



Information about Albinism

National Organization for Albinism and Hypopigmentation

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.

According to the federal Individuals with Disabilities Education Act (IDEA or PL 101-476), 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.

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 supports and services. Beginning at age three, as required by IDEA, public 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 either from the American Printing House for the Blind in Louisville, Kentucky, or 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 handouts 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.

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. ACT's, PSAT's and SAT's are available in large print and on cassette from the publisher through the school. These tests can also be taken under untimed conditions if that is the accommodation that the team has determined appropriate for educational testing situations.

Nonoptical 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.

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. (More information is available in NOAH's "Low Vision Aids" information bulletin).

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.

The American Foundation for the Blind maintains a directory of low vision clinics throughout the United States. (Address: AFB, 11 Penn Plaza, Suite 300, New York, NY 10011. Phone: 800-AFB-LINE. Website: www.afb.org.)

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.

Physical Education

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.

Social Support

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.

Alternatives to Mainstreaming

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 counseling 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, and their rights under the Individuals with Disabilities Education Act. In addition to the federal law, many states have enacted state regulations and the local school district may have its own guidelines. Parents can obtain copies of these laws and regulations from the school system. The School is required by law to provide parents with a copy of their rights under IDEA in a format that is accessible to them.

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 (18 in most states).

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.

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.

*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.*

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