

# Assessment and Intervention for Individuals With CHARGE Syndrome

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CHARGE syndrome is a rare genetic disorder that is regarded as the leading cause of deaf-blindness. Although CHARGE syndrome is typically diagnosed by a medical geneticist, psychologists may be asked to evaluate and treat behavioral and emotional difficulties that manifest from the multisensory problems these individuals face. In addition, psychologists will most likely work with multiple disciplines to address the unique needs of individuals with CHARGE syndrome. This article will provide an overview of CHARGE syndrome and assessment and treatment considerations for psychologists.

Victoria, a 5-year-old girl, has been referred to you for evaluation regarding the possible need for special education services. Her kindergarten teacher reports that she is not progressing as quickly as her classmates, and the teacher also has concerns regarding Victoria's communication and motor skills. Victoria's parents have informed you that Victoria was diagnosed as an infant with CHARGE syndrome, a genetic disorder that primarily affects vision and hearing as well as other parts of the anatomy. Victoria regularly wears glasses and hearing aids. The assessment team must determine if she is eligible for special education services, and must develop and implement overall educational and psychological interventions. However, the whole team has limited familiarity with CHARGE syndrome. Are there assessment tools normed to young children with combined vision and hearing impairments? How do you proceed?

## What is CHARGE Syndrome?

CHARGE syndrome is a rare genetic disorder that manifests in multiple physical, sensory, and behavioral difficulties. It is regarded as the leading genetic cause of deaf-blindness at birth in the U.S. (Thelin & Swanson, 2006). The features of what would eventually be labeled CHARGE syndrome were first identified by Dr. Bryan Hall in 1979 (Hefner, 1999).

The abbreviation "CHARGE" was developed in 1981 to refer to children who had the following features: Coloboma of the eye (i.e., missing tissue in structures that form the eye), Hearth defects, Atresia of the choanae (i.e., blockage of the nasal passages), Retardation of growth and development, Genital abnormalities, and Ear abnormalities (CHARGE Syndrome Foundation, 2018; National Library of Medicine, 2018). However, the clinical features are more complex than the name reflects,



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and no two individuals with CHARGE syndrome present with identical characteristics. CHARGE syndrome is diagnosed in approximately one in 15,000 newborns (Janssen et al., 2012), although the prevalence may vary depending on the region (Hale, Niederriter, Green, & Martin, 2016).

## Diagnostic Criteria

CHARGE syndrome is typically diagnosed by a medical geneticist via genetic testing and a clinical evaluation. Most individuals with CHARGE syndrome are found to have a mutation in the *CHD7* gene, which is located on chromosome 8 (Visser et al., 2004). Approximately 30% of individuals with CHARGE syndrome do not have an identified mutation in the *CHD7* gene (T. Hartshorne, personal communication, March 1, 2019). They may have abnormalities in other genes, although to date no additional genes associated with CHARGE syndrome have been formally identified (National Library of Medicine, 2018).

Because *CHD7* genetic testing is necessary but not sufficient for a diagnosis of CHARGE syndrome, medical geneticists will also perform a clinical evaluation in which major and minor features of CHARGE syndrome are assessed. Major features are characteristics that are very common in CHARGE syndrome (and are rare in other conditions). They include coloboma of the eye (i.e., akin to a cleft in a part of the eye), which can impact vision; choanal atresia or stenosis (i.e., narrow or blocked nasal passages); cranial nerve abnormalities, which can impact sense of smell, swallowing and feeding, aspiration, and facial palsy; short, wide outer ear with little or no lobe; malformed middle ear bones, which can affect hearing loss; and malformed cochlea and small or absent semicircular canals, which can affect hearing loss and balance (The CHARGE Syndrome Foundation, 2018). Minor characteristics can also be identified but are less specific to CHARGE syndrome. These include heart defects, cleft lip with or without cleft palate, kidney abnormalities, genital abnormalities, and growth deficiency. The clinical evaluation and subsequent diagnosis are typically provided during the newborn period (Hefner, 2010).

### **Vision Issues in CHARGE Syndrome**

As stated, one of the major features of CHARGE syndrome includes coloboma of the eye, which subsequently affects the individual's visual field as if parts of the visual field are "absent." Some colobomas are located on the retina in the back of one or both eyes, and they may vary in size. Individuals with retinal colobomas, and ultimately field loss, may turn their head in one direction and look at objects out of their periphery (Brown, n.d.). Other colobomas are located in the iris at the front of the eye, and the pupil may have a visible "keyhole" shape. These colobomas affect vision in terms of light sensitivity instead of field loss.

In addition, many individuals with CHARGE syndrome experience vestibulo-ocular issues that can ultimately affect the use of vision and how images are perceived. The vestibular system coordinates movement with balance, and so the vestibulo-ocular reflex assists in stabilizing images during head or body movement. Individuals with vestibular difficulties may experience challenges with looking at one person, then looking at an object, and then looking at the person again. Often, children with CHARGE syndrome may compensate by lying on their backs on the floor, as that helps stabilize the body and the head (Brown, n.d.).

### **Auditory Issues in CHARGE Syndrome**

As noted, the major features of CHARGE syndrome include small, malformed outer ears, and malformed middle ear bones and cochlea, as well as the absence of semicircular canals. Malformations in middle ears can result in hearing loss in any frequency, especially low frequencies. The absence of the

semicircular canals can impact acts that involve balance, such as walking. As with vision issues, auditory issues are variable and may include asymmetrical mixed hearing loss that is severe to profound (Thelin & Krivenki, 2008).

### **Psychological Manifestations of CHARGE Syndrome**

Many individuals with CHARGE syndrome experience behavioral difficulties, particularly as they reach school age. A common behavioral problem within CHARGE syndrome is repetitive behavior. Bernstein and Denno (2005) indicated that repetitive behavior within CHARGE syndrome can be classified into four categories: self-stimulatory behavior to address sensory needs, maladaptive behavior or routines manifesting from inadequate visual and auditory modeling of appropriate behavior, tic behaviors, and behaviors related to obsessive compulsive disorder (OCD). Due to the wide variety of behaviors that individuals with CHARGE syndrome exhibit, a comprehensive functional analysis of behavior is an essential component in addressing the psychological and behavioral needs of individuals with CHARGE syndrome (Bernstein & Denno, 2005), and intervention should address the function of the behavior.

Children with CHARGE syndrome also frequently demonstrate characteristics similar to individuals with autism spectrum disorder (ASD), which include engaging in sensory-related behaviors and repetitive behaviors as noted above, as well as poor adaptation to environmental stressors such as changes in routine. However, children with CHARGE syndrome tend to be more socially engaging and have stronger communication skills compared to their autistic counterparts (Hartshorne, Grialou, & Parker, 2005). Nicholas (2005) indicated that individuals with CHARGE syndrome may present with attention and executive functioning difficulties that can affect their behavior. For instance, Hartshorne, Nicholas, Grialou, and Russ (2007) found that most children with CHARGE syndrome had significant difficulty shifting or transitioning from one activity to another, monitoring their behavior and its effect on others, and controlling their impulses.

When CHARGE syndrome was first identified 40 years ago, it was thought that most, if not all, individuals with CHARGE syndrome had severe to borderline intellectual disabilities. However, more recent research has indicated that a higher percentage of individuals with CHARGE syndrome have normal cognitive functioning (Salem-Hartshorne & Jacob, 2005).

Many individuals with CHARGE syndrome experience developmental delays, which may be partially attributed to their limitations in the visual, auditory, motor, and physical domains. Nevertheless, Salem-Hartshorne and Jacob (2005) found that the strongest predictor of adaptive functioning and overall development was the age at which an individual with CHARGE syndrome began to walk. Individuals who walked later were more

likely to score lower on adaptive measures, and language development was also more likely to be delayed (Salem-Hartshorne & Jacob, 2005). Furthermore, individuals who walked later were more likely to exhibit autistic- and OCD-like behaviors, and be deaf-blind (Hartshorne & Cypher, 2004).

### Assessment Considerations

There are no psychological assessment tools designed specifically for individuals with CHARGE syndrome. A range of factors should be considered when evaluating individuals with a pattern of features suggestive of CHARGE syndrome.

First, most individuals with CHARGE syndrome will present with visual and/or auditory impairments, which could affect test selection, administration, and interpretation of test results. Psychologists need to be cognizant of the psychometric properties of the tests they select (i.e., are there norms for individuals with vision and/or hearing impairments), as well as any administration considerations for individuals with vision and/or hearing impairments as outlined in the test manual.

Second, psychologists are most likely to receive referrals on individuals with CHARGE syndrome to address behavioral and emotional concerns. As stated, repetitive behavior, as well as autistic- and OCD-like behaviors, are prevalent among individuals with CHARGE syndrome. Thus, additional psychiatric diagnoses of ASD and anxiety disorders such as OCD are more pervasive in the CHARGE population than in the general population (Wachtel, Hartshorne, & Dailor, 2007). The details of problematic behavior and the context in which such behavior does and does not occur is essential. Psychologists are likely to be involved in determining the function of the behavior and in developing a behavior intervention plan.

Third, psychologists are likely to evaluate individuals with CHARGE syndrome within a multidisciplinary team. Input from and coordination among professionals from many disciplines will be required. In an education setting, the team may include speech and language pathologists, audiologists, occupational therapists, physical therapists, orientation and mobility specialists, and vision and hearing itinerant teachers.

The psychological evaluation of a child with CHARGE syndrome should be comprehensive. It should include a review of the child's health and educational records, clinical interview(s) with significant adults in the child's life, observations of the child in one or more settings, and direct assessment of the child's skills.

### Clinical Interview

The psychologist should interview the parent/guardian, as well as any other key adult figures who have knowledge regarding the child's functioning, and seek to obtain information typically sought in psychological evaluations of children (e.g., birth history, early developmental history, medical history, educational history, social history, and so forth).

When interviewing parents of young children with CHARGE syndrome, the psychologist may find it helpful to obtain information about the child's functioning across multiple developmental domains, including communication, adaptive skills, social/emotional skills, cognitive skills, and motor skills. The child's developmental assets (and limitations) should be carefully evaluated within the specific context of his/her sensory difficulties. Among children with CHARGE syndrome, it is important for psychologists to gather information about motor developmental milestones, particularly the age at which the child began to walk, as those milestones are a significant predictor of a child's overall functioning. Should the psychologist desire to compare the child's development with his or her same-aged peers, the *Developmental Profile – Third Edition (DP-3; Alpern, 2007)* can be administered to individuals from birth to 12 years of age. It is typically completed by the parent or caregiver, either via interview or a written questionnaire. This author recommends administration via interview format. Each domain (physical, adaptive, communication, social-emotional, and cognitive) has several items consisting of skills that the parent rates "yes" (the child has or has previously demonstrated the skill) or "no" (the child has never demonstrated the skill). Item responses generate standard scores that can be used to compare the child's development to his/her same-aged peers in the standardization sample. Of note, the standardization sample consists of individuals in the general population.

It is also important to obtain information about the child's adaptive functioning as that will influence intervention recommendations. There are several norm-referenced adaptive measures in existence. I prefer using the *Vineland Adaptive Behavior Scales – Third Edition (Vineland-3; Sparrow, Cicchetti, & Saulnier, 2016)* to assess adaptive functioning in individuals with CHARGE syndrome. The *Vineland-3* can be administered on any individual of any age. It provides ratings-based information of motor skills, communication skills, social skills, and daily living skills. Ratings in each area are provided by teachers and by parents or caregivers. It can be completed in written form or by interview. Normative data for individuals with vision impairments and hearing impairments exist for the *Vineland-3*. Individuals with vision impairments tend to score nearly one standard deviation (i.e., approximately 15 points) lower than matched controls, whereas individuals with hearing impairments tend to score approximately five points lower than matched controls on

the adaptive behavior composite and the index scores. Although information regarding vision *or* hearing impairments may be useful when evaluating the adaptive functioning of individuals with CHARGE syndrome, it is important to note that no normative data exist describing individuals with *concurrent* vision and hearing impairments, which are most common within the CHARGE population. Thus, the psychologist may find it helpful to utilize the qualitative data from the Vineland-3 to identify adaptive strengths and weaknesses.

To gain additional information about the child's behavioral functioning, including sensory processing and unusual behaviors, the psychologist may utilize the Questionnaire of Parent Concerns from the Childhood Autism Rating Scale – Second Edition (CARS-2 QPC; Schopler, Van Bourgondien, Wellman, & Love, 2010). The CARS-2 QPC is an unscored survey for parents to rate the frequency with which the child displays behavior described in the test items (i.e., “not a problem,” “mild-to-moderate problem,” “severe problem,” “not a problem now, but was in the past,” and “don't know”). The authors intended for the Questionnaire of Parent Concerns to supplement the observational information obtained as part of the CARS-2. The domains addressed in the CARS-2 QPC include verbal and nonverbal communication, emotions and social situations, body use, object use and play, routines and adaptability to change, and sensory behavior. I have found that presenting the items via interview has elicited rich qualitative information about the child's functioning.

Although intended as part of an evaluation of individuals with suspected ASD, there are several items on the CARS-2 QPC that are relevant in the evaluation of individuals with CHARGE syndrome. For example, Section 3 of the CARS-2 QPC pertains to body movement and includes items asking about unusual ways of moving the body, engaging in self-injurious behaviors, and clumsiness. Section 5 of the CARS-2 QPC pertains to coping with new experiences and changes in routine, and includes items such as showing anxiety or worry through facial expression or body movement, repeatedly worrying about the same thing, coping with changes in routine or the environment, having specific routines, and having special interests or topics. Finally, Section 6 of the CARS-2 QPC addresses the use of the individual's different senses, including sensitivity and unusual responses to sensory input.

### Record Review

After interviewing the parent, the psychologist should strive to access the child's medical and educational records—with authorization from the parent or guardian. In my experience, parents vary widely in terms of their understanding of their child's medical issues and of the educational system. Therefore, the child's medical and educational records can supplement information provided by the parents. In situations where the infor-

mation obtained from the records appears to conflict with the information provided by the parent, the psychologist should aim to resolve these discrepancies by discussing them with the parent when possible.

Although medical records may be difficult for school-based psychologists to obtain, they can supplement any medical information provided by the parents. When reviewing medical records, the psychologist should look for information on the child's early development, past and present medical issues (including vision and audiological information), medical diagnoses, surgeries, medications, and other nonmedication interventions. In particular, it will be very important for psychologists to obtain information on the child's functional vision and hearing, as that will influence assessment battery selection as well as interpretation of assessment results and intervention recommendations. For example, vision impairment can range from mild visual acuity difficulties to total blindness, and that information could be provided by a behavioral optometrist. Information regarding a child's hearing abilities may be provided by an audiologist, and as with vision, there is a spectrum (i.e., mild hearing loss to total deafness). It is not unusual for children with CHARGE syndrome to present with an extensive medical history during their first few years of life.

Although educational history can be limited for preschool-aged children with CHARGE syndrome, many, if not most, children are eligible to receive early intervention services until their third birthday. While specific eligibility criteria for early intervention differs by state, early intervention services are generally intended for infants and toddlers with physical and mental conditions accompanied by delays in development (Wrightslaw, 2019). Just before the child's third birthday, early intervention service providers will forward the child's service plan and evaluation information to the child's school district, culminating in the earliest educational records for that child.

For school-aged children with CHARGE syndrome, school-based psychologists are likely to have easier access to a child's educational records than clinical psychologists who are not regularly in the schools. Within the educational records, the psychologist should consider attendance, grades, disciplinary records, and (if available) previous evaluations, individualized educational plans (IEPs), and/or Section 504 accommodation plans. Poor grades reflect that intervention is warranted; however, a child with CHARGE syndrome may earn poor grades for a variety of reasons, including learning difficulties, behavioral difficulties, and lack of instruction due to poor attendance. A child with poor attendance may be missing school due to visits with medical personnel. If a child exhibits significant disruptive behavior, which is common among individuals with CHARGE syndrome, they may be subject to disciplinary action, especially

if the teacher and/or principal make faulty assumptions about the function of the child's behavior.

No information exists yet regarding the exact prevalence of individuals with CHARGE syndrome who receive special education services or a Section 504 accommodation plan, nor is there information regarding the average age of initial eligibility for services. That said, it is likely that many, if not most, individuals with CHARGE syndrome will receive special support within the school setting. Therefore, a child's educational records may include an IEP, which would detail academic and functional goals and objectives that the child is expected to attain within a year; types of school-based therapies and specialized instruction the child is receiving such as the amount of time spent in special education; and accommodations and modifications. The IEP may also include a behavior intervention plan to address disruptive or maladaptive behaviors exhibited by the child with CHARGE syndrome. A Section 504 plan would be appropriate for children with CHARGE syndrome who need accommodations in order to receive appropriate education; however, they do not need specially designed instruction that is part of an IEP.

### **Direct Assessment of Cognitive Functioning**

Before selecting a battery of tests, it will be important for the psychologist to determine the individual's degree of vision and hearing difficulties, including the marked effect of the combination of vision and hearing impairments. Individuals who have mild vision and/or hearing difficulties may be administered any cognitive instrument (e.g., Wechsler Intelligence Scale for Children – Fifth Edition [WISC-V; Wechsler, 2014]) with no or few deviations from the standardization procedures. Psychologists should note any deviations from standardized administration procedures. However, for individuals with CHARGE syndrome with more significant vision and/or hearing impairments, a standardized measure will not appropriately estimate their cognitive functioning, and instead will likely underestimate their true abilities.

Cognitive assessment may be a relevant component of a school-based psychological evaluation to determine eligibility for special education services. Cognitive assessment may be used to rule in or out the presence of an intellectual disability. It can be difficult to obtain a reliable estimate of the cognitive functioning of an individual with CHARGE syndrome because most "mainstream" measures of intellectual assessment do not include normative data on individuals with vision *or* hearing impairments (much less individuals with vision *and* hearing impairments).

Most assessment batteries, however, do include administration considerations in their test manuals about working with individuals with vision or hearing impairments. For example, the Woodcock-Johnson Test Battery – Fourth Edition (WJIV; Schrank, Mather, & McGrew, 2014) provides information on

which subtests are optimal for administration to individuals with vision or hearing impairments. Standardized administration of some subtests on the WJIV entails providing the items via recording. From a standardization perspective, the benefit of administering prerecorded items is that all items are presented the same way to each examinee. However, there are limitations of recorded items when administered to individuals with CHARGE syndrome. Notably, some individuals with auditory processing difficulties or hearing impairments may rely on reading lips to aid in processing auditory information, which is not an option with items administered via recording. Although test manuals provide strategies to accommodate individuals with vision *or* hearing impairments, the psychologist should be mindful that no mainstream tests provide strategies to accommodate individuals with combined vision *and* hearing impairments.

### **Behavioral and Emotional Assessment**

Most individuals with CHARGE syndrome present with significant challenging behaviors, particularly as they reach school age. A functional behavioral assessment (FBA) is often performed. The basic components of an FBA include interviewing the parents and teachers regarding the behaviors of concern and formulating an operational definition of the behavior(s) such as frequency, duration, and intensity; observing the child in multiple settings while noting any antecedents (i.e., events precipitating the behavior) and consequences (i.e., events following the behavior) that may be influencing the behavior; and formulating hypotheses about the function of the challenging behavior. Hartshorne et al. (2017) reported that besides genetic factors, challenging behavior in CHARGE syndrome can be attributed to three sources: pain, sensory issues, and anxiety. It is recommended that psychologists account for these sources as part of an FBA, as described below.

With regard to pain, individuals with CHARGE syndrome often experience both intense and chronic pain. Many individuals with CHARGE syndrome may not vocalize that they are experiencing pain due to limitations in communication skills. Individuals with chronic pain may develop higher pain tolerance and would be less likely to report that they are experiencing pain (Hartshorne et al., 2017). Consequently, such individuals may develop challenging behavior such as aggression and self-injury. To assess pain in individuals with limited communication skills, Stratton and Hartshorne (2012) developed the CHARGE Non-Vocal Pain Assessment (CNVPA) questionnaire, a 30-item instrument that can be used to screen for pain based on the presenting behavior of the individual with CHARGE syndrome. According to Hartshorne et al. (2017), the CNVPA has been found to successfully discriminate between behavior due to pain and nonpain behavior. The CNVPA can be found on the CHARGE syndrome foundation website ([chargesyndrome.org](http://chargesyndrome.org)).

One of the core features of CHARGE syndrome is the presence of multisensory difficulties, and many challenging behaviors can stem from these sensory issues. Sensory processing has traditionally been under the purview of occupational therapists; however, psychologists may find it helpful to understand sensory processing, as difficulties in this domain are prevalent in many genetic and neurodevelopmental disorders (e.g., ASD). Although there are several sensory processing tools—such as the Sensory Profile – Second Edition (SP-2; Dunn, 2014), which measures different types of sensory behaviors, including seeking and avoiding behaviors, across different sensory systems (i.e., visual, auditory, tactile, vestibular, etc.)—psychologists are cautioned that intact sensory systems are often assumed, which can affect the ability to interpret sensory processing assessments. Individuals with CHARGE syndrome may engage in unusual behaviors (e.g., self-stimulatory behaviors) as a means of self-regulation. It is essential to determine whether alternative behaviors that serve the same function need to be introduced (Hartshorne et al., 2017).

Anxiety is the most common mental health diagnosis reported among individuals with CHARGE syndrome (Wachtel et al., 2007). Within the anxiety category, the most common diagnosis is OCD (Blake, Salem-Hartshorne, Daoud, & Gradstein, 2005; Hartshorne et al., 2016). Rapp, Bergman, Piacentini, and McGuire (2016) provide a review of evidence-based strategies for assessing symptoms of OCD, including the Children’s Yale-Brown Obsessive-Compulsive Scale (CYBOCS), which is regarded as the “gold standard” for evaluating pediatric OCD. Unexplained pain and sensory overload can also contribute to anxious feelings. Anxiety can be assessed via clinical interview and parent/caregiver behavior rating scales. Observations may yield information regarding compulsive behavior when that is a concern. Some individuals with CHARGE syndrome may be able to complete a self-report measure of anxiety.

### **Video Analysis**

Van Dijk and de Kort (2005) recommend collecting behavioral data via video analysis, in which not only the target behavior is observed and recorded, but its context is recorded as well. They note that while the process can be time-consuming, the information provided can be very useful for analysts to thoroughly assess the behaviors and related factors that may have otherwise escaped observation. Related factors may include the events that precede the behavior and the events that follow the behavior, including an adult’s reaction to the behavior (Van Dijk & de Kort, 2005).

### **Treatment Considerations**

Interventions to address the challenging behaviors among individuals with CHARGE syndrome should address the underlying

causes and consequences of those behaviors (Van Dijk & de Kort, 2005). To start, some interventions entail the prevention of situations that could trigger stress for individuals with CHARGE syndrome. For example, for individuals with CHARGE syndrome who exhibit challenging behaviors due to an unexpected change in routine, it may be helpful for the parent or teacher to provide several verbal and visual reminders of that upcoming event (e.g., “We will be going to the store in five minutes.”).

Van Dijk and de Kort (2005) note that teachers and parents typically initiate more communication with children with CHARGE syndrome than they respond, and when adults are not adequately responsive to these individuals’ needs, the children may either withdraw or engage in more challenging behaviors. Therefore, it is important for parents and teachers to examine how they communicate with individuals with CHARGE syndrome. Brown (2005) recommends reframing behaviors deemed “challenging” as behaviors that are adaptive responses to one’s sensory environment within the context of multisensory processing difficulties.

Due to their multiple sensory limitations, individuals with CHARGE syndrome are more likely to make weaker perceptual connections compared to individuals without sensory impairments. When learning new information, whether it is academic or social information, individuals with CHARGE syndrome would benefit from repeated learning, as well as extra time to process information and adapt to new situations (Van Dijk & de Kort, 2005).

### **Multidisciplinary Teams**

Psychologists who encounter individuals with CHARGE syndrome will likely work in conjunction with providers from multiple disciplines, and it will be essential to understand their areas of expertise as well as the interventions and support they provide. As stated, individuals with CHARGE syndrome will often have difficulties with balance, posture, gross motor skills, and present with low muscle tone, which are issues typically addressed by physical therapists. In addition, hippotherapy (therapeutic horseback riding), has been found to improve energy, walking, and jumping among individuals with CHARGE syndrome (Kruger, 2000).

Difficulties with balance may affect the ability to maintain a stable visual field (Brown, 2005). In addition, individuals with CHARGE syndrome have visual perception difficulties that are related to defects within the ocular system, such as partial visual field loss or deficits in visual acuity. Interventions and accommodations to address visual needs, particularly for reading, may include using a typoscope (a reading shield that isolates one or more lines of text) or magnifying the print on the computer. Individuals with CHARGE syndrome who present with sensitivity to light may benefit from access to tinted glasses (Brown, 2005).

Visual itinerant teachers and orientation and mobility specialists are equipped to help with the needs of visually impaired children.

Ear abnormalities and hearing difficulties can affect auditory processing and ultimately the development of communication skills, and thus it is essential that speech and language therapists and hearing itinerant teachers are part of the multidisciplinary team (Brown, 2005). Many individuals with CHARGE syndrome may have hearing aids or cochlear implants. Some individuals also present with characteristics of central auditory processing disorder (CAPD), a condition that includes difficulties processing and understanding speech and is typically diagnosed by an audiologist. In addition, given that children with CHARGE syndrome have some degree of vision and hearing loss, they would benefit from access to a total communication approach where multiple forms of communication are taught and reinforced, such as picture symbols, sign language, Braille, speech, and so forth (Guerra, 2008). Research has yielded mixed findings as to the prevalence of individuals with CHARGE syndrome whose preferred mode of communication is speech. Nicholas (2005) indicated that most individuals with CHARGE syndrome prefer to use speech; however, fluent speakers and signers combined comprised a minority of individuals with CHARGE syndrome in another study (see Hartshorne & Hissong, 2014, for review).

Given the sensory integration difficulties found in individuals with CHARGE syndrome, an occupational therapist is often part of the multidisciplinary team. Sensory-based interventions to help restore equilibrium can include brushing protocols, deep tissue massage, movement activities, and weighted clothing (Brown, 2005). In addition, children with CHARGE syndrome may require frequent sensory breaks during the school day (Majors & Stelzer, 2008).

### Take-Home Points

- CHARGE syndrome is a rare genetic disorder that involves multisensory impairments. Psychologists will likely encounter individuals already diagnosed with CHARGE syndrome who were referred to them due to behavioral and emotional concerns.
- Obtaining a thorough history is essential, particularly in the developmental, medical, and educational domains. Psychologists will want to inquire as to when the child first learned to walk as that milestone has been linked to prognostic outcomes.
- Assessment of cognitive functioning is complicated by the vision and hearing impairments commonly found among individuals with CHARGE syndrome, because there are few assessments normed to individuals with these combined impairments.
- Although psychologists are trained in behavior, and many psychologists are familiar with functional analysis of behavior, individuals with CHARGE syndrome present with unique—as well as variable—multisensory needs that must be considered when determining the function of challenging behavior.
- Psychologists will often work with professionals representing other disciplines who bring expertise and different perspectives in addressing the needs of individuals with CHARGE syndrome.

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