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THE CLARENCE SEBASTIAN FOUNDATION



Slaosi G. Salesulu

CHAIRMAN OF THE CLARENCE SEBASTIAN FOUNDATION

Preface.

There is no doubt that we are in extremely difficult times and we can have no perception of how our lives will change over the coming months. However, we are a very supportive community, which will give us resilience in the months to come. Our Groups have established strong friendships within them. These will sustain us over what we know will be an exceedingly difficult period of time.

"Voices from the shadows" is funded by Spotlight Initiative through UNDP. The Spotlight Initiative is a joint UN and European Union programme to END all forms of violence against ALL women and girls. Targeting in particular women and girls who are left furthest behind and facing intersecting forms of discrimination.

I enclose and endorse the following which is guide or a text to assist teachers, parents, educators, administrators and even church ministers (faifeau)

As always, I will start by thanking all our supporters, parents and the children with albinism, for their assistance throughout the past year, and also for their attendance and support.

The Clarence Sebastian Foundation Board held its regular meetings at the end of each month and in special instances to discuss urgent and significant issues which requires a Board

deliberation. It goes without saying that formulating and drafting this guide has been a

priority since 2016 and finally we can see the end is nigh.

We wish to also thank our stakeholders, working partners and customers for the support and

understanding that enabled The Clarence Sebastian Foundation to perform its mandated

functions and services.

Special Acknowledgment

Louisa Apelu - Spotlight Initiative UNDP Project Coordinator I am humbled to say "Faafetai

lava/thank you" for your generosity and "good faith" for the funds we have received to write

a kit set for the people of Samoa and the stakeholders of the CSF.

The Good Book says "I thank my God every time I remember you. In all my prayers for all of

you, I always pray with joy," ~ Philippians 1:3-4, NIV

We thank you in advance for your anticipated cooperation and for your goodwill.

Yours Sincerely,

Siaosi G. Salesulu(Rev Dr)

Chairman of THE CLARENCE SEBASTIAN FOUNDATION

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ACRONYMS AND ABBREVIATIONS

- ❖ ACEO Assistant Chief Executive Officer
- ❖ ACT Charitable trust Act 1965
- ❖ AEIS- Academic Excellence Indicator System
- ❖ AEP Alternative Education Program
- ❖ AG Attorney General's Office
- CEO Chief Executive Officer of CSF
- ❖ CSF The CLARENCE SEBASTIAN FOUNDATION
- ❖ GC General Curriculum
- HR-Human Resource
- ❖ KRA-Key Result Area
- ❖ IEE Independent Educational Evaluation
- ❖ IEP Individualized Education Program
- ❖ IFSP Individual Family Service Plan
- ❖ IN Intellectual Disability
- ❖ LD Learning Disability
- ❖ LEA Local Education Agency
- ❖ LEP Limited English Proficient
- ❖ LMA Learning Media Assessment
- ❖ LRE Least Restrictive Environment
- ❖ MD Multiple Disabilities
- MESC-Minis try of Education, Sports & Culture
- ❖ MOF Ministry of Finance
- ❖ MFAT-Ministry of Foreign Affairs & Trade
- ❖ MOU-Memorandum of Understanding
- ❖ OI Orthopedic Impairment
- ❖ O&M Orientation & Mobility

- ❖ OSERS Office of Special Education & Rehabilitative Services
- PACER Parent Advocacy Coalition for Educational Rights
- ❖ PBM Performance-Based Monitoring
- ❖ PBIS Positive Behavioral Interventions & Support
- ❖ PEIMS Public Education Information Management System
- ❖ PPCD Preschool Program for Children with Disabilities
- ❖ PTI Parent Training and Information Center
- ❖ REED Review of Existing Evaluation Data
- ❖ RTI Response-to-Intervention
- ❖ RPTE Reading Proficiency Tests in English
- ❖ SBEC State Board for Educator Certification
- ❖ SBOE State Board of Education
- ❖ SDAA State-Developed Alternative Assessment
- SHARS Student Health & Related Services
- ❖ SI Speech or Language Impairment
- ❖ SSA Shared Services Arrangement
- ❖ TBI Traumatic Brain Injury
- Terms of Reference
- TVI Teacher of the Visually Impaired or Teacher of Students with Visual Impairments

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The CSF of Samoa with the help of this grant has produced this document as a means to enhance teacher education programmes by providing requisite knowledge and skills to trainee and serving teachers on handling learners with albinism and other disabilities. School administrators, teachers, learners and the community should raise sensitization and awareness campaigns on disability issues.

PROTECT THE RIGHTS OF PEOPLE WITH ALBINISM

Alicia Londono, the UN Human Rights Office expert on people with albinism rights expressed concern that people living with Albinism were also unable to immediately access justice for the crimes committed against them as witnesses were often unwilling to testify for fear of victimization.

In 2013, the UN Human Rights Council adopted two resolutions calling on states to take all measures necessary to protect people with albinism and to ensure accountability through the conduct of impartial, speedy and effective investigations into crimes against them.



SCHOOL KIT¹

Purpose

Talofa and greetings this text or guide is to support parents as they advocate for their children's success in the general education classroom².

As with any information, consider that these are suggestions and guidelines, not essentials. Not all students function the same and need the same supports to be successful.

SCHOOL SYSTEMS MUST PROVIDE EDUCATION IN THE "LEAST RESTRICTIVE ENVIRONMENT" TO CHILDREN WITH DISABILITIES. THE PROGRAM MUST MEET THE CHILD'S INDIVIDUAL EDUCATION NEEDS. FOR MOST CHILDREN WITH ALBINISM, THIS ENVIRONMENT IS THE "TYPICAL" LOCAL CLASSROOM SETTING, IN WHICH A TEACHER CERTIFIED IN THE AREA OF EDUCATION OF STUDENTS WITH VISUAL IMPAIRMENTS INSTRUCTS AND FACILITATES APPROACHES TO ALLOW THE STUDENT TO PARTICIPATE IN ALL APPROPRIATE ACTIVITIES.

Assisting Students with Albinism

Most students with albinism can participate in general education programs with appropriate support services. Since not all children with albinism have the same visual acuity, and since not all use their vision with the same efficiency, it is important to consider the individual abilities, needs and skill level of each child.

A Teacher of Visually Impaired (TVI) is a special education teacher with expertise in the education of students with visual impairment. To identify a TVI and to access special education services, parents of a child with albinism should contact their public school system's administrative office. This contact should occur well before kindergarten. In all states, the school system can provide information about preschool and early intervention

¹ NOAH School Kit 2016 Parent To-Do List

² Consultants for this bulletin include William A. Finn, Administrator, Services for Blind and Visually Impaired, New Hampshire Department of Education; Susan M. Dalton, M.S.Ed., TVI, Dept. of Teacher Education, Northern Illinois University and parent of two children with albinism; Sidney C. Wharton, a Teacher of Visually Impaired in Fairfax County, Virginia, public schools; Nan Dempsey, supervisor of programs for the visually impaired for the State of New Jersey; Jeannine Joyce, parent of child with albinism; and Julia Ashley, a doctoral student at Nova University who is studying the needs of students with albinism. Further information is available in Ms. Ashley's booklet, The Student with Albinism in the Regular Classroom, published by NOAH and NAPVI in 1992.

supports and services. Beginning at age three, as required by schools must provide education and educationally related services to children whose physical, emotional, learning or sensory impairment constitutes an educational disability. For children with low vision, these services will include assessment of visual function (A Functional Visual Assessment), as well the educational and other assessments as appropriate. Suggestions to parents about ways to help their child is an important element of the assessment and evaluation process. This assessment paves the way for the child's education team to develop an Individual Education Plan (IEP). The educational placement is then determined by the team with consideration of the array of options which are available and/or need to be made available to the child

The Classroom Setting

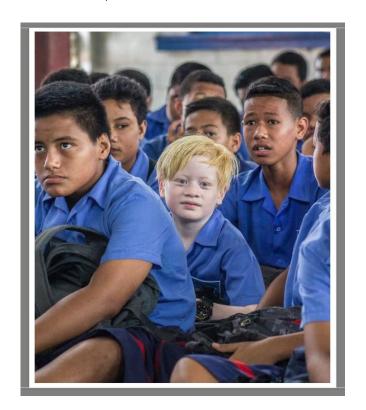
The student, his or her parents, classroom teacher, TVI, and optometrist or ophthalmologist must work as a team. The team should consider seating, lighting, materials, social and emotional growth, the impact of visual impairment on development as well as the use of appropriate technology and optical aids.

The student, classroom teacher, and TVI should discuss classroom seating. Most students with a visual impairment will sit in the front row, but not all can see the blackboard even from there. Some students will not wish to sit up front and should not be forced to do so, but should be provided with the information in other ways. The seating position should avoid glare from the side windows and overhead lights, and should avoid shadow. In a classroom with fluorescent lights, a seat between banks of lights is better than one directly under a bank.

The student may need to move to a different seat to see movies or filmstrips. Many students with albinism will have trouble reading from overhead projector screens because of glare. The student may copy the acetate sheets from the overhead projector as the teacher finishes using them. Or the student may ask to copy another student's notes. Or another student may take notes on carbonized paper and give the original to the student with low vision.

Use of Large Type

Students with albinism may or may not need large print. The team should look at the distance and near vision acuities from the eye examination. The TVI should evaluate the student working with various print sizes. Each spring the TVI can gather all books the class will use during the following year and review the books with the student to ascertain which need to be enlarged. Contrast is probably more important than print size in making this determination. The student's judgment as to which books need to be enlarged is one important element in the decision process.



Standard classroom materials through the third grade use primary size type, which is often sufficiently large for those with low vision. By the third or fourth grade, it may be advisable to enlarge math books because some of the symbols are quite small (fractions etc.). Students may be willing to use large print in school in the fourth through sixth grades. But by junior high they may not want to use large print in the classroom because of peer pressure. They may be willing, however, to use the large print books at home. It is important for the team to think about how they might be able to assist the student in becoming more self-confident

about the tools that are required in the classroom. It is unwise to make the assumption that the student will be uncomfortable about using large print or other aids in the classroom.

Books for keyboarding class usually need to be enlarged and placed on a slanted reading stand because it is not possible to get close to the print while using the keyboard. Likewise, music scores for band and orchestra instruments usually need to be enlarged due to the distance from which they must be viewed.



For those students who require large print books and materials, the TVI usually can obtain large-type versions of the usual classroom textbooks from other sources that reproduce texts in large type. In some cases, the local education agency must photo-enlarge the textbook themselves. Some students may prefer tape recordings rather than large type.

Teacher-prepared hand-outs may be photo-enlarged or read to the student. By photocopying, it is often possible to increase the contrast of low contrast text materials and drawings.

Before School Starts:

Standardized achievement tests may need to be photocopied and enlarged, since the test booklets usually are to be reused and cannot be marked in, and the print is small. The machine scored answer sheets which accompany the booklets are in very small print. The task of looking from test booklet to answer sheet and back, over and over, is extremely difficult for visually impaired children. When the test is enlarged, the student can mark answers directly on the booklet. Later, the answers can be transferred to a machine scored answer sheet.

Non-optical Aids to Vision

Computers can be of great use to students with low vision. Students with albinism should begin to learn keyboarding skills with typing readiness computer games as early as kindergarten; they should begin direct instruction in typing or keyboarding as early as the third grade.

Computers with large screen monitors and software for large character display may help older students with writing projects.

A CCTV (closed circuit television) may help a student to read charts, graphs, pictures and text. When using a CCTV, try reverse polarity (white letters on black background) to reduce glare.

- Locate map of school on school website/Request school map Request to tour the school campus
- Connect with classroom teacher to meet and review classroom setup (Bring tools to class and locate an area to store them within the classroom)
- Plan a time with classroom teacher to set up student's desk prior to first day of school
- Confirm large print texts have been delivered
- Provide student information to classroom teacher

Optical Aids

For reading, the student with albinism may use stand magnifiers, hand-held magnifiers, or special reading glasses, such as bifocals with a strong reading lens or telescopic reading lenses clipped over glasses.

Contact lenses may help for distance vision. Some students use monocular telescopes (small hand-held telescopes). Older students may use a bioptic lens systems, which can improve reading and distance vision. Bioptics incorporate telescopic lenses into standard glasses, to allow the student to use either the standard correctional lens or a telescope for intermediate or distant vision. Some bioptics may include two different telescopes- one for distance and one for reading- mounted in the same carrier lens. Newer designs of bioptics use small lenses that are lightweight and cosmetically more acceptable, but may be more difficult to use because of a smaller field of vision.

In consultation with the TVI, an optometrist or ophthalmologist experienced in low vision should prescribe specific aids for the individual student. In the doctor's office the student should have the opportunity to try all types of aids and to select the most comfortable type of aid for a given visual task.

After an aid is prescribed, the TVI works with the student while he or she learns to use it properly. Low vision clinics should allow students to use aids on a trial basis, and to return them if the aids are not helpful. To review the usefulness of an aid, the student should return to the doctor about one month after an aid has been prescribed.

Students often are reluctant to use optical aids because the aids draw attention. To be like everyone else, students may avoid using the aids and pretend to be able to see when they cannot. Younger students may hide, lose, or break their glasses. It is always appropriate and

important to help the student appreciate the benefit of the aid and feel comfortable using it in a wide variety of situations.

After Start of School – 2 weeks:

- Meet with each service provider to review goals
- Confirm that staff is aware of student needs (ex: lunch supervisors know that student can wear sunglasses / hat in lunch room)
- Provide extra sunscreen, hat, sunglasses, cane... to school nurse or classroom teacher for emergency events
- After Start of School 1 month:
- Request observation of classroom set-up
- Request observation of PE, Music, other extracurricular class set-up

One Month Prior to State Testing:

- Learn about the state testing schedule at your child's school.
- Collaborate with all stakeholders to ensure that all testing materials have been received and online testing settings have been confirmed.



Things Parents Can Ask For

✓ The following is a list of accommodations and/or modifications that may be included for the student with albinism in the general education classroom. All children with albinism experience varying degrees of visual functioning, regardless of acuity.

- ✓ Some items on this list may not be applicable or may offer too much support for your child, hindering the development of independence across environments. Please view this as a list of suggestions, not requirements for attaining success in educational programming.
- ✓ Shades on windows / Classroom lighting adjustments
- ✓ Communication Journal for notations between parents/guardians and service providers/classroom teacher
- ✓ Parent/Guardian participation in field trips
- ✓ Training on technology and tools
- ✓ Technology Assessment from an outside organization such as a school for the blind
- ✓ Orientation and Mobility Assessment
- ✓ Extended time for tests
- ✓ Periodic observations of classes by yourself or service providers
- ✓ In-service with classmates
- ✓ Access to electronic books, electronic book services such as Bookshare and BARD;
 Large print books
- ✓ Slant board, dark pencils, dark lined paper
- ✓ Preferential assigned seating in class and during assemblies
- ✓ Breaks between assignments for eye fatigue
- ✓ Lighting adjustments
- ✓ Resource binder in class duplicates of information displayed in the classroom
- ✓ Testing accommodations
- ✓ Hard copy of classroom notes
- ✓ Request that concrete manipulatives be used when concepts might be difficult to see on paper even when enlarged, i.e. bills and coins, clock, measurements/rulers.

Physical Education-Faamalositino The property of the property

The school staff need to find ways to include students with low vision in all activities, and to avoid leaving them sitting on the sidelines. "Small ball" games (tennis, badminton, softball, baseball) are difficult for children with albinism, due to both the size and speed of the balls. Games involving large balls work much better (soccer, kickball, basketball). Yellow balls and colored bases make ball games more visible for the child with albinism. Swimming, aerobics, gymnastics, track, wrestling, horsemanship and skiing are sports which can be enjoyed with minimal adaptations required. It is important for the Physical Education program to keep in mind that fact that learning about the sports and activities (Playing field, rules, roles of team members etc.) is as important, and sometimes more important, than being able to play the game with increasing success.



Teachers must avoid drawing attention to the student with albinism for reasons directly related to the Albinism. Students with oculocutaneous (skin as well as ocular) albinism stand out in any case, and may require emotional support for responding to their classmates. Parents can help their children deal with teasing or other forms of discrimination by encouraging them to share their experiences and their feelings about them. Conferences including the student, teacher, vision teacher, and parent may help to support a student.

Some families in NOAH have found it helpful to give a presentation to the class about albinism, along with a general discussion about respect for differences.



Though most children with albinism will be able to succeed in a typical education setting, sometimes the least restrictive environment for a child may be a half-day resource room with other visually impaired students, or a special class, or even a special school for students with visually impairments. The child may require education outside the mainstream classroom because the child's self-esteem is very low, or the child's skill levels are below those of his classmates, or the child emotionally cannot deal with the demands of the regular grade placement.

If such problems require removing a child from the classroom, it is important that the educational team develops a plan to address these problems, such as group or individual counselling as part of the school day, individually designed remedial instruction in weak areas, or individual instruction in study skills, organization skill and social skills. It is important to place a time limit on such placements, and review goals and progress closely.

In considering alternatives it is important to consider the fact that no single approach works for all students with albinism. However, with patience, understanding, and hard work, the team can find ways for a student to function successfully in the general education program.

For Parents: An IEP for Your Child

The Individual Education Plan or IEP is an important part of the education process for the visually impaired student. The IEP is the blueprint for the coming year. It describes adaptations and modifications required by students to compete with their sighted counterparts. For parents and students, the IEP meetings sometime prove intimidating and filled with uncertainty, but it helps for parents to understand the process and their rights.

Parents should prepare for the meeting by understanding its purpose. In addition to the federal law, many states have enacted state regulations and the local school district may have its own guidelines.

Parents might consider bringing a list of questions to the meeting or sending them to the special education lead person ahead of the meeting. They should remember that they have at their disposal the collective knowledge of the professionals who will be at the meeting.

It is important to have the most current report from the child's ophthalmologist or optometrist. This report is helpful, along with input from the TVI, in determining the best modifications to the classroom environment and print materials.

Parents should keep a file with past IEP reports and most recent reports by the school psychologist, social worker, and other educational evaluations necessary for meeting federal, state and local IEP regulations. Parents may request these reports from the appropriate school personnel.

The IEP team should include the parent(s), at least one regular education teacher and one special education teacher of the child, a local education agency representative who can authorize services, an individual who can interpret the instructional implications of evaluation results, and any others who have knowledge or special expertise regarding the child, including related services personnel as appropriate. It is important that both parents attend the IEP meeting-it does make a difference. The child may also attend the IEP meeting, and must attend if over the age of majority.

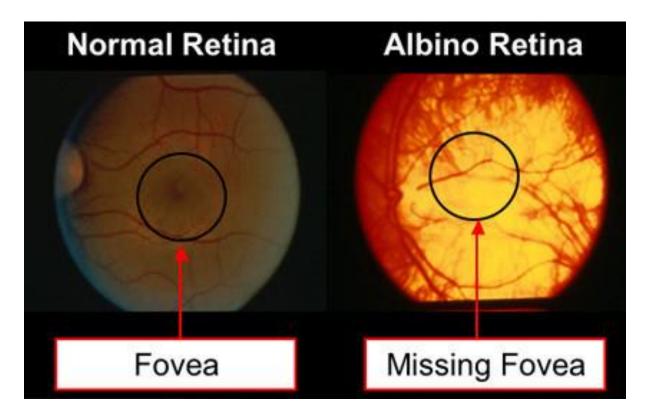
Common ideas about low vision may not apply to the child in question. In particular, large print or pre-recorded text materials are not always appropriate, and should not be accepted as substitutes for poor visual aids. The IEP allows parents of children with visual disabilities to advocate a program tailored for their child.

Parents should keep in mind that they know their child best. They should listen to their child, and advocate for him or her. It is helpful to take notes to remember the points that may need clarification, and ask questions after the report or at appropriate times throughout the meeting. Parents should not sign the IEP until they have read it and agree with its content. However, they may be asked to sign a form that states they were present at the meeting, though the IEP is not yet written. It is appropriate to sign that you attended the meeting.

Observation Guidelines

For use by the Teacher of Students with Visual Impairments

The following are guidelines for observing students with visual impairments in classroom situations. The purpose of this observation is to monitor the student's functioning in the classroom, and determine the focus for VI services, including instruction.



Evaluating Classroom Functions

- Organization:
- Materials
- Furniture
- > Extra work space
- Walkways
- Desk layouts
- Maps

Placement of educational prompts (e.g., alphabet, number line, colors, periodic chart of elements)

Class rules

- Placement of chalkboards / smartboards
- Overhead screen
- Discipline: Reference
- Are rules clearly posted?
- Does the teacher have a system of discipline?
- Does the teacher follow the system with all students, particularly the VI student?
- Are students respectful of the system?
- Classroom (group) behaviors:
- Are students' on-task?
- Can most keep up?
- Are more than just a few fooling around when they shouldn't be?
- Do students get up to turn in papers, get materials, and go to the bathroom?
- Do they wait for cues from the teacher to move from one activity to another or do they do so independently?
- Are most attentive during the teacher's presentations?
- Is the activity in the room constructive?

Evaluating an Activity

- ❖ Does the teacher present or introduce lessons or is there an established routine that is more auto-tutorial?
- ❖ Are tangible objects used to demonstrate concepts where applicable?
- Does everyone need to follow along in a book?
- Do students have to read aloud?
- ❖ Does the activity involve a concept, which is very visual in nature (e.g., adding with carrying)?
- ❖ Are visual materials used (e.g., maps, charts, diagrams)?
- ❖ Is the chalkboard or overhead screen used frequently?
- Do students use a dictionary?
- Is the pace fast, slow, or medium?
- What do students do when the activity is completed?
- ❖ How many handouts are used and what is their quality?

- ❖ Are materials enlarged or brailled for an activity if needed?
- Observing Student Functioning
- Is the student on task?
- Does student look in teacher's general direction?
- ❖ Is student able to get out materials on time?
- Is student using low vision devices, or other necessary devices?
- ❖ Is student attending?
- In what condition is the student's desk?
- ❖ Does the student know how to access the educational prompts posted around the room?
- ❖ Is the student organized?
- Can the student maintain the pace of the lesson presented?
- Does the student get up to get his own materials?
- Do other students help the student in any way?
- Could the student be acting more independently?
- Does the student raise a hand to participate and ask questions?
- Does the student interrupt appropriately?
- Does the student have any distracting mannerisms?
- Does the student use time wisely?
- ❖ What does the student do when work is finished?
- ❖ Does the student interact appropriately with peers in the room, on the playground, in the cafeteria?
- ❖ How does the student get around?
- ❖ How does the student go through the cafeteria line and to the table?
- ❖ What is the student's eating skills?
- Does the student's appearance blend with the group?
- Does the student have friends?
- ❖ What does the student do during free time and on the playground?
- Does the student speak before the class, such as in show and tell?
- ❖ If the student fails to complete his seatwork, is it due to lack of understanding, poor work habits, or inability to keep up with the pace?
- How does the general quality of the student's work compare to peers?

- Does the student talk too much to neighbors?
- Are the student's materials placed so as to be accessible to him?
- ❖ Are games, toys, and materials available for the student to use in interactive play during free time?
- Are lighting and desk location appropriate?
- Are any of the student's materials or equipment inconveniencing another student?
- Can the student fully operate any equipment given to him?
- Is a system in place for the student to correct malfunctioning equipment?
- Can the student manage equipment and materials through class changes?
- How does the student ask for and accept assistance from peers and others.
- ❖ How do peers relate to the student; how is he treated?
- Is the student displaying age-appropriate skills?

Tips FOR Parents FROM Parents

- ✓ Contact teachers before the first day of school and share the webinar link called "How We See". Don't forget to include not only the classroom teachers, but also the PE teacher, the music teacher and the media centre teacher.
- ✓ Reinforce with my student that they must be their own advocate.
- ✓ Meet with the group of teachers including the TVI and share the information on albinism, descriptions of visual

Observing Teacher Behaviors

- Does the teacher move about the room or remain fairly stationary?
- Does the teacher's voice carry well?
- Are chalkboards, overhead screen, and charts used frequently? Does the teacher read aloud what is written down?
- Will a student teacher be taking the class?
- How does the teacher handle misbehavior and off-task behavior?
- Does the teacher check for understanding and how is this done with the VI student?
- If brailled materials are to be handed out, is the teacher organized enough to have the materials ready?
- Can the teacher
 communicate her concerns
 and observations of the VI
 student during a
 conference (beware the
 teacher who always reports
 that "everything's just
 fine")?

- aids, stereotypes, how our student sees and signs of struggling or eye fatigue.
- ✓ Visit each classroom to discuss lighting and seating and where information will be presented so our student knows where to focus her attention.
- ✓ Establish routines for storing and retrieving school supplies, sunglasses, devices and sunscreen so my student will likely reach for them.
- ✓ Explain IEP jargon to the teachers and create an open line of positive communication for questions and concerns.
- ✓ Teach our student to be open about albinism. Teach our student definitions for nystagmus, photophobia, retina and pigment and their relation to albinism.
- ✓ Role-play to ensure our student can give a real answer, a "flip" answer, and a vague answer as needed. This is especially helpful in social situations and if the class has a substitute who may not know your student.
- ✓ Explore the room noting the location of things like Kleenex, the pencil sharpener, assignment trays, hall passes and cubbies.
- ✓ Especially in upper grades middle and high school walk to all of the rooms in order to familiarize and memorize the route for classes.
- ✓ In college, speak with each professor on the first day of class and request notes in advance.
- ✓ When I can I try to volunteer for school activities. It gives me the opportunity to build relationships with the teachers. During these times of an active classroom or assembly, the teacher may think of questions to ask you about how they can support your child during certain classroom/school activities.
- ✓ Work with your IEP team to include consultation time for your TVI to work with the classroom teachers, especially at the beginning of the year. This consultation time can be used to review classroom accommodations and support the classroom teachers with questions they may have about their student's needs.

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