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CHARGE SYNDROME

The education of learners with CHARGE syndrome

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CHARGE syndrome, although a low incidence condition, is now recognised as a leading cause of congenital deafblindness among genetic conditions. Anecdotal reporting has suggested that learners with CHARGE syndrome are distinct from the wider deafblind population. This study investigates the education of learners with CHARGE syndrome, while also examining what the similarities and differences might be between this group of learners and the wider deafblind population. The findings of this study support the identification of potential learning characteristics of individuals with CHARGE syndrome, and also indicate that educational deafblind practice is applicable for this group of learners, although alternative or additional strategies may be required. Both commonalities and distinctions were found, but it was concluded that educationally there may be something unique and distinct in learners with this condition.

Key words: **CHARGE syndrome, learning characteristics, pedagogy**

Introduction

CHARGE syndrome is a highly complex and low incidence condition, first described in literature in 1979 independently by both Hall and Hittner et al., and has become recognised in recent years as a leading cause of congenital deafblindness among genetic conditions (Hartshorne et al., 2011). The acronym 'CHARGE' was suggested by Pagon et al. (1981) to represent criteria that were felt at the time to reflect the primary characteristics used to support diagnosis. Over time, as understanding of this condition has developed, the original diagnostic criteria have been superseded, although use of the acronym continues. Sanlaville and Verloes (2007) identify the major characteristics used for diagnosis (in addition to a range of minor characteristics) as being:

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- coloboma of the eye (a gap in the structure of the eye);
- choanal atresia or stenosis (a narrowing or blockage of the passages at the back of the nose);
- cranial nerve (CN) dysfunction involving:
    - Cranial Nerve I – hyposmia or anosmia (a reduced or absent sense of smell);
    - Cranial Nerve VII – facial palsy;
    - Cranial Nerves IX/X – swallowing problems with aspiration;
- CHARGE characteristic outer ear;
- CHARGE characteristic middle and inner ear, including:
    - ossicular malformations;
    - a malformed cochlea;
    - absent or underdeveloped semi-circular canals.

In literature, and in general practice, this condition is often simply referred to as 'CHARGE', and this will be adopted for the remainder of this article.

There are a wide range of anomalies potentially affecting individuals with CHARGE, as reflected in the diagnostic criteria. These include visual and hearing difficulties. In a previous study by Deuce et al. (2012), within the cohort studied, 91% were reported to have a visual impairment and 93% a hearing impairment. This highlights the fact that most learners with CHARGE will be recognised as being deafblind/multi-sensory impaired (MSI), which will affect their ability to:

- find out information;
- communicate with others;
- move around the environment.

(Aitken, 2000)

The complexities of this condition mean that learners with CHARGE will face many challenges that may interfere with their learning and development and educational success.

There has been some discussion as to whether the population of learners with CHARGE is distinct from the broader deafblind population, with the issues present in CHARGE, in addition to deafblindness/MSI, making this group of learners

different. Some evidence to support this can be found in research by Hartshorne et al. (2005), who found the cohort of learners with CHARGE studied were different when compared to wider deafblind norms (engaging in more sensory related behaviours and presenting a different behavioural profile); in addition, a small study by Bernstein and Denno (2005) found the studied learners with CHARGE engaged in more frequent repetitive behaviours, concluding that these were characteristics of CHARGE rather than a function of their deafblind/MSI functional abilities.

This illustrates the need to examine whether learners with CHARGE do form a distinct sub-group within the wider deafblind population and whether a different educational response is needed. Brown (2011) argued that a deafblind pedagogy is likely to provide the 'best fit' when educating learners with CHARGE, although he also suggests that there is the likelihood or need to consider other issues that might be more specific to this group of learners. As explained previously, there are a wide range of anomalies involved in this condition, and the way in which they come together will be different for every individual, creating what has been recognised as a heterogeneous population. Despite this, it is thought that there are commonalities between learners with CHARGE, with Majors (2011) suggesting that there are common elements in an educational programme and successful teaching strategies that can be applied across the range of learners with this condition.

An extensive review of literature found a heavy reliance on such anecdotal sharing. Some aspects of functioning for individuals with CHARGE were found to have been researched, such as behaviour (for example, Hartshorne et al., 2005) and communication (for example, Thelin & Fussner, 2005). However, there was found to be little research-based evidence regarding the educational practice for learners with CHARGE, except for a study by Lieberman et al. (2012) of the teaching of physical education to learners with CHARGE, and no published work was found on educational philosophy and pedagogy for this group of learners.

The investigation

Given the possible distinctiveness of learners with CHARGE, compared to the broader deafblind population, and the lack of empirical evidence regarding the education of this group of learners, this investigation was undertaken to try and reduce what Petre and Rugg (2012) call 'the problem space'. In this instance this was felt to be the lack of research to support the development of an effective pedagogy for learners with CHARGE. This research is

exploratory and descriptive in nature, with an emphasis on discovery. The intention was to accumulate further knowledge that would strengthen understanding and support the implementation of effective intervention strategies across the curriculum and learning environment. The research reported on in this article was undertaken at the University of Birmingham for the degree of Doctor of Philosophy (Deuce, 2015).

Methodology and methods

The intention of this investigation was to explore two phenomena, namely factors within the child likely to affect learning, and the wider learning environment (particularly teaching strategies). The research framework adopted was that of a case study which would support detailed examination of the subject being explored (Thomas, 2013), the 'case' in question being CHARGE syndrome.

Use was made of document analysis, examining educational reports written for learners with CHARGE; a questionnaire sent to teachers of a child with CHARGE; and semi-structured interviews of practitioners working with learners with CHARGE in an overseas educational setting. Throughout this investigation, requirements for inclusion in the study were that each learner for whom information was provided had a confirmed diagnosis of CHARGE; that they were in a formal educational setting; and that they were under the age of 16.

The document analysis drew on 58 educational reports, written by a number of authors (all specialist teachers for multi-sensory impairment). All statements pertaining to the child's learning and development were extracted for analysis. Use of the constant comparative method was used, breaking down the data into discrete units to be allocated to given categories and compared with all other data obtained (Kolb, 2012). Strauss and Corbin (2007) advocate the use of an external tool to help structure this analysis, and in this instance 'A curriculum for multi-sensory-impaired children' (Murdoch et al., 2009) was used, drawing on the domains identified within this curriculum:

- sensory;
- communication;
- social and emotional;
- conceptual ability;
- response to routine and structure, and understanding of time and space;
- ownership of learning;
- orientation and mobility and motor skills.

Within each of these domains, both internal factors (those within the child) and external factors (those within the learning environment, such as teaching strategies) were identified. This information, together with the findings of an extensive review of literature, was used to inform the development of the surveys then undertaken.

The questionnaire comprised different sections to support data collection and subsequent analysis. A front sheet provided a summary of information and a reminder that completion of the questionnaire was regarded as the participant giving consent. This also gathered initial information to ensure that the individual for whom the questionnaire was completed met the criteria for inclusion in the study and that only one questionnaire was completed per learner. Demographic information was sought, including the presence of some of the anomalies related to CHARGE, the child's current educational key stage and the type of educational provision attended.

The main emphasis of the questionnaire was a section on 'The child' and another on 'Strategies'. Further use was made of 'A curriculum for multi-sensory-impaired children' (Murdoch et al., 2009), with both sections subdivided according to the different domains identified within this curriculum.

The section on 'The child' included exploration of 21 different skills. For example, the section on 'Routine and structure, and understanding of time and space' explored the child's ability to:

- cope with the unexpected and changes to their routines;
- cope without regular routines and structure;
- anticipate what is to happen next;
- predict what is to happen tomorrow or at the weekend;
- recall past events.

The teachers' perception of relative ease or difficulty was sought through the use of a summated rating scale (a Likert scale) to allow for measurement of the degree and intensity of response (Robson, 2011). Respondents were also asked to identify strategies that they might employ and that they considered helpful in teaching the learner with CHARGE. For example, the section on 'Routine and structure, and understanding of time and space', included use of:

- a daily routine and structure implemented consistently throughout the day;
- mini routines;

- concrete tools to support sequencing an activity, transitions and daily routine;
- individualised pacing (may include a reduced timetable);
- ensuring activities have a clear beginning, middle and end;
- structured support for transitions.

After an initial pilot, 67 questionnaires were sent out, with 54 completed and returned, securing a response rate of (81%). Two were discarded as the learners for whom these were completed did not meet the criteria, resulting in data from 52 questionnaires for collation and analysis.

This investigation was dependent on the responses obtained reflecting what is real, and it is recognised that these were likely to be influenced by the respondents' perceptions of the situation, knowledge and experience, including any additional professional development and/or specialism (for example, a respondent working in a school for the deaf may be a qualified teacher of the deaf). Nonetheless, the importance and validity of teachers' perceptions is illustrated in the reliance upon such perceptions within the educational system in scoring profiles of attainment and for the development of individual teaching programmes. The semi-structured interviews sought the views of 11 practitioners with experience of supporting students with CHARGE within the deafblind programme at Perkins School for the Blind (where, at the time of the investigation, 27 out of 57 students on the roll had a medical diagnosis of CHARGE), in order to provide another view and add depth to the overall findings of this investigation.

Ethical consideration

Ethical issues were addressed, drawing on guidelines set out by the British Education Research Association (BERA, 2004). This included ensuring that there was no detrimental effect to each learner with CHARGE indirectly involved in this investigation, obtaining informed consent (from parents on behalf of the learner with CHARGE, and from participant teachers), maintaining confidentiality and anonymity, and safe and appropriate storage and handling of data. Approval was also obtained from the ethics committee at the University of Birmingham.

Demographics

The data obtained showed whether a number of the anomalies/characteristics involved in CHARGE were present in the learners with CHARGE for whom the questionnaire was completed. This included:

- visual impairment reported in 48 (93%) of learners;
- hearing impairment reported in 49 (94%) of learners;
- vestibular difficulties reported in 48 (93%) of learners.

These data closely corresponded to other prevalence rates reported elsewhere (for example, Hartshorne et al., 2011), providing some indication that the sample used for this investigation is consistent with the broader population of learners with CHARGE. The presence of combined visual and hearing impairments was identified in 45 (87%) of the learners, illustrating that most (but not all) learners with CHARGE will be recognised as being deafblind/multi-sensory impaired.

The questionnaire results provided data for children with an even spread across the different educational phases (key stages) from the Early Years Foundation Stage (EYFS) through to Key Stage 4 (but under the age of 16). Similarly, Table 1 shows that data were obtained for learners in a range of different educational settings, including mainstream placements and more specialist provisions. While it is not possible to identify a 'typical' learner with CHARGE due to the complex nature and variability of this condition, by obtaining information on a cohort of learners with CHARGE with a spread of both ages and different types of educational provision attended, it can be argued the sample obtained was more likely to be representative of the broader population of learners with CHARGE. This is further supported by data revealing that the prevalence of the anomalies and characteristics of CHARGE examined within this investigation closely

Table 1: Types of educational provision children were attending

Type of school	Total no. of children N=52
Severe learning difficulties/(SLD/PMLD) (of which 4 are in a sensory/MSI resource)	21 (40%)
Specialist school for the deaf	12 (23%)
Specialist school for speech and language impairment	2 (4%)
Specialist school for physical disabilities/moderate learning difficulties	1 (2%)
Mainstream primary school (including 2 in a hearing impairment resource)	10 (19%)
Mainstream secondary school (including 2 in a hearing impairment resource)	6 (12%)

Note: SLD/PMLD; severe learning difficulties/profound and multiple learning difficulties.

matched other data presented on the CHARGE population. Nonetheless, the importance of guarding against making sweeping generalisations is recognised, particularly considering the heterogeneous nature of this condition.

The child – strengths and needs

For 16 of the 21 skills examined, the most common response given was that the learner was perceived as finding the skill difficult or very difficult, with social and emotional development perceived as being the area of greatest difficulty. Some variation was found between the skills included in each domain; for example, certain skills relating to conceptual ability were perceived to be some of the most difficult (for example, transferring and generalising skills and knowledge), while another (establishing real, concrete concepts) was perceived as being an area of relative strength for this group of learners. This suggests that teachers need to be aware that a learner with CHARGE may demonstrate a mixture of strengths and needs within each developmental area.

Certain skills were perceived as being more difficult for learners in an SLD/PMLD (severe learning difficulties/profound and multiple learning difficulties) setting, including recalling past events and predicting future events; developing relationships and being able to empathise with their peers; and understanding abstract concepts. It is acknowledged that there is a probable link between cognitive ability and the development of some skills; however, there were many skill areas where little difference was reported by respondents as to the perceived degree of difficulty experienced by learners across the educational settings (including coping without a regular routine/unexpected changes, transference and generalisation of skills, self-help functional life skills, and independent learning and play).

Similarly, little variation was noted across the different educational key stages. Although some skills were reported as being easier for older learners (such as recalling past and predicting future events, self-organisation, and the use of problem solving), overall most of the responses did not vary greatly according to age.

Learning characteristics

The data obtained within this investigation supported the identification of the following potential learning characteristics that may be found in a learner with CHARGE.

A combination of sensory impairments (true multi-sensory impairment)

The diagnostic criteria for CHARGE highlight the possibility of an affected individual having impairments of several, if not all, of their senses. This is reflected in the data obtained in this investigation, which showed not only a high prevalence of visual and hearing impairments, but that other sensory impairments may well be present (such as vestibular difficulties, reported by 48 (93%) of questionnaire respondents). The figures demonstrate that most, although not all, learners with CHARGE will be deafblind/MSI but other senses may also be affected.

Behaviours arising from poorly developed or under-stimulated vestibular and proprioceptive systems

The data showed that 37 (71%) of the cohort studied were reported to engage in behaviours to address needs arising from poorly developed or under-stimulated vestibular and proprioceptive systems (for example, Brown, 2007). These included a need to adopt a horizontal position; seeking additional support for their position when standing or sitting; and poor body awareness, with difficulty organising and co-ordinating their body.

Sensory integration difficulties and poor self-regulation

Sensory integration difficulties are considered by some to be inherent in learners with CHARGE (for example, Brown, 2003). The presence of behaviours that may be linked to these were reported for many learners in the cohort studied, these being:

- poor body awareness and co-ordination difficulties (43/83%);
- difficulty using senses together in a co-ordinated way (36/69%);
- difficulty with sensory overload or under-stimulation (39/75%);
- distractibility and difficulty remaining on task (39/75%).

High levels of fatigue, stress and anxiety

It is recognised that multi-sensory impairment 'can result in high anxiety and multi-sensory deprivation' (DfES, 2003). In this investigation, more than half of the cohort reported on were considered to experience increased levels of stress and anxiety (31/60%), but also high levels of fatigue (27/52%).

A preference for using different communication modes for both receptive and expressive communication

Among the learners studied, while 24 (46%) were perceived to prefer to use the same modes for both expressive and receptive communication, the remainder were reported to demonstrate a difference in their preferred communication channels for both reception and expression. There was found to be a greater reliance

on the use of concrete modes (such as object cues, photographs, symbols, the printed word) to support receptive communication than for expression.

Greater ease and more success in forming relationships with adults than with peers

This study found that respondents considered the learners reported on were, on average, felt to have established 5.73 secure relationships with adults in the educational setting. In contrast, the average number of genuine friendships was reported to be 1.73, with 25 (48%) learners (across different educational key stages and educational settings) perceived as having no friendships with their peers.

Difficulty understanding/expressing own emotional state and empathising with peers

Difficulty in developing social and emotional skills is well documented for individuals with CHARGE (for example, Hartshorne et al., 2007). Within this study 37 (71%) of the cohort were perceived to have difficulty expressing their emotional state. These learners, except for two individuals, were those also reported to have difficulty in empathising with their peers. In this instance, it was also found that the greatest difficulty was among those learners attending an SLD/PMLD educational setting, although it did include learners in other specialist and mainstream settings.

Requiring additional time to process information

Given the fact that learners with CHARGE are likely to experience difficulty obtaining information, given their sensory impairments and other difficulties, it is perhaps not surprising it was considered that this group of individuals require additional time to absorb information and formulate a response before being able to make that response.

Development of concrete concepts as a strength and establishment of abstract concepts as a difficulty

Only nine learners were perceived to find it difficult to establish real concrete concepts, while, in contrast, establishing abstract concepts was perceived to be one of the most difficult areas examined in this study. The data reflected the likely impact of cognitive impairment on concept development, with more learners in SLD/PMLD settings reported to find developing abstract concepts more difficult. Nonetheless, abstract concept formation was reported to be difficult for 13 of 31 learners in other educational settings and across the key stages. This suggests that learning may need to be grounded in real-life experiences, using concrete tools to build on any relative strength.

Problem-solving as a relative strength

Simple problem-solving was perceived to be difficult for only 19 (37%) of the cohort, and overall was perceived to be a relative strength for learners across the different educational key stages and settings.

Need for a high level of routine and structure, and use of concrete cues to support transition; difficulty coping when not established

Only seven (13%) respondents perceived that the learner found it easy to cope without a high level of routine and structure – this being one of the greatest areas of difficulty of all those examined for learners across both the educational key stages and settings. The provision of appropriate concrete support systems to support transitions throughout the school day was felt to be important for 35 (67%) learners.

Difficulties arising from executive dysfunction

Executive function concerns a set of higher cognitive processes that enable us to control and regulate our cognitive actions and engage in goal-directed behaviour. Previous research (for example, Hartshorne et al., 2007) suggests that executive dysfunction may be present in a significant number of learners with CHARGE. The data from this study were compared with a summary of the complex skills involved with executive function (Cooper-Kahn & Dietzel, 2008). This showed that executive dysfunction may be linked to the skills perceived as being most difficult for the cohort studied, and may be manifested as:

- lack of flexibility and difficulty coping with unexpected changes;
- difficulty initiating activities and engaging in independent play and learning;
- difficulty developing and implementing self-organisational skills;
- difficulty coping with transitions and shifting attention from one activity to another;
- poor memory;
- difficulty transferring and generalising skills;
- being easily affected by environmental distractions.

A need to be in control and a requirement for a level of negotiation

This was reported by both questionnaire respondents and interviewees, and is possibly a consequence of learners with CHARGE attempting to maintain a sense of order and structure in their learning environment.

Fine motor difficulties and poor pencil/handwriting skills

Fine motor difficulties were reported for 39 (75%) of the cohort, and 40 (77%) were perceived to have poor pencil/handwriting skills. Although these figures

included children across the different educational key stages and settings, all children in a mainstream setting were perceived to have difficulties in these areas. It is possible that these difficulties are more apparent where learners with CHARGE are educated alongside more typically developing peers, but may also be less apparent among those learners in an SLD/PMLD setting who may be functioning at an earlier developmental level.

Strategies

The strategies reported as being most usefully employed reflected those skills perceived to be more difficult for learners with CHARGE, suggesting a structured response to identified needs. One exception was found, however, where a formal response to the fine motor difficulties and poor pencil/handwriting skills was identified as being helpfully employed for only 19 of 40 children who were perceived to have difficulty in these areas.

The implementation and perceived helpfulness of strategies did not vary greatly across the different educational key stages, which suggests that potential strategies should not be considered or disregarded on the grounds of a child's age, but rather according to each learner's needs. In contrast, variation was noted in the data dependent upon the type of setting, with fewer strategies reported as being either employed or useful for learners in a mainstream setting. For example, similar difficulties were reported for most learners in anticipating what was to happen next without the support of appropriate cues, yet the provision of structured support and concrete cues to support transitions were less frequently perceived as being usefully employed for learners in a mainstream setting.

The findings of this investigation suggest that the strategies regarded as useful and implemented are likely to be influenced by:

- the knowledge and skill set of staff involved in supporting the learner with CHARGE;
- the ethos of the school setting;
- perceptions of what might be appropriate for the learner;
- the practicalities of implementing a given strategy within the school day and curriculum.

CHARGE syndrome and deafblindness

This investigation sought to explore similarities and differences that might be found between learners with CHARGE and the wider deafblind population. Literature on the education of deafblind/MSI learners was examined, seeking

reference to those potential learning characteristics identified in this study. This showed that many of the learning characteristics identified during this investigation were also noted for the broader deafblind population, thus indicating many potential similarities between learners with CHARGE and other deafblind individuals. In addition, however, there were a number of significant aspects not identified among the general deafblind population that might be regarded as being more specific to learners with CHARGE, namely, high levels of fatigue; executive dysfunction; sensory processing, sensory integration and self-regulation difficulties; and poor fine motor development and pencil/handwriting skills.

It was also found that the way in which some issues impact upon learning and development may be different for individuals with CHARGE. For example, members of the cohort studied were perceived to have difficulty engaging in independent play and learning. This is identified by Hodges (2000) as a difficulty for many deafblind learners, who explains that this may arise due to the deafblind child not having the skills necessary to engage independently and purposefully with their environment. This reasoning may also apply to the learner with CHARGE, but there is a possible additional cause, namely executive dysfunction, that can prevent independent engagement with their environment as a result of difficulty initiating activity and organising oneself.

This investigation has shown that in addition to most learners with CHARGE having combined visual and hearing impairments, there is potential impairment of other senses and additional anomalies. McInnes and Treffry (1982) explain that to understand the implication of deafblindness, it is necessary to multiply the impact of a single visual impairment and that of a hearing impairment. If this multiplicative effect is considered in relation to CHARGE with all the anomalies that can potentially come together in an affected individual, there is likely to be an exponential (and therefore even greater) impact on learning and development.

The exploration of literature on pedagogy for deafblind learners showed that many of the strategies reported to be helpful in this study are included in established practice with deafblind learners. This supports the view of Brown (2011) that deafblind educational philosophy and practice is best suited to the education of learners with CHARGE. Nonetheless, a number of strategies reported to be helpful by over half of respondents were not found in the literature on deafblind education, suggesting that additional strategies may be needed when educating learners with CHARGE. These additional strategies involved responding to the needs arising from the learner's sensory integration difficulties; the management

of fatigue, stress, anxiety and executive function difficulties; and supporting the initiation and sustainment of social interactions with peers.

Furthermore, seven of the 11 interviewees experienced in working with both learners with CHARGE and other deafblind individuals believed that some strategies may be employed with a different intention when used with a learner with CHARGE. For example, use of visual/tactile calendar systems is well-established within deafblind educational practice to support communication, social interactions and concept development (for example, Pease, 2000). Within this study, it was also reported that such systems are likely to be employed additionally when supporting a learner with CHARGE to support self-organisational skills and to help reduce and manage perseverative behaviour.

Discussion

CHARGE has been medically categorised as a syndrome. This asserts that there is something unique and distinct about this condition since, by definition, 'syndrome' is a term assigned when it is recognised the anomalies involved in a condition come together in a unique way. Some educational practitioners have also suggested that learners with CHARGE are educationally distinct from the wider deafblind population. The findings of this investigation suggest that there are both similarities and distinctions to be found between learners with CHARGE and the wider deafblind population, and the pedagogy most effectively employed.

This investigation supported the proposal that there are potential learning characteristics of the learner with CHARGE. While a clear overlap was found between the features of learners with CHARGE and the wider deafblind population, there were additional characteristics identified that might be considered more specific to learners with CHARGE. These features (namely, true multi-sensory impairment; executive dysfunction; sensory processing, sensory integration and self-regulation difficulties; high levels of fatigue; and poor fine motor development and pencil/handwriting skills) have the potential to impact greatly on learners' ability to engage effectively in the learning environment and will form an important part of the learning profile of each individual with CHARGE.

The view that deafblind pedagogy might provide the 'best fit' for learners with CHARGE was also explored. The findings of this investigation suggest that the deafblind educational philosophy and approaches to teaching are likely to be an effective pathway to follow for educators of learners with CHARGE. In addition, however, it was found that some aspects of established deafblind practice may

need to be applied in an alternative way or for a different purpose, and that a supplementary approach is also likely to be required.

The findings of this investigation contribute to the ongoing debate on the categorisation of special educational needs. Norwich and Lewis (2005) state that the categories currently used 'reflect administrative, placement and resource allocation decision-making ... [but] not necessarily categories of learner characteristics that have pedagogic relevance'. Instead they present a conceptual framework that focuses on two positions that reflect the response made to learners with special educational needs. This research provides evidence to support what they call the 'General Difference' position whereby, in addition to recognising needs that are common to all learners but also unique to the individual learner, recognition is given to 'Needs that are specific or distinctive to a group that shares common characteristics'. While stressing the uniqueness of each individual, it also highlights the importance of a response being considered specifically for all learners who have CHARGE. This is not a new notion and has been acknowledged for other groups of learners, such as those with autism spectrum disorder, visual impairment or hearing impairment. This also applies to learners with Down syndrome, for whom there is a strong research base that provides evidence of likely strengths and needs. This has led to the development of specific teaching approaches such as 'See and Learn' and 'Reading Language Intervention', building on research-based evidence that learners with Down syndrome are visual learners who respond better to a whole-word approach rather than a phonics approach to reading (for example, Buckley & Bird, 1993).

Thus, it may be argued that rather than the concept of primary need defined within the current classification system, 'CHARGE syndrome' as a grouping may be more appropriate in supporting the identification of potential learning characteristics. This recognises that not every child will experience the same level of difficulty in their learning and development, and assumptions must not be made simply because a child has a diagnosis of CHARGE syndrome. Likewise, knowing a learner has a diagnosis of CHARGE can help with the identification of strategies to support effective teaching for this group of learners. This does not automatically imply a specialist pedagogy to be administered in a particular way, but suggests the importance of considering specific aspects to be applied differentially, recognising the need to focus on each individual learner while considering the broader contextual framework.

This study is exploratory in nature, building on the small amount of evidence available from research and the large amount of anecdotal reporting and opinion

expressed in literature. It suggests there are potential learning characteristics that should be considered by educators involved in supporting learners with CHARGE that can inform the response made. The complexity of this condition means that it is a challenging task to provide an effective education for learners with CHARGE and, in reality, since CHARGE is a low incidence condition, many educators teaching a pupil with CHARGE are unlikely to have past experience or a breadth of knowledge to draw upon. Support from different specialists is likely to be needed, and given that this investigation has shown a deafblind approach is likely to be the most effective, this should include input from a specialist deafblind/MSI teacher for all learners with CHARGE, including the minority who do not have combined visual and hearing impairments.

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