) with unique educational needs.

The support that a child with deafblindness/MSI is likely to need is outlined in the document 'Quality



Standards in Education Support Services for Children and Young People who are Deafblind/Multi-Sensory Impaired' (Sense, 2002). It is likely that children who have CHARGE but do not have both visual and hearing impairments will also benefit from access to an MSI educational approach.

CHARGE is a complex condition with a large number of associated anomalies – and there is growing acknowledgement that the CHARGE syndrome population is separate and distinct from the wider deafblind/MSI population, with needs arising specifically from the presence of CHARGE. Majors (2011) perhaps sums this up best, by recognising that learners with CHARGE will have significant challenges



as result of their dual-sensory impairment, but that “the learner with CHARGE syndrome, additionally must cope with multiple challenges along with limited access to both vision and hearing.” (p. 209).

It is not surprising these children are likely to face many challenges that might interfere with their educational success (Smith *et al*, 2010) when the range of anomalies linked to CHARGE is considered. It is not enough, however, to simply recognise the aspects of this condition that a child might experience. Brown (2011) explains that educators also need to recognise the additional demands that are consequently placed on the child with CHARGE – and how this is likely to impact on their learning and overall development.

What might be required to meet the educational needs of a child with CHARGE syndrome?

Here is a list of things to be considered when developing a package of support to meet a child’s educational needs. Not all will be needed for every child.

Input from professionals:

- Specialist teacher for MSI who has knowledge and experience of CHARGE syndrome
- Specialist teacher for the hearing impaired
- Specialist teacher for the visually impaired
- Specialist teacher for physical disabilities
- Speech and language therapist (communication)
- Speech and language therapist (eating and drinking difficulties)
- Physiotherapist
- Occupational therapist
- Sensory Integration therapist
- Paediatric mobility or habilitation officer
- ICT specialist
- Support from an Intervenor.

A clear plan

- A planned response to the child’s visual, auditory and other sensory needs.
- Establishment of clear routines and structure.
- An individualised communication programme.
- Access to appropriate modes of communication and communication systems, including a Total Communication approach.
- Consideration of sensory integration needs and implementation of an appropriate remedial programme.

Strategies

- Strategies to handle sensory overload.
- Strategies to manage fatigue and facilities for safe rest periods.
- Provision of adaptive/supportive seating.
- Support to develop gross motor and fine motor skills.

- Support to develop orientation and mobility skills.
- Alternative recording methods and the use of ICT, including an individual laptop.
- Support for social and emotional development, including structured support to establish positive peer relationships.
- Support to help a child to develop understanding of their own emotions and regulating their own emotional state.

Support and monitoring of concept formation to ensure firm foundations established

- The development of self-help, self-organisational, and functional life-skills.
- Time management and individualised pacing (may include a reduced timetable).
- A planned response to the child’s executive function difficulties including use of a concrete component.
- An environmental audit in relation to the child’s needs (sensory, physical, communication, social etc.)
- Implementation of a behaviour management programme.
- Support to develop a positive self-identity and self-esteem.
- An individualised curriculum delivered flexibly and at the child’s pace.

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GLOSSARY

Heterogeneous: not having a uniform quality throughout.

Intervenor: provides one-to-one support to a child or young person who has been born with combined sight and hearing impairments to enable them to experience and join in the world around them as much as possible.

Total Communication: an educational approach that aims to make use of a number of modes of communication such as signed, oral, auditory, written and visual aids, depending on the particular needs and abilities of the child.

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

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