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Irlen Syndrome: A Case Study

Andrew Yellen, Ph.D.



Recently I received a call at my office from a mother regarding her 20-year-old daughter. When I asked what was going on, she said her daughter was extremely photophobic, i.e., extremely light sensitive. The daughter, whom I will call Monica, was spending a great deal of time in her room. Her bedroom windows were painted black and covered with blackout drapes. Monica

was leading a homebound life and had done so for some time. She had just been denied disability benefits by a state examiner. She was examined by a neurologist who could uncover no trauma or structural problems that might account for her light sensitivity. “Just introduce yourself to a little more light each day, and you’ll be fine,” the neurologist suggested. Apparently everyone who had seen Monica in a professional capacity had concluded she was suffering mainly from emotional problems that prompted her to isolate herself. I arranged with the mother to bring Monica to our office for an initial consultation.

Monica arrived at the office blindfolded. The first thing we did when she came into the room is to turn off all the

lights. The only light source present was a little LED backup light that emitted a weak one-candle glow. Monica took off her blindfold and began to talk. We learned that she had struggled with reading comprehension all through school. She had always been sensitive to light, habitually wearing sunglasses and hats to school. The problem became acute when she was about seventeen years old. Counselors and teachers concluded she suffered from various conditions such as AD/HD, auditory processing problems, and visual processing difficulties. She spent the final year and a half of high school being home schooled and was able to graduate with her class, but she did not go on to college or get a job. Exposure to normal lighting conditions, she said, resulted in her suffering horrible migraine headaches. Monica had been able to maintain one outside activity during her high school years—martial arts, an activity where the risk of head injuries is greater than most other sports. We used a long and detailed screening protocol with Monica during this initial visit, which included cognitive functioning, memory, reading comprehension, and screening for Irlen Syndrome. We then scheduled Monica for psychometric testing.

Monica submitted to approximately seven hours of testing to assess her cognitive, memory, and reading capabilities. Monica’s light sensitivity was so acute that the testing occurred in nearly complete darkness. Creating testing conditions that she could tolerate required some inventiveness. Her mother brought a little gooseneck lamp that was painted black and equipped with a blue 25 watt bulb. The cone of the lamp was positioned three inches off the desk so that a relatively small portion of the desk would be illuminated. We covered the desk with a deep navy gray sheet, because even the sheen on the wood was painful to Monica. On the two days of testing, I alternatively wore shirts that were plain black or plain navy blue. During testing Monica wore not one, but three sets of darkened lenses over her eyes. Even with the lenses, we had to offset the lamp so that it did not directly strike the paper. Astoundingly, Monica had no trouble reading the testing materials, and testing proceeded.

Later, after Monica and her mother left, I showed the testing environment to one of our master’s level special education teachers and our office administrator. Both were shocked. Gazing through the lenses, neither staff person could read the printed material and, in fact, could barely discern that there was a paper on the desk.

From our testing we learned that Monica had average to above average abilities. Despite the labels put on her by teachers, she experienced no problems with attention through 7.5 hours of testing, nor did she have difficulty synthesizing visual information—so long as she was not timed. (She had difficulty with timed tasks.) The testing process had an impact on her memory, though this was likely due to the anxiety created by the situa-

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tion. The striking finding, of course, was that she was unable to work in any kind of normal lighting conditions at all. Even the glare off my face was distracting. Monica presented with one of the most severe cases of Irlen Syndrome I had ever seen.

Irlen syndrome is a disorder first described by Helen Irlen in the 1980s and is characterized by sensitivity to light and a number of visual distortions (Irlen, 2005; Kyrd, Sutherland, & McGettrick, 1992). Individuals with the syndrome can read for brief periods of time, then fatigue quickly. The reason is due to their restricted span of visual recognition on the printed page. These individuals often have difficulty reading across a line of text which, due to one distortion or another, may appear to “move.” (One child described it as being like “ants crawling across the page.”) When we do a screening for Irlen Syndrome, we assess for six types of visual distortions. People may have one or more of the six distortions. However, Irlen Syndrome affects environmental functioning as well. Depth perception is often compromised. Normally, individuals are not first aware of the environmental effects until viewing the difference before and after filters. Because reading is a two-step process, visual processing followed by decoding, the syndrome is generally recognized first through academic visual tasks. The same distortions occur with the environment when, for instance, viewing a tree. However, because the individual does not have to “decode tree bark,” the clarity of the bark is a non-issue.

Irlen Syndrome is not a disorder of the eye but of the visual processing system (Yellen, 2006). Something happens in the brain that prevents a whole line of text from opening up properly, though what causes this is not exactly clear. This makes reading a laborious struggle. Imagine reading a paragraph where each word is written on a separate note card. Reading the cards means the gestalt of the paragraph is easily lost. This approximates the difficulty facing persons with Irlen Syndrome, who must often read a paragraph several times, struggling with their visual distortions, in order to comprehend the content. The syndrome is often diagnosed—if it is diagnosed at all—when a child encounters reading problems in the 3rd or 4th grade. The problem may be hidden in earlier grades due to the child’s normative lack of decoding skills.

One of the questions we often ask children during screen-

ing is, “How often do your parents say, ‘turn on the light, you’re going to ruin your eyes.’” Most people who have the syndrome feel more comfortable in dimmer lighting condition, though less severe than in Monica’s case. Nowadays, most teachers lecture while standing in front of a large whiteboard, which can be painfully bright to a child with Irlen Syndrome (Floyd, Dain, & Elliott, 2004). Sometimes children with the syndrome try to compensate by not looking at the teacher. To the untrained observer, the child may appear inattentive or even defiant, when in fact the child can do a better job of listening by avoiding the whiteboard. Of course it is possible that an individual with Irlen Syndrome could also have a co-morbid deficit of AD/HD or auditory processing. What is really important is that the proper diagnosis is made.

The effects of Irlen Syndrome can often be mitigated with the use of Irlen Filters, lenses specifically tinted with accommodation between two and six colors (Irlen, 2005; Blaskey, Sheiman, Parisi, Ainer, Gallaway, & Selznick, 1990). The combination of colors is determined in a similar fashion to an eye care professional determining which strength of a prescription lens is better. Once the proper combination of colors has been determined, clear lenses are dyed precisely. A color spectrophotometer is used, and a beam of light is passed through the

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(310) 372-4596

Alann D. Dingle, Ph.D.

Clinical Psychology
(PSY 11158)

Child
Adolescent
Adult

2401 Pacific Coast Highway
Suite 102
Hermosa Beach, CA 90254

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lens. The colors must fall within a narrow band when compared to the benchmark standard for a particular color and density.

Fortunately, our assessment enabled Monica to receive the disability benefits she was earlier denied. We have fitted her with Irlen Filters that are as dark as would be practical for daily functioning. Her prognosis at this point is uncertain. Despite the neurologist's report, we suspect that her visual cortex was traumatized at some point in her young life. For years, her condition was misdiagnosed as AD/HD or a mood disorder. Now properly diagnosed, Monica can continue her recovery.

A checklist for use in screening for Irlen Syndrome can be found at: <http://www.yellenandassociates.com/irlen-syndrome-diagnostics.php> ▲

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LACPA member Andrew Yellen, Ph.D., a licensed psychologist, is founder and owner of Yellen and Associates, a private practice in Northridge and Thousand Oaks offering psychological, educational, speech, and language services.

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