



Extract from the CHARGE Family Support Group newsletter. January 2016

Educating learners with CHARGE syndrome

Dr. Gail Deuce

I was introduced to my first child with CHARGE over 20 years ago and have since had the opportunity to work with many other children with CHARGE as a teacher for children who are deafblind/multi-sensory impaired (MSI). These children and young people are some of the most determined, creative and indomitable individuals I have ever met. Working as a teacher with these children and young people has often challenged me to think differently and raised many questions about how we should be working with them and whether learners with CHARGE need a particular educational approach. In a moment of madness, I decided to embark on a PhD to explore the education of this group of very special children and young people and now, having recently completed these studies, here is a brief summary of some of the findings.

There has been much research undertaken relating to the medical aspects of this condition, and also into different aspects of development (e.g. communication, behaviour, social interactions). In contrast, little research has been undertaken relating to the processes and practice of teaching learners with CHARGE (with the exception of Lieberman et al., 2012, who

investigated physical education in learners with CHARGE). Although there has been valuable anecdotal reporting it is important that this is complemented and built upon through research-based evidence, especially in the current climate where there is often a requirement for such evidence to secure the necessary provision for a child.

My research was undertaken in two parts; the first involving extracting and analysing statements from 58 educational reports, and the second a questionnaire sent out to teachers with a child with CHARGE in their class, supported by interviews of practitioners working in the deafblind program at Perkins School for the Blind, USA.

The research questions

The main research question explored whether, if a child has a diagnosis of CHARGE, it follows that a particular educational approach is likely to be required. This question being:

CHARGE syndrome is a medical diagnosis. Can it also be an educational diagnosis?

To help address this question a number of sub-questions were also developed, these being:

- What are the factors within the child likely to affect learning?
- What strategies are likely to be effective in supporting the learning of children with CHARGE?
- What aspects of CHARGE might be distinct from the more general deafblind/MSI population?

- What specialist support is provided from other professionals, and through assessments, to teachers working with a child with CHARGE?

Some of the main findings

- It was found that in addition to all the child's separate sensory impairments and the potential interplay between them, areas of particular note that could potentially affect learning and development were high levels of fatigue; executive function difficulties; sensory integration, sensory processing and sensory self-regulation issues; and neurological issues that may create cognitive impairment and therefore learning difficulties. In addition to gross motor development (that is often reported to be delayed), issues with fine motor skills and poor pencil/handwriting skills were also found.

Drawing on these findings it was possible to identify a set of potential learning characteristics that may be present in a learner with CHARGE. It must be stressed it is important not to assume all these learning characteristics will be present in every individual with CHARGE, but the numbers of children within the study where these characteristics were identified, together with comparison of anecdotal reporting, suggests educators should give consideration to these learning characteristics, and where their presence is identified, this should then inform the development and implementation of a teaching programme.

Potential learning characteristics for individuals with CHARGE syndrome

- A combination of sensory impairments (true MSI)
- Behaviours arising from poorly developed or under-stimulated vestibular and proprioceptive systems
- Sensory integration difficulties and poor self-regulation
- High levels of fatigue, stress and anxiety
- A preference for using different communication modes for both receptive and expressive communication
- Easier to form relationships with adults than peers
- Difficulty understanding/expressing own emotional state and empathising with peers
- Additional time to process information
- Development of concrete concepts a strength
- Abstract concepts more difficult
- Problem-solving a strength
- Needing high level of routine and structure, and use of concrete cues to support transitions- difficulty coping when not established
- Executive function difficulties
- A need to be in control and a requirement for a level of negotiation
- Fine motor difficulties and poor pencil/handwriting skills

Deuce G. (2015)

- CHARGE is now recognised as the leading genetic cause of congenital deafblindness, and most individuals with CHARGE will be considered part of the wider deafblind/MSI population. This research found there were only a few aspects that might be considered distinct to CHARGE, these being true multi-sensory impairment (with potential for all the different senses to be affected), high levels of fatigue, stress and anxiety, executive dysfunction, sensory integration, processing and self-regulation issues and poor fine motor development and pencil/handwriting skills. The study suggested that it is likely to be the combination of anomalies that make them distinct from other deafblind learners, but also that they may

impact upon the child with CHARGE in a different way, creating different strengths and needs to other deafblind/MSI learners.

- When exploring the teaching strategies considered to be most helpful for learners with CHARGE, the findings of this study supported the suggestion by David Brown (2011) and Martha Majors (2011) who both considered the MSI teaching philosophy and approach provides the 'best fit' for learners with CHARGE. This is important since it suggests that children with CHARGE who do not have combined visual and hearing impairments are also likely to benefit from an MSI approach and therefore access to a specialist MSI teacher.

This study, however, also indicates that the philosophy of deafblind/MSI education will not fully meet the needs of a learner with CHARGE and additional strategies were identified, for example, the implementation of a fine motor skills programme and the provision of alternative recording methods. This suggests there is a need to employ established deafblind/MSI practice in an alternative way or for a different purpose.

It must always be emphasised that the primary focus for educational practitioners must be on the child as an individual. Recognition and consideration, however, also needs to be given to the potential impact of CHARGE on a child's learning and development where it is diagnosed. Additionally, it was also found to be necessary to attend to the learning environment itself, including the physical location, the people within it and how the curriculum is delivered.

Overall this investigation found that many aspects may be found to be similar for both learners with CHARGE and the wider deafblind/MSI population. It

was also suggested however, it is the way the anomalies associated with CHARGE come together and the impact they have, together with a small number of aspects that might be considered more specific to CHARGE that create a distinction between them and other deafblind/MSI learners. A similar conclusion was reached with regard to the teaching strategies employed, and it was again suggested that although the MSI approach provides 'best fit' there is a need to implement strategies in an alternative way or for a different purpose, and also that something additional might also be required. Therefore, it is considered that educationally there is something distinct and unique about CHARGE that indicates the need for input from MSI teachers who also have additional knowledge and expertise in the education of children and young people with CHARGE.

I am hoping in due course to publish these findings more formally, and to also provide a series of factsheets for teachers. In the meantime, if you have the stamina and a few wet Sunday afternoons you are very welcome to tackle the full thesis. Be warned though, it is 80,000 words in length! So far, Simon Howard can claim to have read it cover to cover, having proof read it for me before submission. A huge thank you goes to him for this feat, but also to all the families who gave their consent for reports to be shared and persuaded their child's teacher to complete the questionnaire, and to the teachers who took the time to then fill it in!

References

Brown, D. (2011) Deaf- Blindness, Self-regulation and Availability for Learning: Some thoughts on educating children with CHARGE syndrome. **California Deaf-Blind Services resources**, 16: (3): 1-7

Lieberman, L.J., Haibach, P. and Schedlin, H. (2012) Physical education and children with CHARGE syndrome: research to practice. **Journal of Visual Impairment and Blindness**. 106: (2): 106-119

Majors, M.M. (2011) "Educational Considerations for students with CHARGE syndrome". In: Horsh, U. and Scheele, A. (eds) (2011) **Compendium on CHARGE syndrome: Multi-disciplinary and International Perspectives**. Hamberg, Germany: Median-Verlag von Killisch-Horn GmbH. pp. 201-212