



NOAH Ed U

CREATED WITH EDUCATORS IN MIND



Autumn 2017

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.

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Albinism InSight*

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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!

Educating a Child with Albinism

Orientation and Mobility for Children with Albinism

By Anne L. Corn, Ed.D.



I am not a certified orientation and mobility specialist (COMS). I am, however, a teacher of students with visual impairments (TVI), a retired professor who prepared TVIs and leadership personnel, and a woman with congenital low vision. My experience includes teaching children with low vision, including children with albinism, teaching the orientation and mobility course for TVIs, conducting research in O&M topics, sponsoring dissertation research in O&M, and co-authoring *Finding Wheels*, a curriculum to assist adolescents who cannot drive to gain control of their transportation needs. These experiences do not give me the extensive knowledge of an O&M specialist but rather, a view from someone who has high regard for those who hold certification in this specialty. This article is based on my experiences and perceptions and it is about philosophies, assessments, and curricula, including the controversial use of blindfolding students during instruction.

My interest in orientation and mobility skills for students with low vision is longstanding. In the early 1970s I taught in a school district that did not provide O&M services for students who didn't qualify as legally blind or at least 16 years of age. One of my 8th grade students had extreme photophobia (not due to albinism) and low visual acuity, was quite hesitant in his movements, and had not yet crossed a street independently. I bartered my assistance by offering consultation to an adult program at a private multi-service agency for the blind in exchange for having their O&M specialist give

my student instruction after school hours. That was more than 40 years ago but today little has changed for some students with similar needs who are not receiving orientation and mobility instruction. In recent years I have heard of school districts telling parents that their child can find their way around the school and so an O&M assessment is unnecessary, and that a child won't need to be assessed until he or she is ready to travel independently using mainline transportation. Neither of these is an acceptable reason for denying an assessment by a qualified professional.

Orientation, Mobility, and Wayfinding

Simply put, orientation is knowing where you are in space and in relation to other objects. Being able to say "I am in the kitchen and the microwave is to my right" or "I am on the northeast corner of 45th St. and Burnet Rd facing south.", being able to orient oneself, maintain orientation during travel, and to re-orient oneself if unsure of where one is in space, are examples of orientation skills.

Mobility is the manner in which one goes from place to place. Being able to move with a typical gait, being able to keep oneself walking straight, or remaining safe when approaching and crossing a street are examples of mobility skills.

Now, imagine Jon, a typical 4-year-old, who is in your car returning home from the grocery store. If, each time, you needed to make a turn, you asked him, "Which way shall I go?" and Jon points right or left until you arrive home, this would be an early stage of wayfinding, a

term added onto the discipline of orientation and mobility that speaks to knowing your position in space, envisioning where your destination is located, and being able to plot your movements and methods to reach your destination. For some 4-year-old children with low vision this task of directing a parent to home is easy, for others not so.

While little is known about the development of wayfinding skills, I assume there is a progression of learning just as there is a progression of how children learn to use their hands and to speak, to orient themselves and to be mobile. I further assume a typically sighted child develops new skills each year which culminates in independent travel sometime during adolescence. Therefore, all children, with and without visual impairments, need to make progress each year so as to become independent travelers.

How much progress is made each year can be determined through careful assessment. Schools should provide an assurance that knowledge and skills in orientation, mobility and wayfinding receive similar attention to developmental areas such as language and social skills. To enter adulthood with control over one's movements a student must have these skills as well as problem solving skills, confidence, and a desire to travel independently. We all desire the ability to travel alone and opportunities to travel with others; finding a personal balance between independent travel and interdependent travel is important for getting where one needs and desires to go.

Professionals

There are three types of professionals who may be involved with assessing and teaching orientation and mobility skills. Under IDEA orientation and mobility is a "related service" and is to be provided to improve functioning

within a special education program.

- COMS (certified orientation and mobility specialist) These professionals have completed a university training program approved by the Association for Education and Rehabilitation of the Blind and Visually Impaired (AER) and certified by the Academy for Certification of Vision Rehabilitation and Education Professionals (ACVREP). I strongly recommend that a COMS be the professional to conduct an assessment and provide instruction.

- Travel Trainer - Under IDEA all children with disabilities have access to travel training. These specialists provide services to students with physical, cognitive, or other disabilities. While travel trainers may be helpful to a child with low vision, they would not be expected to have extensive knowledge about children with visual impairments. More information about travel trainers may be found on the website of the National Association of Special Education Teachers.



Photo by Rick Guidotti, Positive Exposure

- NOMC (national O&M certification) The National Federation of the Blind prepares travel trainers who adhere to their philosophies regarding how people who are blind should learn needed skills. The National Blindness Certification Board (NBPCB) provides certification to these instructors who "emphasize non visual instruction and Structured Discovery cane travel."

For an overview of the roles and functions of an orientation and mobility specialist, parents may want to read the position paper, "The role of the orientation and mobility specialist in public schools" adopted by the Division on Visual Impairments and Deaf blindness of the Council for Exceptional Children.

Assessments

Some COMS believe services should be available from the time a child is a few months old; others believe an assessment should be given as a preschooler and repeated every three years. I believe an assessment should be given at the time of diagnosis (if later than at birth) and repeated annually while the child is in preschool, then at least every 3 years during schooling. However, in many school districts, it is at the discretion of the teacher of students with visual impairments (TVI) or following a parent's request when a COMS is asked to assess a child. By law, in the state of Texas every child with a visual impairment is provided an O&M assessment.

Under the Individuals with Disabilities Education Act (IDEA) all school systems are obligated to provide (based on assessed needs) "related services". These are services intended to improve a child's ability to function within special education services. Orientation and Mobility, speech and language therapy, and physical therapy are examples of related services.

Orientation and Mobility is also one of the curricular areas of the Expanded Core Curriculum for Students with Visual Impairments (ECC), a curricular approach that has been adopted by many school districts throughout the country and by the state of Texas. The knowledge and skills of O&M also relate to most of the other ECC areas including career education, sensory development, daily living skills, social skills, and technology skills (See TSBVI.edu for more information on the ECC). When assessments are given in these areas, the student's ability to travel should also be considered. For example, if a student's skills for career education are being assessed, his or her ability to travel to a place



Photo by Rick Guidotti, Positive Exposure

of employment needs to be included.

For a student with low vision an assessment includes age-appropriate skills in orientation, mobility, and wayfinding as well as how well a student incorporates his or her functional vision for planning and/or executing a skill. The scope of this article does not allow for a thorough review of skills and parents may wish to read through O&M assessments and curricula used by their child's school district, e.g., TAPS (TSBVI.edu). Assessments and curricula used by a COMS also includes the concepts of visual reach, extending visual reach, visual efficiency, and visual independence (see *Albinism InSight*, Spring 2017).

Typically, an assessment for a child with low vision takes place in a variety of indoor and outdoor locations, in a variety of lighting situations, and during the day and, if age-appropriate, at night. During an assessment a child should have his or her optical and/or electronic devices for both near and distance viewing as well as any light absorptive lenses or clothing used for light control, such as a hat with a brim.

Before I read the narrative of a COMS' report for a child with low vision, I first read the report from the ophthalmologist or optometrist and the clinical low vision evaluation report. I consider the diagnosis, type of visual impairment, clinical measurements, and prescriptions for near and distance vision, as well as for light control. Device recommendations from a clinical low vision evaluation for a child with albinism may include, but not be limited to:

- near vision - hand held, spectacle magnifiers, or portable video magnifiers
- distance vision - handheld monocular or bioptic telescopic system, OrCam system

- light control - tinted lenses or low light transmission spectacle lenses, e.g., with 5% light transmission), tinted or painted (opaque) contact lenses with a fixed pupil, frames that reduce or omit ambient light from entering eyes

In the O&M report I then look for relevant descriptions of how the child uses:

- peripheral vision and awareness of all visual quadrants
- awareness and identification of objects at various distances
- where vision is focused, e.g., ahead or toward the ground
- interpretation of visual information, e.g., an uneven sidewalk, an object vs. a shadow
- use of optical devices, e.g., near devices for price tags, monocular telescope for street signs
- use of electronic devices, e.g., GPS
- use of apps for information about buses, other transportation
- use of light absorptive lenses, e.g., tinted lenses, low level light absorptive lenses
- use of light control devices, e.g., hats, visors
- understanding of where to look for information, e.g., street signs, building directories, addresses
- responses to changing illumination
- responses to changing terrain, e.g., steps, curbs
- use of visual landmarks
- use of vision while stationary, walking, or in a vehicle
- mental visual mapping, e.g., way finding
- social interactions during travel, e.g., explaining one's needs, using eye or face contact
- areas which are challenging, e.g., stairs

with patterned carpeting, large open areas

- ability to interpret environmental cues that provided needed information, e.g., a "broken" shadow indicating a change in terrain.
- speed of responses to visual information

In the summary section of a COMS report, I look for the student's strengths and weaknesses; levels of knowledge and skills in orientation, mobility, and wayfinding; and consideration of the amount of progress a child has made since his last report, including whether the child has achieved his or her IEP objectives in O&M.

When I read the Recommendations section of the report I look for three components: needed reinforcement of skills in the classroom and/or at home, new skills that are need to be taught, e.g., readiness for learning to travel in unfamiliar areas, and whether direct instruction from a COMS is warranted. All recommendations should be based on the narrative within the report with observations that justifies each recommendation.

Students who are often overlooked for O&M assessments are those with potential to become low vision drivers, those whose visual measures meet their state's regulations for pursuing a driver's license with or without a bioptic telescopic system. While these students may have sufficient vision and skills to be pedestrians with or without optical devices, a focused assessment looking at "pre-driver awareness" skills provides much needed information. For a discussion and listing of pre-driver awareness skills, read Huss and Corn (2004).

Currently there is an extreme shortage of orientation and mobility specialists throughout the country. A school district is obligated to provide orientation and mobility services and while this need seems clear for functionally

or totally blind students, parents of children with low vision are urged to advocate for their children when an assessment and instruction are important for their child's travel independence.

White Canes

If there is a recommendation for the use of a white cane, the narrative should also describe observed behaviors leading to that decision, e.g., "On sunny days Troy could not locate drop-offs or see the curbs on the other side of a street." Another description indicating the need for a cane might be, "Alyssa is unable to identify when a car is moving from a half block away." A visual acuity alone should not be a reason for recommending or denying use of a white cane, nor should a cane be recommended for non-functional reasons without an explanation of why the COMS believes a white cane would provide information and safety.

Some additional questions parents may have if a white cane is recommended include the following:

- In what ways will my child be using his vision along with gaining information from the white cane?
- Are there certain times of day or weather conditions, e.g., sunny days, when a cane will be more useful or should it be used at all times?
- Will my child be able to determine in which situations her vision is sufficient for travel and in which situations a cane is a beneficial tool?

When a person with low vision begins to use a white cane, emotional responses should be discussed. As the child also has vision, he may receive questions and comments from

people around him that may be helpful, e.g., "You seem so much more confident when you travel with a cane" or they can be hurtful, such as "You are just pretending, you aren't really blind." Parents may also want to know if their child views a cane as a tool for independence or a tool indicating dependence, as a tool that provides information about the environment, or only as something adults say she needs.

Although I have met few individuals with albinism who use a white cane, I am not opposed to use of a white cane. For some students use of vision may or may not be the most efficient method of travel and for other students a white cane may give added confidence or it may help others, e.g., bus drivers, to understand that a person does have a visual impairment.

Blindfolding

If there is a recommendation that a child be blindfolded during instruction, there should also be one or more related descriptions in the report narrative justifying the use of a blindfold. Proponents for blindfolding have expressed various reasons. Some believe

people with low vision cannot count on their vision (under different weather conditions or because they may lose their vision) and therefore functioning as if blind is safer. Another argument used for blindfolding is that people with low vision just aren't accepting their blindness and they need to learn blind skills to be competent people. I am not totally opposed to blindfolding for some students with low vision but my reasons do not, for the most part, apply to students with albinism. Some examples of when a student may benefit from blindfolding include: having a minimal central visual field, is fearful to look ahead for fear of not finding steps or curbs, is losing vision, or



is overwhelmed by visual images. More than a decade ago there was a debate about this issue; my paper, Low Vision Without Blindfolding may be found at TSBVI.edu

Use of a cane or blindfolding may also be used because of misconceptions about what a person who is legally blind or with a low visual acuity can see. Some factors to consider when considering blindfolding include:

- vision provides far more information about an environment that tactual means for many people with low vision
- there are no data showing benefits for blindfolding people with albinism
- non visual skills may be taught without blindfolding
- vision takes over once a blindfold is removed
- some people with 20/200 on a Snellen eye chart may be able to detect an object 3/4-inch-high at 27 feet and able to identify a coin on the ground at 7 feet, much farther than where a cane will touch
- a person with low vision may not see detail but can see at a distance, e.g., the snowcap on a mountain or a distant building

People with low vision may determine if there are tasks that can be accomplished more efficiently or comfortably without the use of vision. We all can locate objects in pockets or purses without looking, or tie an apron behind our backs without looking. So, too, there are non-visual methods for completing tasks that sighted people do every day. Shaving or applying make-up are examples of such tasks that many people with low vision will learn to do without using vision.

I have been asked about Goal Ball, a game in which all players are blindfolded. Some consider this a game that levels the playing field for those who are blind and it is a game designed so people who are sighted, those with low vision, and those who are blind can

compete. I consider this a game that has rules and if it is a game played without vision, then blindfolding everyone seems reasonable, similar to the children's game, "Pin the Tail on the Donkey." There was even a Star Trek episode, The Icarus Factor, in which there was a sword competition in which participants cannot use their vision.

Instruction

Once there is a recommendation for O&M instruction, parents may wish to look upon the goals and objectives as they would be written for any other disability-specific subject. As stated above, within the IEP there should be plans for a year or more's growth for each child. Goals may be more general but the objectives under each goal should have a description of the type of instruction, the observed behavior, and the criteria for achieving the objective. Also, there should be a method for collecting data as the child begins to move toward achievement of the objective.

When reviewing goals and objectives for orientation and mobility skills on IEPs, parents may wish to consider the following questions:

- Are the goals and objectives based on the O&M assessment and recommendations?
- Are the goals and objectives sufficient for a year or more of growth in orientation, mobility, and wayfinding (for typically functioning students) and for an appropriate amount to growth (for students with visual and additional disabilities)?
- Do the goals and objectives address visual needs during travel, including use of optical and/or electronic devices?

If an O&M curriculum or skills checklist will be used, they should be listed.

Finally, after the goals and objectives are established, the delivery of services is discussed. Will the student have instruction for the duration and intensity that is needed? The amount of instruction should be derived by the

extent of a child’s needs and school districts may use such scales as the Michigan Severity Scale as part of this determination.

Orientation and Mobility services may also be involved in teaching recreational skills such as bicycle riding or skateboarding. These recreational goals may also be placed on a student’s IEP.

Summary

Orientation and mobility services is a related service for students receiving education through IDEA and have an IEP. O&M assessments and instruction should also be available for children who receive an IFSP (ages 0-2). Students with albinism should receive an assessment and a determination whether O&M services should be provided. The use of vision should be incorporated into any assessment and report. All recommendations should be based on one or more observations contained within the narrative of the report. The use of white canes and blindfolds during instruction also need justifications and parents are encouraged to consider functional and emotional factors when these recommendations are made. Students who may become low vision drivers can also benefit from O&M assessments and instruction for pre-driver awareness.

Note: Students receiving accommodations and services on a 504 Plan may also receive O&M assessments and services.

Students I Have Known

Lindsey’s father told me that she had never received an assessment for O&M instruction. A school administrator said she didn’t need O&M because she knew her way around the school and wasn’t traveling independently. I asked when he felt Lindsey, then 13, would need an assessment. He suggested when his daughter

was about 16 and wanted to take a bus to shop with friends or go to a friends house on her own. Having met his daughter a few times, I suggested skills she would need before she could accomplish either of these tasks. He called the school the next day to request an assessment and instruction was offered.

While teaching in New York City, I worked in a school where classrooms needed to be locked and there was only one entrance with personnel at the door for safety. Jim was a student whose family had encouraged him

to “appear” to be fully sighted at all times. If I had hallway duty and one of my students needed to enter the resource room to pick up equipment before their next class, I would give them my key. Jim placed his eyes about two inches from the keyhole as he inserted the key. When I offered to show him a non-visual approach he was hesitant. We stood in the hallway observing the posture of those opening doors with keys. He learned a tactual approach which was more efficient and gave him a more typical appearance.

When visiting a specialized school, I watched a kindergartener with low vision having some difficulty walking in a straight line in a hallway. His teacher commented that she felt Lee should begin to learn to trail the wall (hand touching the wall) to give him more confidence and ability to walk straight. His teacher asked for my opinion. I noticed two colors of tiles on the floor - about a 3 ft. path of dark gray tiles starting at the wall and white tiles running down the center of the hallway. I asked Lee if he could walk only in the gray tile area. This approach worked well as he attended to his distance vision as well as his lower peripheral vision.

At one time I directed a state-wide project, Providing Access to the Visual Environment

(PAVE). Ty was a middle schooler who came to our low vision clinic. He said he wanted to skateboard with the boys in his school. The evaluation showed he had a diminished ability to see contrast. With specialized lenses put into a pair of sports goggles, and with instruction from a COMS, Ty learned to skateboard.

These students present very different types of needs for their orientation and mobility instruction. A COMS should be prepared to assess, establish goals and objectives, provide direction instruction to the student, and work with parents and general education teachers to help further the development of orientation, mobility, and wayfinding skills. As children with albinism typically have low vision acuity and mild to severe photophobia (sensitivity to

light), the COMS is a most important member of the education team.

References:

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Accommodations and Modifications

By Joseph Sartorius, Ph.D.

The education processes in the local school district, state and even federal programs can be very overwhelming. During my years as a parent of children with special needs, teacher, principal and director of special services I have attended numerous IEPs focusing on strengths and weaknesses of students, present level of performance and goals to promote growth and successful performance according to the student’s individual needs.

In reflecting, I found the one area of the IEP process most misunderstood by parents and educators was dealing with the concepts of accommodations and modifications. Of course, as an educator we always want to be helpful and find ways to better any situation for

students. The most important step to helping a student (and their family) realize success at any school is to match the needs of the child with the resources that are available in order to challenge them academically and provide the best learning opportunities possible.

The terms accommodations and modifications are used synonymously. During the IEP meeting they are referred to together and are often presented as a list of items encompassing an entire page which are reviewed quickly and checked to include in the student’s educational plan. Many of the strategies could help a student with a disability access education and perform at levels comparable to peers without disabilities.



Photo by Rick Guidotti, Positive Exposure



The concern is that the two terms are always used together and many parents and educators perceive them as being the same even though they have very different implications for the student and the standard of learning. Accommodations help the student to achieve the standard that have been set for all of the students where modifications actually change the standards to be met. If the standards are changed the students is no longer held to the same standards of peers. Over time the student can be meeting all of their IEP goals at a proficient level but not be on grade level with peers. From one grade to another this discrepancy becomes greater and greater. This scenario is not necessarily bad, but should be looked at by the IEP team and totally understood to ensure the best education practices are providing the greatest outcome for student growth and achievement.

So what are accommodations and modifications? The Missouri Department of Elementary and Secondary Education has defined accommodations as:

“Changes made to instruction and/or assessment intended to help students fully access the general education curriculum without changing the instructional content. Accommodations provide equitable instruction and assessment for students by reducing or eliminating the effects of a student’s disability. They do not change or reduce the learning expectations in regard to the goal being addressed or assessed. Generally, the resulting student product with accommodations is equal to the student product without accommodations.”

Modifications on the other hand are defined be the Missouri Department of Elementary and Secondary Education as:

“Alterations made to instruction and/or assessment that change, lower, or reduce learning or assessment expectations. Modifications change or reduce the learning expectations in regard to the goal being addressed or assessed. More often than not, the resulting student product is not equal to the student product without modifications.”

The compass to navigate through the accommodation and modification process has always been to focus on trying to keep students with disabilities performing at the standard of nondisabled students. Keeping students in the least restrictive environment where they can be successful with standards of nondisabled students. When assistance is needed focus first on accommodations. What can be done to help the student access education material without altering the standard of learning? Next if modifications are needed be sure to discuss the implications of the modifications related to the standards for nondisabled peers.

Delineating the differences between accommodations and modifications along with realistic expectations will provide the positive supports for learning and academic achievement.

For more information and visual aids, visit dese.mo.gov.



New NOAH Resource!

- Having trouble in school or at work due to albinism?
- Searching for information to help educate those around you about albinism?

NOAH's Advocacy and Awareness Program provides information and services to people with albinism and their families. Learn more at www.albinism.org/advocacy or contact us at advocacy@albinism.org.

www.albinism.org/advocacy

NOAH's Parent Connections

IN PARTNERSHIP WITH LIGHTHOUSE GUILD INTERNATIONAL

NOAH, in partnership with Lighthouse Guild International, has developed a free parent support teleconference program as another way to bring the albinism community together.

Parent Connections is an opportunity to talk with others who understand what you are going through as a parent of a child with albinism.

The teleconferences are facilitated by a licensed professional and consist of a limited number of parents. This provides a safe and comfortable environment for you to voice concerns, ask questions, share your experiences, and hear from professional guest speakers.



“It is a great outlet reminding me to nurture and take care of myself so I’m able to truly care for my son.”

– Parent of an infant, Chicago, IL

Top photo courtesy of the Venn family; middle photo courtesy of the Miller family; lower photo courtesy of Positive Exposure, Rick Guidotti.

For more information, contact NOAH at info@albinism.org or 800-473-2310

Accessible Friendships

By Merve Deniz Paker



I guess most of us who have albinism and/or low vision are familiar with that moment of life when the others just live and we try to adapt to them. I remember a lot of times when my “friends” walked too fast or something like that and I just tried to survive and didn’t have the chance to enjoy life. It’s always been heartbreaking for me trying to spend time with people who walk 20 feet before me. I missed life just because I was scared to miss a step and nobody seemed to care. So I will dedicate this article to my high school friends and teachers who have completely changed the way I live!

I’ll go back to summer before I started high school. I was really self-conscious. I thought I couldn’t be a standard person because that was what I was taught. However my high school fortunately changed everything. Let me compare some moments of life:

When I was 5, I fell off stairs and broke my leg because people around me weren’t aware that I needed help to navigate stairs safely. But the first day of high school, it was raining and my teacher somehow knew I would need help and she told one of my friends to help me with stairs. It just felt amazing!

I always had hard times when I tried to explain my situation to my teachers before high school. It was always like this:

“I can’t see well,” I said.

And they answered: “Why don’t you wear glasses?”

“What do you mean?”

“You can see better than I can if you want to hahah.”



But I told my history teacher at high school I couldn’t see the board and he simply said, “That’s okay, how could I help you?” My math teacher started to describe every single line written on the board at her first lecture though she didn’t meet me personally— my teachers told her I was visually impaired.

My childhood “friends” were not really helpful with the visual stuff in classes. There were times when they didn’t want me to take a look at their notes. At the first biology class in high school, the teacher asked, “How will you see the board?” My answer was, “I won’t.” One of my friends suddenly said, “I will read her everything.” And she kept reading things to me until the last day of high school.

School trips were nightmares before high school. All I could do was try to follow people. However we took every step together in high school. I remember that moment when one of my teachers was describing to me a beautiful scene.

I can give thousands of examples like those. Like finding a message from my best friend saying “Hey I’d love to read books to you on summer.” But the main reason why I call them “accessible friends” is that they wanted me to be an independent adult though they would help me with everything.

They encouraged me when I told them I wanted to use a white cane. They always support me when I fight against discriminations. When I read things they wrote in my yearbook, I can understand they just love me because I was me. None of them wrote about my albinism but most of them shared my dream of a completely

accessible world.

Today I’m about to start to study psychology and I’ve just found a great university which provides its students with visual impairments skills of independent living. It’s more than a disability service. You can find it here: www.getem.boun.edu.tr.

My friends and teachers made the whole world accessible to me and now I’m going to try hard to build an accessible world for all people for a lifetime.

Thank you guys for making this white haired “weird” girl a confident, independent and happy person!

