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## Should Individuals Who Do Not Fit the Definition of *Visual Impairment* Be Excluded from Visual Impairment Services?

*Mary T. Morse*

Cerebral or cortical visual impairment (herein referred to as CVI) is not the unknown condition it was 50 years ago. Although research had been conducted and papers published, it was not until the 1980s that it really became an issue of concern and much debate for educators. This interest was primarily sparked by the increasing numbers of children who had been diagnosed with the condition and the prolific efforts of many medical and nonmedical individuals and institutions. During that time, wide variations were discovered among individuals with CVI. Most had difficulty with or the inability to visually recognize objects in general or certain categories of objects such as animals or automobiles, to manage heavy sensory-motor demands, or to use two-dimensional visual representations (Morse, 1999).

Today, more information and training regarding this brain-based visual disability is available through university courses, in-service training sessions, and publications. And more teachers of visually impaired students are providing services to those with CVI. Indeed, many professionals in the field of visual impairment concentrate on providing services to this population and primarily perceive CVI as a condition associated with observable behaviors characteristic of severe neurological insult.

There are, however, many infants, school-age children, and adults with CVI who have not received as much consideration, a population that most professionals are ill-prepared to understand and serve. These unrecognized groups involve people who have typical or near-typical visual acuity but may not have been identified as having CVI or, indeed, as having a visual disability at all; persons who have been identified as having CVI but who also have a range of "hidden disabilities" that may go undiagnosed; or individuals who have some form of CVI-related agnosia as, for example, facial agnosia, prosopagnosia, topographical agnosia, or simultanagnosia (Dutton, 2015). These agnosias typically do not fall within the defined definition of visual impairments. Perhaps a question might be asked: Depending on the effect on functional life skills, should persons with these conditions automatically be excluded from the expertise that professionals in the field of visual impairment may be able to offer even though these

I give many thanks to all the children who gave me new roads to explore and to the various team members from whom I have learned so much.

individuals do not fit the current definition of *visual impairment* (Morse, 2000, 2006)? This short report will discuss two of these hidden disabilities that may be associated with CVI: prosopagnosia and topographical agnosia.

## Prosopagnosia

Prosopagnosia or "face blindness" is not all that rare—some estimates indicate that 1 out of 50 people in the United States have some form of it—yet it is possible that many people reading this short article have not heard of this condition. In Lewis Carroll's classic 1872 novel, *Through the Looking-Glass, and What Alice Found There,* a passage seems to suggest that the character Humpty Dumpty has prosopagnosia:

> "Good-bye, till we meet again!" she said as cheerfully as she could. "I shouldn't know you again if we did meet," Humpty Dumpty replied in a discontented tone, giving her one of his fingers to shake; "you're so exactly like other people." "The face is what one goes by, generally," Alice remarked in a thoughtful tone. "That's just what I complain of," said Humpty Dumpty. "Your face is the same as everybody has—the two eyes, so—" (marking their places in the air with his thumb) "nose in the middle, mouth under. It's always the same. Now if you had the two eyes on the same side of the nose, for instance—or the mouth at the top—that would be some help." (Carroll, 1872, p. 135)

As Humpty Dumpty describes in this excerpt, people with prosopagnosia do not see faces in a distorted manner. Rather, most have difficulty seeing the differences between faces (Dutton, 2015). Others do not see faces unless people are moving or talking. In essence, people with prosopagnosia live in a world surrounded by strangers (Dalrymple et al., 2014; Dutton, 2003).

There has been a lot of research regarding prosopagnosia as related to adults, from electro-physiological recordings of brain activities to behavioral studies of performance (K. Dalrymple, personal communications, 2011–2015). My own research and professional experiences with preschool and school-age children suggest that prosopagnosia may have a significant effect on learning, social interaction, communication, mobility, and personal safety. In addition, those with prosopagnosia may have coexisting conditions or may be misdiagnosed altogether—if they were assessed and diagnosed at all (Mindick, 2011; Morse, 2006). In my own experience, very few of these students have received services from certified vision teachers, rehabilitation practitioners, or orientation and mobility (O&M) specialists.

Perhaps no one can explain prosopagnosia better than Oliver Sacks, a neurologist, author, and professor, who died in 2015 at age 82 years. Dr. Sacks had a hereditary form of prosopagnosia, as did one of his brothers. Five years before he died, he wrote about what he called his "lifelong battle" with this condition. "I have been accused of what is variously called my 'shyness,' my 'reclusiveness,' my 'social ineptitude,' my 'eccentricity,' even my 'Asperger's syndrome,' as a consequence and misinterpretation of my difficulty recognizing faces. . . . My problem with recognizing faces extends not only to my nearest and dearest but also to myself" (Sacks, 2010, p. 3). Dr. Sacks could not visually recognize his own reflection until he touched his own face (Sacks, 2010).

## Topographical agnosia

Dr. Sacks also had severe topographical agnosia, the inability to orient to both familiar and unfamiliar surroundings. He had a lifelong fear of becoming lost and, thus, his desires to travel were thwarted. He could read

 

maps but became lost in familiar environments, unable to recognize his home consistently when standing in front of it unless he could identify a specific visual characteristic. Topographical agnosia, like prosopagnosia, is brain-based and is not a result of visual acuity or fields of vision, although such ocular challenges may coexist (Goodale & Milner, 2004).

I have observed students who identify people by the shoes they are wearing. One student did not recognize a person as more than an object unless he or she moved or talked, and others were invisible to him unless they had a very unique characteristic. There are students who rarely call anyone by name and others who consistently confuse women with the same color hair of a similar length. One student had an idea that all her family members should wear identical bathing suits to the beach so she would not get lost. Another rushed to the cafeteria each day to sit at the same table and waited to see who sat with him since he could not find his friends. This same student was able to find that specific table only by taking a specific route. Although he had visual acuity within the typical range, he needed help in finding various locations even after many months in school. He, like many of the others I have seen, was disorganized with school and personal items and tended to rely heavily on others for assistance although he was an academic student. Most of the students I have seen had great difficulty with or an inability to interpret facial expressions when talking to others but were able to do so when provided with photographs of the same people. Not all, but most, avoided eye contact and had pragmatic difficulties, significant reading challenges, route-finding problems, and anxiety.

## Diagnosis

Most of the documented cases of acquired prosopagnosia have been caused by brain damage from head trauma, stroke, and degenerative diseases that the individuals experienced as adults (Farah, 2004; Zihl & Dutton, 2015). Typically, people with acquired prosopagnosia are in contact with physicians because of the cause of the condition, thus, in these cases, facial-recognition disabilities have a better chance of being identified (Cole, 1999; Dalrymple et al., 2014). By comparison, congenital developmental prosopagnosia may go unrecognized because most individuals do not see a neurologist (Dutton, 2015) about "their problem . . . it is just the way they are" (Dalrymple et al., 2014). Moreover, other members of the family may have the same condition to a greater or lesser extent. Many of these same people not only cannot identify faces based solely on vision but also may have no sense of familiarity. If topographical agnosia also is present, then every face and place appears new and continues to be so even when seen again and again (Sacks, 2010). Current research on childhood developmental prosopagnosia currently does not include those with a diagnosis of, or being at risk for, CVI (K. A. Dalrymple, personal communication).

## Conclusion

Both acquired and developmental prosopagnosia, as well as topographical agnosia, may have a devastating effect on the lives of the children and adults who experience the difficulties associated with these conditions. Yet few of these individuals have been identified or served by those trained to work with people who have visual conditions that affect functional life skills. I have witnessed the effect these conditions have had on more than three dozen preschool and school-age children. I have learned that all these children need trained and experienced teachers of visually impaired students and O&M specialists as part of their assessment teams. However, to provide truly comprehensive and accurate assessments, the teams must work in a multidisciplinary fashion. To do otherwise would

oversimplify complex, multifunctional neurological conditions (Morse, 1999).

## Some implications for practitioners

Many of the following recommendations may be used as part of a team assessment for baseline documentation. Additional testing, beyond a functional visual assessment, might include O&M evaluation; auditory-processing problem screening; speech and language assessment, as related to pragmatics; and occupational therapy for possible dyspraxia—challenges that are frequently associated with prosopagnosia and topographical agnosia. Other assessments may also be necessary, which reinforces the need for a cohesive team approach for planning and providing appropriate services to these students who have perplexing functional neurological profiles. It is the cluster of challenges that are of concern, not a singular one.

Implementing the following suggestions will vary depending on each student's specific needs, the needs of the other students, grade level, subject (for example, science lab versus lecture hall), and other criteria. All these suggestions have demonstrated usefulness with varying students, especially when there is coordinated planning and implementation across disciplines, environments, and activities (Cole, 1999; Mindick, 2011; Morse, 2000).

### *Adaptations for the learning environment*

The following suggested adaptations for the learning environment may allow students with prosopagnosia and topographical agnosia to perform better in the classroom:

- create smaller classes or groups of students
- organize classrooms via assigned seats and include name signs on desks or chairs
- use larger print for names and larger photographs on student and staff identification badges
- take attendance orally
- organize storage areas that contain classroom materials to minimize visual distractions as much as possible, and use color to reduce distractions.

### *Adaptations for teaching*

When working with students with prosopagnosia and topographical agnosia, the following suggested adaptations may improve how students comprehend and follow directions.

- give directions that include clues: for example, "[Student], go join your group" provides no clue, but "[Student], go join your group near the far-right window" provides three clues
- provide optional structured activities tailored for specific locations (for instance, gymnasium, cafeteria, or playground), since movement activities will make both identification and orientation more difficult
- teach social manners and social expectations, since it is common for people with prosopagnosia to lack the ability to interpret facial expressions.

### *Strategies to help students identify people*

The acts of matching photographs of faces or emotions fall into the category of visual discrimination and matching skills; they are not necessarily identification skills. Thus, these students need to learn to:

- visually scan people in a systematic manner (it is often helpful if the student can associate the person to a place, time, and event);

 

- describe varying skin tones, facial marks (acne, wrinkles, moles, scars, or facial piercings), the presence of facial hair (beards, mustaches, or eyebrows), aspects of hair (color, style, length, texture, general neatness or messiness, hairline), body shape and height (pear-shaped, lanky, tall, petite, slim, or heavy set);
- observe clothing type, color, and style;
- recognize mannerisms (rubbing the face, pulling the beard, waving arms or hands when talking, or tapping fingers) and behaviors (head tilt, favorite topic of conversation, and stride when walking);
- identify props that are frequently used or worn by others (sunglasses, crutches, wheelchairs, unique jewelry items)—it should be noted that this identification strategy could be a problem if the prop is missing;
- notice aspects of the voice (pitch, rhythm, tone, accent, volume, lisp, or the tendency to talk hesitantly or fast); and
- become as sensitive as possible to facial expressions, if the student is capable of interpreting facial expressions.

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