Welcome to NOAH Ed U!

The National Organization for Albinism & Hypopigmentation (NOAH) presents this complimentary supplement, geared toward educators, based on our quarterly magazine, *Albinism InSight*. We encourage you to share this publication with other educators who work with children with albinism. To enter your school or email address to this distribution list, please contact info@albinism.org.

Inside this Issue

*From the Summer edition of Albinism InSight*

- Braille, White Canes, Blindfolds & Children
- The 411 on IDEA and 504
- White Lashes: Tips for Gracefully Handling Intrusive Questions
- Standing Tall with Drawboard
- Amber Advocates for Albinism

Does the family of your student with albinism know about NOAH?

Share this supplement with them so they can learn what NOAH has to offer!
In every school program for children with visual impairments, the question arises about which children should receive instruction using print, braille or a combination of the two (dual media) and which children should be blindfolded during braille instruction. Another question arises regarding which children with low vision should receive instruction in Orientation and Mobility (O&M). And further, which children who receive O&M should receive instruction with their vision (with or without optical or electronic devices), which children should learn to use a white cane, and lastly, which children should be blindfolded during their lessons. While school programs address these questions through each child’s IEP, every parent must decide whether to accept or question professionals’ opinions.

In this article, I provide background information which sets the stage for current practices and controversies regarding literacy decisions. This background has also had an impact on practices in teaching Orientation and Mobility. I offer my perceptions of how the historical events leading to the current differences of opinion came about and how they impact individual decisions for children. While I cannot be free from my own biases in writing, I try to present facts and historical events in a balanced manner.

Blindness and Sightedness
First, there needs to be a discussion about concepts and perceptions of blindness and sightedness. Many terms have been used to describe the visual and functional characteristics of children whose vision is uncorrectable with the aid of standard glasses or contact lenses, e.g., partially blind, partially sighted, visually limited. When most people hear the term “blind,” a person without vision comes to mind. Throughout history, people were thought of as being either blind or sighted. Starting with the beginning of specialized schools in the 1800s, children who were totally blind or “seriously” visually impaired were sent to schools “for the blind.” Darkened rooms, high collars and blindfolds were used to teach braille. Children with low vision have had to develop their personal identities as “blind” or “sighted.”

You may also notice that some schools and agencies retain names that are “for the blind” while others have changed their names to be more inclusive, such as the Texas School for the Blind and Visually Impaired.

The American Medical Association (AMA) first defined legal blindness in 1934, and it became part of the Social Security Act of 1935. This was after the Great Depression and the AMA was asked to define those people who were economically blind or vocationally blind. In other words, there was a belief that many people who met certain visual criteria were not considered capable of being employed.
The term “low vision” was first used by ophthalmologists in the early 1960s but does not have a federal definition. As such, a person is legally blind or legally sighted; those people we currently refer to as having low vision may or may not be legally blind. Visually impaired usually refers to both groups but, at times, a visual impairment may only mean that a person doesn’t obtain 20/20 vision without a pair of glasses. In a recent study by Lusk and Corn, among 192 children with albinism, 56% were considered to be legally blind and 44% were not. This does not take into account the impact of light sensitivities when a visual acuity is taken in an eye doctor’s examination room which has different illumination than the environments in which a child functions at school, at home or outdoors.

If you, as a parent, have been told your child is blind or legally blind, you may feel your child has vision so poor that he or she is almost blind. Often the term isn’t explained to parents, or it was defined according to an arbitrary standard. Also, legal blindness was determined long before there was a knowledge base about the functional use of vision and long before optical and electronic devices were used to extend a child’s visual reach or low light transmission lenses were used to ease light sensitivity. In 1935, it may have been impossible for most people who were legally blind to see standard print at near, to read a blackboard at a distance, or to read a sign during travel. It would have been inconceivable to think that some people who are legally blind are able to drive a car with bioptic telescopic systems!

The term “legal blindness” has benefits for people with low vision who meet the definition of blindness. It enables one to receive materials and services, which, without this designation, may not be provided. As there has never been a U.S. definition of low vision, it seems difficult for government agencies to understand when some of the people who need assistance should receive it. For example, federal funding for education materials provided to schools through the American Printing House for the Blind (APH) is based on a registration of only children who are legally blind and not based on a child’s level of functional vision or on their educational needs. States and local education agencies can and do provide for children who don’t meet the federal definition of legal blindness.

Since 1947, APH has produced large print texts and tests. Often teachers chose to provide only large print for children learning to read print. This was free to schools and what wasn’t available from APH, states would supplement by publishing their own large print editions. Some children who only received large print didn’t develop competencies in reading efficiency. There are many reasons for this including limited availability of large print. One size of large print wasn’t the best size for all students, and children didn’t have the opportunity to read at a distance, e.g., blackboards. Further, before some of the newer electronic devices such as iPads and video magnifiers, there wasn’t a way to easily enlarge print to a specific size at the time the information was needed.

Beginning in 1953, newly-conceived, clinical low vision specialists (ophthalmologists and optometrists with low vision specialties) began to prescribe optical devices and methods emerged as to how to determine which devices were best for children needing to use near and distance vision.

**The Pendulum Swings**

In 1964, Dr. Natalie Barraga’s study of visual efficiency showed that, with directed instruction, a child with low vision could learn to better use vision and therefore, become
more visually efficient with their available vision. Her study was replicated, a set of materials and lesson plans were created, and the full kit became available through APH’s federal appropriations. Conferences were held throughout the U.S. to teach teachers of students with visual impairments (TVIs) how to use the materials.

A new philosophy emerged in schools, one that greatly encouraged educators to help students learn to use their vision and become print readers. When I began teaching children with visual impairments in the early 1970s, the philosophy was to teach only braille or only print, to choose the method while the child was quite young and to stay with it. While many children were well served with the visual approach, children with low vision who today would receive dual media (braille and print) instruction or braille as a primary medium were put in a dilemma. They didn’t learn braille and they didn’t gain efficiency with print. Most of these children may not have had optical devices available to them or optical devices would not have helped them to acquire competitive reading speeds. Without intended malice, some children with very low vision who may have benefited from braille instruction came to believe that to look blind or use non-visual skills was a negative aspect of who they were. From this reluctance to provide braille instruction came a strong consumer reaction.

**The Pendulum Swings Back**

People who felt they should have learned braille as children or whose vision became worse as adults and felt they had to learn braille later in life, became strong advocates for more children with low vision to learn braille. There was also a new paradigm shift as TVIs began to question the braille vs. print binary. Dual media was now considered a viable option.

There was also a political movement when five major organizations “of and for the blind” formed the Joint Organizational Effort (JOE). Braille became the issue on which they united, and new language was submitted to the federal government.

In 1997, this language was included in the regulations of the federal special education law, and it remains today. According to the Individuals with Disabilities Education Act (IDEA), instruction in braille and the use of braille became the default learning medium for all children with visual impairments who receive services due to a visual impairment (including those who are not legally blind). Braille is to be taught unless the Individualized Education Plan (IEP) team determines that it is not needed either at the time of evaluation or in the child’s future life. Further, braille must be discussed at least on an annual basis with parents of children with visual impairments.

At the time this language was included in the IDEA regulations there were no data available to justify having braille as the default for all children who received services. While some people with low vision have become proficient with both braille and print, to my knowledge, there are no data to illuminate whether children who add braille to their print instruction gain comparable reading rates and reading levels (using braille) as their typically-sighted peers. Later, a study in Tennessee showed that with optical devices students began to close the gap between their reading speeds and those of typically-sighted peers. Another study in North Carolina described the gains made with optical devices over the use of large print.

Two additional issues were surfacing at about that time. One was the preparedness of TVIs to teach braille. Consumer groups and professionals themselves were questioning how well teachers could retain braille skills...
after many years of not having a student for whom they were providing braille instruction. The other problem was a great shortage of TVIs and, therefore, increases in the numbers of children on the caseloads. It became difficult to provide the intensity and duration of instruction needed to enable children to receive adequate instruction. Despite many efforts to resolve these issues, there are still concerns in many parts of the U.S.

Two Camps Emerge

Until the mid-1990s, literacy decisions were mostly based on an eye doctor’s report and a TVI’s judgment, with parental input. Checklists, reading tests and sensory use profiles were developed as parts of learning media assessments (LMAs) and they offered a more structured way of making better decisions. While these LMAs are quite helpful, they have been called into question, as they are not standardized assessments with the statistical measurements found in many assessments used for children with other disabilities.

In the 1990s, there was also an emergence of multidisciplinary, low vision programs funded by individual cities, state departments of education and private foundations. Optical devices were prescribed by clinical low vision specialists, schools provided optical and / or electronic devices, and teachers and O&M specialists taught their use in functional settings. From my experiences with these programs and the professionals who held leadership positions in them, there was a clear understanding that if a child would benefit from braille instruction, this was considered in addition to the instruction in print with optical and / or electronic devices.

In 2012, the National Reading Media Assessment (NRMA) was developed with funding from the National Federation of the Blind (NFB). In an effort to increase the numbers of children with low vision who would receive braille instruction, this assessment does not allow for children with low vision to use optical or electronic devices, hold the paper any closer to their eyes than a typically-sighted student would, and not to use any accommodations for lighting, except for a visor. The NFB has stated that the NRMA is research-based and standardized. However, I do not believe that at the time there was any standardized learning media assessments that met the standards expected of published tests. There is still no test manual for the NRMA.

In 2013, the Board of Directors of the Association for Education and Rehabilitation of the Blind and Visually Impaired (AERBVI) adopted the position paper, Learning Media Assessments for Students with Low Vision (Lusk, McCarthy and Larson). The position calls for expanded wording to include braille readers, those who will be print readers, and those who will be dual-media readers, and speaks to the need for clinical low vision evaluations, prescribed devices, and instruction in their use.

Also in 2013 and 2014, the American Academy of Ophthalmology and the American Academy of Optometry approved professional guidance and a position paper respectively. In both, they call for the provision of a clinical low vision evaluation for children with low vision, the provision of optical and / or electronic devices, and instruction in their use.

As of May 2017, the legislatures of Virginia and Missouri are considering whether the National Reading Media Assessment or other research-based assessment will be required for all children with visual impairments in their states.
Summary

With this background, it may be easier to understand why learning media has become a controversial topic. Some think teaching braille is a panacea while others use the phrase, “the more tools in the toolbox” for all children, the better. Still others prefer a child’s time be spent learning to extend his or her visual reach and to use vision efficiently if this is viable. A specific diagnosis, a specific set of clinical measures, a specific philosophy, or a specific prognosis, should not be used as a sole determinant of whether a child should use print, large print, print with optical or electronic devices, braille or dual media.

Each child deserves a truly individualized decision regarding his or her reading media and this decision should be followed with high-quality instruction with sufficient time allocation, and revisited with data like reading speeds. When parents receive information about their children’s assessments—clinical low vision evaluations, functional vision and learning media assessment as well as a full explanation of the advantages and disadvantages of each literacy media—decisions may be made with more confidence.
As a parent and educator, I am often asked about IEPs and 504 plans. Understanding how Section 504 of the Rehabilitation Act of 1973 and the Individuals with Disability Education Improvement Act (IDEA), formerly known as PL 94-142, work with and complement each other allows parents to better assist their child’s educational team in ensuring a child’s right to a Free and Appropriate Education (FAPE).

School can be a stressful environment for disabled children and a time of vulnerability. Appropriate accommodations and modifications can reduce stress and can assist in achieving and maintaining educational success. You are your child’s greatest advocate and cheerleader.

**Similarities and Differences between IDEA and 504**

- **504 provides much broader protections than IDEA.** Neither law takes precedence over the other.
- **An IEP student automatically qualifies under 504, however, a 504 student may or may not qualify under IDEA.**
- **Special Education students under IDEA must meet a two-pronged eligibility criteria plus demonstrate a need.** Students under 504 are only eligible under the three broad qualifiers.
- **Both are entitled to FAPE.**
- **Both are protected by Family Education Rights and Privacy Act of 1974 (FERPA) with right to privacy concerning personal information.**
- **504 does not provide additional funds.** The district must financially support. IDEA does provide additional funds.
- **Procedural safeguards apply to both, but the safeguards don’t have to be written for those who are 504-eligible.**

- **IDEA students have stay-put protection if parents / guardians challenge a school’s decision.**
- **Neither requires a full evaluation on parent / guardian request.** However, the team must consider the request.
- **Both require annual notice and review of the IEP or accommodation plan.**
- **504 requires districts to designate a coordinator, provide grievance procedures, provide written assurance of nondiscrimination and see that notice of nondiscrimination is in the handbook. IDEA outlines due process procedures.**
- **504 compliance is administered by the Office of Civil Rights. IDEA compliance is monitored by the Department of Elementary and Secondary Education.**

**Common Accommodations include:**

- Shortened assignments
- Repeated directions
- Highlighted text
- Outlines / teacher notes
- Verbal cues
- Word banks
- Note taker
- Extended time
- Manipulatives
- Preferential seating
- Computer access
- Test centers

IDEA and Section 504 are federal laws that provide special education services for disabled children. Knowing the differences is imperative to provide the appropriate interventions to assure educational success.
### IDEA vs. 504 Comparison Chart

<table>
<thead>
<tr>
<th>Purpose</th>
<th>IDEA</th>
<th>504</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purpose</td>
<td>This law provides remedial and appropriate special education and related services to students with disabilities who are eligible under the 13 specific disability categories defined in the law.</td>
<td>This law prohibits discrimination on the basis of disability in programs and activities that receive federal financial assistance. In the educational context, the law provides otherwise qualified disabled students with appropriate educational accommodations and / or services designed to meet the individual needs of the student to the same extent as the needs of students without disabilities.</td>
</tr>
</tbody>
</table>

| Who is Protected | Students ages 3-21 with disabilities are eligible if they qualify under one or more of the 13 specific disability categories and are unable to access the general education curriculum. Categories include: Autism, Deafness, Deaf-blindness, Hearing impairment, Intellectual disability, Emotional disturbance, Multiple disabilities, Orthopedic impairment, Other health impairment, Specific learning disability, Speech or language impairment, Traumatic brain injury, Visual impairment. | Students with a disability are eligible under Section 504 if a student has a physical or mental impairment (physiological, mental or psychological disorder) that substantially limits one or more major life activities: Learning, Self-care, Walking, Seeing, Hearing, Speaking, Breathing, Working, manual tasks, or has a record of such impairment; or is regarded as having such an impairment. |

| Evaluation | • Parent/guardian must provide written consent before a student may be evaluated or re-evaluated.  
• Assessments are conducted by a multidisciplinary Special Education team in all areas of suspected disability.  
• The Special Education team determines whether a disability exists, identifies type of disability, establishes if limited progress is due to disability, and determines specific specialized instruction if eligible.  
• IEP goals and objectives must be reviewed annually and revised as needed.  
• A re-evaluation must be performed every three years by the IEP team to determine continued eligibility. | • Parent / guardian must provide written consent before a student may be evaluated or re-evaluated.  
• The Section 504 team is comprised of persons knowledgeable about the student, evaluation data and disability.  
• Multiple sources of information must be considered in the area of concern to determine eligibility.  
• The Section 504 team determines whether a disability exists, whether its effect on a major life activity is substantial and if accommodations / services are required.  
• A 504 plan must be reviewed annually and modified as needed.  
• A re-evaluation must be performed every year to determine continued eligibility. |

| Funding | If a student is eligible under IDEA the district receives additional funding. | Additional funding is not provided. |

| General Notice | Requires notification of parent rights | District must include notice of non-discrimination in its employee, parent and student handbooks and must designate the district’s 504 coordinator(s). |
White Lashes: Tips for Gracefully Handling Intrusive Questions

By Elizabeth Childs Drury, Ph.D.

I’ve blown it more times than I can count. A stranger in a crowded store harangues me with questions. A casual acquaintance drops the A-bomb (albino) into an otherwise pleasant conversation, causing an awkward silence. Worst of all, someone asks me to turn toward the light so that they can get a better look.

You’ve been there. And like me, maybe you haven’t known how to respond. I call these people IQAs, or Intrusive Question Askers.

We have options. We could just walk away, although they’ll probably chase us down. We could ignore the question, although they won’t take the hint. We could even make them feel small for saying something so gauche, but ideally, we’d rather take the high road.

It’s tricky enough when the goal is only self-protection. But if you live by a resolve to treat others with respect — even IQAs — formulating a mutually dignifying response with personal boundaries becomes more complicated. My own faith commitment says, “Love your neighbor as yourself,” and it isn’t easy with intrusive people.

On the one hand, I want boundaries. Loving my neighbor as myself doesn’t mean that I have to consent to an invasion. Unwelcome questions and scrutiny (as if I’m a science-fair exhibit) can really rattle me. I don’t have to discuss private matters on the spot merely to satisfy idle curiosity.

On the other hand, I want to be gracious. People usually intrude out of innocent ignorance, rather than evil intent. Just because someone makes me feel uncomfortable by stepping into vulnerable territory does not mean that I need to return the injury. In preserving my own sense of dignity, I don’t want to insult them or make them feel crushingly embarrassed for asking.

So over the years, I’ve tried to set boundaries with graciousness whenever I encounter such situations. No doubt about it, it’s an art that takes practice. Here are three tips I’ve learned from the NOAH community and from my own trial and error.

1. **Control the language.** I will not answer the question, “Are you an albino?” I just won’t do it. Period. I respond firmly and politely, “Well, I’m a person (pause) with albinism,” or simply, “Are you asking whether I have albinism?” Every time an unwelcome word enters the conversation, I redirect. So if they say, “Oh, I once knew this albino guy…” then I interject, “Oh, OK, so you once knew a guy who had albinism,” and then let the conversation continue.

If the A-word doesn’t bother you, great. But for me, it’s still too loaded with middle-school baggage. It even bugs me grammatically, but I’m a nerd. Taking control of the words of the conversation is an absolute first step. I can converse without being defined in a way that makes me writhe.

2. **Expose the effect.** If a stranger or casual acquaintance bursts out with an intrusive question, I sometimes respond with a lighthearted but direct, “Wow, that’s a bold question!” Other times, I extend my hand and say, “I’m not sure we’ve met,” calling attention in a friendly way to the fact that a personal question has just been asked of a complete stranger. Then I follow it up with an
Like many overburdened high school students, I carried a heavy backpack every day. I hunched over like Patsy from *Monty Python and the Holy Grail* and trudged through snow, puddles and construction projects. I was resigned to the inevitability of a heavy backpack and bad posture. I was wrong.

A single device, and in particular, a single app, revolutionized the way I learn and decreased my daily carrying load from 50 to 3.5 pounds.

Upon the demise of my high school laptop, I purchased a Microsoft Surface Book for the trip to college. The Surface Book has a 13.5 inch touch screen which can be detached and used as a super-thin tablet. It also comes with a pen for inking, since almost every office app on the machine allows you to draw in documents such as PowerPoint.
In my first month, the director of our Office of Accessibility put me in contact with a librarian who creates electronic copies of books free of charge for students with visual impairments. He receives books, unbinds them, scans every page into PDF and Word document form, emails the student both electronic formats, and returns the rebound book. Many offices of accessibility can provide a service like this, but I had always found it difficult to find the right PDF annotation app. I experimented with loads of them from Acrobat to Xodo, but none of them worked well. The ability to write on the documents was always fussy, or they didn’t save the annotations properly, or they provided only a limited array of inking options.

After two weeks of failed attempts, I tried Drawboard — the app that came on the Surface Book. I was shocked at how fast, easy to use and varied its array of options were. It allows you to insert text (particularly easy on the built-in keyboard), make bookmarks, write notes in any color you wish, at whatever thickness you desire, and highlight text. The app also allows you to zoom smoothly so you can read at whatever text size is comfortable for you.

Drawboard is a paragon of universal accessibility in that it presumes almost nothing about how you’re going to use it. You are free to set whatever settings will help you see best. I’ve set up some pens and highlighters in varying colors and thicknesses to represent various kinds of notes: blue for daily summary points, green for potential paper material, and red for personal amusement.

Using Drawboard with electronic copies of readings and textbooks means my computer is the only thing I need to take to class because every reading and every textbook is stored in folders on my desktop rather than piled on top of my desk. By hitting a few keys, I can switch between a copy of the lecture I’m watching, a reading I want to reference, and a page of summary notes in mere moments. This is far better than leafing through a pile of papers and frantically scribbling something in faded pencil.

The Surface Book has also increased the amount of time I can focus on a reading. I used to get terrible fatigue and headaches from hunching over readings and squinting fiercely at them for hours on end. On the new computer, I can detach the tablet, put it in my lap, and zoom and scroll naturally with a flick of the wrist. My eyes are less tired, I don’t get frustrated as much, and I have more time to do other things.

The Surface Book also has an outward facing camera (a rarity among laptops) which allows me to zoom in on things professors write on chalkboards. I can get a good view of exactly what they’re writing even when I’m too far away to see it on my own.

I’m also a singer, and any singers will be thinking of parallels to their frustration with piles of music. It’s always poorly stapled, with the music in the center of the page surrounded by a frustrating amount of useless white space, with the gray shadows of poor copies, and with tiny markings to denote complicated musical directions. Now, all my music is accessible on my computer, and the detached screen is even easier to hold than paper copies.

Most of the time a piece of technology is good at solving one, relatively simple, problem, but sometimes a piece of technology enters your life and totally changes the way you operate. The Surface Book, with its detachable screen, amazing PDF annotating software, outward facing camera, and beautiful zoom capabilities has genuinely revolutionized my college experience. I recommend it, and its fellow Surface products, to anyone with a visual impairment.
Once, in a sleep-deprived moment, Amber’s mom Googled “albinism in newborns.” She didn’t search further because Piper was thriving, and their family was ecstatic with Christmas babies. Besides, Amber’s hair looked like corn silk when she was born.

It wasn’t until Piper was three months old that they noticed she did not “track” the same as Roman. She met all of her milestones, but she accomplished them differently than her brother. Through ophthalmology appointments and blood tests, they learned Piper has a never-before-documented genetic patterning among people with albinism (PWA).

Next, came an acceptance phase. Amber
and Adam shared information about how genes work and what albinism is with family and friends. Then, Amber reached out to NOAH and attended a conference in Pennsylvania. She met a wonderful community of people, a family of sorts, who opened their arms and hearts to Adam, Amber, Piper and Roman. NOAH is where this story really starts.

Amber decided to actively participate in albinism awareness and advocacy. In October 2016, Amber coordinated a 5K walk in Dayton, OH to support children with visual impairments. The response was remarkable. Over 20 of Amber and Adam’s family members turned out with their dogs and children to support the cause.

Amber flaunts t-shirts and NOAH materials wherever she goes. Once, when she visited the ER with Piper who had spiked a high fever, she gave the nursing staff NOAH cards and a whole lecture on albinism and nystagmus.

Last winter, Amber sponsored a virtual silent auction to support albinism awareness. She set up the auction through social media and invited everyone she knew to participate. Her approach — if small businesses donated an item, she would pass along their advertisements. Donors also received packets about NOAH and albinism to distribute to their stakeholders. The response was, again, overwhelming. Over 100 donors participated! In 72 hours, Amber raised more than $1,500!

Amber’s commitment to advocate for albinism within her community is a story of her love for Piper. The community responded with love for Piper and her mother, as well.

---

**CARE for you, CARE for our Community**

NOAH’s CARE program collects education plans from early childhood intervention through high school:

- IFSP for students three and under
- IEP for students age three to graduation
- 504 accommodation plans

The content is indexed by state and grade, so you can use this free resource to help establish your child’s Individualized Education Plan.

You can also help the albinism community. Personal information is removed so your privacy is protected. Our resource is only as good as the input we receive, so please consider sharing with CARE.

Visit [www.albinism.org/care](http://www.albinism.org/care) for more information.