

Parent and Teacher Perceptions of Challenging Behavior in Their Children and Students with CHARGE Syndrome

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Abstract

One significantly important portion of the assessment process leading to the development of an appropriate Individual Education Plan (IEP) for children with CHARGE syndrome involves the perceptions of challenging behaviors from both parents and special educators. Research depicting how parents, special education teachers and related service providers perceive challenging behavior in their children and students with CHARGE syndrome is necessary for the collaborative IEP process.

This study (Sheriff, 2012) utilized the *Survey for Parents of Children with CHARGE in Regards to Behavior Problems* instrument (Hartshorne & Cypher, 2004) to survey parents' perceptions of the challenging behavior of their children with CHARGE. Teachers were identified by the parents of the same children to participate in an author-approved adapted version of the same survey renamed the *Survey for Teachers of Children with CHARGE in Regards to Behavior Problems* instrument (Hartshorne & Cypher, 2004). Parent and teacher participant survey results examining their perceptions of challenging behaviors for children with CHARGE were compared using descriptive statistics and multivariate analysis (MANOVA) between participant groups.

Introduction

CHARGE is an acronym for a syndrome of a combination of multiple congenital anomalies and was "coined in 1981 by Pagon and colleagues" (Blake, Salem-Hartshorne, Daoud, & Gradstein, 2005, p. 151). According to Pagon, Graham, Zonana, and Yong (1981) the acronym stands for **C**oloboma, **H**ear defects, **A**tresia of the choanae, **R**etardation of growth and development, **G**enital hypoplasia, **E**ar anomalies and deafness.

Current research studies reflect concern for the emerging evidence about challenging behaviors in children with CHARGE syndrome. Many of these challenging behavior characteristics appear autistic-like (Hartshorne, Grialou, et al., 2005). Owing to the multiple disability combinations among children born with CHARGE, Hartshorne (2001a) states that "children with CHARGE are more different than they are alike" (Hartshorne, 2001a, p. 1) and the assessments for them should vary according to their sensory losses recognizing that "no normal level of functioning" exists for them (Hartshorne, 2001a, p.1). Parents can be valuable assessment team members for children with CHARGE syndrome by providing information regarding the behavioral functions and developmental skills of their children, to help guide the construction of their Individual Education Plan (IEP) goals.

Autism Spectrum Disorder (ASD) is characterized by the American Psychological Association according to three feature characteristics: “qualitative impairments in communication and in social interaction and the presence of repetitive behavior and restricted interests” (Moss & Howlin, 2009, p. 852). The overlapping of behavioral characteristics and ASD features within syndromes such as CHARGE may aid in making the challenging behaviors of children with CHARGE syndrome easier to understand for parents and teachers. Perhaps interventions and strategies useful for educating those with autism may also be needed by some students with challenging behaviors and CHARGE syndrome within home and school environments. Knowing the possibility of parallels between autism and CHARGE syndrome may prove advantageous for early intervention strategies for some students with CHARGE syndrome.

Under the mandates of the Individuals with Disabilities Education Improvement Act (IDEIA, 2004b) special educators and parents participate in a multidisciplinary team process in evaluating students with disabilities such as CHARGE syndrome and then jointly writing an IEP. Best practices for determining functional and academic goals for children with CHARGE syndrome would be to write IEP goals after behavioral observations and in-depth collaboration with parents. As a result of the developmental delays that accompany CHARGE syndrome, many children with this disorder may master skills at different times and rates during their life; therefore, it is “not appropriate to predict severe disabilities merely as a result of the CHARGE diagnosis” (Salem-Hartshorne & Jacob, 2005, p. 267). Parents may offer special educators insight into a fuller range of possibilities for their child with CHARGE syndrome. Through parental collaboration, teachers of children with CHARGE may learn about the full range of possibilities for their students and be encouraged about future independence and quality of life for these students, however delayed it may be (Salem-Hartshorne & Jacob, 2005). Effective early collaboration between parents and teachers of children with CHARGE may lead teachers to view a trajectory toward typical behaviors for students with CHARGE, rather than focus on the severe low-incidence disabilities noted in the acronym for CHARGE and formal assessments.

It would benefit special educators and related service providers who work with students with CHARGE syndrome to respect and value the insight of parents concerning IEP goals for their children. Likewise, parents of children with CHARGE must be willing to collaborate, participate, and value the opinions and observations of special educators and related service providers who work with their children. Programs that serve children such as schools, daycare, and in-home training may also benefit from the collaboration to implement behavior strategies and interventions. By working together, interventions may be matched to the child so that consistency in learning may help these children achieve their IEP goals and objectives (IDEIA, 2004b).

Owing to the importance of collaboration between parents of children with CHARGE syndrome and the professionals who work with their children, this research addressed the need for parents and special educators to view individual behavioral strengths and weaknesses similarly for these children. Agreement between parents and special educators and other professionals on multidisciplinary teams could be very valuable in setting expectations for a child with CHARGE syndrome to achieve behavior-related IEP goals. Setting goals too low or too high could lead to even more frustration and challenging behavioral issues for children with CHARGE syndrome.

Since there is a full range of abilities and disabilities present within the diagnosis of CHARGE (Salem-Hartshorne & Jacob, 2005), it stands to reason that parent and special educator perceptions about challenging behaviors would be a very important portion of the assessment process leading to the development of appropriate IEPs for children with CHARGE syndrome. It also stands to reason that interventions and strategies designed to support IEP goal mastery for children with CHARGE syndrome would also be a collaborative effort between parents and special educators based on both parent and teacher observations as a significant part of each individual child's assessment. Parents and special educators viewing a child with CHARGE similarly may encourage each other regarding possible future outcomes and "not limit their expectations" (Salem-Hartshorne & Jacob, 2005, p. 267).

The purpose of this study was to survey parents, teachers, and related service providers of children with CHARGE syndrome and collect data regarding their perceptions of challenging behaviors in their children and students with CHARGE. This study was "an initial exploration" (Gall, Borg, & Gall, 1996, p. 237) into surveying parents, teachers, and related service providers together to research their perceptions of challenging behaviors for their child/student with CHARGE.

Method

Participants

Parent Participants

The volunteer parent participants surveyed were parents of children with CHARGE syndrome, defined as parents in Section 602 of Part A of the Individuals with Disabilities Education Improvement Act (IDEIA, 2004a). The surveyed parents in Texas were members of the Texas Chargers parent organization. All Texas parent participants had children with CHARGE syndrome ages birth through 22 years and enrolled in Texas public school programs. Parent participants outside of Texas were contacted via a CHARGE Syndrome Foundation e-mail blast sent out from the Foundation. Both organizations also allowed posts to parents about the research study via social media on their Facebook pages.

Teacher Participants

Parents had the opportunity to identify their child's teachers on the research instrument used for this study. Parents nominated teachers and related service professionals who were then contacted and invited via e-mail by the researcher. Locating the school participants in this manner is called snowball sampling (Plano-Clark & Creswell, 2010).

Selection of Participants

Parents were sent an invitation and informational e-mail to enlist their participation in the study. Forty-eight parents (N=48) gave their permission to participate in the on-line survey when they clicked the *Next* box at the bottom of the first page. Parents then completed their survey and identified teachers for the researcher to contact for the study.

Teachers were then contacted via e-mail with a link to the same survey. Twenty-three teachers (N=23) agreed to participate. Owing to confidentiality concerns for children and families, a secure web-based survey tool (*Survey Monkey*) was utilized to host the two separate surveys.

Instrument

The on-line survey instrument *Survey for Parents of Children with CHARGE Regarding Behavior Problems* (Hartshorne & Cypher, 2004) involves use of an ordinal Likert-measurement scale for each descriptive behavior for children with CHARGE syndrome. Timothy Hartshorne, Ph.D., Psychology Department at Central Michigan State, is known worldwide for his research involving children with CHARGE syndrome, conducts the CHARGE Syndrome Lab at Central Michigan State University, and is also the parent of a grown son diagnosed with CHARGE. Dr. Hartshorne's credentials and expertise in the area of CHARGE make him an expert judge for validity of instruments used for data collection for children born with this syndrome. "Experts are used to judge the relative criticality or importance of various parts of an instrument" (McMillan & Schumacher, 2010, p. 175), and "content-related evidence for validity is obtained by expert review" (McMillan & Schumacher, 2010, p. 185). Since Dr. Hartshorne developed the instrument, *Survey for Parents of Children with CHARGE Regarding Behavior Problems* (Hartshorne & Cypher, 2004), by using the diagnostic symptoms defined by the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.) (DSM-IV) for arrangement of the survey questions, this survey instrument was appropriate for "evidence based on test content" (McMillan & Schumacher, 2010, p. 175) for use in this study.

Dr. Hartshorne gave verbal permission to the researcher to alter the word 'child' in the survey to 'student' for teacher participants. He also gave verbal permission for the survey to be used for teachers, which alters the instrument name from *Survey for Parents of Children with CHARGE Regarding Behavior Problems* (Hartshorne & Cypher, 2004) to *Survey for Teachers of Children with CHARGE Regarding Behavior Problems* solely for the purpose of this research

study, called Parent and Teacher Perceptions of Challenging Behavior in Their Children and Students with CHARGE Syndrome (T. Hartshorne, personal communication, July 30, 2011).

The instrument survey included questions concerning child medical issues and demographic questions along with the 71 severe behavior-related survey questions. Justification for use of organizing severe behavior-related questions in this survey is that “reliability can be dealt with directly in structured questionnaires using specific words or phrases rather than general ones” (Herzog, 1996, p. 116). Questions on the instrument survey for this research study were developed by Hartshorne and Cypher (2004) from field psychological expert lists and American Psychiatric Association (APA) diagnostic information (American Psychiatric Association’s DSM-IV) and then categorized into five (5) of the APA’s recognized behavior diagnostic categories: Obsessive Compulsive Disorder (OCD), Tic Disorder, Deafblindness (DB), Autistic Disorder, Attention Deficit/ Hyperactivity Disorder (ADHD). Sixty-nine (69) questions on the survey were behavioral symptoms in OCD, DB, Autistic Disorder, and ADHD. Hartshorne and Cypher (2004, p. 6) included “two questions for verbal and motor tics based on the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.)(DSM-IV).”

Parent and teacher participants ranked their perceptions for each of 71 behaviors on the instrument in one of the five following Hartshorne and Cypher ranks used previously in this survey: Very Much Like My Child, Somewhat Like My Child, Unsure or Neutral, Somewhat Not Like My Child, or Very Much Not Like My Child. The numbers of survey items representing each of the five challenging behavior categories were as follows: the OCD category had 14 survey items, the Tic Disorder category had two survey items, the Deafblindness category had 21 survey items, the Autistic Disorder category had 24 survey items, and the ADHD category had 10 survey items (Hartshorne & Cypher, 2004).

Data Analyses

All e-mails and Facebook postings to parents of children with CHARGE syndrome included the link to the secure SurveyMonkey.com website for the survey. This allowed for easy access for any parents with internet access choosing to volunteer in the survey process for this study. Of the 54 parents who opened the Parent survey, 48 completed all parts of the survey. The parent data collected represents an 89% usable response rate (N=48, 54). Of the 25 teachers who opened and completed the Teacher survey, 23 completed all parts of the survey. The teacher data collected represents a 92% usable response rate (N=23, 25).

Once the online web-based surveys closed after the allotted 60 days for participants to respond, the quantitative information gathered was entered into a computer software program called Statistical Package in the Social Sciences (SPSS) for analysis. Using web-based survey tools

such as SurveyMonkey.com allows for data to be “downloaded into statistical and spreadsheet programs” (Gay, Mills, & Airasian, 2009, p. 186), which was the process for transferring data from the web-based survey to SPSS for this research study. Research question 1 was analyzed using descriptive statistics in an effort to explore whether there were differences in challenging behaviors in children with CHARGE syndrome between parent and teacher groups as a whole. Research questions 2, 3, and 4 were analyzed using multivariate analysis of variance (MANOVA) and followed by a univariate test of Between-Subjects Effects. Use of multiple tests was warranted for variances in the participant groups and for calculation reflecting the differences between the groups in this study. This use of multiple tests allowed for “investigating patterns among many variables” (McMillan & Schumacher, 2010, p. 313) associated with challenging behavior perceptions between parents and teachers of children with CHARGE syndrome, different teachers and their students with CHARGE syndrome, and different perceptions among the parents of different-aged children with CHARGE syndrome exhibiting challenging behaviors.

Discussion of Results

A study collecting data about parents of children with CHARGE syndrome and the teachers of the same children does not currently exist in the literature; this study represents the first. Parent and teacher data about perceptions of challenging behaviors in their children and students was collected via secure web-based surveys, one for parents and another for teachers. Parents nominated teachers to participate in the study. Seventy-one (71) questions were divided into the following five behavior categories: OCD, Tic Disorder, Deafblindness, Autistic Disorder, and ADHD by author design of the original survey in 2004 (Hartshorne & Cypher). Four (4) questions guided the research study, and each follows with a discussion of the study results relevant to each question.

Parents' and Teachers' Basic Perceptions of Challenging Behavior

1. What are parents' and teachers' basic perceptions of challenging behavior of their children/students with CHARGE syndrome as indicated on the *Survey for Parents/Teachers of Children with CHARGE in Regards to Behavior Problems* instrument?

Both the parent group (N=48) and the teacher group (N=23) rated their perceptions in the categories of OCD, Tic Disorder, and Deafblindness exceeding a mean rating of 3 on the five-point Likert Scale used in this instrument. Parent and teacher participants ranked their perceptions for each of 71 behaviors on the instrument in one of the five (5) following Hartshorne and Cypher ranks, which were used previously in their study in 2004: Very Much Like My Child, Somewhat Like My Child, Unsure or Neutral, Somewhat Not Like My Child, or Very Much Not Like My Child. Both the parent group and the teacher group in this study individually rated challenging behaviors in the areas of Autistic Disorder and ADHD to be slightly

below the mean rating of three (3) on the five-point Likert scale for their children/students. The rating of three (3) indicates a positive direction of agreement for OCD, Tic Disorder, and DB between parent participants and the below a rating of three (3) indicates a negative direction of agreement for behaviors in the Autistic Disorder and ADHD categories. Parent participants in this study as a whole group perceived their children with CHARGE syndrome as having more challenging behaviors in the OCD, Tic Disorder, and DB categories. Parents perceived their children had less challenging behaviors in the Autistic Disorder and ADHD categories.

The teacher participants rated challenging behaviors in the areas of OCD, Tic Disorder, and DB to be above a mean of three (3) on the five-point Likert scale. They also rated their students slightly below a three (3) in the areas of challenging behaviors in the categories of Autistic Disorder and ADHD. As a group, the teachers shared a positive direction [score above a three (3)] in the challenging behavior categories of OCD, Tic Disorder, and DB and a negative direction [score below a three (3)] for Autistic Disorder and ADHD. The teacher participants perceived more challenging behaviors for their students with CHARGE syndrome in the categories of OCD, Tic disorder, and DB. They perceived their students with CHARGE to have less challenging behaviors in the categories of Autistic Disorder and ADHD. Further investigation should be done one to one between the parent and teacher of individual children/students with CHARGE to support the IEP writing process. It is noted in this study that the parent and teacher participation groups perceive challenging behavior similarly. In a future study, it would be interesting to collect data on how each individual parent and each individual teacher perceive challenging behaviors prior to collaboration for the IEP process for their child/student with CHARGE.

Parent and Teacher Participant Group Ratings of Challenging Behavior

2. As a group, do parents of children with CHARGE syndrome perceive their children's behavior as the children's teachers' group rates their students' behaviors on the *Survey for Parents/Teachers of Children with CHARGE in Regards to Behavior Problems* instrument?

The answer to Question 2 is that these two (2) adult groups perceive these challenging behaviors in all five (5) categories similarly for the children in this study. According to McMillan and Schumacher, "many of our beliefs and opinions are thought of in terms of gradations" and "we have a positive or negative opinion" concerning something (2010, pg. 198). Considering the idea of our thoughts in terms of gradations and the five-point Likert scale responses used in this study instrument, it appears important to note that the mean rating of three (3) of five (5) indicates that both response directions are in agreement between the two participant groups positively for OCD, Tic Disorder, and DB. The response direction for Autistic Disorder and ADHD are in agreement in the negative direction slightly below the rating of three (3) on the instrument Likert scale.

The 71 total parent and teacher participants perceived the challenging behaviors divided into the five (5) behavior categories similarly for the children in this study. Simply stated, these responses indicate agreement in the positive direction for OCD, Tic Disorder, and DB. Their responses indicate agreement in the negative direction for Autistic Disorder and ADHD. Further investigation beyond mean statistics also revealed no significance between the two adult groups of participants in perceptions of challenging behaviors in the five (5) categories used for rating behaviors in this study. Both parents and teachers in this study perceived challenging behaviors in their children and students similarly. Further investigation using a one-to-one ratio between a parent of a child with CHARGE and his/her teachers would be the next step in assessing whether there is a significance between whether parents and teachers perceive challenging behaviors in their children/students. Since each child with CHARGE can be very different depending on his/her combined medical issues, replicating this survey one to one may be the next step in determining whether there may be significant perceptions unique to individual parent and teacher stakeholders for children/students with CHARGE.

Parent Perceptions of Challenging Behavior as Children Age

3. Do parents of children with CHARGE syndrome perceive that challenging behaviors becomes more severe as their children age?

The parents surveyed in this study with children older than age 13 years see more challenging behaviors in the category of ADHD than the parents of the children under the age of 13 surveyed. In this study, no significance was found between the parents of children under the age of 13 years and those with children over the age of 13 in the behavior categories of OCD, Tic Disorder, DB, and Autistic Disorder.

Diagnostic features of ADHD (DSM-IV) included within the following survey items (Hartshorne & Cypher, 2004, pg. 26) in this study under the category of ADHD are as follows:

“Fidgets with objects, Does not sit still, Frequently interrupts others, Gives up on a task easily or does not complete tasks, Always moving—is overly active, Does not seem to listen or attend when communicated with directly, Appears to daydream, Does not wait their turn in activities, Loses things, Forgets things.”

When considering the survey items within the behavior category of ADHD in this study, it seems relevant to note that many of the survey items indicate behaviors that younger children with CHARGE syndrome may not yet exhibit due to physical limitations. Older children with CHARGE may exhibit these due to more maturity in their physical abilities, responses to body pain as they age, or social frustrations they experience (Hartshorne, Hefner, Davenport, & Thelin, 2011). However; the results found in this study may tend to support evidence in an emerging CHARGE phenotype that includes “high levels of sensation seeking” and “under conditions of stress and sensory overload, (individuals with CHARGE) find it difficult to self-

regulate and easily lose behavioral control” (Hartshorne et al., 2011, pg. 319). The emerging phenotype also includes “difficulty with shifting attention and transitioning to new activities; easily lost in own thoughts” (Hartshorne et al., 2011, pg. 319). Many of the behaviors listed in the above referenced emerging phenotype for individuals with CHARGE syndrome appear to have roots in the ADHD diagnostic category of challenging behaviors within the category of ADHD as listed in the DSM-IV-TR (2004) by the American Psychological Association.

Teachers and Related-Service Professionals Perceptions of Challenging Behavior

4. Do teachers of children with CHARGE syndrome rate their students’ behaviors the same as related service professionals rate their students’ with CHARGE syndrome on the *Survey for Parents* (adapted as *Teachers* in this study) in *Regards to Behavior Problems* instrument?

An overall MANOVA effect was found (Wilks’ Lambda = .80, $F = .89$, $p = .51$). Since $p = .51$ and is $>.05$, the MANOVA revealed no significance between these two adult teacher groups. Because of this finding, a univariate test of Between-Subjects Effects was calculated and found that the only variable approaching significant difference was Autistic Disorder at $p = .08$. In a qualitative one to one study, there may be significance in this area. This approaching significance may indicate a need to study these two groups more closely to determine whether related service providers are better trained to recognize and diagnose challenging behaviors that resemble Autistic Disorder in children with CHARGE. Teachers generally do not have specific training in diagnosing challenging behaviors in children with severe disabilities such as CHARGE syndrome. Further study may reveal a need for related service providers to be integral team members for assessing and writing behavioral IEPs for children with CHARGE syndrome.

Strengths of the Study

Quantitative research studies with small sample sizes such as are available within the population of parents and teachers of children with CHARGE syndrome, may add the conclusion “statistical significance, the relationship or difference is probably a substantial” (McMillan & Schumacher, 2010, pg. 141) to the research base for the small population. Survey samples vary in size “depending on several factors, including the size of the overall population” (Plano-Clark & Creswell, 2010, p. 185), and it is estimated that one (1) in 10,000 to 12,000 children are born alive in the world with CHARGE (Moss & Howlin, 2009), supporting the rarity of participants available for this research study. According to this Moss and Howlin statistic, there would potentially be an average of 11,000 children born alive with CHARGE syndrome in the world. Of those, the ones available for this study would need to have been parent members of the Texas Chargers or The CHARGE Syndrome Foundation to have received e-mail notices of this study. The sample size of 48 parents in this purposeful study is sufficient to add to the research base because “generalization is possible to similar subjects” (McMillan & Schumacher, 2010, pg. 140). The “similar subjects” referenced with McMillan and Schumacher would be other parents

of children with CHARGE syndrome and their perceptions about challenging behavior in their children.

Research using surveys utilizes data collection to answer research questions with a survey instrument to collect opinions on topics (Gay, Mills, & Airasian, 2009). Using an already established survey in this study is a strength. Researchers may choose an already-used and established instrument if one is available (Gay et al., 2009). *The Survey for Parents of Children with CHARGE Regarding Behavior Problems* (Hartshorne & Cypher, 2004) was available, and consent was given by author Dr. Timothy Hartshorne.

Use of secure survey technology was also considered a strength of this study. Online, web-based surveys are efficient, inexpensive, and may be capable of collecting mass data from multiple states and countries for data collection for a research project (Gay et al., 2009), as was the case in this study. This secure web-based survey utilized technology and web-based survey tools to support and analyze statistical data collected through the survey site at SurveyMonkey.com (Gay et al., 2009). The 71 questions utilized in this web-based survey produced data that was available to be analyzed upon completion of the surveys within the websites.

The researcher was able to send e-mail invitations to teacher participants nominated by parents, offering privacy and an opportunity for participants to decline participation without feeling pressured. Using web-based survey tools, the researcher in this study was able to see which teacher participants had responded and which had declined (Gay et al., 2009), so that no further contact was necessary from researcher to participant in order to nudge participation.

Parent participants responding to e-mail invitations or because they saw a Facebook posting, or responding to an e-mail blast from the National CHARGE Foundation elected voluntarily to participate without pressure. Data collection was procedurally uniform for all participants, results were gathered quickly, timely, and inexpensively, and they were easy to score using web-based survey tools (Gay et al., 2009).

Limitations of the Study

Some limitations may be noted in research survey designs utilizing purposeful nonprobability samplings. Due to the small sample size of children born with CHARGE syndrome living and attending schools for educational support, there may not be sufficient statistical data collection from parent-teacher combinations for this sample to generalize to the larger population (McMillan & Schumacher, 2010). There were 48 parents who responded to the survey and 23 teachers who responded. An additional issue could be that those parents and teachers who volunteered to participate may have shown some “unique characteristics of the sample” (McMillan & Schumacher, 2010, p. 140). For example, all participants had to have e-

mail access to have knowledge about the study and then volunteer to participate in it. Firewalls within school e-mail systems may have hindered receipt of teacher e-mail invitations from SurveyMonkey.com.

Motivation for certain parents and teachers to volunteer or not nominate teachers may have “skewed results” in this study (McMillan & Schumacher, 2010, p. 142). Three (3) parents stated they did not want to involve their child’s teachers because their children’s teachers were very busy and they did not want to add to their workload. Another two parents simply wrote, “No thanks” on their surveys when asked to nominate their child’s teachers for contact and participation. One last concern for participants is that this particular volunteer cohort of parents was allowed to participate in only one 60-day window of time (Gay et al., 2009).

Directions for Future Research

Data gathering using web-based surveys for this population may warrant review in future studies owing to the limited number of children born alive with CHARGE and subsequently the limited number of teachers working with them. However, small sample sizes such as those available within the population of parents and teachers of children with CHARGE syndrome could possibly lead to “statistical significance and is probably a substantial” (McMillan & Schumacher, 2010) addition to the research base for the small population. With this in mind, this study could be considered a substantial beginning study in the area of parents and teachers of children with CHARGE syndrome.

The significance of parents of older children with CHARGE syndrome showing more challenging behaviors in the area of ADHD revealed in this study may add to the research base for earlier age strategies and interventions written into school IEPs. In addition, the approaching significance of school related service providers’ perceptions of challenging autistic behavior characteristics in this study tends to suggest another hypothesis for future research. Perhaps interventions and strategies useful for educating those with autism and/or ADHD or OCD may be replicated for some students with challenging behaviors and CHARGE syndrome within home and school environments. Knowing the possibility of parallels between autism and CHARGE syndrome may prove advantageous for possible early intervention strategies for some students with CHARGE syndrome. It is possible that related service providers who have more diagnostic training than classroom teachers should definitely be collaborating and writing behavior IEPs to address challenging behaviors for students with CHARGE syndrome.

Summary

Owing to the multiplicity of disability combinations among children born with CHARGE syndrome, Hartshorne states that “children with CHARGE are more different than they are alike” (Hartshorne, 2001a, p. 1). This thought supports the idea of future research in a 1:1

parent to teacher ratio of studies of individual children with CHARGE syndrome. The knowledge that children with CHARGE vary in their medical issue severity supports the use of behavioral strengths in each individual child's assessment process. Assessments for children with CHARGE should vary according to their sensory losses, recognizing that "no normal level of functioning" exists for these children (Hartshorne, 2001b, p.1).

Parents can be valuable assessment team members for children with CHARGE syndrome by providing information regarding behavioral functions and developmental skills of their children to help guide the constructs of an IEP for these children. A study involving a collaborative IEP writing process addressing behavioral issues for individual children with CHARGE syndrome would be the first of its kind and might support parents and add to consistence in behavior supports for individual children with CHARGE syndrome. Research in the area of behavioral strengths is needed for children with CHARGE syndrome and could be a positive step toward appropriate behavioral IEP programming for children with CHARGE. Research using the observational skills of teachers, the diagnostic training of related service providers, and the behavioral strengths of individual children with CHARGE syndrome could serve as a support model for other school staff with concerns for addressing challenging behavior in their students with CHARGE.

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