

Blue Chair Time

Joyce Ford
Parent

In 1978 my husband and I purchased our first home along with a few new furnishings for it. Our living room would be graced with what I thought to be the two most beautiful and comfortable blue velvet swivel rockers I had ever laid eyes upon—a statement contrary to the rust, gold, and brown era of the 70s. They spoke a message of unpretentious elegance. It was my finest decorating moment.

Two years later, I rocked my newborn daughter in those chairs. We began to see their presence in the family photo albums as a backdrop to every major celebration we held as a young family. These were the chairs that held grandparents and close friends alike. They were special chairs. They were the kind of chairs you chase pets away from and forbid any kind of food near—the kind of chairs one naturally protects from anything that may jeopardize their preservation. They were the kind of chairs that drew people together.

Enter Riley, 1983. Here was my child who waited so long to come home from the NICU—an infant who fought a war to survive. Here was a child whose right to intimate bonding had been stolen by months of hospitalization. I was an invader to his world, just like all of the other humans who had touched him before. As his mother, my job was to try to erase all of the pain that he had known since birth.

Riley knew nothing about fine upholstery fabric. He knew nothing about unpretentious elegance. My blue chairs soon learned about projectile vomiting, inefficient diapers, and excess wear on the rocking mechanism. Preservation had become a low priority in our household. Survival had quickly taken the lead. I think we were destined to stage that physical and emotional survival in the comfort of the blue chairs. It was the only place that felt right. I called it Blue Chair Time.

Early intervention plans mentioned nothing about Blue Chair Time. They talked about “Quality Intervention Treatment” which I found difficult to put my best effort into. Neither Riley nor I were ready for that. We needed time for us. I needed time to grieve all that had been taken away. I didn’t want to answer any more questions. I just wanted some time to hold my baby and cry privately.

The blue chairs learned that men also cry. They held us in our sadness for several years as we heard the diagnoses—blind, cerebral palsy, deaf—and comforted us with their familiarity in our times of making difficult decisions. All the while we held our children close and, for brief moments, we were able to rock the pain away.

I’m not sure how or when it happened, but gradually the painful moments subsided and the painless ones became more frequent. It became pleasant to sit and hold my son—to dream of possibilities and a future. It was an important time we shared each day and a time we both looked forward to, though perhaps for different reasons. We could just be us in the warmth of the blue chairs. Our best times were often the quiet minutes before the school bus arrived and our paths parted for the day. It was my way of saying, “You are important to me.”

So many things have occurred here on the soft fabric of my chairs—heel cord stretches, oral stimulation, turn taking, and sign language. I’ve sung endless repetitions of “Row, Row, Row Your Boat” to Riley here. We’ve counted rings on fingers. We’ve been through struggles and successes here, from self-contained classrooms to inclusive ones. We’ve shared our tears and laughter in the chairs that now squeak when they rock and dip down in all the wrong places. The velvet is creased and marred from the business of living.

In This Issue

Blue Chair Time	1
Joyce Ford	
Funding Alert	2
Bud Federicks	
Can Inclusive Education Work for Students who are Deaf-Blind?	3
Lori Goetz	
Assessing the Instructional Environment to Meet the Needs of Learners With Multiple Disabilities Including Students who are Deaf-Blind	5
Bonnie L. Utley	
DB-LINK: Concept to Clearinghouse	8
Gail Leslie	
TRACES Regional Reports	9
Looking at Self-Stimulation in the Pursuit of Leisure	11
Kate Moss	

Deaf-Blind Perspectives

Volume 1, Issue 2
Winter 1993

**Executive Editor**

Bud Fredericks
Teaching Research

Managing Editor

Bruce Bull
Teaching Research

Consulting Editors

Janice Adams
Deaf-Blind Consultant

Bruce A. Dalke
Teaching Research

Joyce Ford
Parent

Jay Gense
Mid Oregon Regional Program

Marilyn Gense
Oregon School for the Blind

Karen Goehl
Indiana Deaf-Blind Project

Richelle Hammett
University of Maryland

Barbara A. B. McLetchie
Boston College

Kathy McNulty
Helen Keller National Center

John W. Reiman
Teaching Research

Marianne Riggio
Perkins School for the Blind

Art Roehrig
Gallaudet University

Production Editor

Randy Klumph
Teaching Research



Deaf-Blind Perspectives is pleased to consider unsolicited articles for publication. Manuscripts should adhere to *American Psychological Association* standards. *Deaf-Blind Perspectives* employs an anonymous review process for unsolicited articles. Send both a printed copy and a disk copy (preferably DOS format) to:

Deaf-Blind Perspectives
Teaching Research Division
345 N. Monmouth Ave.
Monmouth, OR 97361
(503) 838-8403
TTY (503) 838-8821
fax (503) 838-8150.

Riley and I are becoming awkward in the chairs now as we have both increased in size over the years. We don't quite fit the way we used to, yet both of us struggle to hold onto that special place and time, both of us knowing that very soon Blue Chair Time will only exist as a memory.

And when that times comes, I will remember it with all of the wisdom that Riley has brought to me in this past decade. For as much as I believed that he needed it, Riley I think, knew that I needed it as well. I will remember Blue Chair Time as Riley's way of saying, "You are important to me, too."

**Funding Alert**

Bud Federicks
Research Professor, Teaching Research

The reauthorization of funds for programs for those who are deaf-blind is being discussed as we go to press. Because of the restructuring of educational services, the reform of government planned by the Clinton Administration, and the perceptions of some in the Office of Special Education and Rehabilitation (OSERS) that programs for children who are deaf-blind need no longer be categorically funded, the future of such programs, as we know them, is in jeopardy. Specifically, federal funds may no longer be targeted for programs serving children who are deaf-blind. State-funding for coordinators of state and multi-state projects under Section 307.11 may become obsolete. Specific dollars for research with this population may be melded into the overall educational research budget.

Perhaps this paints a bleak picture and one that may not come to pass. But there are many in various parts of the government who believe that funding for these programs is no longer necessary or desirable. If categorical funding for children and youth who are deaf-blind is eliminated, anyone seeking federal funds for programs for these people will have to compete in programs for those who have other disabilities. When that occurs, programs for low-incidence populations such as people who are deaf-blind, severely disabled, and seriously emotionally disturbed will probably lose much of the funding that they currently have. That funding will move towards larger populations and perhaps into regular education, or it might be transferred to the states in block grants. Most states have very poor records of serving low-incidence populations.

If there is little outside support for children who are deaf-blind, we can imagine that the quality of their services will revert to that prior to the passage of Public Law 94-142. Certainly there will be some school districts who will provide educational programs that are suitable for some children. Certainly some parents will be able to obtain for their children the services they need. But certainly most children who are deaf-blind will not receive the education and support that they need without a 307.11 grantee in each state.

Those who advocate for children and youth who are deaf-blind should write to their senators and representatives to request that not only should allocations to those who are deaf-blind remain as a separate line item in the federal budget, but also that the budget needs to be increased since the number of children identified as deaf-blind has increased significantly over the past five years.

Copies of all letters should go to:

Tom Hehir
U.S. Dept. of Education
MES Building
330 C St. S.W. Room 3090
Washington, DC 20202

Judith Huemann
U.S. Dept. of Education
MES Building
330 C St. S.W. Room 3114
Washington, DC 20202

These letters should cite the need for additional funding. They also need to document the benefits that the current funding has achieved. Stories about specific families are especially poignant.

Can Inclusive Education Work for Students who are Deaf-Blind?

Lori Goetz
California Research Institute
San Francisco State University

Today's education of students who are deaf-blind faces a tremendous and exciting challenge: How to ensure that students who are deaf-blind, and their families, realize all the benefits of inclusive schooling and all the benefits inherent in specialized disability-specific educational practices.

Full inclusion continues to emerge as a promising educational practice. Indeed, in conjunction with widespread school restructuring efforts, inclusive schooling is a practice that may hold the potential for improved educational outcomes for all students (National Association of School Boards, 1993). Full inclusion occurs when students who are disabled are full-time members of age-appropriate, regular classrooms in their own schools, and receive any supports necessary to accomplish participation in both the learning and the social communities of their peers (Neary, Halvorsen, & Smithey, 1992; Sailor, Gee, & Karasoff, 1993). Special education is not a *placement*; it is a *service* that is provided to students in the context of regular classrooms, schools, and communities.

Students who are deaf-blind, however, present unique educational needs to any service delivery system in terms of communication, mobility, and sensory functioning. The heterogeneous nature of these students in terms of cognitive and functional capacities adds complexity to the design and delivery of effective educational programs (Riggio, 1992). While reports of successful participation of students who are deaf-blind in inclusive programs are beginning to emerge (Dennis, Edelman, & Cloninger, 1992), the potential for failure is great. The unique support requirements of these students suggest at least three major areas that fully inclusive programs must address in order to meet the specialized needs of students who are deaf-blind (Collins, 1992).

Curriculum Development

Communication and mobility goals for students who are deaf-blind are appropriate regardless of educational setting or context and must be infused into all educational and social environments. In fully inclusive programs, however, questions emerge concerning the comparative emphasis given to specialized content areas such as experiential learning, functional life skills curriculum, academic participation, and skill acquisition. Further curricular issues include concerns about successful adaptation of both content and teaching methodologies in regular education for learners who do not gather and access ongoing information in traditional ways. How, for example, does an eight-year-old boy who is deaf-blind, has limited mobility and voluntary movement, and uses idiosyncratic means of com-

munication participate meaningfully in a unit about medieval banquets (Gee, 1993)?

One solution to this problem already exists: the federal government has invested in six years of demonstration, research, and validation activities directed by Dr. Kathleen Gee at San Francisco State University¹ to develop specific curricular practices for students who are deaf-blind who are served in inclusive settings. Contextual curriculum development focuses upon identifying the information within ongoing regular classroom events that will assist a student who is deaf-blind to understand and discriminate the routine. Any needed adaptations are used to bring the routine to the student; these adapted cues signal steps in the routine to the student, and systematic instruction of individual performance objectives then occurs.

Contextual curriculum development, for example, was used in determining appropriate instructional objectives for Sally, a second grader who is deaf-blind and multiply disabled. In response to tactile and movement cues that occur during arrival at the Math Table for math enrichment activities, Sally receives systematic instruction in the activation of a loop tape which requests a peer to, "Come here, please." Peers learned to slow down their movements in order to give Sally an opportunity to physically participate with a partner in passing out work materials during the activities.

Contextual curriculum development is an experimentally validated process that enables students who are deaf-blind to continue to learn individualized objectives in inclusive settings. It provides one example, hopefully among many to be developed by the field (Gee & Goetz, 1993), of how to provide effective, individualized curriculum in inclusion programs.

Specialized Services

Students who are deaf-blind need to have available a variety of specialized services ranging from braille, to sign language, to interpreters trained to serve people who are deaf-blind (Curry, 1989; Petronio, 1988). Inclusive programs must also provide these services, rather than conceptualizing the issue as an either/or choice: either inclusion or appropriate specialized services.

A potential solution to this problem also already exists. Full inclusion requires that the teaming process be a *collaborative* one, in which team members—knowledgeable about students who are deaf-blind—share a common vision and goal of the services that are provided (Bruner, 1991; Rainforth, York, & McDonald, 1992). Transdisciplinary and coordinated service delivery models emphasize role release and joint activities, but differ from collaborative teaming models in terms of several essential elements. Collaborative teaming, for example, requires the creation of a common new vision, while coordinated teaming simply reviews the goals of each member for compatibility. Collaborative models utilize dispersed leadership and mutual control among members, whereas in coordinated team

¹ Now at the University of Kansas, Dept. of Special Education, Lawrence, KS.

models, authority rests with individual team members. Effective collaborative teams thus rely upon consensus building and problem-solving strategies that utilize the expertise of all team members. Shared commitment to multiple "experts" greatly increases the likelihood that specialized service needs will be effectively met.

Social Inclusion

One hallmark of inclusive schooling is the greatly expanded potential for increased social interactions. While opportunity is clearly necessary, it is not sufficient to achieve the outcome of being a valued member in the social context (Sacks & Wolffe, 1990). Successful supported schooling must also provide strategies for using increased social interaction opportunities to achieve meaningful social relationships, ranging from relationships between peers who are and are not disabled, to experiences in the context of disability-specific culture (Lipton, 1993).

Fully inclusive classrooms provide the potential to create a meaningful and responsive social community, in which friendship and interaction among peers are valued outcomes, equal to mastery of academic or functional life skill curricular content (Strully & Strully, 1989; Villa & Thousand, 1992). A potential problem is one of ensuring that a student who is deaf-blind is a valued and active member of the social community. A number of promising strategies are available to achieve this end. The role of all instructional staff in modeling and facilitating natural, normalized, and respectful interactions between the students who are disabled and all adults and peers is an essential first step in which all staff may receive training. Use of a Circle of Friends strategy (Forest & Lusthaus, 1989), in which a core group of students meets regularly with the focus student to share successes and challenges and to make new commitments to activities that will include and support the focus student, is a further strategy for achieving social inclusion. Establishing successful circles of support may initially require recruitment strategies and a formal meeting time, agenda, and roles for participation, but once established the positive social outcomes for all students have been well-documented.

Summary

Serving students who are deaf-blind in programs that protect their unique service needs, while supporting full membership in the life of the school, is critical. Full-inclusion programs have great potential for failure in the three areas just discussed. The widespread use of specific practices that address these problem areas, such as contextual curriculum development, collaborative teaming, and support circles depends, of course, upon resource allocation and personnel training at multiple levels: federal, state, and local. The database for how to achieve effective outcomes through inclusionary schooling for all students, including those who are deaf-blind, is still emerging. As the practice of inclusion continues to grow, we must be alert to the potential areas of failure. We must work to avert these fail-

ures before they become accepted inclusive education practices in our nations schools.

References

- Bruner, C. (1991). Thinking collaboratively: Ten questions and answers to help policy makers improve children's services. Washington, DC: Education and Human Services Consortium.
- Collins, M.T. (1992, March). Plenary Address: Reflections and Future Directions. Proceedings of the National Conference on Deaf-Blindness: Deaf-Blind Services in the 90s - Revitalization and Future Directions (pp. 46-58). Washington, DC: Hilton/Perkins National Program.
- Curry, S. (1989). Low Incidence Disability Program Quality Study. Sacramento: California State Department of Education.
- Dennis, R.E., Edelman, S., & Cloninger, C. (1992). I've Counted Jon: Transformational Experiences of General Education Teachers Educating Students With Dual Sensory Impairments. Presented at the National Conference on Deaf-Blindness: Deaf-Blind Services in the 90s - Revitalization and Future Directions. Washington, DC: Hilton/Perkins National Program.
- Forest, M., & Lusthaus, E. (1989). Promoting educational equity for all students: Circles and maps. In S. Stainback, W. Stainback, & M. Forest (Eds.), Educating All Students in the Mainstream of Regular Education (pp. 43-57). Baltimore: Paul H. Brookes.
- Gee, K. (1993, May). An Experimental and Qualitative Investigation Into the Motivation and Competence Of Peer Interactions Involving Students With Severe, Multiple Disabilities in Middle School Classrooms. Unpublished doctoral dissertation, San Francisco State University-University of California, Berkeley, Joint Doctoral Program.
- Gee, K., & Goetz, L. (Eds.). (1993). Active Interactions: Project Manual. San Francisco: San Francisco State University, California Research Institute, Dept. of Special Education.
- Lipton, D. (1993). Inclusion in the 90s: Advocacy, Family, and Curriculum Issues. Keynote address, presented at the Cal-TASH Conference, Burbank, CA.
- National Association of School Boards (NASBE) (1993). Winners All: A Call For Inclusive Schools (Monograph). Alexandria, VA: Author.
- Neary, T., Halvorsen, A., & Smithey, L. (1992). Inclusive Education Guidelines. Sacramento, CA: PEERS Project, CA State Dept. of Education.
- Petronio, K. (1988). Interpreting for Deaf-Blind Students: Factors to Consider. American Annals of the Deaf, 133(3), 226-229.
- Rainforth, B., York, J., & McDonald, C. (1992). Collaborative Teams For Students With Severe Disabilities. Baltimore: Paul H. Brookes.
- Riggio, M. (1992). A Changing Population of Children and Youth With Deaf-Blindness: A Changing Role of the Deaf-Blind Specialist/Teacher (Reaction Paper). Proceedings of the National Conference on Deaf-Blindness: Deaf-Blind Services in the 90s - Revitalization and Future Directions (pp. 20-27). Washington, DC: Hilton/Perkins National Program.
- Sacks, S., & Wolffe, K. (1990). The Importance of Social Skills in the Transition Process For Students Who Are Visually Impaired. Austin: National Institute on Disability & Rehabilitation Research, U.S. Dept. of Education; The American Foundation for the Blind and the University of Texas (Austin).
- Sailor, W., Gee, K., & Karasoff, P. (1993). Full Inclusion and School Restructuring. In M. Snell (Ed.), Instruction of Students With Severe Disabilities (4th ed.) (pp. 1-30). New York: Merrill/Macmillan.
- Strully, J., & Strully, C. (1989). Friendship As An Educational Goal. In W. Stainback, S. Stainback, & M. Forest (Eds.), Educating All Students in the Mainstream of Regular Education (pp. 59-68). Baltimore: Paul H. Brookes.
- Villa, R.A., & Thousand, J.S. (1992). Student Collaboration: An Essential For Curriculum Delivery in the 21st Century. In S. Stainback, & W. Stainback (Eds.), Curriculum Considerations in Inclusive Classrooms (pp. 117-142). Baltimore: Paul H. Brookes.
- Preparation of this manuscript was supported in part by a grant from the U.S. Department of Education, Office of Special Education & Rehabilitative Services/Special Education Programs (Grant #H08600003). No official endorsement should be inferred.



!

Assessing the Instructional Environment to Meet the Needs of Learners With Multiple Disabilities Including Students who are Deaf-Blind

Bonnie L. Utley
TRACES Regional Director, Northern Region¹

Many children and youth who are deaf-blind function in a range of settings where the factors related to lighting and visual contrast may be modified to maximize their use of residual vision. Team decisions regarding such modifications, however, must also include information on needs that may arise from the presence of physical disabilities as well as factors related to audition. For this reason, a check list designed to be completed by two or more team members in collaboration is described, and provides a preliminary framework for decisions regarding environmental adaptations.

Team members who complete this check list should strive to achieve an individualized set of environmental adaptations for each student since no two students are alike in their degree and combination of disabilities. Additionally, team members should recognize that the final outcome of this process is to achieve a *balance* between the adaptations made for a particular student.

Multiple aspects of therapeutic positioning, lighting and contrast, as well as considerations regarding audition, must be coordinated to achieve the best overall environment for instruction.

The appropriate application of information obtained through use of this check list requires thoughtful classroom scheduling to balance the multiple instructional, as well as therapeutic, needs of individual students. For example, it may be recommended that a particular student spend short periods of time in a left sidelying position for good body alignment and relief of discomfort caused by asymmetrical distribution of tone. However, that same student may have only one functional eye which may also be on the left lateral side of the body. Team members who serve this student should design a schedule so that minimal visual demands are put on this student when he or she is positioned in this way.

Finally, please note that the items listed on the check list are to be viewed as *preliminary only*. A more thorough assessment of a particular student's ability to benefit from low vision aids (e.g., magnification), amplification, and adapted positioning equipment should be made by team members according to the knowledge base of their respective disciplines.

¹ The author recognizes the need to consider residual hearing in individuals who are deaf-blind and the need to assess how hearing can be affected by positioning. This paper, however, does not address those assessment considerations. It specifically focuses on visual assessment.

Organization of the Check List

Team members who complete this check list should do so from the perspective of the student (i.e., the orientation in space occupied by the student should be assumed by the team members as well). This practice will increase the accuracy of the decisions to be made with regard to the two sections of the check list: (a) therapeutic positioning and (b) lighting and contrast. Each section of the check list is described in more detail below.

Section I The items contained in this section of the check list are designed to assist team members to determine whether key aspects of therapeutic positioning may be used to enhance sensory functioning as well as physical ability and normalization of muscle tone. The first items address overall body positioning in sitting, sidelying, and supported supine. The items as written reflect general, desirable attributes of these positions. Team members should collaborate to determine whether or not all the features of a particular position are appropriate for an individual student.

An additional item in this section relates to the position of peers and adults during interaction. Please note that team members and peers should assume a position for interaction that is on the same plane as the student's face if possible (i.e., all parties should be seated or standing in a way that promotes face-to-face regard). This position facilitates communication between all parties, whether speech or nonspeech modes are used. This position may also reduce the likelihood that a student will adopt a head position that may result in abnormal posture or tone throughout the rest of the body (e.g., a hyperextended head and neck).

The final item in this section is the most difficult to complete as it relates to the plane (i.e., horizontal, vertical, or an angle in between these points) used for presentation of instructional materials. Selection of the most appropriate plane for presentation of instructional materials is particularly difficult for students without good head control. A neutral head position (i.e., neither turned, nor flexed, nor hyperextended) is the ideal position for many students. For other students, a position in which the head is turned, flexed, or hyperextended may be more visually functional for the student. For those students for whom a neutral head position is desirable, it is recommended that external support be provided to enable this position to be assumed. This is true for the student who is not yet able to maintain his or her head in a neutral position independently for the length of time needed to complete a particular task. Support may be provided by a collar, straps, or through physical assistance provided by an adult, if necessary. For most students, a fully upright posture for at least some periods of the school day is important. Upright posture in either sitting or standing is the most normalized position for participation within more inclusive school or work settings, as well as community-based training. To prevent complete reliance on external support, however, specific intervention strategies to promote more independent head control should be conducted at times other than those that require optimal use of the student's vision. It is simply too difficult for some students

Environmental Check List

Name of Student _____

Date _____

SECTION I - THERAPEUTIC POSITIONING

1a. Overall Body Positioning (Sitting)

- ____ a. Student is upright, or reclined slightly, with hips, knees, and ankles at 90-degree angles, or other angle(s) recommended by a therapist.
- ____ b. Student's head is neutral and upright, with or without external support.
- ____ c. Student's arms are supported by the table top or wheelchair tray so the elbows are flexed between 90 and 120 degrees.

1b. Overall Body Positioning (Sidelying)

- ____ a. Student is supported correctly (i.e., lower shoulder is forward; head is in alignment with the spine; hips, knees and ankles are flexed; pillows are placed between and below bony prominences).
- ____ b. Student is lying on the side that results in the better eye (if known) being on the upper lateral half of the body. (**Note:** Consultation with the team is recommended to determine whether sidelying on a particular lateral half of the body may be contraindicated).

1c. Overall Body Positioning (Supported Supine)

- ____ a. Student is supported correctly (i.e., head in alignment; chin slightly flexed; shoulders rounded forward slightly; hips, knees, and ankles flexed).
- ____ b. Student's head is stable with or without external support.

2. Position of Peers, Adults, and Materials

- ____ a. Depending on the student's head control, materials are placed horizontally, vertically, or somewhere in between those points.
- ____ b. Peers or adults position themselves at or near the student's eye level during interaction.

SECTION II - LIGHTING

1. Amount and Type of Light (indoors)

- ____ a. A combination of light sources (i.e., natural light plus incandescent light, etc.) are available.
- ____ b. The entire work surface is illuminated evenly (dependent upon specific task requirements).
- ____ c. Supplemental lighting is available (if necessary).

2. Position of Light

- ____ a. Student is positioned so that all sources of natural light (e.g., windows) are behind him rather than behind the instructional/social/communicative partners.
- ____ b. Supplemental light source originates from over the student's head so the shade directs the light on only the task materials (if necessary).

OR

- ____ c. Supplemental light source originates from behind and over the shoulder of the student (e.g., over the left shoulder for those who use the right hand and vice versa).

OR

- ____ d. Supplemental light source originates from behind and over the shoulder of the student on the lateral half of the head where the most functional eye.

3. Glare

- ____ a. Work surface is made of (or covered with) nonreflective material.
- ____ b. Materials are made of nonreflective material (if possible).
- ____ c. The amount of light emitted in the direction of the eye is limited or eliminated.

4. Contrast

- ____ a. For tasks that rely on materials that are black or dark in color, the background surface is lighter to enhance contrast. Light colored materials use a dark background surface.
- ____ b. Select or purchase materials that contrast with the work surface (if possible).

Note: The items listed on the check list are to be viewed as *preliminary only*. A more thorough assessment should be made by team members according to the knowledge base of their respective disciplines.

to maintain head erect behavior *and* work on a visual task *and* communicate simultaneously.

Selection of the most therapeutic upright position should be followed by selection of the best plane of presentation for instructional materials and the student's communication materials (e.g., a communication board, the area for presentation of manual signs). The use of more atypical positions such as sidelying, supported supine, or prone should be reserved for instructional sessions that have a different, less structured, therapeutic or instructional function (e.g., a period of time spent prone over a wedge to promote postural drainage before lunch; "long" sitting during story time in the library).

Section II This part of the check list is designed to assist team members to evaluate four aspects of lighting.

- Amount and type of light
- Position of light
- Glare
- Contrast

Again, it is important to achieve a balance between these various aspects of lighting to achieve sufficient illumination without glare.

To enhance visual performance in a school, community, or work setting it is generally desirable to have a combination of light sources available including natural light from windows and doors in addition to fluorescent and incandescent sources. The surface of the table, wheelchair tray, desk or other surface should be illuminated evenly unless the student fails to respond visually to objects on that surface, even after enhancement of the contrast. In the latter situation, supplemental lighting on the task materials alone may be necessary to provide additional contrast between the materials and the background surface.

There are two factors to consider during selection of an incandescent light source such as a table lamp or "study" lamp. The lamp should have a weighted base, or be attached to the work surface with a "C" clamp to prevent tipping, and the shade should be double-layered. A double-layered shade permits the outer shade to stay cool, an important factor when the light source is positioned close to a student for prolonged periods of time. The lamp should be fitted with a standard indoor bulb (not a "soft-white" bulb) of 60-75 watts. Soft white bulbs diffuse the light too much and produce a substantially lower overall output of light than do standard bulbs. Sources for study lamps may be found in catalogs of equipment for students with visual disabilities, but many study lamps found in hardware stores may meet the needs of most students without incurring high cost.

A second aspect of lighting is the position or direction of the light source(s). Generally, a student should be positioned with his or her back to natural light sources. This recommendation is particularly important for students who rely on sign language input as their view of a signing partner may be limited to a silhouette under these conditions. The other primary light source for most set-

tings is found in the ceiling. The location of supplemental light sources should be from directly over the task (if necessary to promote higher contrast of the materials against the work surface), or from over the student's shoulder on the lateral side of the body opposite the dominant hand (i.e., from over the left shoulder for a student who is right-handed and vice versa). In the latter situation, the supplemental light source should originate from over the shoulder on the same lateral side as the more functional eye. The overall goal is to achieve a well-lit work surface without shadows.

Another aspect of lighting to be evaluated is glare. Glare can be reduced or eliminated through the use of nonreflective material for work surfaces and materials. The amount of light emitted in the direction of the eyes should also be reduced or eliminated.

The final aspect of the environmental check list consists of an evaluation of contrast factors in the selection and placement of instructional materials. Supplemental lighting may be needed when dark materials are being used. In general, dark materials should be positioned on light work surfaces and vice versa.

Contrast factors should be considered in the selection and purchase of instructional materials. For example, a red or dark blue toothbrush should be purchased for placement on a white sink for use during instruction on toothbrushing rather than a white toothbrush. For those situations when color of materials is not optional, the background color of the work surface may be modified instead.

Summary

The environmental check list described here should be used by two or more team members as a *preliminary* tool to guide them in meeting the therapeutic and sensory needs of students who are multiply disabled. Key features of this check list are twofold. First, team members need to recognize a balance between the relative priority of various environmental modifications. Second, team members should recognize that all learning relies on the reception of a sensory, but not necessarily visual, stimulus. Instructional planning made on an individual basis, with consideration of each student's particular combination of sensory and physical disabilities, constitutes the primary factors in this process.

Preparation of this manuscript was supported in part by a grant from the U.S. Department of Education, Office of Special Education & Rehabilitative Services/Special Education Programs (Cooperative Agreement No. HO25C30001). No official endorsement should be inferred.



DB-LINK: Concept to Clearinghouse

Gail Leslie
Information Specialist, DB-LINK

October 1993 marked the one-year anniversary of DB-LINK, The National Information Clearinghouse on Children Who are Deaf-Blind. In that year, DB-LINK moved from concept to clearinghouse, complete with an 800 number open to any individual needing information related to children who are deaf-blind.

Clearinghouse imparts the image of a busy hub, a sort of informational Grand Central Station. Phones ring. Papers, books, bits, and bytes arrive, are organized, warehoused, and readied for the next question. From the beginning DB-LINK has had to negotiate new ways of executing the clearinghouse model, because, as a consortium project, DB-LINK is a cooperative effort between five different agencies and organizations:

- American Association of the Deaf-Blind
- American Association for the Blind
- Helen Keller National Center
- Perkins School for the Blind
- Teaching Research

This gives DB-LINK five working addresses instead of one. The challenge has been how to centralize resources and create a viable network that will do the things that clearinghouses do.

To some extent, a network is already in place. Each consortium partner provides a range of services for different segments of the population that is composed of those who are deaf-blind. Each has an extensive network of contacts and resources used in the provision of these services. Each also comes with a particular approach to information. In this field, where the content area is well defined and the service population small, a dispersed and informal approach to information has been the norm. Practitioners and providers have relied on their network of contacts and professional exchange to provide them with information related to current practices, new materials or news of workshops. While this informal network meets the particular needs of those who are in it, it is less than adequate and often inaccessible for those outside of it (i.e., the general public, a parent, a teacher). DB-LINK, which has as its task the coordination and centralization of information, creates a complimentary "formal" network. With the creation of a consolidated repository of resources and materials, DB-LINK ensures a collaborative effort that broadens access, reduces parallel efforts, focuses on needs, and promotes and communicates new developments.

Our first step was to harness the resources of this network. This required building the DB-LINK databases. Using INMAGIC+, a full-text database software program, we designed the Catalog and Resource Databases. Each consortium partner is responsible for the data entry of materials and information at its site.

The Catalog Database is the pathfinder to articles, books, curricula, proceedings, and any other materials related to children who are deaf-blind. Perkins School for the Blind has provided more than 2500 entries from the Samuel P. Hayes Library. American Foundation for the Blind has contributed more than 150 entries from the AFB Deaf-Blind Project. Teaching Research has added more than 200 entries of recent acquisitions. Helen Keller National Center is entering a growing body of articles and books that relate to transition. This database has helped to answer questions such as:

- Is there anything written that outlines what elements should be included in an ITP?
- How do I find out how to fund the technology that the speech therapist says would help my child?
- Are there any new materials on communication that would be useful for parents in our state?
- Is there documentation on the effectiveness of this tactile communication device that would help me to negotiate with my insurance company?

The Resource Database contains names of consultants, programs, services, newsletters, research contacts, and so on. With more than 400 entries, it has provided us with the answers to many questions:

- Are there any conferences or workshops on early intervention coming up?
- Who would know if the state of Florida has a transition plan in place?
- How many persons who are deaf-blind receive service in the state of South Carolina?
- Which state projects produce a newsletter?
- Are there consultants in my state who would do an assessment of a new child in our program?

Technology has provided us with many of the tools crucial to creating one clearinghouse with five partners. Modern telecommunications programming allows us to be bi-coastal with our 800 number. The phone is answered for four hours at Perkins on the east coast and then rolls over to be answered for four hours at Teaching Research on the west coast. Database files and updates are transferred via modem. E-mail allows us to communicate about requests and new occurrences any time of the day.

Technology also allows us to become part of the larger network of information and resources available from both commercial vendors and other federal projects. For example, SPECIALNET has been useful both for promoting ideas and exchanging information via the Deaf-Blind Bulletin Board. The SPECIALNET database ONE SOURCE has been searched in response to some of our requests as well as to update information in our databases. COMPUSERVE allows us to monitor other

disability-related bulletin boards as well as access the full text of the National Organization for Rare Disorders (NORD) database. We also make use of the ABLEDATA database as well as many of the databases available on DIALOG.

The INTERNET is an exciting addition to our resources. DB-LINK makes use of the ERIC databases, the Library of Congress Catalog, and the holdings of the National Library of Medicine. "Gophers" available through university and college campuses give us access to MEDLINE and campus libraries across the world. Through E-Mail on the INTERNET, DB-LINK is an active participant in the DEAF-BLIND Forum, an international network of parents, educators, and service providers who communicate and exchange information and ideas related to all aspects of people who are deaf blind.

As DB-LINK moves into its second year, we continue to expand and refine our ideas for building an efficient and effective clearinghouse. Cooperation and exchange remain the important ingredients for creating the informational "links" that will allow us to take an in-depth approach to the questions we receive. We invite your communication and look forward to your contributions.

DB-LINK

345 N. Monmouth Ave
Monmouth, OR 97361
Phone: (800) 438-9376
TTY (800) 854-7013
dblink@tr.wou.edu

DB-LINK (The National Information Clearinghouse on Children Who Are Deaf-Blind) is funded through Cooperative Agreement No. HO25U20001 by the U.S. Department of Education, OSERS, Special Education Programs. The opinions and policies expressed by DB-LINK do not necessarily reflect those of the U.S. Department of Education.



1992 National Symposium on Children and Youth Who Are Deaf-Blind

The proceedings from the 1992 National Symposium on Children and Youth Who Are Deaf-Blind is now available from Teaching Research Publications.

This three day symposium, supported by the U.S. Department of Education, identified critical issues, effective practices, and future directions in the provision of educational and related services to children and youth (birth to 21 years) who are deaf-blind.

The 240 page book presents the full texts of 20 invited papers and lists recommendations proposed by symposium focus groups covering a wide range of contemporary issues.

The symposium's novel structure is discussed, along with planning, interpreting, and making the conference accessible.

To order your copy send a check or money order to:

1992 Symposium Proceedings
Teaching Research Publications
345 N. Monmouth Ave.
Monmouth, OR 97361

or call: (503) 838-8792
fax: (503) 838-8150
TTY: (503) 838-8821

Price: \$15.00 ea.
Available in Standard print or 3.5" disk
(Wordperfect 5.1 or ASCII - please specify).



For Your Library

Choosing Options and Accommodations for Children (COACH): A Guide to Planning Inclusive Education

by Michael Giangreco, J. Chigee, Virginia Iverson (1993)

COACH is an assessment and planning tool designed to identify the content of a student's educational program based on individually determined valued life outcomes.

189 pages, cost: \$29.00

To order, contact:

Paul H. Brooks Publishing Company
P.O. Box 10624
Baltimore, MD 21285-0624
(800) 638-3775

Continued on page 15

TRACES Regional Reports

DELAWARE

Effective training that is based on needs of students, families, and staff members who provide services to children who are deaf blind is a primary objective of the Delaware Deaf Blind Project.

Peggy Lashbrook, 307.11 Coordinator, and service providers identified technical assistance needs that focus on development and expansion of functional programs. Peggy Lashbrook, Joan Houghton, consultant, and Cheryl Kennedy, TRACES Project Northeast Regional Coordinator, conducted a series of teleconferences to develop strategies for meeting this need.

Two needs assessment surveys, (i.e., Early Childhood Intervention Survey and a School Age Intervention Survey) were developed by Joan Houghton. Participants were requested to complete the items listed on the survey form by reviewing each item, checking their priority need(s) and the method in which they would like technical assistance to be delivered (e.g., inservice training, on-site consultation, meeting with the consultant individually or in a group with all participants, or being provided with information such as where to obtain resource materials). The results from this survey will be used in combination with information gathered during initial on-site consultation visits to plan the format and content for further follow-up consultation visits. The three team members planned to conduct the consultation when they traveled throughout the state the last week of September. Over a one-week period they expected to visit two full inclusion sites, one special school site, and one nursing home.

This technical assistance activity is especially exciting. Not only will it assist the project coordinator in developing a long-range plan for delivery of technical assistance, but it will also afford the opportunity to meet individual needs of service providers.

For information, contact:

Cheryl Kennedy
Dept. of Instruction/Learning
5N01 Forbes Quadrangle
University of Pittsburgh
Pittsburgh, PA 15260
(412) 648-7176 Voice/TTD

or
Peggy Lashbrook
Delaware Program for the
Deaf/Blind
620 East Chestnut Hill
Rd.
Newark, Delaware 19713
(302) 454-2305

MINNESOTA and IOWA

Personnel from the Minnesota Deaf-Blind Project are in the process of developing a coordinated system to provide assessments of the functional sensory abilities of children and youth who are deaf-blind. As one step in this process, Minnesota project personnel have developed a collaborative relationship with the 307.11 project personnel from the State of Iowa. In September, Linda DeRosiers and Steve Maurer traveled to Minnesota to introduce and discuss components of the Iowa Team Assessment Model. The recipients of this information, who are now reviewing the content and process described by Ms. DeRosiers and Mr. Maurer, met in October to discuss replicating this assessment model in Minnesota. Ms. DeRosiers and Mr. Maurer revived the plan and gave recommended strategies for its implementation. They will also provide informal, ongoing

For information, contact:
Eric Kloos or Jo Hauskens
Minnesota Deaf-Blind Proj.
201 Capitol View Center
70 West County Rd. B2
Little Canada, MN 55117
(800) 848-4905

or
Steve Maurer
Iowa Dept. of Special Ed.
Grimes State Office Bldg.
Des Moines, IA 50319
(800) 281-3576

consultation as the team assessment model is developed and implemented.

GEORGIA

For the past three years, Richmond County, Georgia, has been the site of a model program for the education of children with who are deaf-blind. Systematic instruction by consultants has been provided in different areas of the education of elementary aged children who are deaf-blind. Areas of instruction include communication, challenging behavior, functional activity-based curriculum, and community-based instruction. Teachers who have been involved in the program in previous years have found the instruction effective and have used these skills with the students in their classrooms.

As in many school systems around the country, elementary aged students in the Richmond County Schools who are disabled are now moving from one centralized school to schools within their home communities. In some instances, the teachers who now have children who are deaf-blind in their classrooms are not the teachers who participated in the previous model site program. However, to continue the effective educational practices and programming, a number of strategies have been used. A consultant has visited the new classes to review the use of curriculum and community instruction within the new environments. The students have moved to the new schools with detailed reports, not only their of educational program, but also of communication and behavioral systems. Direct contact between new and previous teachers has also been made in a systematic manner to answer any additional questions. These strategies have made the transition to new school settings more effective for both the students and teachers.

For information, contact:

Toni Waylor Bowan
Dept. of Special Education
Georgia State University
Atlanta, GA 30303
(404) 651-4089

PUERTO RICO

Providing effective services to preschool aged children who are deaf-blind is one of the primary goals of the Deaf-Blind Project in Puerto Rico. To reach this goal, the Project has employed the assistance of a local Head Start program. This Head Start program, with space provided in the school where the Deaf-Blind Project is housed, is an inclusive environment where children are and are not disabled learn, play and work together.

Enrolled in the Head Start program are children who are hearing impaired, children of the school staff, children from the local community, and children who are deaf-blind. Bringing these 15 children together in a main classroom has been accomplished with few changes in the usual operating procedures of the Head Start program. Through teaming of the teachers and paraprofessionals originally employed by each pro-

gram, modifications and adaptations for children within the Head Start curriculum are made as needed; new activities incorporating all students are developed; and challenging situations that may arise in the classroom are discussed and proposed solutions are implemented. Through this collaborative effort, the preschool children in this Head Start program are successfully meeting the fascinating challenges that face them.

For information, contact:

Thomas Santana
Antiquo Hospital Ruiz Soler
Edificio B
Bayamon, PR 00923
(809) 782-8994.

WESTERN REGION BROCHURES

Providing awareness level information regarding children who are deaf-blind should be inherent to all 307.11 deaf-blind projects. One method widely used is dissemination of literature describing the project and common behaviors of children who are deaf-blind. For many states, the cost of producing such literature is prohibitive. Through collaboration, the fourteen states in the western region of the TRACES Project have developed an awareness level brochure for use by all states in the region.

The collaborative process was three-fold. First, a resource comprised of generic information that defines deaf-blindness and highlights common behaviors and available services was developed by a small working group. Next, the document was reviewed by an outside expert and the 307.11 coordinators within the western region. Finally, the document was individualized for each state by including the project title, contact person, address and phone number on the back panel of the brochure.

Each state in the western region has shared in the planning, development, and cost of the brochure; however, the singularity of each state's deaf-blind project is retained through dissemination of an individualized product.

Future plans for the brochure include a Spanish translation for the large Spanish speaking populations in the western region.

For information, contact:

Paddi Henderson
Teaching Research
345 N. Monmouth Ave.
Monmouth, OR 97361
(503) 838-8778

UTAH

Access to comprehensive and integrated services is critical to optimum educational opportunities for children who are deaf-blind. Often, families and educators become confused, frustrated, and feel abandoned as they try to access existing services, or create new services. The Utah State Office of Education and the Utah Project

for Children with Dual Sensory Impairments recognized this problem and have engaged in a strategic planning process to coordinate and integrate all services within the state educational system. These two agencies invited representatives from all agencies within the state that could serve children who are deaf-blind to participate in the development of a state-wide strategic plan. The most important outcome of this process, from the consumer's position, has been the establishment of a single point of contact for accessing all services.

By calling the single point of contact, technical assistance services and resources regarding families, schools, transition, supported employment, and state-wide networking may be accessed by families of children who are deaf-blind and educational programs serving these children.

For information, contact:

Blaine Seamons
Utah Project for Children with Dual Sensory Impairments
846 20th St.
Ogden, UT 84401
(801) 629-4896

TRACES (Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments) is funded through Cooperative Agreement No. HO25C30001 by the U.S. Department of Special Education, OSERS, Special Education Programs. The opinions and policies expressed by TRACES do not necessarily reflect those of the U.S. Department of Education.



Looking at Self-Stimulation in the Pursuit of Leisure

Or I'm Okay, You Have a Mannerism

Kate Moss, TSBVI Outreach Family Training Coordinator

Deaf-Blind Perspectives Editor's Note: The following is reprinted with permission from Vol. V, No. 3 of P.S. NEWS!!!

P.S. NEWS!!! Editor's Note: I would like to thank, Jim Durkel, Craig Axelrod, Gigi Brown, David Wiley and Stacy Shafer for taking their time to discuss the topics of leisure and self-stimulation with me. I would also like to thank Gretchen Stone, Ann Silverrain, Barbara Bellemo-Edusei, and Robbi Blaha for their help.

Leisure time, the time free from work or duties, is important to all human beings. It is the time for doing something that will relax us or energize us so that we can renew ourselves to face the demands of our lives. It is something we require as much as food or sleep to stay healthy and sane.

We all have different ways of spending our leisure time. What might be a leisure activity for me (reading a mystery) might not be leisure to you. We know and accept this about each other. When considering leisure skills for children who are deaf-blind, however, we often focus on activities that do not relax or positively energize them. We spend their time getting them to participate in "play work" as one young man who is

Sensory Channels	Miss Manners Guide to Appropriate Self-Stimulation	Creative Variation Which May Plug You Into a Written Behavior Plan
Tactile: Information received by touch (throughout body surface) includes sensitivity to light touch, pressure, pain, and temperature.	Twirling hair, drumming fingers, playing with condensation on a drinking glass, fingering fabrics, rubbing eyes, pulling on beard	Pulling hair, lying in front of the air vent, slapping face/ear, playing with spit, rubbing head
Proprioceptive: Information about the relative positions of parts of the body. This information comes through sensations arising in the muscles, joints, ligaments, and receptors associated with the bones.	Snuggling in quilts, cracking knuckles, jiggling/crossing legs, sitting on your leg	Burrowing into furniture, wrapping arms inside tee-shirts, wrist flapping
Visual: Information received through the eyes/seeing.	Gazing at your fingernails, hands and rings, watching television without the sound, window shopping, flipping through magazines, eye pressing	Flicking hand in front of eyes, flipping pages of books, light gazing, playing with transparent or shiny objects, eye poking
Auditory: Information received through the ear/hearing.	Humming/whistling, tapping a pencil on a surface, playing background music	Vocalizing or making sounds, banging on objects, tapping objects together next to ear
Olfactory: Information received through the nose/smelling.	Wearing perfume, sniffing magic markers, scratch and sniff stickers, burning incense	Rubbing feces on the body and smelling, smelling other peoples' hands or shoes
Gustatory: Information received through the tongue/lips, tasting. Closely tied to the sense of smell.	Chewing flavored toothpicks, sucking on mints/hard candy, smoking, sucking on pens/jewelry	Mouthing objects, chewing on hair, sucking on fingers, licking objects
Vestibular: Information received through receptors in the inner ear that enables us to detect motion, especially acceleration and deceleration. Closely tied to the visual system which provides information to the vestibule located in the inner ear.	Rocking in chairs or rocking body, amusement park rides, dancing, twisting on bar stools, skating, sliding	Rocking body, spinning, twirling in swings, head rocking
Our brain seeks out stimulation through the channels of our senses. Each of us seek out this stimulation in a variety of ways. Society accepts some of these behaviors without question, yet feels very differently about others. This acceptance seems to be arbitrary in some cases. This chart shows examples of how individuals typically fulfill this craving for stimulation and how some self-stimulation behaviors of children who are deaf-blind parallel these behaviors.		

deaf-blind terms it. Learning to play games, participate in arts and sports activities, or other pursuits as a part of their educational programming may be beneficial for children in many ways, but these activities don't necessarily meet their needs for leisure.

The type of activities that often do provide relaxation or amusement for these individuals includes behaviors that most of us find unacceptable: flicking your hand in front of your eyes, pulling threads out of your clothes, making repetitive sounds, and so on. These behaviors are considered self-stimulation. As such they are often perceived negatively because they do not look normal, may interfere with learning, and can often become self-injurious. Yet these behaviors serve a positive purpose for these individuals as well.

Changing our perception of these self-stimulation behaviors may be the most reasonable course to take in addressing this issue. Especially if this change of perception also helps us find ways to give more information to the child who is deaf-blind and consequently

reduce his need to find stimulation on his own. These behaviors may also hold the key to information about his or her personal preferences, which we may tap into to select more appropriate choices for typical leisure options.

Stimulating Experiences

Most of our leisure activities are nothing more than self-stimulation behaviors that have become highly ritualized over time and made socially acceptable. There is nothing intrinsically valuable or reasonable about leisure pursuits such as bungee jumping, playing cards, dancing, playing video games, listening to music, or smoking.

People participate in these different activities because they find them to be pleasurable and because they alter their physical state. Each of these activities provide us with a particular type of sensory input (see Table 1). There is not necessarily a great difference in so-called self-stimulation behaviors and some of these activities

beyond the fact that some are more socially acceptable and normal in appearance than others. For example, what is really so different about banging a table and banging a drum, rocking to silence and rocking to music, making repetitive sounds and imitating bird calls, spinning for no apparent reason and spinning in a ride at the amusement park?

Each day a good portion of our energies is spent in self-stimulation. Look at the people around you. You are in a room with your family watching television or at a meeting with a group of co-workers. Although you are seemingly engaged in the same activity, your daughter or colleague is playing with her hair. Your son or your office mate is shaking his leg and tapping out rhythms on the arm of the chair. Your husband is flipping channels with the remote or your boss is flipping papers. If you ask them what they were doing, they would reply that they are watching television or having an important meeting. They would be less likely to say they were channel surfing, twirling their hair, practicing the drum part for "Wipe Out," or fanning their papers.

Each of us, even those of us with more intact central nervous systems, also tolerate differing degrees of stimulation. Look at the difference in the preferred musical tastes (and intensity levels) between the teenager and the 40-year-old. Although most teenagers enjoy a megawatt rock concert with all the trimmings, most adults are more inclined to seek out softer music or silence in a dimly lit room. In the same way, children who are deaf-blind vary in the amount and intensity of stimulation they need.

If we come to accept that self-stimulation is an important and valid activity for individuals who are not disabled, then we must begin to revise our thinking about addressing self-stimulation behaviors in individuals who are deaf-blind.

Can this behavior be stopped?

In looking for the answer to this question, first take a look at yourself. Try this little exercise: Identify one of your own deeply cherished self-stimulation behaviors such as cracking your knuckles, humming, or sliding a charm on your necklace. Try to keep track of how many times during the course of a 24-hour period you engage in this behavior. Then spend the next 24 hours refraining from this behavior. If you succeed, then try to extinguish that particular behavior for a year. Stop this behavior under all kinds of circumstances such as times of stress or times of idleness. Can this behavior be stopped? Answer the question for yourself.

Children who are deaf-blind participate in self-stimulation behavior to calm, to energize, or to get feedback just as you or I do. Most of the time you can't completely extinguish the behavior, nor should you because it does serve a purpose.

Can this behavior be redirected?

Most parents find that their child is more likely to participate in self-stimulation behaviors when he or she is

idle or stressed. Interacting with your child in some way may break up the self-stimulation. If the behavior appears in response to stress, finding ways to help him relax (e.g., massage, being wrapped up in a quilt, etc.) may reduce the amount of time spent in this behavior that you find inappropriate or harmful. However, if your child is left alone, it is likely he or she will re-engage in this activity as soon as the opportunity presents itself.

Can this behavior be contained by allowing it in certain locations or at certain times?

Some behaviors may present problems because they are considered socially inappropriate. Those of us who are smokers have learned to refrain from our favorite self-stimulation behavior on airline flights, but we all know exactly where to go in the airport to have that last cigarette before the flight leaves.

With some effort many children can learn to remove themselves to their bedroom or a private place when engaging in self-stimulation that is considered socially unacceptable. Using calendar symbols to represent this favored activity and scheduling the activity as part of the child's day may help the child refrain from this particular self-stimulation behavior for increasingly longer periods of time. He or she may stay involved in other kinds of activities.

Can this behavior be modified or expanded into more socially acceptable self-stimulation behaviors?

The value of self-stimulation behaviors is what the behavior tells you about how your child takes in information. If your child likes to burrow down inside the cushions of the couch, be held or hugged a lot, enjoys massage, you can assume that he or she is stimulated by information received proprioceptively. If your child likes to vocalize, listen to music, or bang things together, you can assume he or she is stimulated by information received auditorially.

These behaviors can be used as a way to explore the individual's preferred sensory channels for receiving information from the world. With this information we may find preferred sensory experiences around which we can develop more mainstream leisure activities for children—activities that they will also come to view as leisure. For example, if a child enjoys the visual sensation of lights we can find age-appropriate toys that might be motivating to him. In addition to familiar toys such as Lite-Brite, consider lava lamps, continuous wave machines, lighted drafting tables for drawing, and even some Nintendo-type games. You might also consider extra curricular events such as visiting arcades, decorating with lights for appropriate holidays, or lying in a hammock under a tree watching the play of light through the leaves.

Take time to observe the types of self-stimulation that your child participates in and when this behavior occurs. Watch him or her and make notes about what you see and when you see it. Then try to see if there is any

pattern to these behaviors that would give you insight to the types of stimulation preferred and what purpose it serves. At the same time note what types of activities he or she finds aversive.

When you have a good understanding about preferences, brainstorm ways to offer other stimulation activities or perhaps modify or expand on the preferred self-stimulation. Ask for help from your child's teacher, physical therapist, occupational therapist, and others. Look at children of the same age and try to find toys or activities that may make the self-stimulation behavior appear more normal.

Sometimes your child's favorite self-stimulation activity can be modified or expanded in a way that will make it more socially acceptable. For example, everyone knows the nail-biter, but do you recognize them when they become the manicurist? Several of my friends substitute the more acceptable behavior of nail care for their favorite activity of nail biting. They carry a complete manicure set with them at all times and can often be seen in meetings quietly filing or clipping a nail. They buff, cream, and polish. They examine them for chipping, snags, splits. They are rewarded by others who admire their efforts instead of being held in low esteem as one of those nervous nail-biter types.

You should realize, however, that generally your child will need support from you to seek out these more acceptable behaviors. Their first preference will generally be for the behavior they have developed on their own.

Can the environment be engineered to make this behavior safer if the behavior is detrimental to the child or those nearby?

People who like to jump off things are great examples of engineering the environment to make a dangerous self-stimulation behavior safer. These folks (skate-boarders, skydivers, skiers, etc.) have developed elaborate ways of placing themselves in extremely dangerous activities and surviving. We have industries based on protective clothing and equipment that will allow them to hurl themselves through space and make a safe landing.

Frequently, with children who put themselves in danger of bodily harm by participating in self-stimulation activities that may create physical danger to themselves or others, the best you can do is to provide protection. Splints, helmets and other devices sometimes must be used *temporarily* to protect the child and others who are nearby.

In addition to providing protection from the effects of the behavior, it is important to look at the cause of the behavior. Often times these behaviors erupt in response to real physical problems that the child is not capable of communicating. Emergence of these behaviors or increase in these behaviors might indicate pain (e.g., ear infections) or decrease of sensation (e.g., retina detachment). Seeking out appropriate medical examinations when this type of behavior emerges or escalates is very important to the child's health and safety.

Emotional and environmental conditions may also provoke increases in these self-injurious behaviors. One young woman exhibited a dramatic increase in self-stimulation behavior after the death of her father. The amount and intensity of the behavior posed concerns for her safety and the safety of others. Since there was no physiological basis for her behavior, the family spent time with her looking at pictures of her dad, going to the cemetery with her, and trying to participate with her in activities that were associated with her father. After a period of time, the behaviors decreased to levels that were in line with the period before her father's death.

Changes in schedules or moves to new environments can also bring about increases in self-stimulation. Helping the child anticipate these changes and providing as much consistency as possible through routines during times of change are strategies that may prove helpful.

Conclusion

Like you and me, children who are deaf-blind have a need to participate in self-stimulation activities. Because their behaviors appear very different from our own and can interfere with learning, or even become dangerous, they are viewed negatively by many people. Changing our perception about these behaviors may help us to deal with them in a better way.

There are a number of ways to deal with self-stimulation behaviors. Plan ways to keep the child more involved with others during the course of the day. Work to help him or her contain the behavior or engineer the environment to make the behavior safer. Schedule time in the day to allow your child this preferred activity. Look at ways to adapt the behavior so that it will appear more normal. Learn to use the information these behaviors offer about your child's preferred channels of sensory input to develop recreational and social pursuits that may be enjoyable—even if these activities will not entirely meet his or her leisure needs. Finally, accept that you will probably never completely extinguish these behaviors without having them replaced by other self-stimulation behaviors. Self-stimulation is common to all humans and serves an important purpose.

Resources and Additional Reading:

Levack, N., Stone, G., & Bishop, B. (1991). *Low Vision: A Resource Guide with Adaptations for Students with Visual Impairments*. Texas School for the Blind and Visually Impaired.

Kotulak, R. (1993 June 6). Unlocking the Mysteries of the Brain. *Austin American Statesman*, pp. G1, G4-6.

Restak, R. (1984). *The Brain*. New York: Bantam Books.

Romanczyk, R. G., Kistner, J. A., & Plienis. (1982). A. Self-stimulatory and Self-injurious Behavior: Etiology and Treatment, pp. 189-254 in *Autism and Severe Psychopathology, Advances in Child Behavioral Analysis and Therapy*, Vol. 2. John Steffen & Paul Karoly (Eds.). Lexington: Lexington Books.

Rojahn, J. & Sisson, L. A. (1990). Stereotyped Behavior, pp. 181-223 in *Handbook of Behavior Modification with the Mentally Retarded*, 2nd Ed. Johnny Matson, (Ed.). New York: Plenum Press.

Stone, G. (1987). An informal paper: *Self-stimulation and Learning Behavior*.

Silverrain, A. (1991). An informal paper: Teaching The Profoundly Handicapped Child.

Van Dijk, J. (1968). Movement and communication with rubella children. Presentation: Annual General Meeting of the National Association for Deaf/Blind and Rubella Children.

Wiley, D. (1993 May). It's More Than a Game: Acquiring Skills for Leisure Time, VISIONS, Texas School for the Blind and Visually Impaired, Outreach Department.



For Your Library

continued from page 9

Innovations for Meeting Special Problems of Children with Deaf-Blindness in the Context of Regular Classroom

by Washington Research Organization (1992).

Ten documents presenting data that demonstrate the level that students were interacting with their peers in school and the effectiveness of collaborative teams.

Number of pages: (varying length), cost: varies from \$1.00 to 10.00 (\$19.00 for all 10).

To order, contact:

Washington Research Organization
103 Miller Hall DQ-05
College of Education
University of Washington
Seattle, WA 98195
(206) 543-8565

MAPS: A Plan for Including All Children in School

by Services for Children and Youth with Deaf-Blindness Project, Kansas State Board of Education (1991)

The McGill Action Planning System (MAPS) provides guidelines for bringing together family members, friends, educators, the student, and peers, for full inclusion planning of students who are disabled.

19 pages, cost: none

To order, contact:

Services for Children and Youth with Deaf-Blindness Project
Media Division
P.O. Box 189
Girard, KS 66743
(800) 531-3685

Collaborative Teaming for Inclusion-Oriented Schools: An Introduction and Video Guide

by In School and Community Settings Project, Kansas State Board of Education (1991)

A videotape and videoguide describing the concept, purpose and rationale of collaborative teams. The videotape and guide may be borrowed free of charge. The borrower pays for return postage.

To order, contact:

In School and Community Settings Project
Media Division
P.O. Box 189
Girard, KS 66743
(800) 531-3685

Collaborative Teaming for Inclusion-Oriented Schools: A Resource Manual

by In School and Community Settings Project, Kansas State Board of Education (1992)

This resource manual focuses on the development and enhancement of student program planning teams in inclusion-oriented schools.

39 pages, cost: none

To order, contact:

In School and Community Settings Project
Media Division
P.O. Box 189
Girard, KS 66743
(800) 531-3685

We encourage you to copy and share information from Deaf-Blind Perspectives, but please provide appropriate citations.

Deaf-Blind Perspectives

- I enjoyed this issue of *Deaf-Blind Perspectives* but I am not on your mailing list. Please send future issues to the address below.
- I've moved! Please send future issues of *Deaf-Blind Perspectives* to my current address.
- I'm buried in interesting publications! Please remove my name from your mailing list.

Name: _____ Agency: _____

Street: _____ City: _____ State: ____ Zip: _____

Comments _____

Mark appropriate categories (3 max.)

- | | |
|--|--|
| <input type="checkbox"/> Person or parent of person with disabilities | <input type="checkbox"/> Regular education (non Spec.-Ed.) |
| <input type="checkbox"/> Special education (e.g., teacher, aide) | <input type="checkbox"/> Therapist (e.g., OT/PT/speech) |
| <input type="checkbox"/> Administration (e.g., Dept. of Ed., project director) | <input type="checkbox"/> Teacher trainer |
| <input type="checkbox"/> Service provider (e.g., social worker, group home) | <input type="checkbox"/> Government personnel |
| <input type="checkbox"/> Technical assistance provider | <input type="checkbox"/> Medical professional |
| <input type="checkbox"/> Higher education teacher/researcher | <input type="checkbox"/> Other _____ |

Please send my copy in:

- Grade 2 braille Large print
- Standard print ASCII

Mail to: Deaf-Blind Perspectives • Teaching Research Division
• 345 N. Monmouth Ave. • Monmouth, OR 97361 • or call
Randy Klumph (503) 838-8885, TTY (503) 838-8821,
fax: (503) 838-8150.

1293

Deaf-Blind Perspectives is published quarterly by the Teaching Research Division of Western Oregon State College. Information contained within the newsletter does not necessarily reflect the position of the Teaching Research Division.

Deaf-Blind Perspectives
Teaching Research Division
Western Oregon State College
345 N. Monmouth Ave.
Monmouth, OR 97361

Non-Profit Organization
U.S. Postage
PAID
Permit No. 12

*Forwarding & Return Postage Guaranteed,
Address Correction Requested*