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ABSTRACT

This final report describes activities and accomplishments of a 3-year federally supported project in Arizona to identify all children with deaf-blindness, empower families to advocate for their children, and train service providers. Major accomplishments of the project included: a 21 percent increase in identified children; provision of early intervention services through the Parent Outreach Program; direct services to 27 students, ages 14-22, involved in transition planning; publication of five newsletters; development of a parent/professional lending library; planning and implementation of annual Family Learning Weekends which served 29 families; and development of a transdisciplinary assessment team and a training model. Individual sections of the report describe the project's purpose, goals and objectives, accomplishments, findings, problems solved, effects, recommendations, and products developed. Much of the report consists of attachments such as brochures, a training agenda, a list of the items in the lending library, newsletters, and a draft of a manual on program standards. (DB)

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**SERVICES FOR CHILDREN WITH DEAF-BLINDNESS  
CFDA-84.025A - STATE AND MULTISTATE PROJECTS**

**FINAL PERFORMANCE REPORT**

PROJECT NUMBER: H025A20036

PROJECT START DATE: 10/01/92  
PROJECT END DATE: 09/30/95

PROJECT TITLE: Arizona Deaf-Blind  
Project

GEOGRAPHIC AREA SERVED:  
Arizona

PROJECT DIRECTOR: Earlene Dykes  
MAILING ADDRESS:  
AZ STATE SCH FOR THE DEAF & BLIND  
P.O. BOX 85000  
TUCSON AZ 85754

DIRECT SERVICE OFFERED BY PROJECT:  
AGES OF CHILDREN: Birth - 2 yrs.  
NO. OF CHILDREN: 24

TECHNICAL ASSISTANCE:  
NO. OF PARENT CONTACTS: 521  
NO. OF TEACHER CONTACTS: 1,325  
NO. OF ADMINISTRATOR CONTACTS: 87

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**EXECUTIVE SUMMARY:** (Intent of Project: Who, what, how, where, when, why; Accomplishments)

**INTENT:**

The purpose underlying the Arizona Deaf-Blind Project service delivery plan is that all children with deaf-blindness be identified statewide, families be empowered to advocate for their children, and service providers be skilled in meeting the needs of these children in their homes and natural communities.

**WHOM:**

Services for children with deaf-blindness, their families, and service providers in Arizona were made available through the Arizona Deaf-Blind Project.

**HOW MANY:**

In the three years of this Project, the number of children identified with deaf-blindness, birth to 22 years of age, increased from 81 to 103.

**PURPOSE OF THE PROJECT:**

The Project addressed the purpose of the grant with the activities of the nine (9) operant objectives:

1. To identify children with deaf-blindness;
2. To provide early intervention services for children with deaf-blindness birth through two years of age;
3. To provide counseling and consultation services to families;
4. To provide consultation and technical assistance to service providers of school age children with deaf-blindness 3 through 21 years of age;
5. To arrange pre-service and in-service training to service providers of children with

- deaf-blindness;
6. To promote transition services for children with deaf-blindness between the ages of 14 to 22;
  7. To disseminate relevant information to service providers and families of children with deaf-blindness;
  8. To maintain and utilize input from the advisory committee in planning, development, and implementation of services;
  9. To identify and train team members in transdisciplinary assessments of individuals with dual sensory impairments.

In the time period of this Project there was a 21% increase in the child count for deaf-blindness, increasing the total to 103. Families of children between the ages of birth through five years of age received both early intervention services through the Parent Outreach Program, and assistance for transition into center based programs. The Project collaborated with the SEA and other agencies to provide many presentations at statewide and regional conferences. A Transition Specialist was hired on the Project. Direct contact was made with twenty-seven (27) students ages 14-22, and helped develop numerous transition plans. To disseminate relevant information, five (5) newsletters were distributed through the Project, and a parent/professional lending library was developed. Multiple contacts with agencies and LEAs were provided through direct consultation and technical assistance. The Arizona Advisory Committee on Deaf-Blindness met every other month throughout most of the three years of the Project, and completed activities in which technical assistance needs were identified. TRACES and HKNC-TAC were contacted for technical assistance when appropriate. Identification and provision of technical assistance was greatly improved due to increased collaborative activities with the SEA and the Regional Services Program. The Project planned and implemented annual Family Learning Weekends each summer. A total of twenty-nine (29) families participated in the Family Learning Weekends which offered opportunities for parents to meet other families, network, and obtain counseling and information. A transdisciplinary assessment training team was formed which developed a training model.

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## ACCOMPLISHMENTS OF THE PROJECT

### OBJECTIVE 1: IDENTIFICATION

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A cooperative effort with the SEA resulted in joint letters being sent on February 16, 1993 and January 6, 1994 to LEAs to gather student count information, increase agency awareness of deaf-blindness, and inform LEAs of available services. The SEA assisted in the development of a process to verify the Deaf-Blind Student Count with the statewide census. The SEA also devised a category so that children with deaf-blindness could be counted as deaf-blind on the statewide census. This new category of Multi-Disabled Severe Sensory Impaired (MDSSI) in which each of the multi-disabling conditions of the child could be reported, allowed a way to separately count the children receiving services because of deaf-blindness, from those children who were multi-disabled for other reasons.

Cooperative efforts with the Interagency Coordinating Councils (ICCs) resulted in informational exchange on infant and toddler programs, and in coordinated services being offered to families. The ICC Tracking System, which was designed to keep an accurate count of birth to three year old children who are receiving special services throughout Arizona, was implemented and there were some necessary adjustments (computer programming, development of forms, and a reporting process). ICCs continued to share information and referrals during regional meetings.

Advertisement of the Deaf-Blind Project occurred in a variety of ways including: personal contact with Special Education Directors and teachers; informational letters mailed jointly with the SEA; provision of media display tables or inclusion of information in conference packets at regional and statewide conferences/in-services/workshops; presentations at workshops and university classes; and in the five Project newsletters.

Informational brochures and newsletters generated through the Project and by TRACES, a Project newsletter mailing list sign up sheet, and Arizona student count information were made available at seven (7) statewide conferences and at numerous other workshops and in services (see objective 5).

Numerous presentations on identification of deaf-blindness and programming needs of children who are deaf-blind occurred.

There was a 21% increase of children identified with deaf-blindness; from eighty-one (81) individuals in October 1992 to one hundred and three (103) individuals at the end of the grant period. There were 60 new referrals made to the Project. The distribution of children and youth on the 1994 Student Count by age was as follows:

- eleven (11) birth to two year olds
- eleven (11) three to five year olds
- fifty (50) six to thirteen year olds
- forty-two (42) fourteen to twenty-two year olds

During the identification process, functional vision assessments and audiological evaluations were provided by the Project Manager and the Parent Outreach Program audiologists to children between the ages of birth and five years, at risk or suspected as having deaf-blindness.

### Accomplishments of the Project

Three ophthalmological evaluations were provided. In conjunction with most identification activities, Project staff provided technical assistance and training to Parent Advisors. Efforts to assist agencies and parents in obtaining appropriate assessments resulted in the development of a preliminary listing of experienced clinicians and teachers who were able to provide quality evaluations to children and youth with deaf-blindness. This list was distributed to parents and agencies upon request. The Project responded to requests from the Advisory Committee and educational professionals for information and statistics from the Child Count for Deaf-Blindness.

Another activity to insure that the Project was identifying all at risk students, was the development of an Usher Syndrome Screening and Tracking System. At the end of the Project period, the student count reflected only two (2) students with Usher syndrome. Since the projected rate of incidence of Usher is 3-6% of the deaf population, it is conceivable that the student count does not reflect an accurate rate of occurrence. On May 5-6, 1995 the Project Director attended a TRACES sponsored "Usher Syndrome Screening Workshop". Since there was a pool of hearing impaired and deaf students to draw upon at Arizona School for the Deaf, the supervisor of the ASDB Student Health Center was also invited to attend. As a result of the conference, a screening procedure was developed and piloted. It includes: identification of need for this effort; identification of the most appropriate persons to involve in this effort; screening formats and set-up which range from parent questionnaires as a primary screen, to reviewing school audiologicals, to actual testing; identification of children at risk; and determining the appropriate next steps in confirming the presence or absence of Usher's for each at risk child. The pilot effort was started in August of 1995, and the screening formats and actual screening has occurred.

Note: Presently, determination of the follow up steps are being developed.

### OBJECTIVE 2: EARLY INTERVENTION SERVICES

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Over the last three years, sixteen (16) experienced Parent Advisors (PAs) trained in deafness and blindness have received additional training in deaf-blindness. Parent Advisor training sessions in deaf-blindness were held on November 5-6, 1993, April 22-23, 1994, and September 8-9, 1995 (See Products Developed Section). The PA Training in Deaf-Blindness made available to the participants information on identification and education of the young child with deaf-blindness, current literature and video materials available to use with parents during home visits, and discussion sessions in which the experienced PAs shared successful strategies. An effort was made to answer questions the PAs may have had in serving their upcoming assigned families. Recommendations for delivering services to American Indian families (developed through the Arizona Hilton-Perkins Project entitled "Families Show the Way") were included in the training schedule. The satisfaction surveys returned at the end of each training recommend the following to improve the PA Training in Deaf-Blindness:

- more information on introducing braille
- a better understanding on borrowing the available materials
- use of more hands-on activities such as a simulated lesson
- demonstrations of augmentative systems
- lengthen time allotted for the trainings

During the three year funding period, forty-five (45) families with children between the ages of birth to 5 years were identified, twenty-seven (27) families requested and received PA services,

## Accomplishments of the Project

and eighteen (18) families were jointly served with other early intervention agencies or preschool programs. At the end of the three year period, twenty-two (22) families of children between the ages of birth to five years old were identified, and thirteen (13) were receiving PA services. In October 1992 satisfaction surveys were distributed to both parents receiving Parent Advisor Services and PAs providing the services. Parents of children having deaf-blindness returned their surveys and indicated:

- great satisfaction with the program
- a high level of caring in the service
- they and their children learned a great deal

Nine PAs returned their surveys and all indicated that they felt the strengths of the program were the early intervention model and the family focus. Suggestions to improve parent advisor services included a request for more opportunities for parent advisors to talk about strategies and techniques used by their peers with similar children, and more training sessions on topics such as: legal/advocacy issues, effects of vision loss on child development, strategies when a child hits a plateau, and viewing or touring resources and good model programs.

Through the Parent Outreach Program, thirty-two (32) families with children approaching their third birthday or who were three to five years of age, were provided assistance to facilitate transition into preschool programming. Parent Counseling and Transition services to 3-5 year olds included:

- sensory assessment
- case management
- specific teaching strategies
- program recommendations
- distribution of information

Nine (9) of these children were provided with in-depth sensory and educational assessment to assist LEAs in identifying the optimal educational program. Continued follow along consultation was (and will continue to be) provided by the Project as requested by the family and the educational program.

The Project, in cooperation with RSP, consistently attended the statewide Networking and Child Find conferences to continue to build information sharing, and to gain further insight on how both public and private agencies in the state work together.

In cooperation with RSP, the Project assisted in the preparations and planning for regionalized workshops on identifying children at risk for visual disabilities. These workshops were presented by Dr. Irene Topor from the University of Arizona's Teacher Preparation Program in the area of Visual Impairments, and were attended by early education service providers, including those working with AZEIP on the Child Find Screenings.

### OBJECTIVE 3: PARENT COUNSELING AND CONSULTATION

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As stated in Objective 2, during this period, thirty-two (32) children who were three to five years of age, and their families, received assistance during the transition process into center based or LEA programs. Nine (9) children and their families obtained comprehensive educational evaluations which were provided by the Arizona State School for the Deaf and the



## Accomplishments of the Project

Blind (ASDB) and were coordinated by the Parent Outreach Program, of which the Deaf-Blind Project is part. Information and technical assistance support was provided to the assessment teams and the RSP staff providing the assessments, to assist in their completion. Follow along services were provided by the Project as needed, to assist in implementation of the recommendations developed through the evaluations. Further consultation included specific teaching recommendations, case management, program recommendations, and identification of materials and resources. Parent education and counseling occurred through consultations provided by the coordinators and supervisors of the Parent Outreach Program, and through parent advisor services as needed by the family.

The following opportunities for families to attend in-service workshops and conferences occurred during this period:

- On July 30 through August 1, 1993 nine (9) families attended the Fourth Annual Family Learning Weekend in Heber, Arizona. Four (4) of these families had not attended the weekend in the past. In total there were 94 individuals in attendance including family members, staff, presenters, and volunteers (with their families). Bonnie Goldsmith, a counselor with Sonoran Human Development, led the parent discussion group, while certified teachers, para-professionals, and volunteers ran the children's groups. Satisfaction survey results indicated that the majority of the parents felt their needs were met in the areas of networking with other families, learning new information, and learning relaxation techniques. Recommendations for the next year included: more instruction in sign language, longer periods of time for discussion, and outdoor meetings. Surveys from the children indicated that all of them liked coming to camp and would like to return again the next year. Staff and volunteers were also surveyed, and indicated that they felt the weekend was well organized, that they were well supported in the planning and implementation of activities, and felt included and appreciated by other staff members.
- On July 29th through 31st, 1994, nine (9) families attended the Fifth Annual Family Learning Weekend. (Note: fifteen families responded that they planned to attend, however six canceled.) In total, there were 66 people present, including family members, staff, presenters, and volunteers (with their families). Kay Seward and Bonnie Goldsmith, of Sonoran Human Development facilitated the parents groups. Special sibling sessions had been planned for brothers and sisters, but were canceled due to the number of families that changed their plans and didn't attend. The weekend began Friday night with introductory activities, a communication experience (sign language & Spanish) and movies. It continued Saturday with parents and children breaking into their own groups for activities. Parents particularly enjoyed their Round Table sharing sessions and stress management activities. Formal presentations for parents included speakers from the SEA on Transition, from HKNC on Support Services and National Resources, and from the AZ Association for Parents of the Visually Impaired on Local Resources and Supports. While parents were in their groups, the children

## Accomplishments of the Project

participated in nature walks, sports activities, and arts and crafts. The day ended with a dance for everyone.

On Sunday, family games and awards ended the weekend. Parents, children, and staff all had a great time and felt the weekend met its objectives of networking, relaxing, learning, and fun for both parents and their children.

- On August 17, 1994 and September 7 and 8, 1994 the Project arranged with five families and four LEAs for Dr. June Downing to consult with the families and the classroom teachers on appropriate programming for each student. These contacts occurred in LEAs in the Yuma area. For one student, the family pursued further in-depth sensory and educational assessments for their child to aid in development of appropriate educational programming.
- On September 22-23, 1994, the Project, in cooperation with RSP staff, arranged for consultations by Marcia Dunn Klein, OTR/L. A feeding assessment was provided by Ms. Klein to the children of two families in Prescott, AZ. During and following the assessment, Ms. Klein provided information, answered questions, offered recommendations, and taught techniques to the parents (and to local service providers). Ms. Klein also followed up by making any medical contacts that were needed to ensure the family had support in following her recommendations. The families reported great satisfaction with this contact in that their direct questions were answered, and they saw progress in their children.
- On October 27-29, 1994, four (4) families attended an HKNC-TAC conference entitled "Best Practices and Real Life Issues" in St. Louis Missouri. In addition, a parent who was a representative of the Arizona Association of Parents of the Visually Impaired attended this conference. Two of the families wrote articles for the Winter/Spring 1995 Project Newsletter explaining the benefits they found from the conference. All of the parents that attended were very satisfied with the information they obtained.
- On June 16-18, 1995, eleven (11) families attended the Sixth Annual Family Learning Weekend. In total, there were 113 people present, including family members, presenters, and staff and volunteers (with their families). Kay Seward of Sonoran Human Development led the parent groups throughout the weekend, with help from James Schiller of Community Outreach Program for the Deaf. Friday night introductory activities included a "Getting to Know You" activity, communication experiences in Navajo/ Spanish/ and American Sign Language, and a camp-fire sing-a-long. In addition to the favorite Parent Round Table sharing session, separate mothers and fathers groups were held. This activity was very successful, as both the moms and dads shared information they indicated they were uncomfortable sharing while with their spouse. Parents received presentations on "Getting to Know Your Legislators", "Parent Resources", and "Stress Management" including information on a newly forming parent group. On Saturday while parents broke into their groups, children separated into three groups based on age. They played beep baseball and kick ball.

## Accomplishments of the Project

participated in arts, crafts, and theater activities, and went on nature walks. The Saturday night activity was a dance with a live disc jockey and Karaoke. The children all learned a camp song in sign and voice, and sang it to the parents at the closing awards ceremonies. Parents, children, and staff all rated the weekend as exceptional, and stated that it met all of their expectations (See Products Developed section).

- On September 29-October 1, 1995, two (2) families (one parent and two children for each family, for a total of six people) attended the Washington State Services for Children with Deaf-Blindness Usher Syndrome Retreat in Seattle, Washington. Both families expressed great satisfaction with the conference. One family however, also expressed some fear for the future, but were grateful to get the information. Both families reported that the children were very excited about meeting other kids that were effected by Usher Syndrome.
- On October 19-21, 1995, three (3) parents attended an HKNC-TAC workshop entitled, "Life Beyond the Classroom: Putting the Pieces Together" in Falls Church, Virginia. The parents reported a high degree of satisfaction with the information gained at this workshop, and at least one mother initiated a transition plan with her LEA upon returning.
- Since February 20, 1995 the Project worked cooperatively with a newly formed parent group supported by the Community Outreach Program for the Deaf and the Helen Keller National Center - TAC. The small core group met in Tucson and named their group "Arizona Statewide Parents Connection Advocating for People Who Are Multiply Disabled Sensory Impaired." Project staff attended almost every parent meeting and collaborated with the group to distribute a mailing to determine the interest of parents throughout the state. This parent group is planning to use a variety of options to make the following available to parents:
  - attendance at meetings
  - information
  - social activities
  - resources available to parents statewide.

A preliminary resource directory of services and educational materials was developed, and was distributed to parents at the Annual Family Learning Weekends. Suggestions for improvement were gathered, and a revised edition was distributed at statewide conferences.

#### OBJECTIVE 4: TECHNICAL ASSISTANCE

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The Project and the Parent Outreach Program staff provided transition and technical assistance in-services for children in preschool programs throughout the state. When needed, in-depth sensory and educational assessments were provided to the programs through written reports,

**Accomplishments of the Project**

video taped information, direct consultation with the assessment team, and at Multi Disciplinary Committee meetings. Continued follow along consultation was provided as requested by the family and the educational program.

For programs requesting assistance in serving school aged children, direct consultation with professionals recognized in the field of Deaf-Blindness and Multiple Disabilities was provided to ten (10) children, their families, and teaching staff.

A "Request for Technical Assistance" form was developed in April 1993 to help structure the request system and to expedite service delivery. Other types of technical assistance which were provided included:

A team of teachers and evaluators from ADTEC traveled to Tuba City Public Schools on 11/19-20/92, and 1/19-20/93 to consult on community based/functional skills programming. The staff from two classrooms received consultation which benefitted at least two children who are deaf-blind.

In March 1993, a variety of meetings were requested by the Casa Grande High School District to provide an appropriate sensory evaluation and development of a transition plan for an eighteen year old who had recently been identified as having deaf-blindness. Reports by the family indicated great satisfaction with the developed transition plan.

On May 26, 1993 a communication in-service was provided to seventeen (17) staff members of the Paradise Valley School District by Dr. Caroline Musselwhite. Emphasis was placed on engineering a classroom to meet the communication needs of a seven year old student with deaf-blindness. Initial evaluation of the workshop was favorable, with 83% finding the workshop well organized, and 75% felt the workshop was good to excellent. The frustrating aspect of the workshop was that the materials made during the workshop stayed with the child and the teacher. The participants wanted to bring samples back to their classrooms and students.

On August 2 - 6, 1993 an in-service was provided to the staff of the ASDB Northern Cooperative Program on functional sensory assessment and community based/functional skills programming. Kathee Keller was the main presenter, and participants included representatives from the SEA and teachers of the sensory impaired serving 31 school districts. The teachers used actual sensory information and IEPS of four students with deaf-blindness served by the Cooperative Program. Satisfaction survey results indicated that the information was useful and the teaching strategies could be implemented.

On December 2, 1993 a consultation on communication modes and functional skills programming was provided to the staff teaching a thirteen year old in the Phoenix Union High School District. Further consultation was provided on March 3, 1994 and on September 8, 1994. An in-service was also provided on September 7, 1994 on Functional Skills and a Future's Plan was developed.

On August 17, 1994 the Project arranged with Dr. June Downing to consult with classroom teachers on appropriate programming for two students in LEAs in the Yuma area. Following each consultation for the individual student, a general presentation was made on communication, functional programming, and community based instruction in which area LEAs and children's services personnel were invited to attend. In general the families and school staff felt the consultation were helpful and meaningful for the children. Opportunities for further consultation were available to each team.

#### Accomplishments of the Project

On September 22, 1994, the Project, in cooperation with ASDB/RSP staff, arranged a presentation by Marcia Dunn Klein, OTR/L on the "Effects of Vision Loss on Motor Development and Feeding in Infants and Young Children" in Prescott, Arizona. Twenty-one (21) people evaluated the workshop, and the majority responded that the presentation was excellent and the information would prove to be very beneficial.

On March 2, 1995, the family of a preschool aged child, and the school staff providing services to this child, attended the Twelfth Annual Conference on Individuals with Severe Disabilities "Building Bridges". At this conference, Fran Maiuri of Alaska's Project PALS presented on "Supporting Students with Intensive Needs in Regular Classes". On March 3, 1995, the Project arranged for a special in-service presented by Fran Maiuri of Alaska's Project PALS with the family and the LEA staff providing services to the child. All of the participants felt that the objectives for the TA were met and the outcomes were achieved. A follow up visit to the school with an in-service and classroom consultation were provided by Project staff in May, 1995.

On March 24, 1995 in Phoenix, Arizona, an in-service was provided to the Foundation for Blind Children infant and preschool program staff by the RSP and Deaf-Blind Project staff. The Project had received a request from the Coordinator of the preschool program for audiological information and practical suggestions in working with young blind and Visually Impaired children who had been identified as having multiple impairments, including deaf-blindness. Since this preschool and infant program served children who were identified as having, or at risk for vision loss throughout the Phoenix area, it was important to provide information on serving children with hearing loss and deaf-blindness. It was reported that the preschool staff were appreciative of the information provided.

The Project staff arranged for John Walters of the HKNC-National Training Team to meet with ASDB staff serving a young man who is deaf-blind. Social and human development issues for individuals who are deaf-blind were discussed with the classroom teacher, one of the school counselors, a teaching parent from the residential hall, and an adult services provider. The participants felt that the information shared was helpful.

Arrangements were made for future in services on October 20, 1995 and October 24 and 27, 1995 to be provided to teachers in three preschool programs that were serving two children who are deaf-blind. Stephanie MacFarland was contracted with by this Project to provide direct consultation with two preschool programs who were jointly serving a child who is deaf-blind in the Phoenix area, and a preschool program in Tucson which was serving a child who is deaf-blind. All three of the preschool programs had served other children who are deaf-blind, and were very likely to serve more children with deaf-blindness.

#### OBJECTIVE 5: PRE-SERVICE AND IN-SERVICE TRAINING

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During the 1992-95 grant cycle, the project provided resources for presentations at numerous statewide conferences through full or partial funding of speakers fees and travel costs. These conferences and sessions included:

## Accomplishments of the Project

- Noel Matkin, PH.D. and Irene Topor, Ph.D. jointly presented on "Dual Sensory Impairment: A Team Approach" at the SEA's Seventh Annual AZ Networking Conference entitled Gathering Momentum on November 5-6, 1992.
- The Project Manager presented information about "Incidence and Prevalence of Deaf-Blindness in Arizona" to rehabilitation counselors throughout Arizona at the Orientation To Deaf-Blindness and Case Discussion Seminar on October 21-22 1992.
- Dr. Caroline Musselwhite presented a session entitled "Assistive Technology for Individuals with Multiple Disabilities Including Deaf-Blindness" at the Tenth Annual AZ Integration Conference on Individuals with Severe Disabilities: Helping Everyone Belong on March 4-5, 1993.
- On June 8, 1993 the Project Manager presented on "Incidence and Prevalence of Deaf-Blindness in Arizona" to a Summer Institute class provided through an SEA/DOE teacher preparation grant awarded to June Downing, PH.D. at the University of Arizona.
- The Education-Transition Specialist presented a session entitled "Deaf-Blind Transition Team Initiative" at the Fall 1994 AZ Department of Education Transition Leadership Institute on September 19-20, 1994.
- Deaf-Blind Project staff hosted an information display table at the AZ Department of Education's annual Directors' Institute on October 11, 1994.
- Caroline Musselwhite presented a session entitled "Interactive Alternatives and Augmentative Communication: Just Do It, Make It, and Take It" at the Eleventh Annual AZ Integration Conference on Individuals with Severe Disabilities: Celebrating Abilities on March 3-4, 1994.
- The Transdisciplinary Team trained through the Deaf-Blind Project presented a session entitled "Contextual Assessment and Educational Programming" at the Eleventh Annual AZ Conference on Individuals with Severe Disabilities: Celebrating Abilities on March 3-4, 1994.
- The Transdisciplinary Team trained through the Deaf-Blind Project presented a session entitled "Transdisciplinary Assessment Model for Children With Deaf-Blindness" at the Arizona AER Conference in May of 1994.
- Fran Maiuri presented a session entitled "Supporting Students With Intensive Needs In Regular Environments" at the Twelfth Annual AZ Conference on Individuals with Severe Disabilities: Building Bridges on March 2, 1995.

## Accomplishments of the Project

During this Project period, in collaboration with the Community Outreach Program for the Deaf (the Arizona Helen Keller Affiliate Program) and the Rehabilitation Services Administration, Project staff planned and organized the first statewide conference on deaf-blindness titled Addressing the Needs of Individuals Who Are Deaf-Blind. The conference was planned during the 92-95 grant cycle, but was held on October 13-14, 1995 in the 95-99 grant cycle. Speakers included nationally known presenters from the Helen Keller National Center, as well as state and local presenters. The Deaf-Blind Project sent out over 1,000 conference announcements, and Rehabilitation Services Administration in conjunction with the Arizona Department of Education, sent out another 1,000.

In addition, throughout the three years of the Project, both Project staff made numerous presentations on deaf-blindness, functional programming, and project services at the University of Arizona, Family Learning Weekends, Parent Advisor Trainings, and other formal and informal settings.

A TRACES conference on grieving "From Grief to Growth" was held on April 27-28, 1995 for the 14 western states 307.11 staff. Assistance was provided by AZ Project staff to contact Gwen Whiting as the presenter; and arrange accommodations, materials, and demonstrations for this conference. A follow-up conference was provided to a select group of twenty-five (25) participants whose jobs required directly working with parents facing grief issues.

At almost all of the conferences listed above, Project staff provided a display table with pertinent resources, and Project information.

Project staff made every attempt to inform service providers, administrators, and parents of upcoming conferences, higher education course work at universities (both in-state and out of state), and SEA CSPD summer institutes and other workshops. This was done through dissemination of announcements, advertisements in the Project newsletter, advisory committee minutes, and word of mouth during phone or on-site contacts. There are Masters level teacher training programs at the University of Arizona in the areas of Severe Disabilities, Vision, and Hearing. During part of this Project period, the University also had a program in Deaf-Blindness. Project staff disseminated information on upcoming course work for these programs, including on-campus courses for summer school and school year, tele-conference classes/courses, and special outreach courses held around the state.

When Project staff facilitated parental attendance at conferences, LEAs serving the student were always notified. Examples of this were the funding of four parents to attend the Statewide Transition Conference in November 1993, funding six family members to attend an out of state conference on Usher Syndrome in September 1995, disseminating information and funding two of the eight Arizona parents to attend Helen Keller National Center workshops in the fall of 1994 and 1995, and funding a team of parents and professionals to attend the Integration Conference in March 1995 (see objective 2).

Additionally, the Project facilitated attendance of five staff from around the state of Arizona at the Perkins National Deaf-Blind Training Project's Summer Institute held in conjunction with San Diego State University from July 9-13, 1995. The topic was, "Communication with Learners Who Are Deaf-Blind." The Project funded two of the five participants to attend, one of whom was a Project staff member.

Project staff worked collaboratively with several key state agencies to ensure that training for deaf-blindness be incorporated into conferences and workshops. Conference planning

## Accomplishments of the Project

committees that Project staff were on included: Arizona TASH for the annual Integration Conferences, AZEIP's annual Networking Conferences and other AZEIP trainings, Arizona Child Find Conferences, and SEA annual Summer Institutes.

Project staff developed, disseminated, and collected a Needs Assessment Survey for AZ AER to identify training needs for upcoming state conferences.

When able, Project staff video taped appropriate tele-conferences to make them available for interested parties around the state. Conferences which were video taped include:

- Pennsylvania V. Oberti tele-conference on Inclusion
- "Transition In The IEP" sponsored by the SEA
- two Local Team Training workshops sponsored by the HKNC-TAC and the Arizona Transition Team on Deaf-Blindness

Project staff attempted to stay abreast of best practices in deaf-blind education. In order to do so, they tried to attend conferences and workshops which would enhance their skills. During the three years of the Project, trainings that Project staff attended included: AAER conferences, AZTASH conferences, AZ Networking and Child Find conferences (early childhood), AZ Statewide Transition conference (fall 1993), AZ Department of Education Director's Institute (fall 1994), regional Transition workshops, Helen Keller National Center Transition Workshop (summer 1993), Kephart Symposium (summer 1994), American Foundation for the Blind "Hand In Hand" Training (summer 1995), and Perkins Summer Institute (summer 1995).

#### OBJECTIVE 6: TRANSITION SERVICES

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Prior to the 1992-95 grant cycle, the Transition Specialist position was funded at a half time level. The Project was never able to fill the position at this level, therefore in the 92-95 cycle, it was expanded to full time. It took until August of 1993 (almost one full year into the grant) for a staff person to be interviewed, hired, and in place. Up until then, some basic level of activity was conducted in the transition area. It was not however a coordinated, long range effort, nor was it interagency in design. The activities which were conducted included:

- responding to individual requests for information from parents and teachers
- collaboration with, and referral to, the ASDB Vocational Department, the Community Outreach Program for the Deaf's Helen Keller Affiliate program (both located in Tucson), and statewide Vocational Rehabilitation
- publication and distribution of a single focus Project newsletter on transition
- attendance by Project Manager at a week long transition conference sponsored by the Helen Keller National Center
- incorporation of transition services into the Project brochure

During years two and three of the Project, there were many avenues through which Project staff both promoted and provided transition services. Upon hiring the full time Education-Transition Specialist, information was immediately disseminated to parents and service providers regarding new levels of services available to them. This was done through an



## Accomplishments of the Project

introductory article in the fall 1993 Project newsletter, and through a single page descriptor disseminated throughout the state. During her first month on the job, the new staff person:

- attended an SEA sponsored workshop on Federal Transition Regulations
- met with local Vocational Rehabilitation counselors
- met with the ASDB Transition Specialist
- assisted ASDB and other Project staff in revising the school IEP form to include transition components

The Advisory Committee then had a single focus meeting on transition, to which SEA transition staff were invited. At this meeting, information was shared on:

- SEA's statewide transition initiative: Project ACTT, and the locations of its local community teams
- past efforts of the Deaf-Blind Project to meet transition needs
- distribution of deaf-blind transition aged students in the state
- the annual Statewide Transition Conference

Ideas were discussed on ways to work together, although no firm plans were made.

That year, the SEA's State Transition Conference was held in November. Deaf-Blind Project staff sent out conference announcements to parents of the 38 transition aged students on the Deaf-Blind Count, with a letter briefly describing "transition" and an offer to fund parents to attend the conference. Staff received responses that eight parents wanted to attend, and arrangements were made with these parents. These contacts with parents began to generate requests for project staff to be involved with transition and futures planning for some students.

Additionally, due to contacts with parents at this conference, Dr. June Downing was hired as a consultant to provide in-service training on Person Centered Planning to staff and families at two programs. These culminated in futures planning sessions for both students involved.

In the remaining two years of the grant, the Education-Transition Specialist was involved in IEP/transition/futures planning meetings for 27 students. In most cases, 307.11 participation was initiated through parents or Project staff, rather than through school districts.

In the spring of 1995, the Deaf-Blind Project participated in Tucson's first Transition Fair. Information from over 60 agencies/services was available for consumers, families, and professionals.

In order to learn about local resources and state policies, the Education-Transition Specialist joined a Tucson based group, the COALITION, whose purpose was to promote transition services for individuals who have the most significant disabilities. This group hired a case manager to work directly with students chosen by the COALITION as most challenging to serve; while COALITION members served as active problem solvers who identified community resources and created options.

During the grant period, three agencies in Arizona (the University of Arizona, the SEA, and the COALITION) sponsored a number of workshops and tele-conferences on transition. At least two of the tele-conferences originated at Virginia Commonwealth University. Project staff not only attended many of these, but disseminated information on them to professional staff and parents throughout the state. Topics included:

- Creating Employment Options
- Transition in the IEP
- Person Centered Planning
- Values and Family Support
- Home Ownership
- SSI Funding for Work & Community Living

## Accomplishments of the Project

Project staff worked with the SEA to organize and publicize a Regional Transition Workshop. Additionally, Project staff arranged to have presentations and information on transition at each of the Family Learning Weekends. Presenters included Dr. June Downing from the University of Arizona, Laura Love from the SEA, and Matt Frantz from the AZ School for the Deaf and the Blind.

Project staff worked with their HKNC Regional Representative to arrange meetings with several students and their families. In response to concerns of adult service agencies that they weren't finding out about deaf-blind clients, Project staff distributed a letter to parents of all transition aged students, asking for their permission to share their child's name with Vocational Rehabilitation, Community Outreach Program for the Deaf, and the Helen Keller National Center. This resulted in favorable responses by several (but not all) families.

Also during the fall of 1993, the Project received an RFP from the HKNC-TAC concerning a State and Local Team Partnership Project with an interagency approach to transition. Staff took the information to the Advisory Committee, invited SEA transition staff and HKNC-TAC staff to the meeting, and ultimately formed a state team which applied for and was accepted to participate in the project (winter 1994).

In forming the State Team, Project staff were looking for representatives from key state agencies which would naturally be stakeholders in the transition process. Groups which joined together to form the State Team, called the "Arizona Transition Team on Deaf-Blindness" (ATTDB) included: RSA Vocational Rehabilitation, Community Outreach Program for the Deaf, Behavioral Health Services, the Division of Developmental Disabilities, Arizona Department of Education, University of Arizona, and AZ Parents of the Visually Impaired. Individual parents were also on the State Team, and HKNC-TAC staff provided technical support for the project.

The Arizona Deaf-Blind Project was an integral member in the formation and continuation of the ATTDB. This project was developed not only to address the needs of individuals who are deaf-blind, but also to create a statewide model for team collaboration for transition services. The model emphasized multi-level systems change, implementation of individual transition and futures plans, and active solicitation and participation of adult service agencies. Experience in Arizona has shown us that unless all of the key adult service agencies are invested in planning with the transitioning student, services may be spotty and the individual may fall through the cracks at a later date. For this reason, partnerships with key agencies are critical to ensuring smooth and effective transitions.

The ATTDB, following the HKNC requirements for the project, used a three tiered approach to develop transition services simultaneously from the state level down and the local, individual level up:

- Level 1 - State Team: Addressed statewide systems change through interagency planning, collaboration, and problem solving at the state level through the ATTDB.
- Level 2 - Local Community Team: Addressed local systems change, problem solving, and leadership through Local Transition Team interagency planning and collaboration.

## Accomplishments of the Project

- Level 3 - Direct Service Site Team: Addressed planning and problem solving at local sites with individuals who are deaf-blind, direct service providers, families, and future service providers.

The State and Local Team Partnership Project was a major component of the Education-Transition Specialist's efforts to develop transition services for deaf-blind individuals in Arizona (see Products Developed section). This interagency group has met almost monthly since its inception in the winter of 1994. Some accomplishments of the team included:

- development of an Interagency Agreement committing to the project, with signatures from administrators of all participating agencies (note: for the most part, Arizona does not have intergovernmental agreements)
- decision to piggyback with the SEA's Project ACTT and work with existing SEA local community transition teams
- presentations to SEA Project ACTT local teams
- hosted information booth at SEA's Directors' Institute
- developed criteria for selection of teams
- developed letter and application form for local teams soliciting applications to participate
- developed letter and application to Special Education directors soliciting new teams for joint Project ACTT and ATTDB participation
- reviewed applications and selected four local teams
- planned, hosted, and presented at two Local Team Training Workshops (February 1995 and September 1995) in conjunction with HKNC-TAC
- attended monthly local team meetings as State Team liaisons
- assisted local teams in targeting at least two focus case studies each
- facilitated personal futures planning meetings for focus persons
- planned and hosted half day training sessions for each local team
- conducted individual local team in-services as needed on topics such as "Team Collaboration" and "Personal Futures Planning"
- participated in local community teams' Transition Fairs
- attended and presented at SEA Transition Leadership Institutes

Note: As of this writing, a third Local Team Training is being planned. A major goal of the training will be to link ATTDB and Project ACTT teams with other existing community teams in order to encourage collaboration.

#### OBJECTIVE 7: DISSEMINATE RELEVANT INFORMATION

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The primary methods that Project staff used to disseminate information included newsletter publication, lending materials through the loan library, presentations (refer to goal #5), and hosting display tables at conferences and workshops.

- Five newsletters were published during the grant cycle. Three of them dealt with a single topic:
- Positive Behavior Support (Vol. 1, Number 3)
  - Transition (Vol. 1, Number 4)
  - Recreation and Leisure (Vol. 1, Number 5)

#### Accomplishments of the Project

The remaining two newsletters (Vol. 2, Number 6 & Vol. 3, Number 7) each covered a wide range of resources of interest to parents, administrators, teachers, and other staff dealing with students who are deaf-blind. These topics included: parent advocacy tips, new publications and resources, homemade materials, communication, Arizona Child Count summary information, employment options, legislation, Usher Syndrome, Anophthalmia, Retinitis Pigmentosa, assistive technology, upcoming conferences, and Project updates (see Products Developed section).

In order to disseminate information, staff must first be aware of it. One of the best methods of gaining this information is attendance at national conferences. Much information is gained informally through discussions, as well as in formally attending presentations and poster sessions. The Project Director attended all 307.11 Project Director meetings, as well as all planning meetings for the Western States Consortium of Deaf-Blind Projects. Other Project staff were able to participate in additional deaf-blind related trainings as follows:

- the Project Manager attended a week long workshop in July 1993 on transition, sponsored by the Helen Keller National Center
- the Education-Transition Specialist went to the Perkins Summer Institute on Communication in July 1995
- both the Project Manager and the Education-Transition Specialist attended a "Hand In Hand" trainers training in San Francisco in August 1995

Several books, pamphlets, and video tapes were added to the Project library during this funding cycle. Staff and parents of all deaf-blind students throughout the state of Arizona were made aware of new materials kept in the Project office library through newsletters, word of mouth, and a bibliography disseminated by Project staff. (See attached appendix for lending library bibliography.) If Project staff were unable to provide materials requested by an individual or agency, every effort was made to track down the resources and refer the requesting parties to the appropriate source.

At the outset of this grant period, the plan for the Loan Library was to:

- expand the number of new books, tapes, pamphlets, and articles in the library,
- purchase duplicate materials, and
- move the duplicates to the ASDB Parent/Professional Loan Library

By moving the Loan Library materials, it was thought that the number of people with access to them would be increased. What duplicate copies there were, were distributed to the ASDB Parent/ Professional Lending Library in September 1993.

A preliminary resource directory of services and educational materials was developed and distributed at the Annual Family Learning Weekends. Suggestions for improvement were gathered, and a revised edition was distributed at statewide conferences.

#### OBJECTIVE 8: ADVISORY COMMITTEE

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The Arizona Advisory Committee for Deaf-Blindness (AACDB) met almost every two months for the duration of the funding period. There was a core group of people that consistently attended, while others maintained contact through meeting minutes and phone conversations.

## Accomplishments of the Project

The active members represented a wide range of expertise, service provision, and interests. They included personnel from:

- University of Arizona personnel preparation programs
- Division of Developmental Disabilities
- Rehabilitation Services Administration, Vocational Rehabilitation
- Local Education Agencies
- Adult Service Providers
- Arizona Department of Education
- Behavioral Health Services

The active members of Advisory Committee are an extremely committed group of people. Most of them have been on the AACDB from its inception over eight years ago. They not only serve as the advisory committee for the 307.11 Deaf-Blind Project, but for all projects relating to deaf-blindness in Arizona, including the HKNC Affiliate Program and the (now defunct) Deaf-Blind Personnel Preparation Program at the University of Arizona.

The Advisory Committee was very helpful in providing input and guidance on a wide range of issues. These issues were guided not only by Project activities and relevant concerns at a given time, but also by surveying the AACDB members to determine what needs they wanted to address in the upcoming year.

The system used with the Advisory Committee was to present issues and pertinent information; discuss the issue and potential solutions/ approaches; solicit and research additional information if necessary or form a sub-committee to work on the area; and present recommendations. The Project staff utilized these recommendations in planning and implementing Project activities.

During this past Project period, input was provided on, and sub-committees were formed for:

- 1) annual Family Learning Weekends
- 2) Deaf-Blind Standards (see Products Developed section)
- 3) annual Summer Institutes (ended in 1994)
- 4) Transition (which evolved into the ATTDB State Team)

#### OBJECTIVE 9: TRANSDISCIPLINARY ASSESSMENT TRAINING

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This objective was accomplished in collaboration with the California Deaf-Blind Services Pilot Project, TRACES, and the Deaf-Blind Projects of Idaho and Nevada.

In the first year of the Pilot Project (1992-93) a training model was developed by California Deaf-Blind services with the input from the three states. Also, there was a need to develop a model to assess children statewide as they were referred to the Project. The model would have to provide technical assistance to teams receiving training while being careful to outline the limitations of the training. In that way the teams would be aware of the questions they had skills to address, and be able to refer to others who had greater expertise in deaf-blindness.

In May of 1993 five professionals with training in sensory impairments, and prior experiences in assessment were identified as the team of trainers for Arizona in this Pilot Project. These five professionals, a school psychologist, a communication specialist, a teacher (who was also a parent of a child who is hearing impaired), a teacher of the hearing impaired/low vision

## Accomplishments of the Project

specialist, and an occupational therapist are currently employed through ASDB Arizona Diagnostic and Educational Testing (ADTEC) program. The ADTEC program evaluates 35-40 children who are sensory impaired and multiply disabled each year. On May 19-22, 1993 and August 2-6, 1993, the TEAM, along with the Project Director traveled to California for trainings in the assessment model. These trainings were jointly sponsored by California Deaf-Blind Services and TRACES. The TEAM returned to Arizona after the first training and began to implement the assessment model with children with sensory impairments, including deaf-blindness as part of the ADTEC assessment. The focus of the second training session was to address issues which were raised as the TEAMS tried implementing the assessment model.

During the second year of the pilot project (1993-94), the TEAM advertised the availability of providing this technical assistance in training LEA assessment teams in transdisciplinary assessments, while being careful to explain that this training would not make the LEA assessment team experts in deaf-blindness, and that they might be called on to assess children outside of their school district but within their region of the state. On March 3, 1994, the TEAM presented at the Arizona TASH Eleventh Annual Conference on Severe Disabilities entitled "Celebrating Abilities". At that time the TEAM also prepared an informational flyer which was distributed at the conference and could be used as a referral form for any interested LEA assessment teams. On May 6, 1994 the TEAM presented at a regional conference of the Arizona Association for the Education and Rehabilitation of the Blind and the Visually Impaired. The informational flyers were also distributed at this conference.

The TEAM developed a training package to customize the assessment model so that the trainees could be made fully aware that they were not being trained as experts in deaf-blindness, but as a resource for transdisciplinary assessments so more appropriate educational programming could be started for any referred child.

The TEAM trainers provided consultation to the Washington Deaf-Blind Project for two children with deaf-blindness, using the transdisciplinary model. This was conducted by reviewing records and frequent conference calls with the Washington Deaf-Blind Project staff, LEA staff, and the parents of the two children.

The TEAM provided an assessment to a child who is deaf-blind on September 27 and 28, 1993 at a Phoenix area LEA which was requesting assistance in assessing and determining appropriate educational programming for this newly identified child. Following the TEAM assessment, the LEA was so satisfied with the technical assistance that they requested training in the assessment model. The LEA identified a school psychologist, a speech/language teacher, a teacher of the Hearing Impaired, a teacher of the Visually Impaired, and a Physical Therapist. The Special Education Director for the LEA agreed to the commitment to make the team available to assess children with deaf-blindness outside of the LEA's geographic area and to provide release time for the team while was being trained in the assessment model.

So that all members of the TEAM trainers could have in-depth information on deaf-blindness, the Project Director and the occupational therapist on the TEAM attended the Kephardt Symposium on Deaf-Blindness in Vail, Colorado on July 25-29, 1994.

During the third year of the pilot project (1994-95), a date for training the LEA assessment team in the assessment model was set for November 14-17, 1994. The training included information on: Transdisciplinary assessments, working jointly with each other's personalities, simulation of deaf-blindness, testing procedures with children who are sensory impaired

**Accomplishments of the Project**

including deaf-blindness, and the parent's role. Gail Harris, of the Arizona Parent Connection, discussed the encouragement parents need in interacting with the assessment team. The LEA team immediately received a chance to implement the gained information by jointly completing an assessment with the TEAM assessment members. The assessment of a preschool aged child included case review, review of a videotape of the child interacting in a variety of environments, parent interview, assessment in different school locations, report writing as a joint project, and sharing information with the parent and LEA at the Multi-Disciplinary Committee meeting. The LEA TEAM found this training to be very relevant and valuable. Following the training, they have been assessing district children, including those with hearing and visual impairments, using the Transdisciplinary model. Conference calls were used between the two teams to provide training and support. The LEA assessment team initiated some of these calls because they knew they were not experts in deaf-blindness. On March 24, 1995, the TEAM provided follow-up technical assistance to the program and teacher serving the preschool child that was jointly assessed.

Note: In the fourth year of the pilot project (1995-1996), the focus will be implementation of the Arizona Model. The process has begun in the identification of a child and family in the Phoenix area so that the LEA assessment team in that area can implement from start to finish the assessment model. The TEAM trainers will shadow the LEA team, and provide support with conference calls and site visits as needed. From this experience the LEA assessment team will identify any additional training needs to be included in the process.

Identification of a third team to train in the Northern region of the state is essential. The two trained teams will provide training to the new team.

## FINDINGS/PROBLEMS SOLVED/EFFECTS/RECOMMENDATIONS

### OBJECTIVE 1: IDENTIFICATION

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Presently, the system of identification of infant/toddler population at risk for deaf-blindness is very successful. This is due partly to the Project's interaction with the Regional Services Program (RSP) and partly due to the growth of the Arizona Early Intervention Program (AZEIP). In fact, while the RSP vision services staff were working on a vision screening format to use at the Arizona Early Intervention Program (AZEIP) Child Find activities, consultation with the Project staff, and awareness of this priority occurred. However, for older children (6-22 years) there is little to no assurance that the at risk population is being routinely referred to the Project. The Project relies on referrals from LEAs, medical practitioners, and children's and adult services. Factors that effect the referrals being made include:

- lack of knowledge on how to assess if dual sensory losses are present
- lack of knowledge in the educational community of the effects of deaf-blindness and effective teaching strategies
- lack of adequate medical services to provide and pay for evaluations/glasses/aides/supplies
- lack of case management to best use available educational, medical and children's and adult services
- time and resources required to make direct contact

Some strategies to address this situation are:

1. immediately send an introductory packet with information that is appropriate to each referral source
2. in collaboration with ASDB's RSP/ADTEC/LEA/COOP programs arrange for a school visit as soon as possible after the referral has been made
3. develop a process for referral, and evaluate and refine this process periodically

### OBJECTIVE 2: EARLY INTERVENTION SERVICES

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Continued Parent Advisor (PA) trainings are necessary due to:

- turn over
- the limit in the number of families which one PA (who is probably also working as a professional in an LEA) can serve
- specific training must be made available so the PA can meet the needs of the individual child and family

Service Delivery is effected by language/culture, traveling to the rural/remote areas of the state, and the availability and identification of professionals in the local communities. Continuous efforts are made to make adjustments in training, and implementation to insure families receive services.



#### OBJECTIVE 4: TECHNICAL ASSISTANCE

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Continued effort is needed to respond in a timely fashion and evaluate the effectiveness of responses to requests for in-services and technical assistance. Continued use of the Technical Assistance Request Form and the development of the request process will insure a collaborative approach to meeting the needs of the LEA/agency.

#### OBJECTIVE 5: PRE-SERVICE AND IN-SERVICE TRAINING

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Because Project staff had excellent working relationships with staff from other key state and local agencies, collaboration and training on deaf-blindness at conferences and workshops was increased. However, a major problem currently exists in Arizona at the level of higher education. For several years, the University of Arizona (Tucson) had a personnel preparation grant to train teachers at the Masters level in deaf-blindness. This grant was not refunded after September 30, 1993. University personnel were informed that refunding was denied due to the lack of teacher certification/accreditation in Deaf-Blindness from the AZ Department of Education. This created a void in personnel preparation that has, and will continue to impact, direct services to students with dual sensory impairments in Arizona. All training needs for teachers in this area cannot be adequately met solely through workshops, presentations at state conferences, or university course work in the area of severe disabilities.

#### OBJECTIVE 6: TRANSITION SERVICES

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Developing systematic transition services for students with dual sensory impairments had to begin from the ground floor up. Although much has been accomplished in the last two years of this funding cycle, there is a tremendous amount left to do. LEAs in Arizona were not used to specialized transition services for students with deaf-blindness, and to date, many have not taken advantage of the services. In most of the LEA transition meetings for individual students, either Project staff or parents initiated attendance by 307.11 staff. This could be due to any number of factors; regardless, a problem exists in enticing LEAs to utilize transition services available through the Project. This was brought up several times at Advisory Committee meetings, and it was felt by LEA personnel that we were "ahead" of the districts, and that they would most likely recognize the value of transition assistance in the next year or two.

We will continue to publicize available services, present whenever possible, and educate both parents and professionals concerning transition. This seems particularly important because our SEA's federal transition grant expired in the fall of 1994, and they have not been able to sponsor a state transition conference since the fall of 1993.

### OBJECTIVE 7: DISSEMINATION OF INFORMATION

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The major problem that existed with this objective was the limited funding to add books, videos, and other resource materials. Although some materials were added during the Project period, the library is still incomplete. Next year's funding levels were not added to, but were cut, thus obtaining even one copy for our office library will be difficult.

### OBJECTIVE 8: ADVISORY COMMITTEE

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More parent involvement is needed in the AACDB; at this time three parents are receiving committee meeting minutes, but parent participation at meetings is limited. It was very difficult to identify parents able to attend AACDB meetings, although we offered to make the meetings at convenient times and locations, and offered a stipend for travel. Arizona is both a rural and a remote state which is geographically quite large, making travel time lengthy. There are only two major urban population centers, and although many of our students live in them, many more are from the outlying areas of the state. In addition, most of our parents work, and simply do not have the time or energy to commit to being on the Advisory Committee.

Also, many of members of ATTDB and AACDB are the same, and all extremely busy people. We've begun to lose meeting participation on the Advisory Committee because people attend the State Team meetings. Some of the methods we are just beginning to try to regenerate the Advisory Committee include:

- piggyback AACDB meetings with ATTDB meetings, so the meetings are on the same day, thus eliminating traveling to two meetings
- meet every three months instead of every two
- move the meeting locations between Tucson, Phoenix, and Casa Grande (currently the meetings are in Casa Grande which is mid way between Tucson and Phoenix).

### OBJECTIVE 9: TRANSDISCIPLINARY ASSESSMENT TRAINING

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The Transdisciplinary Assessment Training successfully resulted in having two teams trained to conduct this type of assessment for children with deaf-blindness in the two urban areas of Arizona. These teams impacted children with multiple disabilities and severe sensory impairments both with the ADTEC program, which serves LEAs statewide, and in the Gilbert Unified School District, which serves the largest metropolitan area in Arizona. The issues which still confront the Project in being able to conduct needed transdisciplinary assessments with identified children statewide are:

- identification of new team members so that the specialty areas needed to comprise a team are represented.
- coordinating calendars, securing release time, and keeping the two trained teams in communication with each other (even with commitment

**Findings/Problems Solved/Effects/Recommendations**

for involvement from the supervisory personnel and the use of conference calls).

- locating funding to utilize a transdisciplinary approach due to the need to have available all members of the team for assessments, generation of reports, and travel and consultant fees.

Additional funds in the future need to be allocated to ensure the continuation of this very valuable and viable method to obtain accurate information on how to program for a child with deaf-blindness.

## PROJECT IMPACT/PRODUCTS DEVELOPED/PUBLICATIONS

Project staff continuously reviewed and revised activities based on the needs of families, children, and staff throughout Arizona to ensure service provision was meaningful. The overall impact of the Project during the last three years was significant in several areas.

In the area of identification, sixty new referrals were received, which indicated that agencies were made aware of our services and contacted us more frequently. Cooperation with the SEA and the LEAs in getting an accurate child count changed from not having a reporting category for deaf-blind, to having one and assisting us in reporting information from the SEA and the Deaf-Blind Project being better reconciled.

In the area of early intervention services, Arizona has one of the most comprehensive referral and case management procedures in the country. This allowed families with children who are deaf-blind to receive immediate assistance with accurate assessments and parent education. Transition from early intervention services to preschools was a major focus for the three year old population. The assistance and training given to preschool staff facilitated better services for children.

For families, our focus was to empower them to become better informed advocates for their child. In our dealings with the families, we found that no two families wanted or needed the same assistance. We built relationships with each family who asked for assistance by listening to their needs, working together to meet those needs, and developing a trust with the Project staff.

In the area of transition and technical assistance, the Project collaborated with various state agencies. We identified systems that were already in place for children with disabilities and provided them with training and funding to extend services to include the deaf-blind. In so doing, state agencies and projects increased the impact for all children.

Collaboration with the Western Region 307.11 Projects and TRACES brought about the opportunity to identify similar issues and solutions in serving families of various cultural backgrounds in rural and remote areas. This collaboration truly allowed our region to increase quality of services by sharing expertise and resources.

Finally, the Advisory Committee for this Project is a committed group of professionals and parents who have a history and interest in quality services for individuals who are deaf-blind. This committee had a significant impact on the direction and success of Project activities.

Efforts to organize the system of service delivery have resulted in the development of the following products and publications: Project brochure, Brochure on Deaf-Blindness developed jointly with TRACES, and the flyer on the Project's Education-Transition Services.

To disseminate information about the project activities and educational strategies for deaf-blindness the following products and publications have been developed: Parent Advisor Training (see agendas), Family Learning Weekends (see agendas), a statewide workshop on deaf-blindness titled "Addressing the Needs of Individuals Who Are Deaf-Blind" (see announcement), participation in the Arizona Transition Team on Deaf-Blindness activities (see informational flyer, parent article, and agendas), Bibliography for the Parent and Professional Lending Library, five newsletters (Vol. 1, No. 3; Vol. 1, No. 4; Vol. 1, No. 5; Vol. 2, No. 6; and Vol. 3, No. 7), and the Transdisciplinary Educational Assessment Model (TEAM) informal flyer and training agenda.

**FURTHER INFORMATION**

The Final Report on the activities completed by this project can be found in ERIC. To obtain information on the ASDB Parent Outreach Program or to obtain copies of any of the above products contact:

The Arizona Deaf-Blind Project  
Regional Services Program  
Arizona State Schools for the Deaf and the Blind  
1200 W. Speedway/ P.O. BOX 85000  
Tucson, AZ 85754  
(520) 770-3677

E-mail Address: [early@indirect.com](mailto:early@indirect.com)

**ASSURANCE STATEMENT**

This final report has been submitted to ERIC on 03/08/96.

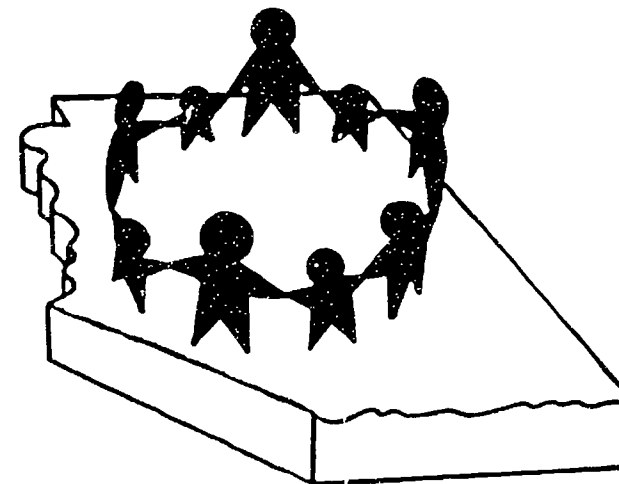
**For further information or to make  
a referral contact:**

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Tucson, AZ 85703-0545**

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## **Services to Children and Youths with Deaf-Blindness**



## **Arizona Deaf-Blind Project**

**Arizona State Schools  
for the Deaf and the Blind**

## Services to Children and Youth with Deaf-Blindness of Arizona

### Programs and Services

Services are available to children with deaf-blindness in Arizona through a federally funded project.

The purpose of this project is to provide both direct services and technical assistance to parents and agencies serving children with deaf-blindness. Direct services take the form of detection, evaluation, programming and follow-up for infants and toddlers birth through two years. Technical assistance is available to educational agencies and families of students from birth through 21 years.

#### Federal Definition of Deaf-Blindness

Individuals are deaf-blind or have dual sensory impairments if they have "auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their educational needs due to these concurrent disabilities."

Infants and toddlers with deaf-blindness "means individuals from birth through age 2 who are experiencing developmental delays in hearing and vision, have a diagnosed physical or mental condition that has a high probability of resulting in developmental delays in hearing and vision, or are at risk of having substantial developmental delays in hearing and vision if early intervention services are not provided."

CFR Title 34, Part 307.4

#### IDENTIFICATION

The Arizona Deaf-Blind Project maintains a record of persons identified with deaf-blindness between the ages of birth through 21 years, residing in Arizona to insure appropriate services are available. The pupil count is reported to state and federal agencies in order to develop incidence data and identify service needs. The pupil count data is also used to provide information on deaf-blindness to parents and service providers as quickly as possible.

#### PARENT AND FAMILY SUPPORT

##### Parent Outreach Program

The Arizona Deaf-Blind Project may provide infants (birth to five years) at risk of being deaf-blind with audiological services and functional vision assessments.

The Project in association with ASDB offers a Parent Outreach Program to help parents meet the needs of their birth to five-year old child with deaf-blindness. These services are free of charge and are available to families in local communities throughout Arizona.

##### Parent and Family Workshops

Workshops on transition issues, utilizing available services, and building family support systems may be presented in coordination with various state agencies.

#### TECHNICAL ASSISTANCE

Consultation and assistance in program development is available to educational agencies serving children and youths with deaf-blindness. The objectives for this priority are to:

- coordinate technical assistance to pre-schools, educational agencies and other service providers.
- provide in-service training based on local needs and requests for professionals and other personnel serving children and youth with deaf-blindness.
- assist in transition planning.
- arrange for sensory and educational evaluations of children at the Arizona Diagnostic Testing and Education Center (ADTEC) as a support to LEAs not having resources to evaluate a child with dual sensory impairments.
- provide information on Best Education practices for students with deaf-blindness.
- facilitate visitation to model or demonstration sites in Arizona.
- present information at selected conferences/workshops.

## For More Information...

If a child's behaviors lead you to think that he or she might have both hearing and vision impairments, please contact the Arizona Deaf-Blind Project for further information and referral.

### Arizona Deaf-Blind Project

Earlene Dykes, *Project Director*  
Emma Wiseley, *Project Manager*  
Cindi Robinson, *Education-Transition Specialist*  
ASDB  
P.O. Box 5545  
Tucson, AZ 85703-0545

Ph. (602) 770-3677  
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Arizona Deaf-Blind Project  
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ARIZONA  
Deaf-Blind Project

*This brochure is produced and distributed through a joint effort between TRACES (Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments (Cooperative Agreement No. HO25C00001) and the Arizona Deaf-Blind Project (Grant Contract No. HO25A20036) with funding from the U.S. Department of Education.*

*The Arizona State Schools for the Deaf and the Blind is committed to the principles of equal opportunity and affirmative action and shall implement procedures to ensure that all personnel transactions (including recruitment, hiring, promotion and training) be based upon merit principles without regard to race, color, sex, religion, national origin, age, disability status (except when any of these factors is an existing bona fide occupational qualification), or political affiliation (except for certain specified employees in the unclassified service).*

*Information and Assistance  
for Individuals Who Are  
Deaf-Blind*



## What Is Deaf-Blindness?

Deaf-blindness is a loss in both the vision and hearing senses\*. This condition affects over 8,000 children between birth and 21 years of age in the United States. Deaf-blindness has over 70 known causes; however, regardless of the cause, the challenges of deaf-blindness are lifelong. Appropriate education must address **both** the hearing and vision impairments as well as any other disabilities that may be present.

Children who are deaf-blind may exhibit a wide range of behaviors during interactions with family, friends, and their environment as a result of the sensory losses. The losses may occur in varying degrees and a child need not exhibit all of the behaviors identified in this brochure to be considered deaf-blind. For example, a child may show only one of the behaviors that indicates a hearing impairment; but show several of the behaviors that indicate a vision impairment. The **combined effects of both of these sensory losses, even if both are mild, may qualify him or her as deaf-blind.**

Parents and professionals, upon observing these behaviors, may need assistance in confirming the sensory loss. This brochure provides general information on deaf-blindness. Contacting the Arizona Deaf-Blind Project is the first step to securing assistance.

*\*The federal definition of deaf-blindness states "children and youth having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services, beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their educational needs due to these concurrent disabilities."*

## Behaviors that May Indicate a Dual Sensory Impairment

The following questions are designed to help parents and professionals determine if there is a possibility of a vision and hearing loss. If you answer yes to questions in **both** of the following sections, the child may have a dual sensory loss and should receive complete vision and hearing assessments. The Arizona Deaf-Blind Project can assist with referrals for assessments.

### Behaviors that May Indicate a Visual Impairment

*Does the child or student...*

- often bump into persons and objects?
- have difficulty walking or crawling smoothly across shadows or areas that look different (carpet or tile)?
- need to touch or have an object close to the face to identify it?
- prefer only brightly colored or shiny objects?
- have difficulty reaching for and grasping objects in a coordinated manner?
- squint, cover, or close one eye when looking at objects?
- lose interest or tire easily when performing close tasks?
- usually turn toward a light source?
- fail to recognize and respond to familiar faces?
- have difficulty following moving objects with his/her eyes?
- have eyes that are red or watery, not clear?

## Behaviors that May Indicate a Hearing Impairment

*Does the child or student...*

- fail to react to loud noises?
- frequently ask to have things repeated or follow directions incorrectly?
- seem confused when verbal directions are given in noisy environments such as playgrounds or school cafeterias?
- indicate agreement (nods head) when you know he/she does not understand what was said?
- have difficulty locating the sources of sounds?
- fail to recognize and respond appropriately to words or common home noises (telephone, door knock, television)?
- understand better when looking directly at the speaker?

## Services Provided by the Arizona Deaf-Blind Project

- Assistance in identification
- On-site technical assistance (e.g., training, one-on-one consultation, in-service workshops, program design and review) for families, educators, and others based on individual needs
- Lending library with up-to-date books, articles and manuals.
- Access to programs, professionals, and parents who are involved with individuals who are deaf-blind and their families.
- Newsletters and project mailings for up-to-date materials on deaf-blindness.

## Para más información...

Si los comportamientos de un niño le hace a usted pensar que el mismo podría tener ambos impedimentos del oído y de la vista, favor de comunicarse con el Proyecto de Arizona para Sordos y Ciegos para más información y referencias.

### Arizona Deaf-Blind Project

Earlene Dykes, *Project Director*  
Emma Wiseley, *Project Manager*  
Cindi Robinson, *Education-Transition Specialist*  
ASDB  
P.O. Box 5545  
Tucson, AZ 85703-0545

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*Este folleto es producido y distribuido por medio de un esfuerzo conjunto entre TRACES (Asistencia en la Investigación de la Docencia para los Niños y Jóvenes con Impedimentos Sensoriales (Contrato Cooperativo Número H025C00001) y el Proyecto de Arizona para Sordos y Ciegos (Contrato de Subvención Número H025A20036) patrocinado por el Departamento de Educación de los Estados Unidos.*

*Las Escuelas Estatales para Sordos y Ciegos están comprometidas a los principios de la igualdad de oportunidad y a la acción afirmativa e implementarán los procedimientos para asegurarse de que todos los trámites de personal (incluyendo reclutamiento, empleo, acenso, y entrenamiento) se busquen en los principios de mérito sin tomar en cuenta raza, color, sexo, religión, origen nacional, edad, estado de deshabilidad (salvo que uno de estos factores es una calificación ocupacional auténtica existente), o afiliación política (excepto ciertos empleados especificados en el servicio no clasificado).*

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Proyecto de Arizona para Sordos y Ciegos  
ASDB  
P.O. Box 5545  
Tucson, AZ 85703-0545

Proyecto de  
ARIZONA  
para Sordos y Ciegos

Información y Asistencia  
para los Individuos  
Sordo y Ciegos

Ser Sordo y ciego significa la pérdida del sentido del oído y de la vista a la vez.\* Esta condición afecta a más de 8,000 niños desde el nacimiento hasta los 21 años en los Estados Unidos. Ser sorde y ciego tiene más de 70 causas conocidas; sin embargo, lo que sea la causa, los desafíos de ser sordo y ciego son de toda la vida. La educación apropiada tiene que tomar en cuenta los impedimentos del oído y de la vista a la vez, así como cualquier otra deshabilidad que pueda estar presente.

Los niños que son sordos y ciegos pueden mostrar una gran variedad de comportamientos durante las interacciones con la familia, los amigos y el ambiente como consecuencia de las pérdidas sensoriales. Las pérdidas pueden ocurrir en grados diversos y un niño no necesita mostrar todos los comportamientos identificados en este folleto para que se le considere sordo y ciego. Por ejemplo, un niño puede mostrar solo uno de los comportamientos que indican un impedimento del oído, pero muestra varios de los comportamientos que indican un impedimento de la vista. Los efectos combinados de estas pérdidas sensoriales, aunque ambas sean leves, pueden calificarlo como sorde y ciego.

Los padres de familia y profesionales, al observar estos comportamientos, pueden necesitar asistencia para confirmar las pérdidas sensoriales. Este folleto provee información general sobre ser sordo y ciego. La primera etapa para conseguir la asistencia es comunicarse con el Proyecto de Arizona para Sordos y Ciegos.

\* La definición federal de ser sorde y ciego abarca "niños y jóvenes que tienen impedimentos auditivos y visuales, la combinación de los cuales crea necesidades tan severas de la comunicación, el desarrollo y el aprendizaje que no pueden ser educados apropiadamente si la educación especial y los servicios relacionados además de los que se suministrarían solamente para los niños con impedimentos del oído impedimentos visuales o deshabilidades severas, para tratar sus necesidades educativas debidas a estas deshabilidades con urgencia".

## **Pueden Indicar un Impedimento Sensorial Doble**

Las siguientes preguntas han sido diseñadas para ayudarles a los padres de familia y profesionales a determinar si hay una posibilidad de una pérdida de la vista y del oído. Si usted responde sí a las preguntas en ambas de las siguientes secciones, el niño puede tener una pérdida sensorial doble y debe hacerse unos análisis de la vista y del oído. El Proyecto de Arizona para Sordos y Ciegos puede ayudar con referencias para los análisis.

### **Los Comportamientos que Pueden Indicar un Impedimento de la Vista**

*¿El niño o estudiante...*

- se da golpes a menudo contra personas y objetos?
- tiene dificultad en caminar o gatear con fluidez a través de las sombras o áreas que se ven diferentes (la alfombra o el azulejo)?
- necesita tocar o tener un objeto cerca de la cara para identificarlo?
- prefiere solamente objetos de colores vivos o brillantes?
- tiene dificultad en alcanzar y agarrar objetos en una manera coordinada?
- entrecierra, cubre, o cierra un ojo cuando está mirando objetos?
- pierde el interés o se cansa fácilmente cuando está haciendo tareas de cerca?
- generalmente volteo hacia una fuente de luz?
- no reconoce y responde a las caras conocidas?
- tiene dificultad en seguir con los ojos los objetos en movimiento?
- tiene los ojos rojos o llorosos en vez de claros?

## **Pueden Indicar un Impedimento del Oído**

*¿El niño o estudiante...*

- no reacciona a los ruidos fuertes?
- pide a menudo que le repita lo que se le dijo o sigue las instrucciones incorrectamente?
- parece confundido cuando se le dan instrucciones verbales en ambientes con mucho ruido tales como áreas de juego o cafeterías escolares?
- indica estar de acuerdo (asiente con la cabeza) cuando usted sabe que no entiende lo que se dijo?
- tiene dificultad en localizar las fuentes de los sonidos?
- no reconoce ni responde apropiadamente a palabras o ruidos comunes de casa (el teléfono, el tocar la puerta, el televisor)?
- entiende mejor cuando mira directamente al orador?

### **Servicios Suministrados por el Proyecto de Arizona para Sordos y Ciegos**

- Asistencia en la diagnosis
- Asistencia técnica (por ejemplo, entrenamiento, consulta individual, talleres en el área de trabajo, diseño y revisión de programas) en donde se encuentran las familias, educadores y otros basada en las necesidades individuales
- Biblioteca con libros, artículos y manuales al día para prestar.
- Acceso a programas, profesionales y padres de familia participando con individuos sordos y ciegos, y sus familias.
- Boletines y correspondencia del proyecto sobre materiales al día acerca de ser sordo y ciego.

### Deaf-Blind Project Education-Transition Services

The Arizona Deaf-Blind Project has added an education-transition position to its staff, and is now able to offer Arizona LEAs expanded services in the area of transitioning for those districts with students on the Deaf-Blind Count. This is quite timely since new mandates in IDEA, passed into law in September 1992, require the addition of transition services to the educational process. For all students 16 years of age and older, transition services must be provided and documented in the students' IEP. For students with more severe disabilities, transition services may begin at age 14, or even younger.

Studies have shown that graduates of special education programs have had difficulty finding and maintaining employment, becoming involved in their communities, accessing adult service systems, and in short, building support systems for themselves. The identification and provision of transition services to these special education students is meant to assist in the movement from school to adult environments, and to build and provide the support systems necessary for the students to succeed in post-school environments.

Students with both hearing and vision losses have unique educational and life needs which add to their difficulty in transitioning to adult life. Additionally, they often have other physical and/or cognitive impairments. This combination of impairments frequently necessitates beginning transition services at or before 14 years of age. Because they do not easily fit into existing adult service delivery systems, post-school situations must be individually developed for each student.

A major goal of the deaf-blind project is to help build the necessary transition services for students with deaf-blindness. Support through the Deaf-Blind Project could take the form of technical assistance, consultation, sponsoring workshops and other in-service training, participation in transition teams, or simply problem solving.

Areas which might be addressed by us together include:

- functional programming
- community-based instruction
- developing transition plans
- establishing interagency linkages
- job placement
- supported employment
- independent or semi-independent living options
- post-secondary education options
- other areas as identified

For information please contact:

Cindi Robinson  
Education-Transition Specialist  
Arizona Deaf-Blind Project  
Arizona State Schools for the Deaf and the Blind  
P.O. Box 5545  
Tucson, AZ 85703  
(602) 770-3677

# ASDB ARIZONA STATE SCHOOLS for the DEAF and the BLIND

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**AGENDA**  
**PARENT OUTREACH PROGRAM FOR THE VISUALLY IMPAIRED**  
**Initial Parent Advisor Training**  
**September 8, 1995**  
**Phoenix, Arizona**

**Friday, September 8, 1995**

- 8:30 - 9:00 a.m.           **REGISTRATION**  
Grace Inn (Ahwatukee)  
10827 S. 51st Street  
Phoenix, AZ 85044  
(602) 893-3000
- 9:00 - 9:30 a.m.           Welcome and Introduction  
Dr. Wilbur Lewis, Interim Superintendent  
ASDB  
Joni Kiser, Director  
Regional Services Program (RSP)  
Earlene Dykes, Assistant Director  
Regional Services Program (RSP)
- 9:30 - 10:00 a.m.       History and Overview of the Parent Outreach Program  
Peggy Kile, Supervisor  
Central Region--RSP
- 10:00 - 10:10 a.m.       **BREAK (go to meeting rooms)**
- 10:10 - 12:00 p.m.       Intro Activity  
Heart to Heart, a video about families, Part I  
Resource Folders  
A Walk through the Curriculum  
Heart to Heart, a video about families, Part II  
PRESENTERS: Linda Reed, Coordinator  
Southern Region--RSP  
Susan Greer, Coordinator  
Visually Impaired Preschooler's Center (VIP)  
Emma Wiseley, Supervisor  
Arizona Deaf-Blind Project

(Friday agenda continued on reverse side)

12:00 - 1:00 p.m.

**LUNCH**

1:00 - 1:45 p.m.

Home Visit Procedures

PRESENTERS: Linda Reed  
Susan Greer

1:45 - 2:15 p.m.

Cross-referencing the INSITE and the HELP at Home

PRESENTER: Linda Reed

2:15 - 2:35 p.m.

Families Show the Way (A Video from the Hilton-Perkins Project)

PRESENTER: Linda Reed

2:35 - 2:45 p.m.

**BREAK**

2:45 - 3:05 p.m.

"In Sight, How the Eyes Work", (A Video about Eye Conditions)

PRESENTER: Emma Wiseley

3:05 - 4:15 p.m.

Functional Vision Assessment

Vision Program, INSITE Curriculum

PRESENTER: Linda Reed  
Susan Greer

4:15 - 4:45 p.m.

Forms, Pay Vouchers

PRESENTER: Linda Meiners, Supervisor  
Northern Region--RSP

4:45 - 5:30 p.m.

Vision Goals Activity

PRESENTER: Susan Greer

5:30 - 6:30 p.m.

Effects of Vision Loss on Motor Development

PRESENTER: Jill Martindale, OTR  
Pueblo Pediatrics

# ASDB ARIZONA STATE SCHOOLS for the DEAF and the BLIND

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**AGENDA**  
**PARENT OUTREACH PROGRAM FOR THE VISUALLY IMPAIRED**  
**Initial Parent Advisor Training**  
**September 9, 1995**  
**Phoenix, Arizona**

**Saturday, September 9, 1995**

- 8:15 - 8:30 a.m. Coffee and Juice
- 8:30 - 9:30 a.m. Discussion of the Grieving Process and Family Confidentiality  
PRESENTER: Joni Kiser
- 9:30 - 9:40 a.m. **BREAK (change meeting rooms)**
- 9:40 - 9:50 a.m. Announcements and Housekeeping Miscellaneous
- 9:50 - 11:00 p.m. Vision Loss and Communication in Infants and Toddlers  
PRESENTER: Irene Topor, Ph.D.  
University of Arizona
- 11:00 - 11:45 a.m. Hearing Screening and Risk Factors  
PRESENTER: Cindi Robinson, Education Transition Specialist  
Arizona Deaf-Blind Project
- 11:45 - 12:15 p.m. Vision Simulation Activity  
PRESENTER: Emma Wiseley
- 12:15 - 1:15 p.m. **LUNCH**
- 1:15 - 2:00 p.m. The Role of the Parent Advisor:  
Parent Advisor Panel
- 2:00 - 2:15 p.m. Wrap Up  
Joni Kiser
- 2:15 - 4:00 p.m. Personnel Forms

# ASDB

**ARIZONA STATE SCHOOLS  
for the DEAF and the BLIND**

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**AGENDA**  
**PARENT OUTREACH PROGRAM FOR THE HEARING IMPAIRED**  
**Initial Parent Advisor Training**  
**September 8th and 9th, 1995**  
**Phoenix, Arizona**

**Friday, September 8, 1995**

- 8:30 - 9:00 a.m.           **REGISTRATION**  
Grace Inn (Ahwatukee)  
10827 S. 51st Street  
Phoenix, AZ 85044  
(602) 893-3000
- 9:00 - 9:30 a.m.           Welcome and Introduction  
Dr. Wilbur Lewis, Interim Superintendent  
ASDB  
Joni Kiser, Director  
Regional Services Program (RSP)  
Earlene Dykes, Assistant Director  
Regional Services Program
- 9:30 - 10:00 a.m.         History and Overview of the Parent Outreach Program  
Peggy Kile, Supervisor  
Central Region--RSP
- 10:00 - 10:15 a.m.       **BREAK**
- 10:15 - 10:45 a.m.       Introduction to the SKI\*HI Curriculum and Information for Parent Advisors  
Barbara Schrag, Coordinator  
Southern Region--RSP
- 10:45 - 11:45 p.m.       Auditory Program Resources  
Peggy Kile
- 11:45 - 1:00 p.m.       **LUNCH**
- 1:00 - 2:00 p.m.         Hearing Aid Program Resources  
Kathy Wexler, Audiologist  
Central Region--RSP

(Friday agenda continued on reverse side)

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- 2:00 - 3:00 p.m.            Communication Program Resources  
                                  Geri Nelson, Supervisor  
                                  Southeast Regional Cooperative
- 3:00 - 3:15 p.m.            **BREAK**
- 3:15 - 4:15 p.m.            The Home Language Program  
                                  Barbara Schrag
- 4:15 - 4:45 p.m.            Completion of Workshop Forms  
                                  • Linda Meiners, Supervisor  
                                  Northern Region--RSP
- 4:45 - 6:00 p.m.            Assessment and Planning:
- The Individualized Family Service Plan,  
   IDEA, PL 99-457 and AzEIP  
   Geri Nelson
  - Individual Assessments  
   Debbie Pollicove, Coordinator  
   Central Region--RSP

**6:00                            DINNER**

**Saturday, September 9, 1995**

- 8:15 - 8:30 a.m.            Coffee and Juice
- 8:30 - 9:30 a.m.            Discussion of the Grieving Process and Family Confidentiality  
                                  Joni Kiser
- 9:30 - 9:45 a.m.            **BREAK**
- 9:45 - 10:45 a.m.           Forms and Logistics of the Home Visit  
                                  Debbie Pollicove
- 10:45 - 12:00 p.m.           Planning the Home Visit; Case Studies  
                                  Coordinators and Supervisors
- 12:00 - 1:15 p.m.           **LUNCH with your Coordinator**
- 1:15 - 2:00 p.m.            The Role of the Parent Advisor:  
                                  Parent Advisor Panel
- 2:00 - 2:15 p.m.            Wrap Up  
                                  Joni Kiser
- 2:15 - 4:00 p.m.            Personnel Forms  
                                  Coordinators and Supervisors

# ASDB ARIZONA STATE SCHOOLS for the DEAF and the BLIND

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**PARENT OUTREACH PROGRAM  
PARENT ADVISOR WORKSHOP ON DEAF-BLINDNESS  
SEPTEMBER 8TH AND 9TH, 1995  
PHOENIX, ARIZONA**

**\*NOTE\*** The Parent Advisor Workshop on Deaf-Blindness will provide you an opportunity to attend on Friday, September 8, the Initial Parent Advisor Training sessions in a different sensory area than what you have completed in the past and other sessions developed on issues in deaf-blindness. Below is the schedule when you will be pulled from the initial training group.

**Friday, September 8, 1995**

- 8:30 - 9:00 a.m.     **REGISTRATION**  
Grace Inn (Ahwatukee)  
10827 S. 51st Street  
Phoenix, AZ 85044  
(602) 893-3000
- 9:00 - 10:00 a.m.    Deaf-Blind issues group will move to meeting room (Yuma Room)  
Overview of Deaf-Blindness and Characteristics of Best Practices  
Cindi Robinson, Education Transition Specialist  
Arizona Deaf-Blind Project
- 10:00 - 10:10 a.m.   **BREAK**  
(Join your Parent Advisor Training group)  
Vision Impairment Training - Prescott Room  
Hearing Impairment Training - Ahwatukee B

**Saturday, September 9, 1995**

- 8:15 - 8:30 a.m.     Coffee and Juice (In large group meeting room)
- 8:30 - 9:50 a.m.     Move to Deaf-Blind Issues Meeting Room (Yuma Room)  
Development of Communication Skills  
Emma Wiseley, Manager  
Arizona Deaf-Blind Project
- 9:50 - 11:00 a.m.    **BREAK** (Return to Parent Advisor Training Group)
- 12:15 - 1:15 p.m.    **Lunch**
- 1:15 - 2:45 p.m.     Communication (continued)  
Emma Wiseley
- 2:45 - 3 00 p.m.     Wrap-Up and Evaluations

**ADULT AGENDA  
ARIZONA FAMILY LEARNING WEEKEND  
CAMP SHADOW PINES, HEBER, ARIZONA  
JUNE 16 - 18, 1995**

**FRIDAY, JUNE 16**

4:00 - 5:00 p.m.	<b>Registration and Room check in</b>	Dining room
	<b>Free Time with Family</b>	
5:15 - 6:30 p.m.	<b>Dinner</b>	Dining room
6:30 - 8:00 p.m.	<b>Welcome, Introductions and Communication Experience</b>	"
	Cind Robinson, Family Learning Weekend Coordinator	
	Lead Instructors, Parent and Children Group Leaders,	
	Families, Staff, Volunteers, and Language Interpreters	
8:00 p.m. - On	<b>Camp Fire Sing-A-Long</b>	Fire Pit
	<b>Popcorn and Video Movies</b>	MR 1

**SATURDAY, JUNE 17**

8:00 - 9:00 a.m.	<b>Breakfast</b>	Dining room
9:00 - 9:30 a.m.	<b>Communication Experience</b>	"
9:30 a.m.	<b>Children/Youth to Assigned Activity Area (parents accompany)</b>	Ramada
9:45 - 11:45 a.m.	<b>Parent Roundtable</b>	MR 1
	Kay Seward, Ph.D.	
	Sonoran Human Development, Scottsdale, Arizona	
11:45 - 12:00 p.m.	<b>Parents Meet Children/Youth at Assigned Activity Area</b>	Ramada
12:00 - 1:00 p.m.	<b>Lunch</b>	Dining room

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**SATURDAY, JUNE 17**

1:00 p.m.  
1:15 - 2:00 p.m.

**Children/Youth to Assigned Activity Area (parents accompany)**  
**Getting To Know Your Legislators: Why & How**  
Mary Hoelt, Parent

Ramada  
MR 1

2:00 - 3:15 p.m.

**Parent Resources: Gene Harding, Jim Schiller, Emma Wiseley, Mary Hoelt**  
-AZ Statewide Parent Connection -AZ Assoc. for Parents of Visually Impaired  
-Helen Keller National Center -Pilot Parents  
-AZ Deaf-Blind Project -NFADB

"

3:15 - 4:00 p.m.

**Dad's Meeting, Jim Schiller**  
**Mom's Meeting, Kay Seward**

MR 2 (or outside)

MR 1 "

MR 1 "

4:00 - 4:45 p.m.

**Stress Management**  
Kay Seward

4:45 - 5:00 p.m.

**Parents Meet Children/Youth at Assigned Activity Area**

Ramada

5:00 - 6:00 p.m.

**Dinner**

Dining room

6:00 - On

**Choice of Camp Recreational Activities- Families, Staff, Volunteers**  
Jog/Walk Along the 1.4 Mile Track  
Visit with Other Participants  
Horse shoes, Baseball, Croquette, Tetherball, Billiards, Ping Pong,  
Foosball, Volleyball, Video Movies

6:30 p.m.

**Visit the Ice Cream Parlor**

7:00 - 10:00 p.m.

**Dance & Karaoke (under the ramada)**



Ramada

**SUNDAY, JUNE 18**

**HAPPY FATHER'S DAY!**

8:00 - 9:00 a.m.

**Breakfast**

Dining Room

9:00 - 9:30 a.m.

**Communication Experience - Families, Staff, Volunteers**

"

9:30 a.m.

**Children/Youth to Assigned Activity Area (parents accompany)**

Ramada

9:45 - 10:30 a.m.

**Parent Roundtable Wrap Up (all parents)**

MR 1

10:30 - 11:00 a.m.

**Camp Evaluations & Videos**

MR 1

11:00 - 11:30 p.m.

**Family Games**

Ramada

11:30 - 12:00 p.m.

**Closing Ceremony and Awards**

"

12:00 - 1:00 p.m.

**Lunch Cookout**

"

1:00 p.m.

**Departure**

Ramada BBQ

**ACTIVITY SCHEDULE  
CHILDREN BIRTH TO 4 YEARS**

**ARIZONA FAMILY LEARNING WEEKEND  
CAMP SHADOW PINES, HEBER, ARIZONA  
June 16 - 18, 1995**

**FRIDAY, JUNE 16**

4:00 - 5:00 p.m.

**Registration and Room check-in  
Free time with family**

Dining Room

5:15 - 6:30 p.m.

**Dinner**

Dining Room

6:30 - 8:00 p.m.

**Welcome and Introductory Activities**

Fire Pit

8:00 p.m. - on

**Camp Fire Sing-A-Long  
Popcorn and Video Movies**

MR1

**SATURDAY, JUNE 17**

8:00 - 9:00 a.m.

**Breakfast**

Dining Room

9:00 - 9:30 a.m.

**Communication Experience**

"

9:30 a.m.

**Children to Assigned Activity Areas**

Little House

**Lead Instructors: Phyllis Brodsky & Terri Litt :**

**Morning Activities**

"

Welcoming Activities

"

Arts/Crafts: Dinosaur Eggs

"

Sensory: Rock Pendants

"

Motor: Obstacle Course

"

Play: Toys

"

12:00 p.m.

**Parents Meet Children at Assigned Activity Areas**

Little House

12:00 - 1:00 p.m.

**Lunch**

Dining Room

**SATURDAY, JUNE 17**

1.00 p.m.

**Children to Assigned Activity Areas  
Afternoon Activities**

Arts/Crafts: Bird Seed Squiggles  
Sensory: Junk Food Sculptures  
Motor: Jumping Games  
Play: Toys

Little House

"  
"  
"

5.00 p.m.

**Parents Meet Children at Assigned Activity Area**

Little House

5.00 - 6.00 p.m.

**Dinner**

Dining Room

6.00 p.m. - on

Choice of Camp Recreational Activities-Families, Staff, Volunteers

Various Locations

Ice cream parlor opens at 6:30 p.m.

7.00 p.m.

**Dance & Karaoke**



Ramada

**SUNDAY, JUNE 18**

8.00 - 9.00 a.m.

**Breakfast**

Dining Room

9.00 - 9.30 a.m.

**Communication Experience**

"

9.30 a.m.

**Children to Assigned Activity Areas**

Little House

**Morning Activities**

"

Arts/Crafts: Pine Cone Flowers  
Sensory: Rock Collection  
Motor: Ball Throwing/Catching  
Play: Toys

"

"

"

"

11.00 - 11.30 a.m.

**Family Games**

Ramada

11.30 - 12.00 p.m.

**Closing Ceremony and Awards**

"

12.00 - 1.00 p.m.

**Lunch**

Ramada BBQ

1.00 p.m.

**Departure**

Note to Parents: Children will have a variety of alternative activities to choose from if they do not wish to participate in planned activities. This will include water play, playdough, blocks, toys, puzzles, stories, and music. Snacks and naps will be provided at planned times or as needed.

ACTIVITY SCHEDULE  
CHILDREN 5 TO 11 YEARS

ARIZONA FAMILY LEARNING WEEKEND  
CAMP SHADOW PINES, HEBER, ARIZONA  
June 16 - 18, 1995

FRIDAY, JUNE 16

4:00 - 5:00 p.m.

Registration and Room Check-in  
Free time with Family

Dining Room

5:15 - 6:30 p.m.

Dinner

Dining Room

6:30 - 8:00 p.m.

Welcome and Introductory Activities

Fire Pit

8:00 p.m. - On

Campfire Sing-A-Long  
Popcorn and Video Movies

MR 1

SATURDAY, JUNE 17

8:00 - 9:00 a.m.

Breakfast

Dining Room

9:00 - 9:30 a.m.

Communication Experience

"

9:30 a.m.

Children to Assigned Activity Areas

Ramada

Lead Instructors: Paul Ohm & Feliza Garcia-Laos

9:45 - 10:00 a.m.

Introductory Games

Ramada/Outdoors

10:00 - 10:30 a.m.

Nature Walk and Rock Sculptures

"

10:30 - 11:00 a.m.

Choice of Nature Centerpiece, Paper Mache Sculptures,  
Potpourri Balls

"

11:00 - 11:30 a.m.

Beep Baseball or Kickball (or continue art projects)

"

11:30 - 12:00 p.m.

Group Song (or continue art projects)

"

12:00 p.m.

Parents Meet Children at Assigned Activity Areas

Ramada

12:00 - 1:00 p.m.

LUNCH

Dining Room





**ACTIVITY SCHEDULE  
YOUTH AND YOUNG ADULTS 12 AND OLDER**

**ARIZONA FAMILY LEARNING WEEKEND  
CAMP SHADOW PINES, HEBER, ARIZONA  
June 16 - 18, 1995**

**FRIDAY, JUNE 16**

4:00 - 5:00 p.m.	<b>Registration and Room Check-In</b>	Dining Room
	<b>Free time with Family</b>	
5:15 - 6:30 p.m.	<b>Dinner</b>	Dining Room
6:30 - 8:00 p.m.	<b>Welcome and Introductions</b>	"
8:00 p.m. - On	<b>Campfire Sing-A-Long</b>	Fire Pit
	<b>Popcorn &amp; Video Movies</b>	MRI

**SATURDAY, JUNE 17**

8:00 - 9:00 a.m.	<b>Breakfast</b>	Dining Room
9:00 - 9:30 a.m.	<b>Communication Experience</b>	"
9:30 a.m.	<b>Youth to Assigned Activity Areas</b>	Ramada
	<b>Lead Instructors: Penny Rosenblum &amp; Glenda Brown</b>	
9:30 - 10:00 a.m.	<b>Introductions (Balloons &amp; Person to Person)</b>	Ramada/Outdoors
10:00 - 10:30 a.m.	<b>Nature Walk, Jewelry</b>	"
10:30 - 11:00 a.m.	<b>Wall Plaques</b>	"
11:00 - 11:30 a.m.	<b>Beep Baseball or Kickball</b>	Outdoors
11:30 - 12:00 p.m.	<b>Memo Boards, Group Song</b>	Ramada
12:00 p.m.	<b>Parents Meet Children at Assigned Activity Areas</b>	Ramada
12:00 - 1:00 p.m.	<b>Lunch</b>	Dining Room

**SATURDAY, JUNE 17**

1:00 p.m.

**Youth to Assigned Activity Areas**

**Afternoon Activities**

Partner Tag, Wall Plaques

Relay Races

Memo Boards, Pillows

Sidewalk Chalk, Hats, Cards

SNACK Food Sculpture, Group Song

Paper Bag Skits, Human Tic Tac Toe, Pillows

Memo Boards, Group Song

**Parents Meet Children at Assigned Activity Area**

**Dinner**

**Choice of Camp Recreational Activities - Families, Staff, Volunteers**

Ride bikes

Jog/walk along the 1.4 mile track

Visit with other participants

Visit the game room (billiards, ping-pong, fooseball, horseshoes)

Basketball, volleyball, kickball, soccer, tetherball

Horseshoes, baseball, croquette

Video Movies

**Ice cream parlor opens at 6:30 p.m.**

**Dance & Karaoke**



Ramada

Ramada

Outdoors

Ramada

"

"

"

"

Ramada

Dining Room

Throughout Camp

"

"

"

"

"

"

"

Ramada

5:00 p.m.

5:00 - 6:00 p.m.

6:00 - On

7:00 p.m.

**SUNDAY, JUNE 18**

**HAPPY FATHER'S DAY!**

8:00 - 9:00 a.m.

9:00 - 9:30 a.m.

9:30 a.m.

9:30 - 10:30 a.m.

10:30 - 11:00 a.m.

11:00 - 11:30 a.m.

11:30 - 12:00 p.m.

12:00 - 1:00 p.m.

1:00 p.m.

**Breakfast**

**Communication Experience**

**Youth to Assigned Activity Areas**

**Scavenger Hunt, Camp Evaluations**

**Group Games (Beep baseball, kickball, wiffel ball)**

**Family Games**

**Closing Ceremony and Awards**

**Lunch**

**Departure**

Dining room

"

Ramada

"

"

"

Ramada BBQ

## COMMUNICATION EXPERIENCE

### PHRASE LIST

#### Friday

Good night / morning.

My name is \_\_\_\_\_.

What is your name?

How are you?

I am fine / tired / sad / hungry.

I am happy to have met you (nice meeting you).

#### Saturday

Do you need help?

Please / Thanks.

You're welcome.

Do you like: -ice cream

-hot dogs

-pop

Yes / No.

Do you want to play?

Excuse me / Sorry.

Do you like to: / Lets:

-ride bikes

-sing

-dance

-(do) crafts

-baseball, shoot pool,  
ping pong, beepball

-watch (a) video

#### Sunday

Have a safe trip home.

Have a good summer.

Please write.

Here is my address.

Please call me.

Here is my phone number.

Hope to see you again.

1995 Volunteer/Staff Directory  
Family Learning Weekend

Presenters

**Kay Seward, Ph.D**  
Parent Group Leader  
Sonoran Human Development  
6360 East Thomas Road  
Scottsdale, AZ 85251  
Work: 949-7008

**Mary Hoefft**  
AZ Association for Parents of the  
Visually Impaired  
6726 East Nicaragua  
Tucson, AZ 85730  
Hm/Wk: 747-2995

**Gene Harding**  
AZ Statewide Parent Connection  
1920 W. Ahmed Ave.  
Tucson, AZ 85704  
297-6618

**Jim Schiller**  
Community Outreach Program  
for the Deaf  
268 W. Adams  
Tucson, AZ 85705  
792-1906

**Music by Mr. Music**  
Dan Gerard, Disc Jockey  
PO Box 2577  
Payson, AZ 85547  
474-5173

Staff/Volunteers

Cindi Robinson - Weekend Coordinator  
Emma Wiseley - Deaf-Blind Project

Phyllis Brodsky - Instructor  
Glenda Brown - Instructor  
Feliza Garcia-Laos - Instructor  
Terri Litt - Instructor  
Paul Ohm - Instructor  
Penny Rosenblum - Instructor

Brenda Albee - Nurse  
Lynne Brady - Volunteer  
Denise Brenden - Volunteer  
Tess Calvert - Volunteer  
Sue Capron - Volunteer  
John Cornn - Volunteer  
James Dixon - Volunteer  
Stephanie Hale - Volunteer  
Lilly Jacqueline - Volunteer  
Brenda Jager - Volunteer  
Rene Laos - Volunteer  
Amanda Mortensen - Volunteer  
Vicki Mortensen - Volunteer  
Molly Myers - Photographer  
Donna Riccabono - Volunteer  
Christa Savely - Volunteer  
Jim Schiller - Volunteer  
Rhonda Stewart - Volunteer  
Gina Trail - Volunteer  
Ken Williams - Volunteer  
Darrell Wiseman - Volunteer

Spanish Interpreters

Scott Brenden  
Robert Galaz

Sign Interpreter

Chris Akins

Native American Liaison

Katie Yazzie  
Stacy Yazzie

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**FAMILY LEARNING WEEKEND**

**1995**

**SUPPORTING CONTRIBUTORS**

Arizona Advisory Committee on Deaf-Blindness

Arizona Association For Parents of the Visually Impaired

Arizona Deaf-Blind Project

Arizona Department of Education

Arizona State Schools for the Deaf and the Blind

Community Outreach Program for the Deaf

Helen Keller National Center for Deaf-Blind Youths and Adults

Pilot Parent Partnerships

Teaching Research Assistance to Children and Youth  
Experiencing Sensory Impairments  
TRACES

Rehabilitative Services Administration

Department of Economic Security/Division of Developmental Disabilities

University of Arizona/ College of Education  
Division of Special Education

Tucson Association for the Blind

Mission Chips

Safeway at Oracle and Ina

Bookman's Used Books

# ***ADDRESSING THE NEEDS OF INDIVIDUALS WHO ARE DEAF-BLIND***

**Thursday and Friday, October 12 and 13, 1995**

Berger Performing Arts Center  
Arizona State Schools for the Deaf and the Blind  
1200 W. Speedway Blvd., Tucson, Arizona  
(Parking in East Parking Lot only)

## **TOPICS**

Thursday, October 12, 1995  
8:00 am - 5:00 pm

- Philosophy of Service Provision to Individuals Who are Deaf-Blind
- Overview and Etiologies of Deaf-Blindness
- Basic Behavioral Practices & Principles
- Accessing the Community
- Recreation and Leisure Experiences

Friday, October 13, 1995  
8:00 am - 4:00 pm

- Vision Conditions and Their Effect on Functioning
- Environmental Considerations & Adaptations
- Assistive Technology and Communication Devices
- Personal Futures Planning As a Tool To Drive Services
- Individual Question & Answers sessions with the experts on:  
Behavioral issues, Interpreting, Transition, Recreation,  
Orientation & Mobility, and Deaf-Blindness.

**Conference sponsored by:**

Community Outreach Program for the Deaf  
Arizona Deaf-Blind Project  
Rehabilitation Services Administration/ DES  
Arizona State Schools for the Deaf and the Blind

## ARIZONA TRANSITION TEAM ON DEAF-BLINDNESS STATE AND LOCAL TEAM PARTNERSHIP PROJECT (ATTDB)

The ATTDB is a statewide interagency group which is working with Local Community Transition Teams to improve transition outcomes for people who are deaf-blind.

The team is using a three tiered approach to developing transition services which work simultaneously from the state level down and the local, individual level up:

- Level 1 - Statewide systems change through interagency planning, collaboration, and problem solving with the State Transition Team (ATTDB).
- Level 2 - Local problem solving and leadership through interagency planning and collaboration with Local Transition Teams.
- Level 3 - Planning and problem solving for deaf-blind individuals at the local sites with direct service providers.

The teams at all levels will be comprised of stakeholders in the transition process including parents, educational agencies, adult service agencies, and students. One goal of the ATTDB is to develop a model to plan for transition, which if successful with this most challenging group of students will be replicable for all students.

Participation in the project is available to local school districts and communities which apply. Together with the Helen Keller National Center, the State Transition Team will provide training and technical assistance to participating districts through three Local Team Training workshops and other consultations. Each local team participating in the project must identify two deaf-blind individuals to target for transition planning, and must commit to attending the Local Team Training workshops. Local teams will be chosen from those participating in ADE's Project ACTT.

The State Team (ATTDB) is comprised of members from:

- AZ Department of Education
- AZ Deaf-Blind Project, ASDB
- Parents and parent groups
- University of Arizona
- Division of Developmental Disabilities
- Vocational Rehabilitation
- Department of Health Services
- Community Outreach Program for the Deaf

The project is receiving technical support from the Helen Keller National Center for Deaf-Blind Youths and Adults - Technical Assistance Center.

### FOR MORE INFORMATION CONTACT:

Cindi Robinson, AZ Deaf-Blind Project: (520) 770-3677  
Laura Love, AZ Department of Education: (602) 542-3184

# **STATE and LOCAL PARTNERSHIP PROJECT**

## **Three tiered approach to transition services:**

### **Level 1: Interagency State Team**

Address statewide issues with representation from state agencies and resources who can provide input or implement policy changes:

- AZ Deaf-Blind Project
- AZ Dept of Education
- AZ Behavioral Health
- Parents
- AZ Assoc of Parents of VI
- HKNC TAC staff
- Vocational Rehabilitation
- COPD (Adult Service Agencies)
- University of Arizona (personnel prep)
- HKNC Regional Representative
- Division of Developmental Disabilities

### **Level 2: Local Transition Team**

Address and problem solve local/regional issues with representation from agencies involved with transition:

- Educational representation (LEAs, Tribal/BIA Schools)
- Vocational Rehabilitation representation
- Behavioral Health representation
- Student representation
- Adult Service Provider representation (COPD, DDD, group homes)
- ASDB Regional Cooperative staff

### **Level 3: Local Site Team**

Address and problem solve issues specific to individuals ages 14-22+ in process of transitioning, with representation from direct service providers:

- teacher, therapists, aides, etc.
- group home staff
- parents, student/individual
- vocational personnel: job coach, teacher, boss, etc.



# TRANSITION

## Arizona Transition Team on Deaf-Blindness

*by Linda Carpenter, Parent*

I am a parent of a young adult who will be transitioning out of school in a few short months. I am also a member of the Arizona Transition Team on Deaf-Blindness, which is an interagency team sponsored by the Helen Keller National Center/Technical Assistance Center and consisting of representatives from the following agencies: DES/Vocational Rehabilitation, DES/Division of Developmental Disabilities, Arizona Department of Education/Exceptional Student Services, College of Education/University of Arizona, Department of Health Services/Behavioral Health Services, Arizona Deaf-Blind Project, Community Outreach Program for the Deaf, Valley Center of the Deaf, and Arizona Association for Parents of the Visually Impaired. The focus of the team is an interagency approach to achieving person-centered outcomes through a state and local team partnership. I was fortunate to have my son, Kevin, designated as one of the case studies to implement this interagency approach.

For me personally, from a parent's point of view, the process has been very rewarding. A local team, again consisting of representatives from the afore-mentioned agencies, is now collaborating to creatively problem-solve barriers to Kevin's inclusion in the community through personal futures planning, where Kevin's desires are becoming reality with support services being accessed. The sharing of information, the understanding of the various roles of different agencies, and just the fact that we all sit down together to communicate has been a great source of support for me. The state team provides training and additional resources and support. A consequence of attempting to bridge Kevin's gaps to inclusion in the community is systems change, which in turn will benefit even more young adults going through the transition process. End result - individuals with disabilities have opportunities to transition into integrated, normalized environments.



## ATTDB LOCAL TEAM TRAININGS

### 1st Local Team Training - Feb. 1995

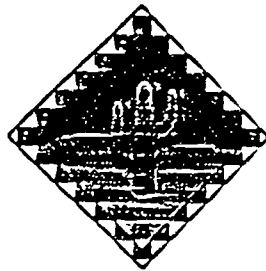
History of Deaf-Blind Services  
The Model: State & Local Team Partnership Project  
Overview of Transition Services Nationally  
Overview of Person Centered Planning  
Deaf-Blind Simulation Activity  
Best Practices in Transition  
Adult Service Options in Arizona  
Team Building & Interagency Collaboration  
Case Study Approach  
Values & Mission Statements  
Action Planning  
Team Activities and Processing

### 2nd Local Team Training - Sept. 1995

Group Reports  
Team Effectiveness  
Deaf Culture  
Deaf-Blind Culture  
Communication Styles and Strategies  
Accessibility  
What Are We Learning About the Model?  
Transportation:     -Seattle Metropolitan Transit System  
                          -Rural Montana Approaches  
                          -Rural Arizona Issues & Solutions  
Team Activities and Processing

### 3rd Local Team Training - April 1996

The Big Picture: Where & How You Fit In  
Linking With Other Community Teams  
Interagency Roles and Relationships  
Effective Leadership Strategies  
Community Representation and Activation  
Dreams & Directions  
Team Ownership & Responsibility  
Community Showcase  
Next Steps: Where Do We Go From Here?  
Team Activities and Processing



**ARIZONA TRANSITION TEAM ON DEAF-BLINDNESS  
STATE AND LOCAL TEAM PARTNERSHIP PROJECT**

Local Team Training  
February 8-10, 1995  
Hassyampa Inn  
Prescott, Arizona

**AGENDA**

Wednesday, February 8th

Noon - 1:00 p.m.	Registration	Parents
1:00 - 2:00 p.m.	History of Deaf-Blind Services & Project Goals of Conference, Getting Acquainted	C. Robinson L. Love
2:00 - 3:00 p.m.	Overview of Transition Services Nationally & Locally	
3:00 - 3:15 p.m.	BREAK	
3:15 - 4:30 p.m.	Overview of Person Centered Planning	J. Everson
4:30 - 5:00 p.m.	BREAK	
5:00 - 6:00 p.m.	Deaf-Blind Experiential Activity	J. Schiller & J. Enos
6:00 - 7:30 p.m.	Group Dinner & Discussion of Simulation Experience Overview of Deaf-Blindness	
7:30 p.m.	Adjourn	

Thursday, February 9th

9:00 - 9:15 a.m.	Re-cap of Wednesday & Overview of Thursday	C. Fuller J. Downing
9:15 - Noon	Best Educational Practices Leading to Transition	
12:00 - 1:00 p.m.	LUNCH	
1:00 - 1:45 p.m.	Adult Service Options	A. Levy L. Love & G. McLaughlin
1:45 - 3:00 p.m.	Team Building & Interagency Collaboration	
3:00 - 3:15 p.m.	BREAK	
3:15 - 5:00 p.m.	Values & Mission Statements, Ground Rules, & Action Planning Teams work together to develop value statement, mission state- ment, and ground rules	J. Everson & J. Enos
5:00 - 6:00 p.m.	BREAK	
6:00 - 7:30 p.m.	Group Dinner	
7:30 p.m.	Adjourn	

Friday, February 10th

9:00 - 9:30 a.m.	Bringing It All Together: Case Study Approach, Personal Futures Planning, the Team Process, and Transition Planning	J. Everson
9:30 - 11:30 a.m.	Team Action Planning	

## LOCAL TEAM TRAINING II

Prescott Arizona

September 18 - 20, 1995

### Monday, September 18, 1995

1:00 - 2:00 pm	Introductions Group Reports (10 min. ea.)	Cindi Robinson Gay McLaughlin
2:00 - 5:00 pm	Team Effectiveness (break included)	Jerrie Ueberle
5:00 pm	Adjourn	

### Tuesday, September 19, 1995

8:00 - 8:45 am	Deaf Culture	Barbara Hyde
8:45 - 9:30 am	Deaf-Blind Culture	Mark Landreneau
9:30 - 9:45 am	Break	
9:45 - 12:00 pm	Communication: Styles & Strategies	Stephanie MacFarland
12:00 - 1:00 pm	Lunch	
1:00 - 2:45 pm	Communication (con't)	Stephanie MacFarland
2:45 - 3:00 pm	Break	
3:00 - 3:30 pm	Accessibility For All Team Members	Chris Fuller
3:30 - 5:00pm	"What Are We Learning About The Model?"	JoAnn Enos
5:00 pm	Adjourn	
6:00 pm	*****Dinner at El Chaparral, Sponsored by Arizona Deaf-Blind Project*****	

LOCAL TEAM TRAINING II  
Prescott, Arizona

Wednesday, September 20, 1995

8:30 - 12:00 pm

"What the Community Can Do To Help  
Expand Transportation Options"

8:30 - 10:00 am	Seattle Metro System	Mark Landreneau Bob Carroll
10:00 - 10:15 am	Break	
10:15 - 11:30 am	Rural Transportation	Steve Dalin
11:30 - 12:00 pm	Prescott Transportation	Wendy Alexander
12:00 - 1:00 pm	Lunch Action Planning Evaluation	JoAnn Enos
1:00 pm	Adjourn	

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THE ARIZONA DEAF-BLIND PROJECT

PARENT AND PROFESSIONAL LENDING LIBRARY

The materials listed on the following pages are available on loan on a-first-come-first-serve-basis by contacting the Arizona Deaf-Blind Project at:

Arizona State Schools for the Deaf and the Blind  
1200 W Speedway Blvd/P.O. Box 85000  
Tucson, AZ 85754

or call

(520) 770-3677

**Due to the high volume of requests, the loan period is TWO WEEKS.**

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(Availability of alternative formats of the materials will be indicated in the description of each title.)

## BOOKS/PAMPHLETS IN ENGLISH

- An Assessment Instrument for Families: Evaluating Community-Based Residential Programs for Individuals with Deaf-Blindness  
Helen Keller National Center - Technical Assistance Center,  
Hilton/Perkins Project, Members of the National Parent Network  
Advisory Committee, HKNC 111 Middle Neck Road, Snads Point, NY  
11050, 9/91.
  
- Augmentative Communication for Children with Deaf-Blindness:  
Guidelines for Decision-Making  
C. Cress, P Mathy-Laikko, J Angelo, Communication SKills Center,  
Teaching Research Division, 345 North Monmouth Ave., Monmouth, OR  
97361,
  
- Choosing Options and Accommodations for Children (COACH) A Guide to  
Planning Inclusive Education  
Michael F. Giangreco, Ph. D., Chigee J. Cloninger, Ph.D., and  
Virginia Salce Iverson, M.ED., 1993, \$29.00, Paul Brooks Publishing,  
P.O. Box 10624, Baltimore, MD 21285-0624, 1-800-638-3775)
  
- Collaborative Teaming for Inclusion Oriented Schools: An  
Introduction and Video Guide  
Brief guidelines for developing instructional teams for deaf-blind  
students.
  
- Communication Development In Young Children With Deaf-Blindness:  
Literature Review I  
M. Bullis Editor, Deaf-Blind Communication SKills Center, Teaching  
Research Division, 345 North Monmouth Ave., Monmouth, OR 97361, 1985.
  
- Communication Development In Young Children With Deaf-Blindness:  
Literature Review II  
M. Bullis Editor, Deaf-Blind Communication SKills Center, Teaching  
Research Division, 345 North Monmouth Ave., Monmouth, OR 97361, 1988.
  
- Community-Based Curriculum  
Mary A Falvey, Ph.D., 2nd ed, 1994, \$31.00, Paul Brooks Publishing,  
P.O. Box 10624, Baltimore, MD 21285 0624, 1 800-638 3775)
  
- Curricular Adaptations: Accommodating the Instructional Needs of  
Diverse Learners in the Context of General Education.

- Dancing Cheek to Cheek  
Discusses beginning social, play and language interactions, Blind Children's Center, 4120 Marathon Street P.O./Box 29159, Los Angeles, CA 90029-0519.
  
- Deaf-Blind Services in the 90's, Proceedings of the National Conference on Deaf-Blindness  
March 21-25, 1992, Hilton/Perkins National Program.
  
- Developing Sign Communication with the Multi-Handicapped Sensory Impaired Child  
Handbook to Accompany the INSITE Communication Program on the Development of Primitive, Co-active and Interactive Signing, S. Watkins, Home Oriented Program Essentials (HOPE) Inc., 809 North 800 East, Logan, Utah 84321, (801) 752-9533
  
- Employment Options for Young Adults with Deaf-Blindness, Philosophy, Practice, New Directions  
S Barrett, A Smith Editors, Helen Keller National Center - Technical Assistance Center, HKNC 111 Middle Neck Road, Sands Point, NY 11050, 7/86.
  
- Enhancing Interactions Between Service Providers and Individuals Who Are Severely Multiply Disabled: Strategies for developing Non-Symbolic Communication  
E. Siegel-Causey, and D. Guess, Editors, Communication Skills Center, Teaching Research Division, 345 North Monmouth Ave., Monmouth, OR 97361, 1988.
  
- Friends: A Manual for Connecting Persons with Disabilities and Community Members, A networking resource book.
  
- Get a Wiggle On  
A booklet for parents of blind or visually impaired infants with suggestions for assisting development from birth to the walking stage.
  
- Hand-In-Hand: Essentials of Communication and Orientation and Mobility for your students who are Deaf-Blind  
Huebner, Prickett, Rafalowski Welch, and Joffee, 1995, AFB Press  
Eleven Penn Plaza Suite 300, NY, 10011,  
Volume I and II - Self Study Curriculum, and Appendix and Glossary  
Volume III - Selected Reprints  
Volume IV - Trainer's Manual



--Heart to Heart

Parents of blind and partially sighted children talk about their feelings, Available in English and Spanish, Blind Children's Center, 4120 Marathon Street P.O./Box 29159, Los Angeles, CA 90029-0519.

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J. Meadows, A training module developed in cooperation with the Accessing Technology Through Awareness in Indiana Project, Indiana State University, Terre Haute, IN, 7/95.

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Donna Sauerburger, American Foundation for the Blind, 15 West 16TH Street, New York, NY 10011, (7118) 852-9873, 1993, \$35.00

--Inclusive Instructional Design: Facilitating Informed and Active Learning for Individuals Who Are Deaf-Blind in Inclusive Schools

K. Gee, M. Alwell, N. Graham, L. Goetz, California Research Institute, San Francisco State University, 612 Font Boulevard, San Francisco, CA 94132, 8/94.

--Individualized Curriculum Sequence and Extended Classroom Models for Learners Who are Deaf and Blind

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--Interagency Collaboration for Young Adults with Deaf-Blindness: Toward a Common Transition Goal

J. Everson, P. Rachal, and M. Michael, Helen Keller National Centers, 111 Middle Neck Road, Sands Point, NY 11050, 1/92.

--It's Never Too Early, It's Never Too Late

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--John Tracy Clinic Correspondence Learning Program for Parents of Young Deaf-Blind Children

John Tracy Clinic 806 West Adams Boulevard Los Angeles, CA 90007, 1-800-522-4582.

- Learning to Play  
Discusses how to present play activities to the visually impaired preschool child, Blind Children's Center, 4120 Marathon Street P.O./Box 29159, Los Angeles, CA 90029-0519.
- Learning the Way: A Guide for the Home Visitor Working With Families on the Navajo Reservation, 1995. AZ Schools for the Deaf and the Blind, PO Box 85000, Tucson, AZ 85754. Regional Services Program, (520) 770-3677.
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- Move It  
A sequel to Get a Wiggle On, this booklet contains suggestions for assisting the development of a preschool blind or visually impaired child from walking to school entrance age.
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A parent's guide to movement development for visually impaired babies, Blind Children's Center, 4120 Marathon Street P.O./Box 29159, Los Angeles, CA 90029-0519.
- Maps: A Plan for Including All Children in Schools  
Strategies for full integration of students with disabilities.
- A Needs-Assessment of Agencies Serving Individuals with Deaf-Blindness: A National Profile of Transitional Services  
L. Seiler, J. Everson, T. Carr, Helen Keller National Centers, 111 Middle Neck Road, Sands Point, NY 11050, 1/92.
- New Horizons: For father of Children with Special Needs
- A New Way of Thinking  
Minnesota Governor's Planning Council on Developmental Disabilities, a history and outlook on governmental policy concerning developmental disabilities.
- One Step at a Time: A Manual for Families of Children with Hearing and Vision Impairments  
Minnesota Governor's Planning Council on Developmental Disabilities.
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J Rich, and E. Rich, Communication Skills Center, Teaching Research Division, 345 North Monmouth Ave., Monmouth, OR 97361.
- Proceedings of the National Symposium on Children and Youth Who Are Deaf-Blind  
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Marathon Street P.O./Box 29159, Los Angeles, CA 90029-0519.
  
- Read My Lips It's My Choice ... Workbook for Community Integration  
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- Research on the Communication Development of Young Children with  
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M. Bullis, Editor, Communication Skills Center, Teaching Research  
Division, 345 North Monmouth Ave., Monmouth, OR 9736, 11/89.
  
- A Resource Manual for Understanding and Interacting With Infants,  
Toddlers, and Preschool Age Children With Deaf-Blindness  
Home Oriented Program Essentials (HOPE) Inc., 809 North 800 East,  
Logan, Utah 84301 . (801) 752-9533.
  
- SAILS Systematic Approach to Independent Living Skills, A Functional  
Assessment and Programming guide for deaf-blind youths, and other  
moderate or severely handicapped individuals  
Independent Living Project, Florida School for the Deaf and the  
Blind, 1209 San Marco Ave., St. Augustine, FL, 4/85.
  
- A Series of Training Modules on Educating Children and Youth with  
Dual Sensory and Multiple Impairments  
VOL. I - Parent Training Modules, VOL. II - Professionals Training  
Modules, TASH/TRACES, Teaching Research Division, 345 North Monmouth  
Ave., Monmouth, OR 97361.
  
- Selected Readings on the Preparation of Personnel for the Education  
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and Low Vision, P.O. Drawer 6189, Mississippi State, MS 39762, 1993.

- Sensory Assessment Manual  
P. Cress, Communication Skills Center, Teaching Research Division,  
345 North Monmouth Ave., Monmouth, OR 9736.
- Setting a New Course: Defining Quality Lifestyles for Students with  
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- Speak Up for Health: A Handbook for Parents. Strategies for  
preparing adolescents with chronic illness in his disabilities for  
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4826 Chicago Ave. S., Minneapolis, MN 55417 (612) 827-2966. 1993
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Talladega, AL 35160, 1979.
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A.B. Best, BIMH Publications, Foley Industrial Park, Stourport Road,  
Kidderminster, Worcs., Dyl17QG, 1987.
- Supporting Children with Disabilities in Early Childhood Programs.  
Service strategies for preschoolers with disabilities and their  
families.
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Transition Planning Guide for Service Providers, Families, and  
Friends  
Edited by Jane M. Everson, Ph.D., 1994, \$39.00. Paul Brooks  
Publishing, P.O. Box 10624, Baltimore, MD 21285-0624, 1-800-638-3775
- Talk to Me  
A language guide for parents of blind children. Available in  
English and Spanish, Blind Children's Center, 4120 Marathon Street  
P.O./Box 29159, Los Angeles, CA 90029-0519.
- Talk to Me II  
A sequel to Talk to Me. Available in English and Spanish, Blind  
Children's Center, 4120 Marathon Street P.O./Box 29159, Los Angeles,  
CA 90029 0519.
- Teaching Youth who are Deaf-Blind, Observed Practices  
B.J. Maxson, and A. Lamb, Mississippi State University,  
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- Technology Resources Nationally, A resource directory  
L. Trachtman, and J Brown Jr., Center for Rehabilitation Technology  
Services, South Carolina Vocational Rehabilitation Department, West  
Columbia, South Carolina 29171 0015, 9/90.

- Usher's Syndrome: What It Is, How to Cope, How to Help  
Earlene Duncan, Hugh Prickett, Dan Finkelstein, McCay Vernon, Toni Hollingsworth, with support from the Center on Deafness at Western Maryland College, Charles Thomas Publishers, 2600 South First Street, Springfield, IL 62794-9265, 1988
- Value-Based Services for Young Adults with Deaf-Blindness  
A. Covert and T. Carr, Editors, Helen Keller National Centers, 111 Middle Neck Road, Sands Point, NY 11050, 3/14-16/88.
- Vocational Preparation and Employment of Students with Physical and Multiple Disabilities. J. Sowers and L. Powers. Paul H. Brooks Publishing Co. P.O. Box 10624, Baltimore, MD 21285-0624. 1991
- Watch Me Grow  
This Spanish/English book contains month by month suggestions for assisting the development of a blind or visually impaired infant from birth to age three.

## VIDEOTAPES IN ENGLISH

--Addressing the Needs of Individuals Who Are Deaf-Blind (Conference videotapes) AZ Deaf-Blind Project. P.O. Box 85000, Tucson AZ, 85754.

Tape 1: Keynote by Deaf Blind Consumer Philosophy of Service Provision for Deaf-Blind Individuals.

Tape 2: Overview and Etiologies of Deaf-Blindness.

Tape 3: Behavioral Practices and Principles.

Tape 4: Accessing the Community Through Independent Travel.

Tape 5: Recreation and Leisure Experiences for Individuals with Deaf-Blindness.

Tape 6: Psychological and Environmental Aspects of Dual Sensory Loss (Ushers Research).

Tape 7: Personal Futures Planning As A Tool to Drive Services.

Tape 8: Assistive Technology and Communication Devices for Individuals With Dual Sensory Impairments.

--Administrative Issues in Community-Based Instruction.  
Southeast Kansas Education Service Center, P.O. Box 189, Girard, KS 66743, 1-(800)531-3685.

--Ain't Misbehavin': Strategies for Improving the Lives of Students who are Deaf-Blind and Present Challenging Behaviors  
Texas school for the Blind and Visually Impaired, Deaf-Blind Outreach, 1100 W 45TH St., Austin, Texas, 78756, (512) 454 8631, 1993, 17 min.

--Changes In Paces In South Dakota  
South Dakota Dept. of ED., Nine Tape Series, WalkerVision Video, P.O. Box 930182, Verona, WI 53593-0182, 1-800-438-9832, available in English or Spanish, closed captioned.

Volume OneWhen and Where to Teach

This program discusses when and where teaching works best for the whole family.

Examples show teaching done in natural settings and at normal times throughout the day.

Teaching Self Control

This program covers why teaching can sometimes be a challenge for all parents.

Examples show ways to help children with special needs learn to express themselves more appropriately.

Teaching Playtime Skills

This program explains the importance of play. Examples demonstrate ways parents can enhance turn taking and choice making.

Volume TwoWhat to Teach

This program discusses skills and behaviors children with special needs must learn.

Examples show ways parents can break down learning tasks into small manageable steps.

Teaching Choices

This program examines choice as a skill critical to all children.

Examples show different ways children communicate, and the importance of practice on a daily basis.

Teaching Dressing Skills

This program outlines ways parents can help children develop dressing skills.

Examples show parents using guiding techniques as children learn to dress.

Volume ThreeHow to Teach

This program discusses how learning occurs and ways parents help the process be successful

Examples show verbal, physical, and visual cues that help children learn.

Teaching with Adaptations

This program highlights how adaptations can increase a child's participation and independence. Examples show ways adaptations allow children to be successful.

Teaching Mealtime Skills

This program examines how to select mealtime skills to teach children with special needs.

Examples show how to move with and support children as they learn.

- Collaborative Teaming for Inclusion-Oriented Schools. Note:  
request accompanying Introduction and Video Guide booklet, Southeast  
Kansas Education Service Center, P.O. Box 189, Girard, KS 66743, 1  
(800) 531-3685.
  
- Community-based Independent Living Training for Students with Severe  
Multiple Handicaps and Deaf-Blindness  
Southeast Kansas Education Service Center, P.O. Box 189, Girard, KS  
66743, 1 (800) 531-3685.
  
- Community-based Recreation and Leisure Training for Students with  
Severe Multiple Handicaps and Deaf-Blindness  
Southeast Kansas Education Service Center, P.O. Box 189, Girard, KS  
66743, 1 (800) 531-3685.
  
- Community-based Vocational Training for Students with Severe  
Multiple Handicaps and Deaf-Blindness  
Southeast Kansas Education Service Center, P.O. Box 189, Girard, KS  
66743, 1 (800) 531-3685.
  
- Hand-In-Hand: It Can Be Done  
Huebner, Prickett, Rafalowski Welch, and Joffee, 1995, AFB Press  
Eleven Penn Plaza Suite 300, NY, 10011, videotape to accompany the  
Hand-In-Hand curriculum, 60 min, closed captioned.
  
- Integrated Delivery of Related Services  
Southeast Kansas Education Service Center, P.O. Box 189, Girard, KS  
66743, 1 (800) 531-3685.
  
- MAPS: A Plan for Including All Children in Schools, request booklet  
of the same title.  
Southeast Kansas Education Service Center, P.O. Box 189, Girard, KS  
66743, 1 (800) 531-3685.
  
- Now Is The Time: Integrated Work for Persons with Dual Sensory  
ImpairmentsTASH, 11201 Greenwood Avenue N, Seattle, WA 98133.
  
- The Oberti Decision: A Discussion on Inclusion  
GATEWAYS Project, Distance Learning Center, Pennsylvania Department  
of Education, Proceedings from the November 1, 1993 Video  
Teleconference.
  
- Partners in Success  
HKNC, 111 Middleneck Rd., Sandpoint, NY 11050, (516) 944-8900.



--SKI\*HI Coactive Tactile Sign Language Videotape Program  
 Home Oriented Program Essentials (HOPE) Inc., 809 North 800 East,  
 Logan, Utah 84321, (801) 752-9533

Tape 1

Lesson 1: Family Members and Interacting with Family  
 Mini Lesson 1: How to Approach and Leave Your Child; Importance of  
 Touch

Lesson 2: Foods  
 Mini Lesson 2: Positioning Yourself When Using Coactive Signing

Tape 2

Lesson 3: Daily Routines: Eating  
 Mini Lesson 3: Deciding Which Coactive Signs to Use First

Lesson 4: Daily Routines: Dressing and Undressing; Toileting  
 and Diapering  
 Mini Lesson 4: A Model for Daily Coactive Sign Use

Tape 3

Lesson 5: Daily Routines: Washing and Bathing  
 Mini Lesson 5: Form and Speed in Coactive Signing

Lesson 6: Daily Routines: Teeth and Hair; Getting Up and  
 Going to Bed

Lesson 6: Helping Child Learn Coactive Signs Through  
 Frequency and Consistency

Tape 4

Lesson 7: Daily Routines: Play and Sensory Stimulation  
 Mini Lesson 7: Encouraging Your Child to Make Signs on His Own:  
 Reinforcing

Lesson 8: Feelings; Being Sick  
 Mini Lesson 8: Encouraging Child to Make Signs on His Own:  
 Turn-Taking

Tape 5

Lesson 9: Action Words in Daily Routines  
 Mini Lesson 9: Maximizing Child's Residual Senses When Using  
 Coactive Signing

Lesson 10: More Action Words and Prepositions in Daily  
 Routines  
 Mini Lesson 10: Optimizing Coactive Signing for Children with  
 Different Visual Impairments

Tape 6

Lesson 11: Going Places and Visiting People  
 Mini Lesson 11: Conveying Meanings and Emotions in Coactive Signing

Lesson 12: Special Words for Sensory Impaired Children  
 Mini Lesson 12: Moving from Coactive to Interactive Signing

Tape 7

- Unit 1: Toys and Animals
- Unit 2: Body Parts
- Unit 3: Colors
- Unit 4: Letters and Numbers
- Unit 5: Things in the Home
- Unit 6: Food
- Unit 7: Being Sick and Getting Hurt
- Unit 8: Time Words

Tape 8

- Unit 9: Prepositions, Connectors, and Question Words

--SKI\*HI Using Tactile Interactive Conversational Signing With Individuals Who are Deaf Blind  
Home Oriented Program Essentials (HOPE) Inc., 809 North 800 East, Logan, Utah 84321, (801) 752-9533, closed captioned.

Tape 1

- Topic 1- Encouraging Independent Signing: Moving from Coactive to Interactive Signing (18 min.)
- Topic 2- Establishing a Foundation for Conversational Interaction: Encouraging the Child to Sign Interactively (15 min)
- Topic 3- Suggestions to Encourage Language Development: Vocabulary (16 min.)

Tape 2

- Topic 4- Suggestions to Encourage Language Development: Using Comments, Directions, and Questions (15 min.)
- Topic 5- Creating a Communicative Environment: Using Calendar Systems (16 min.)
- Topic 6- Creating a Communicative Environment: Encouraging Independence and Providing Rich Language Opportunities (14 min.)

Tape 3

- Topic 7- Selecting Materials and Activities that Promote Interaction (10 min.)
- Topic 8- Establishing Guidelines for Effective Conversation (15 min.)
- Topic 9- Conveying Emotions and Meanings Through Tactile Signs (10 min.)
- Topic 10- Fingerspelling (14 min.)

Tape 4

- Topic 11- Encouraging Interaction with Peers and Others Within the Community (18 min.)
- Topic 12- Interpreting for the Individual who is Deaf-Blind (18 min.)

Tape 5

- Topic 13- Introduction to Tactile Communication Series (22 min.)

--SKT\*HI Using Tactile Signals and Cues with Children Who are Deaf  
Home Oriented Program Essentials (HOPE) Inc., 809 North 800 East,  
Logan, Utah 84321, (801) 752-9533, closed captioned.

Tape 1

- Topic 1- Encouraging Your Child To Relate to People
- Topic 2- Letting Your Child Know Who You Are and What You Will Do
- Topic 3- Deciding What Signals and Cues to Use
- Topic 4- A Model for Using Signals and Cues

Tape 2

- Topic 5- Skill: Anticipation / Activity: Getting Up and Playing
- Topic 6- Skill: Awareness of the Child's  
Signals / Activity: Toileting/Bathing

Tape 3

- Topic 7- Skill: Responding to Your Child's Signals / Activity:  
Eating/Feeding
- Topic 8- Skill: Encouraging Turn-Taking / Activity: Waking/Going to  
Bed

Tape 4

- Topic 9- Skill: Giving Choices / Activity: Playing and Actions
- Topic 10- Skill: Using Coactive Signs / Activity: Placing and  
Calming Your Child

Tape 5

- Topic 11- Skill: Enriching Activities to Encourage Communication /  
Activity: Feelings and Senses
- Topic 12- Skill: Encouraging Your Child to be an Active Communicator  
Activity: Going Somewhere

--State and Local Team Partnership Project: First Local Team Training  
(Conference Videotapes).

- Tape 1: Overview of Transition.
- Tape 2: Person Centered Planning, Overview of Deaf-Blindness.
- Tape 3: Functional Programming and Best Practices.
- Tape 4: (Con't) Functional Program, Adult Service Options.
- Tape 5: Values, Mission, Ground Rules.
- Tape 6: Action Planning.

--State and Local Team Partnership Project: Second Local Team Training  
(Conference Videotapes)

- Tape 1: Team Effectiveness.
- Tape 2: Deaf Culture; Deaf-Blind Culture.
- Tape 3: Communication.
- Tape 4: Communication (Con't).
- Tape 5: Transportation - Seattle (Urban).
- Tape 6: Transportation - Montana and Prescott (Rural).

- Within Reach: Getting To Know People Who Are Deaf-Blind  
Technical Assistance Project, 1987, TASH, 11201 Greenwood Avenue N,  
Seattle, WA 98133
- What Are You Trying to Tell Me? ("Que Estas Tratando de  
Decirme?")  
Foundation for the Junior Blind - Infant Family Program, 5300  
Angeles Vista Boulevard, Los Angeles, CA 90043. Information in  
Spanish with English subtitles (open captioned).
- What IDEA Says About Transition In the IEP  
AZ Department of Education, 1535 W. Jefferson, 3rd Fl., Phoenix, AZ  
85007. (602) 542-2805.
- Workplace of the 90's  
Telesensory, 455 N. Bernardo Ave., P.O. Box 7455, Mountain View, CA  
94039.
- You & Me, A Five-Part Video Series About Educating Children Who Are  
Deaf-Blind  
Teaching Research Division, 345 N. Monmouth Ave., Monmouth, OR  
97361, (503) 838-8792, 1994, \$15.00 ea  
Tape 1: Introduction (Do not have other 4 tapes.)

## BOOKS/PAMPHLETS IN SPANISH

- De Corazon a Corazon (Heart to Heart)  
Padres de ninos ciegos y parcialmente ciegos hablan acerca de sus sentimientos, Blind Children's Center, 4120 Marathon Street P.O./Box 29159, Los Angeles, CA 90029-0519.
- Hablame (Talk to Me)  
Una guia de lenguaje para padres de ninos ciegos.  
Blind Children's Center
- Hablame II (Talk to Me II)  
Preocupaciones Comunes.  
Blind Children's Center
- John Tracy Clinic Programa de Ensenanza Por Correspondencia Para Los Padres de Ninos Sordo-Ciegos  
(John Tracy Clinic Correspondence Learning Program for Parents of Young Deaf-Blind Children), John Tracy Clinic 806 West Adams Boulevard Los Angeles, CA 90007, 1-800-522-4582
- Muevete Conmigo (Move With Me)  
Guia Para los Padres Sobre el Desarrollo de Movimientos de Bebes Impedidos de la Vista  
Blind Children's Center
- Reaching, Crawling, Walking ... Let's Get Moving  
Orientation and mobility for visually impaired preschool children.  
(Available in English and Spanish.)  
Blind Children's Center
- Watch Me Grow  
This Spanish/English book contains month by month suggestions for assisting the development of a blind or visually impaired infant from birth to age three.  
Blind Children's Fund 230 Central Street Auburndale, MA 02166

## VIDEOTAPES IN SPANISH

- South Dakota Dept of Ed.--Changes in Paces in South Dakota  
"Helping Your Child Learn With Adaptations",  
Entire series available in Spanish dub, (English closed captioned).  
WalkerVision Video P.O. Box 930182 Verona, WI 53593-0182
- Foundation for the Junior Blind-Infant Family Program  
"Que Estas Tratando de Decirme?" (What Are You Trying to Tell Me?)  
Foundation for the Junior Blind - Infant Family Program 5300 Angeles  
Vista Boulevard, Los Angeles, CA 90043, English open captioned.



# ARIZONA DEAF-BLIND PROJECT NEWSLETTER

Arizona State Schools for the Deaf and the Blind

Vol. 1, Number 3

## Deaf-Blind Update Don Welch

(Project Director)

The Arizona Deaf-Blind Project has been funded for another three year cycle. We were successful in getting an increased grant amount, which will enable us to employ a Transition/Education Specialist to assist Emma Wiseley, the Project Manager, to better serve the children with deaf-blindness in the state, along with their parents and service providers.

The 'Project' has three major purposes:

1. To identify all children with deaf-blindness in the state of Arizona.
2. To empower parents to be effective advocates for their children.
3. To assure that service providers have the knowledge and skills to effectively serve the children with deaf-blindness in the state of Arizona.

Nine objectives and numerous activities are identified in the grant to address the major purposes, all of which are obtainable and should result in the grant having greater presence statewide. Since it is very important that we identify all children with deaf-blindness, your help is needed. If you know of any child or youth, birth through 21 years of age, who is deaf-blind who is not, or may not be known to the project, contact Emma Wiseley at 770-3677. Grant activities can only be directed to parents and service providers of children on the project's pupil count.

Currently 81 children with deaf-blindness are on the pupil count, however, according to available statistical data, we should have at least 120 such children in the state. Certainly, one of the problems of identification is the fact that Arizona does not have a funding category for educating children with deaf-blindness. These children are generally reported as Multiply Disabled Severely Sensory Impaired (MDSSI).

The definition for deaf-blindness is: Children and youth between birth and 21 years who have diagnosed or suspected impairments in both vision and hearing which are significant enough to impact the students  
(See Definition)

## Positive Behavior Change: New Thinking, Old Problems

By Larry Douglass

*Taken from the CA Deaf-Blind Services Newsletter Resources March/April, 1991.*

A series of five training days has just been completed in a southern county and one of the teachers has come to a completely new way of looking at the behavior problem of a ten year old boy in her classroom. She now believes that Pete's grabbing and holding onto staff and children is a social skill, a greeting, that we helped him learn. She is ready to abandon her drastic behavior modification measures to "decrease the behavior" and is ready to teach additional social skills to this young man. In addition, she expects that her plan to teach Pete these new skills will take months, if not years. Her analysis is refreshing and her new ideas have opened up a new world for her to try in the classroom. She will now be infusing very specific social skills training into the individual curriculum for Pete. She knows that the new greeting must be physical but something that can happen very quickly so that Pete does not have time to get a firm hold. Alternative ways to say "hi" have now been identified as very functional for this young man.

In a nearby junior high school, Lonnie is on the verge of failing seventh grade because he does not complete his homework. This problem has existed for many years, but now his grades depend more heavily on his completing the homework assignments. His teacher, counselor and mother are involved in a training series that asks them to look at this behavior problem from a new angle. Their analysis has led them to make some drastic changes in how they provide support to Lonnie around his homework. They have made changes so that he could complete his homework before leaving school with help from a family member. The plan included getting this young man on the right track and then working on the skills he needed to be better organized, to arrange for a better homework environment and to establish effective home/school communication about homework assignments. The result of this refocusing on the "behavior problem" has brought Lonnie up to honor roll status. For the first time in his school experience, Lonnie has access to the natural rewards available to students with good  
(See PBC)

**Attention Arizona Teacher and Administrators:**  
You may experience the same success as the above  
California teachers by attending the Tenth Annual  
Integration Conference on Severe Disabilities  
March 4 & 5, 1993

Featured Speaker: Mark Durand, Ph.D.

Topic: Positive Behavior Support

Also, Dr. Caroline Musselwhite will present on  
"Assistive Technology for Individuals with Multiple  
Disabilities Including Deaf-Blindness"

SEE ANNOUNCEMENTS

**(Definition)**

ability to learn, communicate or function in a variety of environments. Any student who has a condition or syndrome known to result in such a degree of combined losses may also be referred regardless of current functioning levels.

In determining which child or youth to refer, acuity levels should be only one factor. Even a mild loss in one sense may be devastating for some students. There are numerous factors which affect perception in addition to acuity. Other factors to consider in determining who to refer may include:

- o children or youth who do not function as well as expected based on current audiological or ophthalmological information;

- o children or youth who have not had their hearing or vision tested, but their parents and teaching staff feel the child may have hearing and vision problems;

- o children and youth who's complex, multiple conditions do not clearly pinpoint the impact of the sensory impairments on learning;

- o children and youth who have audiological and ophthalmological information available, but who's parents and teaching staff are unable to determine the implications of this information in planning for the child;

- o children and youth who are functioning well at this time, but the likelihood of degeneration in one or both senses may need consideration in both current and future planning.

If there is a question about referral, it is better to refer the child who may later be excluded following more intensive evaluation than to overlook a child who could benefit from services. ■

**What is he trying to tell me?**

*Taken from the CA Deaf-Blind Services Fact Sheet for Students 0-22 years of age.*

Some students with dual sensory impairments cannot express some or all of what they want to say through speech, sign language, fingerspelling, writing or gestures. When the students cannot express themselves in these traditional ways, they often choose other ways of expression. The students choose the way that is easiest to get their message across. This expression is communication. The student may communicate through facial expression, body movement, posture, vocalization, crying, tantrums, etc. These reactions are frequently seen by parents and/or professionals as behaviors that need to be eliminated, when in fact the student is trying to communicate and becomes more and more frustrated when his communication is misunderstood. If, instead the student's attempt to communicate can be acknowledged and expanded, difficult behaviors may begin to decrease.

*Points to Remember:*

1. Look at all of the student's behavior as an attempt to communicate.
2. Be sure the student has had medical problems eliminated.
3. Attempt to understand the student's communication efforts.
4. Teach the student a more acceptable way to communicate what he has to say, after showing you understand the effort.

Note by Ed: When teaching a new more acceptable way to communicate, make sure what is being taught allows the student to get what he/she wants as quickly or more quickly than the original communication. ■



(PBC)

(continued from page 1)

academic status. Has this change in focus been healthy for people other than Lonnie? The answer is clearly affirmative. All the adults involved are basking in the success of the effort and share Lonnie's enthusiasm and triumphs. But didn't they try using rewards and contracts as a means of getting Lonnie "on track?". Once again, the answer is yes, but these measures did not work and they were left with expulsion as their only alternative.

These are only two of the success stories that have been the result of a newly initiated training effort from the Special Education Division, California Department of Education, Sacramento. During the school year 1990/91, about 150 teachers, parents, administrators and support staff throughout California have been involved in specific training in the area of Positive Behavior Change.

#### What has changed?

#### Why are we looking for new insights?

In the field of special education, we are routinely working with students who possess significant learning problems as well as challenging behaviors. Our traditional focus has been to look at these problems as being unrelated to the person's quality of life or an issue of non-verbal communication. Consequently, we have used our time and energy to design reactive, consequence-based behavioral interventions to contain and manage difficult behavior problems.

Today in California, we are trying to change our focus when we are working with students with challenging behaviors. We now know that there is something causing most behavior problems and it is only fair that we deal with those issues before we put our efforts into designing a "behavior modification program". It's just good sense to try this positive approach since we know that we have failed to reduce the problems in the past. With the opportunity for training in the exciting area of positive behavior change, teachers, parents and others are making new and creative decisions about student's challenging behaviors. These decisions are leading to the creation of innovative solutions that will teach new skills or will make changes that will better support the individual with challenging behaviors. This notion of examining behavior problems and their origins as communication is different and strange to those who rely most heavily on traditional

behavioral interventions, but throughout this state people in the field are accepting the challenge to refocus their energies and to design creative teaching strategies and plans to promote behavior change in their students. ■

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#### Positive Behavioral References

*In Arizona contact Judy Crowell with the Arizona Department of Education, Special Education Section, at 542-3184, if you are interested in learning more about positive behavioral support or to discuss success strategies used in your classroom.*

o *Progress without punishment: Effective approaches for learners with behavior problems.* Donnellan, A., LaVigna, G., Negri-Shoultz, N., and Fasbender, L. (Teachers College Press, NYC, NY; \$15.95)

o *An educative approach to behavior problems: A practical decision model for interventions with severely handicapped learners.* Evans, I., and Meyer, L. (Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-9945, \$18.75)

o *Cognitive counseling & persons with special needs.* Lovett, H. (Greenwood Press, Inc., Saw Mill Rd., West Haven, CT 06516-4117, \$17.95)

o *Gentle Teaching: A non-aversive approach to helping persons with mental retardation.* McGee, J., Hobbs, D. (Creighton Univ., ATTN: Marie LaGrou, Dept. of Psychiatry, 2205 S. 10th St., Omaha, NE 68108)

o *Alternatives to Punishment: Solving Behavior problems with non-aversive strategies.* Donnellan, A., LaVigna, G., 1986. (Irvington Publishers, Inc., 740 Broadway, Suite 905, New York, NY 10003)

o *Selected references on the use of nonaversive behavior technologies with students who are severely disabled.* (Self-addressed envelope to: Clearinghouse on Community-Referenced Behavior Management, San Francisco State Univ., 612 Font Blvd., San Francisco, CA 94132)

o *Teaching social skills to young children: a parent's guide.* Learning Disabilities Research Project, Interstate Research Associates/NICHCY, Box 1492, Washington, DC 20013)

## Teaching Receptive Communication

Kathryn Heller

Southeast Regional Coordinator

*Taken from TRACES Newsletter by Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments, Summer 1991.*

Providing information and on-site consultation in the area of communication for individuals who are deaf-blind has been the focus of many technical assistance activities. Over the past two years, teachers, service providers, parents, paraprofessionals, administrators and children and youth who are deaf-blind from Maryland, Virginia, North Carolina, Georgia and Puerto Rico have received assistance in this area. These activities have stressed the importance of developing receptive, as well as expressive, communication systems.

Although residual hearing varies among individuals who are deaf-blind, many are unable to rely solely on hearing for receptive communication. Additional receptive input is necessary for the individual to understand what is being communicated. Input may be supplemented through the use of: object cues, touch cues, movement cues, tactile gesture cues, tactile signing, or tactile graphic symbols.

### Types of Additional Receptive Input

Object cues use real objects which relate to the message being delivered. These cues may be whole objects, parts of objects, associated objects, miniatures or arbitrary symbols (Rowland & Stremel-Campbell, 1987). An object related to the activity being discussed is placed in the learner's hand. One advantage of object cues is that they continue to provide information to the learner throughout the course of the activity. Learners who are given a piece of chain to let them know they are going outside to the swing set are not likely to forget where they are going as long as they are holding the chain.

Initially, whole objects that are part of a routine activity are used. For example, the learner is handed a spoon to indicate it is time to eat. Later, an activity may be represented by part of an object, an associated object or an object in miniature form. Handing a learner a piece of sponge to indicate it is time to clean up, or giving the learner the top of the laundry detergent bottle to indicate it is time to do wash are examples of the use of part of an object. Associated objects are not part of the object itself, but are related to the object in some way. A coat hook

could be used to represent a coat. Miniatures and abstract object cues may be used, but they are often more difficult to learn. Giving the learner a miniature table to indicate that it is time to go sit at the classroom table or giving the learner an arbitrary symbol of a smooth circle, to mean work time are examples of the use of miniature and abstract object cues.

Touch cues are minimal physical contact cues which are given to provide information to the learner. The communicator touches the learner in a particular manner on certain body locations to provide information. Examples of touch cues include: touching the learner's mouth to indicate it is time to eat, tapping the learner's mouth to indicate it is time to eat, tapping the learner's shoulder to indicate time to sit down, and rubbing the learner's palm to ask if he or she wants more. For the learner to understand their meaning, these cues must be delivered in the exact same manner across communicators and activities.

Several types of movement cues can be used to provide additional receptive information (Siegel-Causey, & Guess, 1989; Sternberg & McNeerney, 1988; van Dijk, 1986). At first, these involve the communicator and learner moving together at the same time and in the same space. The communicator and learner may move their arms together, making arm to arm contact, as they open a door. To stand, the communicator may sit right next to the learner, with leg to leg contact, and rise together. Later, the movement cues may be given at the same time but without the physical contact.

Tactile gestures, tactile manual signs, or finger-spelling may be used for receptive input as well. Tactile gesture cues are concrete and natural motions while signs are often more abstract movements. With these two systems, the learner's hands are placed over the communicator's hands as he or she is gesturing or signing. For example, the communicator may sign or gesture to go outside while the learner feels what signs or gestures are being communicated. The more difficult system of finger-spelling in the learner's hand may be used with some individuals who are deaf-blind.

Tactile graphic systems provide additional receptive information through the use of raised pictures or symbol which the learner can feel. Some teachers outline the symbols with glue or other materials to provide additional information.

Braille, on the other hand, provides semantic and syntactic information and is a complex, written form of communication. This is a more abstract system which may be too difficult for some learners to use.

(See Teaching)

## (Teaching)

### Use of additional Receptive Input

When using these types of receptive input, there are some general guidelines which should be followed:

1. Selection of the type of receptive input is based on what the learner responds to. Easier systems such as object cues or touch cues may be taught initially. Gradually, more complex forms such as tactile signing or tactile graphic symbols may be taught. However, these more complex forms require the use of more advanced tactile and cognitive skills (Rowland & Stremel-Campbell, 1987).
2. Combination systems may be used (i.e., using object cues and touch cues together); however, too many different kinds of cues may be confusing to the learner.
3. When starting out, it may be helpful to begin with four or five cues and expand as the learner begins to respond.
4. There is no set list of object or touch cues. Teachers and parents should make up their own to fit the learner and the situation. It is helpful to have a list describing each cue the learner responds to. This list should be given to all people working with the learner.
5. It is important that the type of receptive input selected is used consistently with the learner. Touch cues, for example, should be given in the same manner and body location by all people communicating with the learner.
6. Always accompany the selected additional input with spoken words. It is important that the learner use his or her residual hearing.
7. Use additional input cues several times a day during different functional activities.
8. Although the additional input may not be meaningful at first, consistent use and clear outcomes of what happens when the input is used will teach the learner its meaning for signs of anticipation or recognition when the input is used.
9. Often these receptive forms of communication may be used as expressive forms of communication as well. ■

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## References

- Rowland, C., & Stremel-Campbell, K. (1987). Share and share alike: Conventional gestures to emergent language for learners with sensory impairment. In L. Goetz, D. Guess, & K. Stremel-Campbell (Eds.), *Innovative Program designs for individuals with dual sensory impairments* (pp 49-75). Baltimore: Paul H. Brookes.
- Siegel-Causey, E., & Guess, D. (1989), *Enhancing nonsymbolic communication interactions among learners with severe disabilities*. Baltimore: Paul H. Brookes.
- Sternberg, L., & McNemey, C. (1988). Prelanguage communication instruction. In L. Sternberg (Ed.), *Educating students with severe or profound handicaps* (pp. 311-363). Rockville, Maryland: Aspen Pub.
- Van Dijk, J. (1986). An educational curricula for deaf-blind multi-handicapped persons. In D. Ellis (Ed.), *Sensory impairments in mentally handicapped people*, (pp. 375-382). London: Croom-Helm.

*NOTE: The Arizona Deaf-Blind Project has a variety of resources focusing on receptive and expressive communication development. If you would like further information on a method of communication mentioned in the above article, would like more information on different communication methods, or have a specific question, please contact Emma Wiseley at 6770-3677 or write ASDB, P.O. Box 5545, Tucson, AZ 85703. Over the next three years, we hope to expand our services by developing a lending library on a variety of topics which meet the informational needs of individuals with deaf-blindness, their parents, family, teachers, and friends. The depth of the information available depends on your interests. Please let us know them.*



## Child's Play

The following contacts and articles may be helpful in identifying toys which are safe, fun, age-appropriate, and can help your child build friendships and functional skills.

Before purchasing a toy, you may wish to contact your local Lekotek or toy lending library. You and your child may be able to try out the toy you were thinking of or a similar toy. Also, other play ideas may be made available.

For more information contact:

- Tucson: Darri Johnson 745-5222  
Easter Seals Lekotek  
Yuma: Beth Snyder 344-0010  
Easter Seals Lekotek  
Phoenix: Children's Lekotek of Phoenix  
Southwest Human Development  
956-2711 or 266-5976

Computer technology is available through Compuplay for preschool through teenage children and youth.

Contact:

- Tucson: Robyn LaBrosse  
Easter Seals 745-5222  
Phoenix: Sue LeHew  
Easter Seals 252-6061 or  
Children's Lekotek of Phoenix  
956-2711 or 266-5976

## Community Advisory Council Toy Lending Libraries

For Flagstaff residents of Coconino County a toy library is in the planning stages. For more information, contact Debbie Resnick, Department of Health, 779-5164 in Flagstaff or 1-800-458-01601 statewide.

Through a grant from the Arizona Coordinating Council for infants and toddlers and the Four County Conference on Developmental Disabilities, toy lending libraries have been established for use by families with young children (birth -3 years) with delays. The newly developed libraries will be opened soon and located in:

- Prescott: Prescott Public Library  
Cottonwood: Cottonwood Public Library  
Lakeside: Country Care Foundation  
Springerville: Round Valley Public Library

For more information contact:

- Joann Brownlie  
Network for Infants and Toddler Project  
778-3391

## Toy Ideas for Young Children

VIP Newsletter Original Title:  
Christmas Gift Ideas

What can I get my child for Christmas (or birthday)? This list of gift suggestions was put together by the staff of the Center for Blind and Visually Impaired Children, Milwaukee, Wisconsin. Most of these toys can be found at your local toy store.

### Tactile Toys for the Early Learners

1. Koosh Balls
2. Caterpillar squeak toy or wrist toy
3. Spiny hedgehog squeak toy
4. Clutch ball with knobs (good to hold and put in mouth)
5. Plastic slinky in bright orange color

### Light Toys

1. Disney Lighted Mobile
2. Disney Carousel and Music Box

### Cause/Effect Toys for Early Learners

(These toys will give a response to a child's action.)

1. Teddy Beddy Bear Jack-in-the-box by Fisher Price. Roll the box to get the bear to pop-up.
2. Push 'n Dance Bear by Tomy. Push down on a globe, the globe squeaks and the bear moves.
3. Push n' Go Merry-Go-Round by Tomy. Push down on handle and a dingling bell rings for fifteen seconds.
4. Playskool Band. Makes six different instrument sounds. Child sits under the toy as if holding a tab on lap.
5. Popping Car by Fisher Price. Roll it back and forth to produce a popping sound made by balls hitting a trap door and when popping up into a globe.
6. Little Tykes piano or zylophone. Uses an up-and-down hand motion to produce a sound. The sound not continuous and requires a hand motion for each sound.
7. Two-foot-long mini organ. Plays like a piano or organ or in auto-play will produce an entire melody with one key stroke
8. Vibrator pillow. Small, plush pillow that vibrates when pushed in the middle. (Found with back rest pillows in personal products department.)
9. Personal massager (egg shaped). Push down action on a small ball. One name brand in Patata by Homedics.
10. Sound animals. small. push. hand-held animals that make a sound when you tip them over. (See Toys)

(Toys)

**Visual Motor Toys**

1. Stacking rings
2. Pegboards. Get one with pegs that are stackable.
3. Pounding toys. There are several wooden or plastic versions. One has four balls which child hits with a mallet. Balls are pounded into a hole, roll down a ramp, and then appear out of a hole in the bottom.
4. Formboard puzzles that use geomatric shapes rather than cutouts of food or toys. These shapes are more easily recognized by our children.

**Preschool Ideas for the 4's and 5's**

1. Popoid.
2. Duplo blocks
3. Fisher Price Alphabet Desk
4. Memory match cards and lotto board matching games
5. Nesting cups (circles are the easiest to fit together)
6. Magnetic blocks
7. Magnetic mosaic or parquetry blocks to make designs
8. Write Start (wipe-off cards to practice pre-writing skills)
9. Visual discrimination worksheet activity books (practice concepts like same and different, mazes, matching letters and numbers.)
10. Fun With Food items by Fisher Price
11. Little Tykes tea set (large pieces for easy handling)
12. Light Brite (Practice fine motor control by putting pegs into holes on a vertical plane. Promote creative play and reinforce color recognition.)

**Cause/Effect Toys for Toddlers**

1. Busy boxes such as the Touch 'n Talk Train
2. Pop-ups. Push a button and a toy pops up.
3. Pop-up Pals. Disney or Sesame Street themes. Each of five buttons causes different character to appear.
4. Discovery Cottage by Fisher Price.
5. Music boxes to reinforce twisting and winding wrist motion.
6. Sounds-go-round. Uses a pull-down handle to produce a sound.
7. Spinning Bee. Push down on the handle to make the toy spin while the bee flies inside the clear globe.
8. Color spin. A set of eight colorful balls rotate in

a clear globe as the child slides his hand a roller ball.

9. Playskool flashlight. Light can rotate between red, green, and white.
10. Playdough is always a winner.
11. Sparkle Doll. When doll is pushed, her earrings and heart light up.
12. Jack-in-the-box with a large handle
13. Brite Bear by Colorforms. ■



**Toy Catalogs Available**

*Taken from the Washington State Services for Children with Deaf-Blindness Newsletter Update, Fall 1992.*

**Kapable Kids** 1-800-356-1564

Features adaptive toys for children with disabilities.

**Special Populations** 1-800-221-5185

For Infants to Adult

Call for a free catalog of adaptive toys, playground equipment, furniture, rehab products, sport and water toys, handcars, adapted trikes, educational tools, etc.

**Jesana, Ltd.** 1-800-443-4728

Features many adapted toys and equipment for children with special needs, also dolls with disabilities, greeting cards and books for children describing various disabling conditions.

**Able Net, Inc.** 1-800-3220-0956

Various adaptive switches for battery operated toys, video games, etc.

**Constructive Playthings** 1-800-255-6124

Offers equipment, educational toys, games and creative materials for children of all ages. Reasonable prices.

**Toys to Grow On** 1-800-542-8338

Provides a large selection of toys for infants and children up to 12 years of age. Infant toys are stimulating to the senses with bright colors and various textures.

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*This newsletter can be made available in: large print and braille. Please contact Emma Wiseley at 770-3677 (voice/TDD) for more information.*

### "Share Your Ideas"

Many of you who are parents and teachers of children with deaf-blindness may feel isolated because the children and you are spread across the state. One purpose of the newsletter is to keep in touch. Do you have information to share with service providers or with parents? Do you have a particular idea that has worked? Do you know of a resource that others should know about? What have you found to be a particularly helpful technique? We would like to know! Send in your ideas or items you run across that we can share in one of the three newsletters that come out each year.

**Reminder:** We are here for you. Our purpose is to provide technical assistance and training to school districts, other service providers and families at no charge.

## INFORMATION

### Deaf-Blindness; Some Causes and Challenges Harvey H. Mar, Ph.D

*Taken from Teach Research Assistance to Children and Youth Experiencing Sensory Impairments, Spring 1992.*

Though people tend to think of deaf-blindness as a specific disability, there are more than 70 known causes. Among persons with deaf-blindness, issues of concern involve not just vision and hearing, but communication, thinking, behavior, health, mobility, social learning, and daily living skills. In most definitions of deaf-blindness, such as that adopted by the US Department of Education, there are no formal criteria as to how deaf "deaf" is and how blind "blind" is. Rather, the emphasis is on how the combination of visual and hearing loss presents varied and unique challenges to people with deaf-blindness, their families, their friends, and those who serve them.

Rather than describing all 70-plus causes of dual sensory impairments, it may be more useful to think about the major "etiologies". Those of us who are "hearing-sighted" could never truly understand how deaf-blindness affects an individual's concepts of the social and physical world. But knowing something

about the etiology, or source of the disability, can help us understand and prepare for current and future issues of education, medical, and psychological concern.

Among causes of deaf-blindness resulting from intra-uterine infections, Congenital Rubella Syndrome (CRS) is the most common and most serious. The epidemic of Rubella, popularly known as the German measles, which occurred in 1964-66 severely affected about 6,000 infants. The greatest danger of CRS occurs if the mother is infected during the first trimester of pregnancy when the virus can affect the eyes, heart, central nervous system, and ears of the developing fetus. Consequently, an infant with CRS may have visual problems (mild to total blindness, cataracts), from mild to profound hearing loss (usually both ears), heart defects, diabetes (later in life), and other medical problems. Some persons with CRS also have mental retardation, excess behaviors (self-injury, aggression, sensory stimulation), emotional difficulties, and specific learning problems. Most of these problems are recognized during infancy and early childhood. When conditions remain fairly stable and individuals make forward progress, there are some late onset medical problems of CRS, including increased incidence of diabetes, thyroid dysfunction, and glaucoma. In rare instances, hearing may get worse or neurological issues may arise.

Communication is usually the major educational challenge, and effective interventions might promote the use of signs, "tactile signs" (signing into one's hand), gestures, assistive devices such as picture boards or electronic devices, speech or vocalizations, tactile impressions such as Braille, or simple human contact. CRS is often associated with multiple disabilities (many persons have mild symptoms, but we know that persons with the most severe conditions can actively and productively take part in educational, social, family and community activities).

Other intrauterine infections capable of affecting visual and hearing development include Congenital Cytomegalovirus (CMV, a virus of Herpes family affecting hearing), Syphilis (a bacterial infection), and Toxoplasmosis (caused by organisms called protozoa, affecting vision). Concerns related to these congenital infections have to do with early detection of symptoms that might otherwise have late onset, and decreases in visual and hearing abilities that youngsters may express in the form of agitation, inattention, poor social responses, increased clumsiness, school problems, or other ways.

The most common hereditary disorder, or genetic cause, of deaf-blindness is Usher's Syndrome. Today, there are more than 16,000 people with the syndrome. In this condition, both parents carry a gene responsible for  
(See Causes)

### (Causes)

deafness and retinitis pigmentosa, or degeneration of retina. The chances are one in four that an offspring will have the syndrome; two in four that he or she will "carry" the defective gene. Visual loss, often beginning with impaired vision in the dark and progressing to total blindness in adulthood, is due to retinitis pigmentosa. Deafness or hearing impairment, very often severe to profound, is usually detected early.

There is no prevention of Usher's Syndrome, but genetic counseling for the family to discuss its implications can be of great value. The progressive nature of visual loss makes it important to consider how to prepare for the adaptations that an individual will require at home, at work and in the community. Orientation and mobility is especially of concern if the person moves about independently. Forms of communication such as tactile signing or braille may need to be introduced well before severe visual loss. The need for low vision devices, such as magnifiers or tactile-input communication devices, should be reviewed periodically. Problems of adjustment by the individual and his or her family are normal, and must be dealt with openly. Other genetic causes of deaf-blindness include Albinism in association with hearing impairment.

Retinopathy of prematurity (ROP), previously termed retrolental fibroplasia, is associated with very low birth-weight and premature delivery. Infants of low birth-weight require oxygen therapy to thrive, but the oxygen stimulates tissue growth in the retina, which can lead to visual impairment. While there is no direct association of hearing loss to ROP, infants with low birth-weight are at heightened risk for this disability and developmental delays.

In infancy, fragile health is the primary concern, and may include risk of infection, cardiovascular problems, respiratory distress, and brain damage. As with all children who have disabilities, early intervention involving parents and families is necessary. Frequent monitoring of sensory development, motor skills, learning, and social and communication behaviors is important to determine areas of strength and weakness for program planning, and to ensure that there is consistency of the child's experiences at home and in the program.

Many causes of dual sensory impairments are unknown. CHARGE Association (CHARGE being an acronym to describe a cluster of abnormalities including eye, ear, and other deformities) was first described in 1979. It is possible that use of some chemical or drug is related or that there is some genetic cause.

Because children with CHARGE association may have multiple disabilities, intensive, transdisciplinary approaches to education are required. Other causes of deaf-blindness may include injury, trauma or neurological problems, or meningitis acquired in childhood.

Regardless of the cause of dual sensory impairments, the concerns and challenges last a lifetime. Deaf-blindness is a severe disability. Yet, given appropriate supports, and the recognition of our own need to learn to communicate more effectively with persons who have deaf-blindness, we can ensure there are no limitations to an individual's ability to participate fully in their schools, homes and communities.

*Harvey H. Mar, Ph.D is the Psychology Coordinator of the Developmental Disabilities Center, St. Luke's-Roosevelt Hospital Center in New York City.* ■

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### Rubella Symposium

Karen Norwell  
NPN Advisory Board

*Taken from National Parent Network Newsletter, Spring 1992.*

This June, in response to parents' continued and growing concerns regarding the late emerging medical manifestations of our Congenital Rubella Syndrome (CRS) population, a symposium was held in Boston, MA, sponsored by the Hilton-Perkins Program.

#### Background

For many years, we, as parents, have been providing medical information about our children to health and service professionals for studies, surveys, etc. These children have been tested and retested and we have willingly and enthusiastically shared all of these findings. Unfortunately, in most instances, we have turned out to be just a statistic or clinical case history for these studies. Often, this valuable data has not been disseminated or made available to the people who can indeed benefit from the findings the most--our Rubella children, their families and physicians.

The recognition of this situation, and how to resolve it has been a priority of the Massachusetts Coalition of Parents and a very personal goal of mine. My son Steve's life, and ours, changed dramatically as he began to develop additional medical conditions. The most difficult things to cope with were his sudden changes in behavior, "out of the blue" outbursts and subsequent deterioration. Unfortunately, he was not easily understood or diagnosed

(See Rubella)

**(Rubella)**

It wasn't until we were finally alerted to the possibility of late onset manifestations that his condition was determined to be a uncommonly diagnosed type of seizure activity. Now, with a complicated daily schedule of medication, as well as a seizure management program, Steve is doing much better. Access to this medical information made the difference in our lives and Steve's!

After this experience, I was determined that no family or caretaker should be without information on the latest health development of young adults with CRS. The Hilton-Perkins Foundation very graciously responded to my urgent request to find a way to collect and disseminate this information by hosting a symposium. In such a forum, it was possible to pull together current and detailed information from the medical community and service providers around the country.

As a result of this gathering, two valuable documents are being developed. The first is a brochure designed to help us understand and be aware of all the late manifestations and their symptoms. It will also enable us to make our children's doctors more aware so that they can diagnose, and possibly prevent many of these health issues before they become more serious. The second product of the proceedings will be detailed papers written by each of the participants, which will be available upon request. I am eternally grateful, as I am sure all Rubella families will be, to all the symposium participants from around the country for sharing their knowledge. Knowledge is power and being alerted to these potential and unique medical issues can and will make a difference in our children's future! ■

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< **OUTCOMES OF ABOVE  
MENTIONED SYMPOSIUM** >

**Congenital Rubella Syndrome: Health Care Challenges.**

This brochure is for parents and professionals to inform them of the unique medical issues experienced by some individuals with Congenital Rubella Syndrome (CRS) later in childhood and early adulthood. Some delayed problems of CRS which may be experienced are: Diabetes; Thyroid gland disfunction;

underdevelopment; changes in vision development of glaucoma or detached retinas; changes in hearing ability; changes in the neurological system--development of seizure disorders; changes in behavior--attention deficit disorder, impulsivity, self-injurious behaviors; and renal artery stenosis.

By drawing attention to these issues, it is hoped that parents and health care providers can actively collaborate to recognize if these problems exist and provide appropriate medical treatment.

For a free copy of this pamphlet or information on the proceedings from the June, 1991 Symposium on the Late Onset manifestations of Congenital Rubella Syndrome, contact:

Hilton-Perkins National Program  
175 North Beacon St.  
Watertown, MA 02172  
(617) 972-7220

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**For A Report on a Survey of Late  
Emerging Manifestations of  
Congenital Rubella Syndrome**

This report documents the findings of a survey conducted in 1990-1991 to determine the frequency of various medical and behavioral problems in adult children with Congenital Rubella Syndrome.

To order write to: The Helen Keller National Center  
Community Education Depart.  
111 Middle Neck Road  
Sands Point, NY 11050

The cost of the Rubella Report is \$2.00. Please make all checks or money orders payable to "HKNC".

**FOR MORE INFORMATION ON CRS CONTACT**

Perkins School for the Blind, Deaf-Blind Program  
175 North Beacon Street  
Watertown, MA 02172  
(617) 924-3434, Ext. 7500  
Fax (516) 926-2027

Helen Keller National Center  
111 Middle Neck Road  
Sands Point, NY 11050  
(516) 944-8900, Ext. 270  
Fax (516) 944-7302







(AFB)

- o review existing curricula and materials for in-service training, teacher training, and for direct use with individuals who are deaf-blind;
- o identify individuals to assist in development of new materials; and
- o identify sites for field-testing the newly developed in-service materials.

For more information and to receive project updates contact:

Dr. Jean Glidden Prickett  
Coordinator of Materials  
AFB Mid-Atlantic  
Regional Ctr.  
1615 M St., NW #250  
Washington, DC 20036  
(202) 457-1487  
(202) 296-3470 FAX

Ms. Terry Rafalowski Welch  
Coordinator of Consortium  
Activities  
AFB Deaf-Blind Project  
P.O. Box 143  
Webster, NY 14580  
(716) 671-9777  
(FAX Available)

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**The Arizona Deaf-Blind Project  
and The Arizona State Schools for the  
Deaf and the Blind**

Is accepting applications for the position of:

Deaf-Blind Education/Transition Specialist  
(40 Hr./Wk.--210 Days /Yr.)  
Salary Range: \$26,302 - \$33,191 Annually  
Deadline: Open until filled.

*This position is located in Tucson,  
but will require travel and varied  
daily and weekend hours  
dependent on service needs.*

APPLY TO: ASDB/PERSONNEL  
1200 W. Speedway Blvd.  
P.O. Box 5545  
Tucson, AZ 85703-0545  
(602) 770-3677

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**International Parents Council of  
People with Deaf-Blindness**

The North American subcommittee of this Parents Council is being coordinated by Faye Eldar (USA) and Connie Southall (Canada). Membership is open to all parents, family members and foster parents of deaf-blind people.

The goals are:

- o promote parent-to-parent support
- o sharing information and resources on a worldwide basis.

For more information, please contact:

Faye Eldar  
8331 Kimball Avenue  
Skokie, IL 60076-2926  
(703) 677-3796 Fax (708) 677-3808

**CONFERENCES AND WORKSHOPS**

The Arizona Department of Education, University of Arizona, the Division of Developmental Disabilities, the Arizona Chapter of the Association for Persons with Severe Handicaps, the Statewide Coordinating Council for Systems Change, and the Arizona Deaf-Blind Project, will co-host the **Tenth Annual Integration Conference on Individuals with Severe Disabilities**, March 4th and 5th, 1993 at the YWCA Leadership Development Center, 9440 N. 25th Avenue, Phoenix, Arizona.

The tentative program agenda includes nationally recognized speakers, workshops, demonstrations and luncheons.

This year's theme is "Helping Everyone Belong." The conference objective is to provide a multi-disciplinary approach towards the goal of full integration of individuals with severe disabilities into our society.

Featured Speaker: Mark Durand, Ph.D.

Topic: Positive Behavior Support

The conference will have a new series of break-out sessions and tracks specifically geared to students who are serving or are interested in serving as peer tutors for students with severe disabilities. The Peer Tutor Conference will be held over a three-day period, March 3-5, 1993.

For more information, contact Pam Jones/Judy Crosswell at 542-3184.

The Arizona Deaf-Blind Project will provide support to a limited number of parents wishing to attend this conference--look for more details in the mail.

■■■■■■■■■■

**Third European Conference of the  
International Association for the  
Education of Deaf-Blind People  
July 31 - August 5, 1993  
Potsdam, Germany Equal ... And Exceptional  
Access to Culture for Deaf/Blind People**

Any inquiries and correspondence concerning the conference should be addressed to:

IAEDB Conference Secretariat  
Oberlinbaus  
Rudolf-Breitscheid-Straße 24  
0-1591 Potsdam, Germany  
Telephone: + 331/763-5228  
Telefax: + 331/763-5230

Dear Reader:

Please give us your opinion. We'd like to know if you find the *Arizona Deaf-Blind Project Newsletter* interesting and informative. With your input we can make it more valuable. Please mail or FAX your responses to us.

Thank you!

1. Circle the number beside the job title that best describes you: (circle only one)

1. Student
2. Parent
3. Legal Advocate
4. Person experiencing disabilities
5. Educator (University/College)
3. Teacher (Direct Service) \_\_\_\_\_
4. School Administrator \_\_\_\_\_
5. Therapist/ \_\_\_\_\_
6. Human Service Provider
7. Social Worker/Psychologist
10. State/Federal Government Personnel
14. Teacher Trainer
15. Other: \_\_\_\_\_

2. Rate your interest in the following sections in the Newsletter.

	Great	Some	Slight	None
a) Front page article	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Announcements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Conferences/ Workshops	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Watch for the next  
Arizona Deaf-Blind Project Newsletter  
in February, 1993*

- TOPICS -

*Transitions Through School to Work  
and Living in the Community*

*Information on Usher Syndrome*

4. Rate the *Newsletter* on each of the following attributes:

Great    Some    Slight    None

a) Your overall opinion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Writing Style	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Ease of reading/ appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Variety of articles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Is the newsletter informative?

Very    Somewhat    Not too    Not at all

6. Is the newsletter relevant to you?

Very    Somewhat    Not too    Not at all

7. Articles are generally:

too long    too short    just right

8. Please list topics you would like to see in future issue:

9. What suggestions do you have to improve the *Newsletter*?

Return surveys to:  
Emma Wiseley  
Arizona Deaf-Blind Project  
Arizona State Schools for the Deaf and the Blind  
P.O. Box 5545  
Tucson, AZ 85703  
(602) 770-3677  
or fax to (602) 770-3711

**ARIZONA DEAF-BLIND PROJECT NEWSLETTER**

**Vol. 1, No. 3**

*This newsletter has been provided by the Arizona Deaf-Blind Project located at the Arizona State Schools for the Deaf and the Blind with support from the U.S. Department of Education, Division of Special Education Programs, under cooperative agreement #H025A20036. The views expressed in this newsletter do not necessarily reflect the opinions of either the U.S. Department of Education, or the Arizona State Schools for the Deaf and the Blind, and no official endorsement should be inferred.*

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# ARIZONA DEAF-BLIND PROJECT NEWSLETTER

Vol. 1, Number 4

## Deaf-Blind Project Update Don Welch

What happens to youth with deaf-blindness when they exit from school is dependent on what happens while they are in school. During the past ten years many changes have occurred in the field of special education which have increased the adult living options for persons with deaf-blindness. Not too many years ago the options available were to remain at home or group home, and possibly spend a part of the day in an activity center or sheltered workshop. Placements were based on what was available with little relevance to the interests and abilities of the individual with deaf-blindness. Any recreational activities were a function of the home or group home and may or may not have been chosen by the individual with deaf-blindness.

Community-based/functional instruction, integration, mainstreaming, inclusion, adult living alternatives, supported employment, job coach, transitioning are among the many terms and concepts that have been introduced as "best practices" during the past several years. We have the practical evidence that instructional processes associated with these concepts do make a difference. There is something available for all youth upon exit from school, however, the plans must be laid well in advance of graduation.

Transition services designed to prepare youth with deaf-blindness for such post-secondary outcomes as employment, independent living, adult services, post-secondary education and community participation. The 1925 Education for ALL Handicapped Children ACT (EHA), (Public Law 94-142) required Individualized Education Programs (IEP) to include goals, objectives, instructional activities and related services that all of you are very familiar with. The latest amendment to EHA--now entitled the Individuals with Disabilities Education Act or IDEA (Public Law 101--476)--has added the new components of a transition services statement which must be included in IEPs for students 16 years of age. When appropriate, these statements must be included in the IEPs of younger students and has

(See Update)

## TRANSITION

### Parent Tips for Transition Planning

By Trish Matuszak

*Taken from the Transition Link Newsletter, November, 1991, Vol. 2, No. 3.*

The more you plan ahead, the better prepared you will be when action needs to be taken. This is true in all aspects of life--including the transition from home and high school to living and working in the community. Team planning--a collaboration of student, parents, teachers and other--can make that transition successful.

Since 1987 a transition plan has been a required component of Individualized Education Programs (IEPs) for Minnesota students no later than age 14. Recently passed federal legislation now requires transition planning in all states for students 16 and older, or by age 14, if determined appropriate.

In order for the IEP to appropriately meet the person's transition needs, both parents and school personnel must assess the student's abilities, skills and interests. The school accomplishes this through diagnostic assessments, evaluations and informal observations; and parents do it through their day-to-day knowledge of their son or daughter and conversations with him/her about future goals.

The best transition plans will be those that help the student achieve his or her dreams and aspirations. To insure this, include the student in all aspects of planning and goal-setting, and encourage his/her participation at IEP meetings. This participation will help keep all team members focused on the student's individual needs and desires. It will also help the student develop his or her own decision-making and self-advocacy abilities.

By planning ahead, by being proactive and by knowing the issues, you and your teenager can become powerful members of the transition team--contributing to a comprehensive plan that provides a direction for your teenager's goals.

(See Parent)

(Parent)

### Prepare for the IEP meeting

Prepare yourself for an IEP meeting or transition staffing by going over the following points:

- Ask your teenager what they would like to do with their life. What are their goals? Incorporate their responses into all aspects of transition planning. If your son or daughter is non-verbal or has difficulty communicating these thoughts to you, use your own knowledge of them to make sure their transition plans reflect their likes, dislikes, etc.
- Know your son/daughter's needs abilities and skills. Be familiar with how much assistance he/she needs or does not need to accomplish tasks.
- Know what outcomes you want. Bring suggestions to meetings on what actions you feel are needed to meet or move toward goals in the transition plan.
- Know what programs, services, accommodations/modifications you want. Be clear on what your transition needs or issues are.
- Become familiar with the roles and functions of team members.
- Determine who will be responsible for what on the transition plan. Ask for specific timelines.
- Decide whether educational and transition programs should emphasize practical or academic goals or a combination of both.
- Decide how your son/daughter's educational and transition program could be more integrated into regular programs.
- Contact team members to ensure that they attend IEP meetings.
- Arrange for a family member, friend or advocate to accompany you to planning sessions for support or note taking.

In general, becoming familiar with adult service systems/agencies now will help in making decisions that will impact on your teenager later.

A final tip--start thinking about what you will do regarding your teenager's legal status once he/she is 18. If he/she isn't able to make decisions, with informed consent, about major issues (medical treatment, living accommodations, ...), learn the difference between full guardianship and conservatorship early so you can make an educated decision when the times comes. ■

## Transition Legislation

*Taken from the Transition Link Newsletter, February, 1991.*

In October, President Bush signed a bill that amended the Education of the Handicapped Act (EHA, PL 94-142). The amendments include a name change in the law to the "Individuals with Disabilities Education Act" (IDEA). This is in accordance with the movement to use terminology that focuses on the person rather than the condition.

The law also:

- adds a new definition of transition services.
- mandates the inclusion of transition services in Individual Education Programs, and
- gives attention to the transition needs of students who use assistive technology.

According to the law, transition services should focus on outcomes, promoting movements to future environments, such as post secondary education, vocational training, integrated employment and community participation. The intent of the law is that these services will focus on the individual needs of the student and include instruction and experiences which will prepare the student for adult living. Individual Education programs must now include transition plans for students beginning at age 16 (or at age 14 when determined appropriate) and specify inter-agency responsibilities for implementing those plans. ■

### (Update)

become common to begin these statements by age 14.

The National Information Center for Children and Youth with Disabilities (NICHCY) publishes a Transition Summary once each year. Volume 3, Number 1 March, 1993, is a must read for parents and educators interested in the ramifications of this IEP expansion component of IDEA.

"With the addition of transition services, the IEP becomes longer term, with objectives spanning across several years. For the first time, planning is oriented towards life after high school, with plans including adult services agencies and community agencies, where applicable."

Now parents, educators, adult service personnel, and others significant in the life of the individual with deaf blindness, can participate in a futuring process beginning as early as age 14. This process, which includes the

(See Update)

## New Transition Regulations

*Taken from the PACESETTER Newsletter, January, 1993.*

Here are four key provisions of new federal transition-related regulations for the Individuals with Disabilities Education Act (P.L. 101-476--IDEA), that became effective November 13, 1992:

**Students Must Be Invited**--If a meeting is to consider transition services for a student, the public agency (school) must invite the student and a representative of any other agency likely to be responsible for providing or paying for transition services. If the student does not attend, the public agency shall take other steps to ensure that the student's preferences and interests are considered; if an invited agency does not attend, other steps shall be taken to obtain its participation in planning of any transition services. (300.344)

**Parent Notification**--If a meeting is to consider transition services for a student, the notice to parents must indicate this purpose, and that the student and other identified agencies will be invited. (300-345)

**IEP Content**--The IEP for each student, beginning no later than age 16, younger if appropriate (Minnesota stipulates by age 14 or grade 9) must include a statement of the needed transition services in four areas of content: Instruction, community involvement, work/vocational skills, and daily living skills and functional assessment if needed. It must also address each public agency's responsibilities or linkages or both, before the student leaves the school setting. If the IEP team determines that services are not needed in one or more of the areas specified, the IEP must include a statement to that effect and the basis upon which the determination was made. (300.346)

**Agency Responsibilities for Transition Services**--If a participating agency fails to provide agreed-upon transition services contained in the IEP of a student with a disability, the public agency responsible for the student's education shall, as soon as possible, initiate a meeting to identify alternative strategies to meet the transition objectives, and, if necessary, revise the student's IEP. Nothing in this part relieves any participating agency, including a state vocational rehabilitation agency, of the responsibility to provide or pay for any transition services that the agency would otherwise provide to students with disabilities who meet the eligibility criteria of that agency. (300.347)

## (Update)

disabled person, as represented by him/herself and/or through significant others, identifies the ultimate level of functioning or the projected parameters for adult living, and allows several years to address the required critical skills. Assessments to reveal individual's strengths, weakness and interests will be necessary. Many sources are needed to provide the broad range of information to make effective educational decisions resulting in a successful post-school life.

If you would like more information on the March 1993 NICHY Newsletter, contact Emma Wiseley at (602) 770-3677. ■

## Making "Person-Centered" Dreams Come True

Dr. Ian Pumpian, Colleen Campbell, and Shirley Hesche  
Interwork Institute, SDSU

*Taken from CA Deaf-Blind Services Resources, May/June, 1992, Vol. 4, No. 4.*

How comfortable are service providers and families sitting at an Individualized Education Program (IEP) and Individual Program Plan (IPP) meeting? How often do these meetings allow for participation of friends, siblings, neighbors, employers and others? How often do they focus on scores, deficit measures, compliance and procedures? How often do these processes lead to a time of sharing, dreaming, celebrating, and planning the future? Stated another way, without disputing the importance of these meetings, do people look forward to them with enthusiasm and do they leave them with a feelings of satisfaction and accomplishment? Unfortunately, answers to these questions from most families, students, teachers, service providers and administrators would too often be negative.

New initiatives to try and create a more collaborative outcome-oriented planning process are occurring all over the country. A process which invites participation and focuses on an individual's strengths and desires for school and community inclusion, a process in which collaboration requires real commitments from paid and nonpaid support people and the expectation that roles and responsibilities will be shared and released, a process designed to be dynamic and comfortable as opposed to time-limited and procedure-driven. These developing processes have been organized in several

(See Dreams)



**(Dreams)**  
formats, by several names with many creators. These processes as they are being referred to here come under the general heading of person centered planning.

We have been using different versions of person centered planning with adolescents and young adults who are deaf-blind. This article highlights some of our grant activities with the Sweetwater Union High School District. The readers should not fool themselves by assuming that this is a simple party-like process. Rather it is time-consuming and each person centered planning team requires a great deal of personal commitment, creativity, and perseverance. The results and outcomes, however, even in our infancy, have been so exciting and have created renewed energy to all involved.

Person-centered planning meetings, such as McGill Action Planning (MAP) meetings or Personal Futures Planning Meetings, are designed to generate an action plan to more fully include and enhance a focus person's participation in activities at school, home, and in the community (Vandercook, York, & Forest, 1989). These planning meetings often facilitate a student's transfer from one class to the next, or are frequently planned to help with IEP, Individual Transition Plan (ITP), or IPP development. The goal is to focus on the choices, strengths and needs of the focus person by coordinating services around this life rather than the needs of staff or service providers (Mount and Swemik, 1989).

Depending on the age of the "focus person," and individual circumstances, a person-centered planning team, or "circle" will have various members (e.g. the child or adult, family members, friends, neighbors, general and special educators, classmates, or co-workers). Usually one adult acts as facilitator, and one records comments and ideas on large chart paper, or a chalkboard. A variety of information is collected from some, or all, of the following topical questions below (Vandercook, York, & Forest, 1989; Mount & Swemik, 1989).

1. What is the focus person's history/background?
2. What are the dreams/goals for the focus person?
3. What are the nightmares/things we don't want to happen? What are the concerns or fears?
4. Who is the focus person?
5. What does the focus person now do? (relationships, roles, activities, preferences, choices.)
6. What are the focus person's strengths, gifts and abilities?
7. What are the focus person's support needs?
8. Action Plan (who will do what to support the focus person's goals).

Maximizing the focus person's participation in the meeting is emphasized. This is accomplished by individualizing the specific language of the topical questions and by adapting the format of the meeting to accommodate the focus person's communication style and maximize choice-making. We will illustrate how MAPS and Personal Futures Planning meetings have been organized in our deaf-blind demonstration project by sharing the stories of three students: one in junior high, one in high school, and a student in transition. George was a new 7th grader in junior high school this past Fall. He came from Kim Jubala's elementary class at Lafayette School in San Diego. Fortunately Kim went to great lengths to make sure a solid support system was in place by writing a wonderful IEP, and meeting with George's new teachers throughout the summer to facilitate his transition.

George has had many new experiences this year! Instead of being picked up by the typical yellow school bus, George was trained by mobility specialist Dale Tompkins, to use the city bus. He also changes classes, uses an interpreter, and is struggling to establish his identity (just like the other junior high students).

Three of his teachers, from special and general education, decided to plan a MAP meeting to prepare for the 8th grade. Mary Jo Prinz, Judi Garcia, and Nonnie Richards wanted to focus primarily on the goals to help George's family learn more sign language, George develop less physical, and more conversational strategies to make friends using a communication book, and to discuss potential ideas. Next the discussion focused on potential problems which could block our efforts, i.e. being too physical and getting into fights, not always listening and following directions, and not having a good interpreter. Finally, the discussion turned to brainstorming the action plan "what can we do to help?" We made a list of support ideas and specifically listed who would help. For example, Judi will teach another sign language class on campus that George's family can attend after school, and George's teachers will help adapt the 8th grade classes' curricula.

Paulo has also moved to a new school this year. He transferred to Montgomery High School and a MAP meeting was planned by his teacher, Tami Wheeler. Although there were many things for Paulo's team to discuss (goals for communication, mobility, etc.), Tami decided the most important goal for this particu-

(See Dreams)

## (Dreams)

lar meeting was to generate ideas and strategies to help Paulo become a more connected and participating member of his new high school.

Tami made and sent invitations to Paulo's family, teachers, instructional assistants, educational specialists, his peer job coach, and peer tutors. Tami opened the meeting with introductions. Paulo is completely deaf and blind and receptively uses object communication. In order to maximize Paulo's participation, we felt it was important to make sure he knew who was present, and to make sure he was comfortable. Paulo sat in his favorite rocking chair in the center of the room. As they introduced themselves, each participant went to greet Paulo by using their name-sign. He became noticeably more excited once he knew he was surrounded by "his circle".

Tami and Paulo's family shared some background information by showing slides of Paulo from his past. This helped new members of his support circle to appreciate his accomplishments. Next each participant was asked to think of one or several words they would use to describe Paulo. Words like "wonderful," "stubborn," "funny," "challenging," "determined," "gorgeous," "real special," "coordinated," "has a good sense of humor," and "loving" were used to describe Paulo.

Participants were then asked to share their dreams and goals for Paulo, as well as their fears regarding potential obstacles. Answers ranged from learning to walk without his walker, to being able to express his needs with an object communication system, to using the community, to learning more recreational activities, to making more friends. Using goals generated by the group, and addressing potential obstacles such as "people forgetting to use his object communication system consistently," or "he's unhappy when he gets bored," the next step became to develop an action plan which more specifically identified who would take on what responsibility for each goal.

One of the most positive outcomes of the meeting was initiated by a high school peer tutor who had attended Paulo's meeting. After the discussion regarding making friends, enjoying wrestling, and developing more recreational skills, she asked the wrestling coach if Paulo could become a member of the wrestling team. He said yes! Unfortunately, it was the end of the wrestling season but the track season was just getting underway. Guess who the newest member of the track team is? Paulo is responsible for filling the water bottles.

Paulo's teacher and mobility instructor scheduled a

Paulo joined the team and to solicit their help and ideas. They asked many questions and enthusiastically agreed to help include Paulo in their practices and competitions. Instead of receiving isolated mobility instruction around campus, Paulo's mobility program will be infused into a much more natural environment, with much more potential to make friends!

Our final story is about a young lady and her transition from the school system to the adult world! "Let's Get the Show on the Road!" was the theme of Cristina's Future Planning Meeting.

Although she had had a transition plan developed at her IEP meeting, the Future Planning meeting accomplished the goal of developing a strong support circle/network to more comprehensively and actively set her goals into motion.

Since Cristina's family lives in Richmond, and Cristina presently lives in San Diego, a telephone conference call was set up. Cristina's meeting was planned by Cristina, Kathy Mack-Burton (her teacher), and Suzanne Weiler from Interwork Institute. Cristina is a young woman with definite goals and desires. She has been separated from her family since the age of ten and has lived in approximately ten foster or group homes. Her primary goals are to live close to her family, to have her own apartment with only one roommate, and to keep her job at Lucky's grocery store where she earns \$5.75 per hour.

Cristina's meeting not only focused on Cristina's goals, which were written and read with the help of her friend Janet, but also her fears and concerns that she and her family had about the transition from San Diego to Richmond. Her family now has a much clearer picture of Cristina's support needs for the transition/moving process.

To help Cristina's dreams become reality, the circle identified activities for each participant to focus on. At this time staff, family and participants have identified an independent living skills training program within two miles of Cristina's family members. A Lucky's grocery store is also within walking distance of the program and her current employer has agreed to facilitate her job transfer! Also within the new neighborhood is an adult education program and community college.

The teamwork involved in Cristina's Future Planning Meeting has resulted in successful collaboration between family, friends, and professionals. Cristina is well on her way to realizing her dreams through the assistance of a combination of a committed support circle, and an effective transition plan! ■

## PROJECT L.I.F.E. (Lifelong Impact from Education)

*Taken from the Vermont I--Team News, October, 1992.  
Center for Dev. Disabilities, Univ. of Vermont, 499C  
Waterman Bldg., Burlington, VT 05405-0160. (802)  
656-4031 (Voice/TDD)*

Project L.I.F.E. is a three-year federally funded research grant designed to study innovative practices for educating students with dual sensory impairments and multiple disabilities in general education settings. Over the past year, project staff have developed six products. Listed below are the product titles, brief description, and information on where they can be obtained.

### 1. Choosing Options and Accommodations for Children: A Guide to Planning Inclusive Education (Giangreco, Cloninger & Iverson)

This guide, known as "COACH," is an assessment and planning tool designed to develop individualized educational experiences for students with disabilities. COACH is built on a family-centered perspective and the pursuit of valued life outcomes. COACH will be available from Paul H. Brookes Publishing in late October, 1992. COACH may be ordered by calling 1-800-638-3775 (approximate cost \$29.00).

### 2. COACH Part 1: Family Prioritization Interview: Video and Companion Forms (Edelman, Giangreco, Cloninger & Dennis)

This videotape (approximately one hour in length), provides an unedited demonstration of COACH Part 1 being facilitated with a mother of a student with dual sensory impairments. Companion forms allow the viewer to see how the interviewer completed COACH forms. The forms and tape are based on the pre-publication version of COACH. Therefore, while the substance will be the same as the published version, the forms will look slightly different. The tape is open-captioned for people with hearing impairments. The tape and companion forms are available for \$20.00, from the Center for Developmental Disabilities, (CDD), the University of Vermont, 499C Waterman Building, Burlington, VT 05405-0160. A limited number of tapes are available.

### 3. Evaluation of Impact Process: (Giangreco, Cloninger, Edelman & Dennis)

This brief document (9 pages) describes an evaluation process that matches the COACH process. It is available for \$3.00 from the CDD.

### 4. Problem-Solving Methods to Facilitate Inclusive Education: (Giangreco, Cloninger, Dennis & Edelman)

This manual (draft version) describes variations of the Osborn-Parnes Creative Problem-Solving Process developed to facilitate the inclusion of students with disabilities in general education classes. The manual is available for \$10.00 from the CDD; limited copies are available.

### 5. National Expert Validation of COACH: Congruence with Exemplary Practice and Suggestions for Improvement (Giangreco, Cloninger, Dennis & Edelman)

This study describes two studies which provide initial validation the COACH is consistent with exemplary practices. It offers suggestions for the improvement of COACH. The article is available for \$5.00 from the CDD.

### 6. Quality of Life as a Context for Planning and Evaluation of Services for People with Disabilities: (Dennis, Williams, Giangreco & Cloninger)

This article provides an extensive review of the literature regarding quality of life as it pertains to people with disabilities. This article is available for \$45.00 from the CDD.

If you are interested in ordering any of the products, you may either call Casey Hayes at (802) 656-4031 or send a check in the appropriate amount made payable to "The University of Vermont."

Send payment to:

The University of Vermont  
The University Affiliated Program of Vermont  
The Center for Dev. Disabilities  
499C Waterman Building  
Burlington, VT 05405-0160  
Attention: Casey Hayes

(See L.I.F.E.)

Another two articles you may find useful as you plan for next year are:

Giangreco, M.F., Dennis, R., Cloninger, C., Edelman, S., & Schattman, R. (in press). "I've counted Jon:" Transformational experiences of teachers educating students with disabilities. *Exceptional Children*.

Giangreco, M.F., Edelman, S., Cloninger, C., Dennis, P. (in press). Having a classmate with severe disabilities: What parents of non-disabled children think about it. *Developmental Disabilities Bulletin*.

*NOTE: If you would like to preview these products prior to purchase, the AZ Deaf-Blind project has copies available in the lending library. Please contact Emma Wiseley at (602) 770-3677. ■*

## COMMUNICATION

### Creating a Need to Communicate

*Taken from the CA Deaf-Blind Services Fact Sheet, February 10, 1992.*

Individuals with dual sensory impairments may show beginning communication skills in many ways. This communication may take the form of body movement, gestures, facial expressions, vocalizing, use of objects or people, pointing to pictures, or more formal systems. As these skills begin to develop, it may be helpful to create a need for increasing the use of these new communication forms.

1. You may do movements together with the individual which the person really enjoys (e.g., rocking, dancing or stirring batter). You can stop your movement, pause for a few seconds, and see if the individual indicates he wants to continue. He may indicate he wants to continue by his body movement, facial expression, gestures, vocalizing etc. This is the beginning of communicating needs and wants.
2. As the individual becomes familiar with various routines, you can watch to see if he anticipates each step of the routine. As you do the familiar routine, pause before moving on to the next step of the activity. During the waiting period of a few

seconds, watch for movement, body posture, facial expression, gestures, vocalizing, etc., which indicates that the individual wants to complete the activity. (For example, you may assist the individual with dressing and may pause after the socks are placed on his toes. The individual may wiggle his toes to indicate he wants to finish dressing.)

3. Many times a person with dual sensory impairments learns a variety of tasks well which do not require the need to communicate. You can create a need to communicate within the routine/task by "forgetting" to put out all materials he will need for finishing the task (e.g., putting out a can of soup without the pan, putting out the toothpaste without the toothbrush, or placing a desired object just out of reach). The individual will then need to ask for the missing item in whatever way he can. You should not, however, interrupt his independence by removing materials he is currently using. It is also not recommended to insist he describe what he is doing in order to continue his task (e.g., the teacher removes the child's cookie for each bite until the child says/signs/gestures, "I want the cookie"). If you interrupt by removing materials he already has, the individual may feel punished and may not wish to communicate. If you block his independence by requesting a description of what he is doing, he may stop functioning independently and may always wait to be prompted to continue actions.
4. After the individual expresses his desire to continue these activities, it is very important to let him know that you understood his attempts to communicate. You may say "Oh, you need the toothbrush!" or "You want your sock on?", etc. Your movements as you speak can be an imitation of his movement. Your statements should tell him that you "heard" what he was saying and that you respect his wishes. Be sure that your facial expression, body language, vocalization, and speech all give a message of positive feelings about his communication. ■

## Object Communication

*Taken from the CA Deaf-Blind Services Fact Sheet,  
February 10, 1992.*

Many students with dual sensory impairments need a variety of communication systems for their different needs and settings. Using objects for communication is a form which is easily understood by most listeners in both new and familiar situations. This system may also be used with sign language and/or speech to make sure the listener clearly understand their message.

The purpose for using object communication is to provide students with dual sensory impairments with an alternative form of communication. Objects are used to represent activities, places, and people. Examples of these objects include: textures (i.e., piece of carpet, blanket, wood, plastic), miniatures, pieces of the real object, and objects that are exactly the same as those being used. The student uses these objects for getting information about the activities, people, and places around him, making choices, and/or telling others his message.

### *Points to remember:*

1. Students, families, and teachers need to work together to choose the objects which will have the most meaning for the student's needs.
2. The number of objects used to represent the student's daily activities can be increased over time. When the student understands that the objects represent something that is about to happen, additional objects can be added.
3. The use of objects can begin with the purpose of giving the student information about activities, people, and places. Later a few objects can be shown to the student to see which activity, person, and place the student prefers. The choice can be made by a hand movement, body movement, or facial expression (i.e., if the student throws one object on the floor and allows one to stay in front of him, he may be telling you he is choosing the object on the table).
4. Students should be encouraged to speak and/or sign in addition to using the objects if they have those skills.

5. Objects can be used with students in a number of different ways: daily calendar boxes, portable systems, or both.

### *Procedure for Calendar Boxes*

1. Objects are put into the boxes before the student comes to school, in order of the day's activities.
2. The student is taken to the boxes and looks at or feels all the objects in the boxes. The adult labels each object or activity with speech or sign as the student examines it. If the student does not like objects to touch his hands, then the object can be placed on another part of the student's body (e.g., elbow or shoulder) which may not be as sensitive to touch.
3. After examining each object in sequence, the student returns to take the object out of the first box and goes to that activity with the object.
4. At the place of the activity, the student matches the object to the activity. He will see or feel how that object always is a part of that activity (e.g., spoon during lunch, blanket during nap time, ball during P.E., etc.). As the object and activity always happen together, the student will begin to expect the activity when the object is in his hand.
5. As the activity ends, the student returns to the calendar box and puts the object in a separate "finished" box or puts the object back into the original box and covers it. The adult labels this box, object or activity verbally or by sign as "finished".
6. Move to the next box and repeat the same procedure.

### *Portable Object Systems for Use in the Community*

Objects can be used in the same way described when the student is going out into the community. The student can easily use a purse, hip pack, or backpack in place of the boxes when a portable system is needed.

### *Resources*

American Printing House for the Blind  
1839 Frankfort Ave./P.O. Box 6085  
Louisville, KY 40206-0085

☎ (502) 895-2405 ■

## How To Interact With Individuals With Dual Sensory Impairments

*Taken from the CA Deaf-Blind Services Fact Sheet,  
February 10, 1992.*

Individuals with dual sensory impairments need to use their senses of touch and smell to be aware of the people, places, and things in their environment. These individuals may have some remaining vision and/or hearing, yet still rely upon their senses of touch and smell to confirm what they saw/heard. This confirmation becomes even more important in new situations or with new people.

It is important to ask family or staff familiar with the person with dual sensory impairments how the person likes to be approached. The following points are some general guidelines to provide a positive interaction.

1. Touch the shoulder of the person to signal an interaction is going to happen.
2. Introduce yourself by a name sign (fingerspelling the first letter of your name in a position relating to your unique characteristic, e.g., hair, watch, glasses, smile, etc.), by smelling your wrist to learn your distinctive scent/perfume/cologne, or by a distinctive object (e.g., keychain, jewelry, belt buckle, etc.)
3. Touch the person with warm hands to avoid a startle response.
4. Touch the person with deep, firm touch on the bony areas (e.g., elbow, knees, shoulders) to avoid overstimulating the person. Many individuals with dual sensory impairments are very sensitive to touch and can be easily overstimulated.
5. If the person with dual sensory impairments has difficulty with seizure management, avoid light, brisk touch as this type of touch will overstimulate the person and could cause seizures. For individuals with cerebral palsy, light, brisk touch may cause inappropriate reflex movements. Deep, firm touch relaxes the nervous system and will allow the person to be responsive rather than overstimulated. ■

## INFORMATION

### BOYS TOWN USHER SYNDROME PROJECT

*Taken from the CA Deaf-Blind Services Fact Sheet,  
February 10, 1992.*

Usher syndrome is an inherited recessive disorder with hearing loss, progressive loss of vision due to retinitis pigmentosa and in some cases, balance problems. There are two main types of Usher syndrome.

- |         |   |
|---------|---|
| Type I  | Profound Hearing loss present at birth, balance problems, and retinitis pigmentosa. |
| Type II | Moderate to severe hearing loss, no balance problems, and retinitis pigmentosa.     |

About 90% of all Usher syndrome patients have either Type I or Type II.

Usher syndrome is inherited as a recessive disorder, which means that a person must have two Usher genes, one from each parent, to have the syndrome. A person who has only one copy of the gene will not develop Usher syndrome, and is called a carrier. Most people do not know they are carriers until they have a child with Usher syndrome.

The geneticist at Boys Town National Research Hospital (BTNRH), under the direction of William Kimberling, Ph.D., are currently conducting a study of Usher syndrome in an effort to identify the gene(s) which causes the disorder. Recently, the geneticists at BTNRH discovered the location of the gene for Usher syndrome Type II on chromosome 1. The discovery is important because now the gene can be isolated and then studied, to learn how it causes hearing and vision problems.

If you would like to participate in the Usher syndrome study, write or call:

**Usher Syndrome Project/Genetics**  
**Boys Town National Research Hospital**  
**555 North 30 Street**  
**Omaha, Nebraska 68131**  
**(402) 498-6742 Voice**  
**(800) 835-1468 Voice/TDD**

For more information on Usher Syndrome contact:

**RP Foundation Fighting Blindness  
National Headquarters  
1401 Mt. Royal Avenue, 4th Floor  
Baltimore, Maryland 21217  
(301) 225-9400  
(301) 225-9409 TDD for the deaf  
1-800-638-2300**

.....

**Helen Keller National Center for  
Deaf-Blind Youths and Adults  
111 Middle Neck Road  
Sands Point, NY 11050  
(516) 944-8900 (Voice/TDD)**

### **Usher's Syndrome: For Some, Merely a Bend in the Road**

By Chellis Rogers

*Taken from California Deaf-Blind Services Resources, December 1991/January 1992.*

An archaic definition of the word "usher" is "an assistant teacher". One would usually look favorably on such a definition unless the word "Usher" comes in the form of a medical diagnosis. And yet, we are finding that "Usher's Syndrome" truly is a "teacher" in the real sense of the word. It has forced us to focus our energies and efforts and to appreciate even the smallest of successes in our lives.

In November of 1986, just before my son Doug turned 16 years old, an ophthalmologist had the unpleasant task of informing us that Doug appeared to have RP--retinitis pigmentosa. In layman's language, for our benefit, she explained that the retina was becoming bony and spine-like and gradually deteriorating; the result would undoubtedly mean blindness for Doug. Time spans began to race before us as well-meaning professionals from the education and medical fields started predicting Doug's future. Everything was presented, from "Doug will be blind within a year" to the ultimate diagnosis and assessment from John Heckenlively at UCLA Jules Stein Institute who assured us we were looking at a number of years, perhaps up to 20 of usable sight.

True, we were to learn there was currently no cure or means of stopping the deterioration--no help currently on the horizon except prayer and support from each other, and certainly a thousand questions were left unanswered. However, slowly, as the tears gave way to reality and some smattering of actual facts began to take shape, Usher's truly did become a teacher. The things we learn were not always positive, yet each was a step toward acceptance and mobility to a new future, bright with hope and full of potential--seemingly bounded only by the limitations within Doug's mind. Usher's unlike RP which stands alone--apart from the deafness, apparently rarely takes sight within a year. Fortunately, that gives one time to prepare to search out resources without the panic of suddenly adapting to a new environment. Also, while true that no cure currently exists, research is being conducted in the field, and new discoveries are currently being made each one a step closer to finding the cause, cure, and prevention of such a disabling disease.

How does Doug treat this diagnosis? Not as a friend, I assure you. However, he tends to approach this new development as he has the years of just "being deaf": one day at a time; one question at a time. He tries to focus on the positives, and certainly there are many. He attends college, works part-time, works as a student aide with individuals with orthopedic impairments at the Easter Seals pool, and was even a camp counselor this last summer to a group of young people who were hearing impaired. He also has his "down times" and tries his mother's patience by being a 21 year old going on nine one minute and the next being 35 years old the next. Typical? I think so, and while Usher's is not the most welcome companion for our walk through life, it indeed has taught us to appreciate people, places, things, and moments as memories to be made and built upon.

Usher's is not an end to life as we know it; merely a bend in the road that has its own mountains to climb and its own streams to ford. It is an opportunity to look into the future, plan a dream, and then work toward its fulfillment.

Another source of information and referral is the:

**National Information Center for  
Children and Youth with Disabilities  
(NICHCY)  
1-800-999-5599  
NICHCY  
P.O. Box 1492  
Washington, DC 20013-1492**

## ANNOUNCEMENTS

### Fourth Annual Family Learning Weekend

The Fourth Annual Family Learning Weekend for families with children and youths who have both hearing and visual impairments is being organized for the weekend of July 30 to August 1, 1993. Activities during this weekend will include information, teaching strategies, and support for parents, siblings, and other family members in emphasizing the dignity, rights, and skills of people with deaf-blindness even if severe multiple disabilities are present.

The Arizona Advisory Committee on Deaf-Blindness (AACDB) is coordinating this weekend. The AACDB includes representatives from the Arizona Department of Education/Special Education; Arizona State Schools for the Deaf and the Blind; Arizona Deaf-Blind Project; Services for the Blind and Visually Impaired; the Community Outreach Program for the Deaf and other state/national agencies serving the deaf-blind.

We will hold the Family Learning Weekend at Camp Shadow Pines in Heber, Arizona. This is a cool, comfortable dormitory setting where each family is provided with a private room. Separate men's and women's restroom facilities are located in each dorm. The camp kitchen staff will prepare meals.

The Family Learning Weekend provides supervised recreational and learning activities for children and youths with deaf-blindness, and their brothers and sisters by experienced staff. This is a camping experience for the whole family to share with family members with dual sensory impairments. There is no required skill level for attendance at this weekend.

Topics suggested for the parent discussion groups at the Family Learning Weekend in the past have been: Identifying ways to prepare for and get your input into the IEP process; Job opportunities; Strategies to deal with stress; How to help siblings; Discussions with adults who are sensory impaired; and sharing information and resources. A schedule for

both the parent and the children's groups will be based on your input. There will also be ample opportunities for families to get to know each other and relax in an informal setting.

Registration may be limited and total cost is \$10 per family for registration fees. Some funds are available to assist families with the registration fees as needed. If interested in attending, please fill out the enclosed registration request form.

Please share this information with your son's or daughter's DDD case manager, school, or vocational program. School or work personnel who support your family may be able to attend the weekend with you.

If you and your family would like to attend or have any questions about the Family Learning Weekend, please contact:

Emma Wiseley  
AZ State Schools for the Deaf and the Blind  
P.O. Box 5545  
Tucson, AZ 85703  
(602) 770-3677

#### Parent Comments From Last Year's Family Learning Weekend

Name some things you learned during the weekend:

- "What resources are available"
- "My son can go on vacation"
- "I'm not the only one who has to fight for help"
- "Names of friends to keep me going"

What did you like best about the weekend?

- "The weather"
- "Meeting others and sharing" ■



## Special Interest Group for Interpreters Who Work with Deaf-Blind People

Reprinted from Fall 1992 Issue of the Informer  
Vol. 2, Issue 1

*Taken from SPECNET Deaf-Blindness. (Reprinted  
from Fall 1992 issue of the Informer, Vol. 2, Issue 1.)*

The Registry of Interpreters for the Deaf (RID) is the national, professional organization of sign language interpreters. Recently, a Special Interest Group in Interpreting with Deaf-Blind People (Deaf-Blind SIG) was established. The purpose of the group is two-fold:

1. to establish and assist with a national network of interpreters working with individuals who are deaf-blind,

and

2. to promote and encourage further interpreter education and accessibility to interpreting information in the area of deaf-blindness.

For more information, write to:

**RID Deaf-Blind Special Interest Group**  
9329 Angelina Court  
Columbia, MD 21045

## National Deaf-Blind Bulletin Board

### Goal

The national Deaf-Blind Bulletin Board offers parents, educators and others access to timely information and assistance to enhance the quality of services, education, and the life of infants, children and youth with deaf-blindness.

### Purpose

This national Deaf-Blind Bulletin Board helps in:

- networking among those who provide services and education to individuals with deaf-blindness and their families;

- updating, administrators, parents, teachers, specialists, and individuals with deaf-blindness;
- providing a national forum for seeking assistance and collaboration regarding issues and needs;
- disseminating information regarding conferences, training, resources, and other activities relevant to those interested in the education and services for individuals with deaf-blindness, ages 0-22, and their families;
- announcing events, competitions, and activities;
- encouraging and supporting interactive communication.

### How to subscribe

If you are not a subscriber to SpecialNet, you can register for a small setup fee and an annual subscription fee. Simply call 1-800-927-3000 (GTE Educational Services Customer Support Service) for more information about how to become a SpecialNet subscriber.

The national Deaf-Blind Bulletin Board on SpecialNet is titled *DEAFBLIND*. It is sponsored by TRACES to benefit all who work to improve the education and life of individuals with deaf-blindness and their families. The editor for the *DEAFBLIND* bulletin board is California Deaf-Blind Services.

For further information, contact TRACES or California Deaf-Blind Services.

### TRACES

Teaching Research Division/WOC  
345 N. Monmouth Avenue - Monmouth, OR 97361  
(503) 838-8391  
FAX: (503) 838-8150  
SpecialNet: TRD

California Deaf-Blind Services  
Calif. Dept. of Ed.  
721 Capitol Mall, Rm. 666  
P.O. Box 944272  
Sacramento, CA 94244-2720  
(916) 657-3256  
1-800-822-7884  
FAX: (916) 657-5086  
SpecialNet: CA.SE.JOHNSON

Dear Reader:

Please give us your opinion. We'd like to know if you find the *Arizona Deaf-Blind Project Newsletter* interesting and informative. With your input we can make it more valuable. Please mail or FAX your responses to us.

Thank you!

1. Circle the number beside the title that best describes you: (circle only one)

- 1. Student
- 2. Parent
- 3. Legal Advocate
- 4. Person experiencing disabilities
- 5. Educator (University/College)
- 3. Teacher (Direct Service) \_\_\_\_\_
- 4. School Administrator \_\_\_\_\_
- 5. Therapist/ \_\_\_\_\_
- 6. Human Service Provider
- 7. Social Worker/Psychologist
- 10. State/Federal Government Personnel
- 14. Teacher Trainer
- 15. Other: \_\_\_\_\_

2. Rate your interest in the following sections in the Newsletter.

Great    Some    Slight    None

a) Front page article				
b) Communication				
c) Information				
d) Announcements				
e) Conferences/ Workshops				

4. Rate the *Newsletter* on each of the following attributes:

Great    Some    Slight    None

a) Your overall opinion				
b) Writing Style				
c) Ease of reading/ appearance				
d) Variety of articles				

5. Is the newsletter informative?

Very    Somewhat    Not too    Not at all

6. Is the newsletter relevant to you?

Very    Somewhat    Not too    Not at all

7. Articles are generally:

too long    too short    just right

8. Please list topics you would like to see in future issues.

9. What suggestions do you have to improve the *Newsletter*?

**Return surveys to:**  
**Emma Wiseley**  
**Arizona Deaf-Blind Project**  
**Arizona State Schools for the Deaf and the Blind**  
**P.O. Box 5545**  
**Tucson, AZ 85703**  
**(602) 770-3677**  
**or fax to (602) 770-3711**

Watch for the next  
 Arizona  
 Deaf-Blind Project  
 Newsletter

- TOPIC -

RECREATION

**ARIZONA DEAF-BLIND PROJECT NEWSLETTER**

**Vol. 1, No. 4**

*This newsletter has been provided by the Arizona Deaf-Blind Project located at the Arizona State Schools for the Deaf and the Blind with support from the U.S. Department of Education, Division of Special Education Programs, under cooperative agreement #H025A20036. The views expressed in this newsletter do not necessarily reflect the opinions of either the U.S. Department of Education, or the Arizona State Schools for the Deaf and the Blind, and no official endorsement should be inferred.*

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# ARIZONA DEAF-BLIND PROJECT NEWSLETTER

Arizona State Schools for the Deaf and the Blind

Vol. 1, Number 5

## Deaf-Blind Project Update

Don Welch

The Arizona Advisory Committee on Deaf-Blindness (AACDB) offered learning and fun to families.

### AACDB Family Learning Weekend

The Fourth Annual Family Learning Weekend, held in Heber, Arizona at Camp Shadow Pines on July 30 through August 1, 1993, was a wonderful time for parents/staff and the children. Families came as far as Yuma, Ganado and Tuba City to attend. For some families, the retreat provided their first opportunity to be away from home with their children overnight and offered the chance for all families to get some much needed respite from the day-to-day challenges and stresses of parenting.

Phyllis Brodsky, who coordinated the entire weekend, did a wonderful job of planning. She was able to contact and assemble one of the most capable group of staff members and volunteers. The staff and volunteers planned and carried out activities for the children and smoothed the way so the camp was enjoyed by all.

Families arrived Friday afternoon and spent time relaxing, checking into the dormitory, eating a hearty meal, and meeting each other while leaving common phrases in sign language, Spanish, and Navajo.

On Saturday while the children were occupied in safe, fun, recreational and craft activities, the parents spent time sharing their experiences on common issues. June Downing, Associate Professor at the University of Arizona, volunteered her time to share information on how to help children with deaf-blindness build friendships with neighborhood children, and classroom or schoolmates.

Bonnie Goldsmith, Ph.D., a family therapist specializing in issues encountered by individuals with deafness and co-founder of Sonoran Human Services, encouragingly supported the discussion groups and dynamically led the group in fun activities to manage stress through humor.

(See Update)

## RECREATION

### Strategies to Promote Community-Integrated Recreation: Guidelines for Leisure Coaches

By Jane Enos

*Taken from the Technical Assistance Center of the Helen Keller National Center Newsletter, Winter-Spring, 1991-92, Vol. 6, No. 1.*

1. Begin by assessing an individual's recreation preferences. Interview individuals, their family members, and service providers. Ask simple questions: What are this person's likes and dislikes? What things work and don't work for this person? What experiences has this person had in the past? Many young adults with deaf-blindness have limited recreation experiences and may have difficulty making choices and showing preferences until they are exposed to new activities. Partial participation is an important value in recreation programming. One does not have to be an accomplished athlete, musician, or other expert to participate in sports, music, and other community activities.

2. Assess community recreation opportunities. Community presence is also an important recreation value. Community presence enhances public education and acceptance and builds friendships and other natural supports. Following assessment activities, explore options available in the community:

- △ What services and activities are available?
- △ What are the cost, time and equipment requirements?
- △ Are there activities that do not require any fees, or might waive fees, or provide scholarships?
- △ Are there possible modifications to the activity or prosthetic devices that may be used?
- △ Are there any Therapeutic Recreation staff available?
- △ Are volunteers currently used within the programs?
- △ Can they be used to maximize participation of individuals with deaf-blindness?

(See Strategies)

(Strategies)

- Δ Is the program physically accessible?
- Δ Are there possible adaptations to the setting?

3. Develop and utilize listings of community events to choose a range of recreation options. Read newspapers, church and recreation center newsletters and flyers. Visit libraries, community fairs, civic groups, community colleges, community businesses, and associations. Be flexible and creative in developing recreational opportunities. Remember recreation happens in homes, community establishments, and schools as well as recreation centers. It involves individuals as well as groups. Develop calendars, pictorial or object systems, or other methods to enable individuals to choose preferred activities from a range of available settings and activities.

4. Look for a variety of transportation options.
- Δ Is walking a possibility?
  - Δ Is public transportation available?
  - Δ Are volunteers available to provide transportation?
  - Δ Are community members already going to the activity who would be willing to provide transportation?

5. Provide individuals with deaf-blindness and community members with modifications, adaptations, training and support. Complete a discrepancy analysis of the activities and skills needed by young adults to participate in leisure settings and activities. Most recreation settings will not have personnel skilled in serving adults with deaf-blindness. But this should not deter recreation activities. Family members, friends and service providers will need to model communication strategies for both individuals with deaf-blindness and community members. Assist young adults with deaf-blindness with orientation and mobility in new environments: provide tours, plan emergency routes, describe equipment and materials, and explain rules. Even if individuals have no prior knowledge of an activity or limited skill, they can still participate in portions of many activities. Modifications to activity rules, adaptations to settings and equipment will need to be problem-solved by family members, friends, and service providers with community members.

6. Develop partnerships with key personnel and/or volunteers. This will enhance understanding of the sensory and communication needs of individuals

with deaf-blindness, while at the same time increasing everyone's comfort and participation. Share ideas, ask for advice, provide feedback and reinforcement. Provide information to friends, family members, and other service providers about the young adult's progress.

7. Encourage volunteer activities. Individuals with deaf-blindness can become visible community members by distributing tee-shirts or pins at fund-raising or sports events, distributing programs at a concert in the park, taking tickets or serving refreshments at fairs or athletic events.

For more information about therapeutic recreation, contact:

American Therapeutic Recreation Association  
P.O. Box 15215  
Hattiesburg, MS 39404-5125  
1-800-553-0304

National Therapeutic Recreation Society  
3101 Park Center Drive  
Alexandria, VA 22303  
(703) 820-4940

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## New Recreation Ideas

A new book by Michelle Clyne and Laura Cummings details leisure options for people with dual-sensory or multiple impairments. *A Life of Leisure* covers everything from aerobics to "Zaks" and includes activities for all ages. To order the book, call (708) 790-2474 and ask for Peggy Pausche. The cost is \$15 and includes shipping and handling. ■

(Update)

Teresiana Mayfield, M.C., M.S., from Children to Children in Tucson, Arizona which provides counseling services to children conducted a sibling session with the children and spoke to the parents about how brothers and sisters have special needs too, and offered parents tips on handling the balancing act. Parents also squeezed in time to do some planning on issues they may like to tackle when at home. With the days' information sessions completed, families reunited for a wonderful cook-out dinner. After, plenty of time was had to talk, play volleyball, and go for a hayride. The evening was capped with rollicking dance provided by disc jockey Gary Roberts who volunteered to join us (and his wife Phyllis Brodsky) at camp. Also, Phyllis and Gary celebrated their first wedding anniversary with us!

Sunday, after breakfast, the group again learned common phrases in our trilingual communication experiences. Afterwards, the parents had another opportunity to take time to share opinions, experiences, resources and just talk. While the children prepared for the Family games of balloon stop and wacky relay races.

Throughout the entire weekend the infants and toddlers were cared for in nearby cabins by a wonderful team of staff and volunteers. Children had a great time playing in the wading pool, taking nature walks, and engaging in outdoor games.

Older children and youths played basketball, decorated painter's camps, learned to sign and sing a song, rode bikes, took pictures and framed them with tree bark, pine cones, and flowers, and made GLERTZ!! At the closing ceremony the children used rhythm sticks to make their own songs and signed and sang our them song, "That's What Friends Are For." The staff and volunteers with these groups of kids really slept soundly at night!

The parents and kids agreed that the weekend was fun, informative, and exciting. We can hardly wait for next year's weekend together.

Thanks to all the staff and volunteers and contributing agencies.

*Arizona Association for  
Parents of the Visually Impaired*

*Arizona Dept. of Ed.*

*Arizona State Schools for  
the Deaf and the Blind*

*Community Outreach Program for the Deaf*

*Teaching Research Assistance to Children  
and Youth Experiencing Sensory Impairments  
TRACES*

*Department of Economic Security/Rehabilitative  
Services Administration Services for the  
Blind and Visually Impaired*

*Department of Economic Security/Division  
of Developmental Disabilities*

*University of Arizona/College of Education  
Division of Special Education*

*Children to Children*

## **Ideas for Recreation and Leisure Activities**

By Jane Enos

*Taken from the California Deaf-Blind Services  
Fact Sheet, February 10, 1992.*

Both parents and professionals frequently have difficulty developing a variety of ideas for including individuals with dual sensory impairments in recreation and leisure activities. The goal of both parents and professionals is to include the person in home, school, and community activities. Areas to consider within recreation and leisure are activities for private time, time with family members, time with friends, and break time at school or work. These activities should be fun, age-appropriate and based upon the choices of the individual with dual sensory impairments.

Choices for teaching activities should be based upon family activities, neighborhood activities, school activities, and an observation of the individual within those activities. The family member or teacher assisting with the instruction can work on a small step of the total activity, can teach basic skills needed for the activity (e.g., communication skills, motor skills, social skills, etc.), and/or can use adaptive devices to allow the individual to compensate for the areas of need.

(See Ideas)

(Ideas)

The following charts give some suggestions for age-appropriate activities, the modifications needed for individuals with dual sensory impairments, and where to find needed materials.

Suggestions for Recreation/Leisure Activities

Age 0-3 years

<u>Activities of Nonhandicapped peers</u>	<u>Modifications for Individuals w/Dual Sensory Impairments</u>	<u>Where to Find Age-appropriate Materials</u>
Toys	Toys with bright colors, motion lights, and/or sound	Gymboree; Toys R Us
Textured objects	None needed; Multiple textures best	Target; Educational supply stores
Mobiles	Black and white or bright colors; Musical	Same as above
Swimming and/or water play	Sunscreen and visors; Gradual desensitization	Backyard; Mommy & Me Kitchen sink/tub
Playground equipment	Gradual desensitization Resonance or co-active movement	Educational supply stores; Playground equipment stores

Age 4-6

<u>Activities of Nonhandicapped peers</u>	<u>Modifications for Individuals w/Dual Sensory Impairments</u>	<u>Where to find Age-appropriate Materials</u>
Toys which imitate parent's routines and materials	Adaptations to assist with grasp, reach, size, or to accentuate relevant cues	Hardware stores; Target; Domestic aid catalogs
Dolls	Clothing with velcro and elastic	Yardage stores
Building materials	Bright colors; Textures; Shapes Light box; Trays	American Printing House for* the Blind
Balls	Bright colors; Textures; Sounds	American Printing House for the Blind; Make your own
Musical instruments Tape players/stereos Radios	Adaptations to assist with grasp, reach, size, or to accentuate relevant cues	Hardware stores; Target; Domestic aid catalogs

\*American Printing House for the Blind Catalog of Instructional Aids, Tools and Supplies (no charge for the catalog) P.O. Box 6085, Louisville, KY 40206-0085

**Age 7-10 years**

<i>Activities of Nonhandicapped peers</i>	<i>Modifications for Individuals w/Dual Sensory Impairments</i>	<i>Where to Find Age-appropriate Materials</i>
Creative materials	Bright colors; Textures; Shapes Lighting; Contrasting background; Light box; Trays; Visual aids	Arts/crafts store; Stationery stores; American Printing House for the Blind; Optometrists
Sports	Bright colors; Adaptations to accentuate relevant cues; Sounds; Rule modifications; Textures; Peers	American Printing House for* the Blind; Sporting goods stores; Make your own
Clubs	Peers, Lighting; Enlarged printed materials; Communication systems	Make your own
Collecting/exploring	Visual aids; Adaptations to assist with grasp, reach, size, or to accentuate relevant cues	Hardware stores; Stationery stores; Domestic aid catalogs

**Age 11-14 Years**

<i>Activities of Nonhandicapped peers</i>	<i>Modifications for Individuals w/Dual Sensory Impairments</i>	<i>Where to find Age-appropriate Materials</i>
Creative materials	Bright colors; Textures; shapes Lighting; Contrasting background; Light box; Trays; Visual aids	Arts/crafts; Stationery stores; American Printing House for the Blind; Optometrists
Sports	Bright colors; Adaptations to accentuate relevant cues; Sounds; Rule modifications; Textures; Peers	American Printing House for* the Blind; Sporting goods stores; Make your own
Clubs	Peers, Lighting; Enlarged printed materials; Communication systems	Make your own
"Hanging out"	Communications systems; mobility aids; Domestic aids; Sunglasses	DIS **services; Regional Center; Domestic aid catalogs
Music	Adaptations to assist with grasp, reach, or to accentuate relevant cues. Wooden floor; Close proximity to speakers	Hardware stores; Domestic aid catalog; Radio Shack
Makeup (girls)	Magnifying mirror with lights; Peer; Lighting	Cosmetic department

\*See address at bottom of Ideas page

\*\*DIS (Designated Instruction Services) = IEP. Consult your child's IEP, teacher or other service provider



## Age 15-17 years

<i>Activities of Nonhandicapped peers</i>	<i>Modifications for Individuals w/Dual Sensory Impairments</i>	<i>Where to Find Age- appropriate Materials</i>
Sports	Bright colors; Textures; Shapes; Lighting; Contrasting Background; Light box, Trays Visual aids	American Printing House for* the Blind; Sporting goods stores; Make your own
"Hanging out"	Communications systems; Mobility aids; Domestic aids; Sunglasses	DIS **services; Regional Center; Domestic aid catalogs
Music/Dancing	Adaptations to assist with grasp, reach, or to accentuate relevant cues, Wooden floor; Close proximity to speakers; Peers; Resonance and co-active movement	Hardware stores; Domestic aid catalog; Radio Shack
Cruising	Communication system; cues from peers regarding appropriate body language	
Shopping	Communication system; Peers; Lots of money; Mobility aids; Braille	DIS services; Regional Center
Movies	Seating; Visual aid; Mobility aid; Unlock accessible restrooms; Communication system; Peer(s)	DIS services; Optometrist

## 18+ Years

<i>Activities of Nonhandicapped peers</i>	<i>Modifications for Individuals w/Dual Sensory Impairments</i>	<i>Where to find Age- appropriate Materials</i>
Music/Dancing	See 11-14 and 15-17 charts	
Sports	See 7-10 chart	
Shopping	See 15-17 chart	
Nature	Communication system; Mobility aids; Peers; Visual aids; Braille; Use of senses of touch and smell to accentuate relevant cues	DIS services; Optometrist; Camping stores
Hobby	Bright colors; Textures; Shapes; Lighting; Contrasting background; Light box; Trays; Visual aids; Communication aids	Arts/crafts stores; Stationery stores; American Printing House for the Blind; Optometrist

\*See address at bottom of Ideas page

\*\*DIS (Designated Instruction Services) = IEP. Consult your child's IEP, teacher or other service provider

## Guidelines for Play Interaction with Young Children who are Deaf-Blind

by Tanni Anthony

*Taken from the Infant-Toddler News Exchange,  
Hilton Perkins National Program, April, 1993.*

√ Establish a rapport with the child. This is true with all children, but it is especially important for the child who is deaf-blind. A relationship of trust must occur in order to witness the child at her best skill level. Rapport is earned by respecting the child's interactions and building on her responsiveness to you. Allow the child to initially have free time to explore the surroundings with you as a part of the environment. As he discovers your presence, provide him with touch reinforcement such as holding him in close contact or rhythmic patting on his body. Pay attention to her acceptance of this touch. Evidence of an established rapport will be demonstrated by the child's self initiated actions toward you--either as a person or as a perceived play item.

√ Acknowledge and respond to the child's communicative signals. Be sensitive to the child's non-verbal and individual communication signals. Provide ample opportunity (e.g. wait time) for the child to communicate. Seek input from the family, teachers and others who know her well for assistance in eliciting and interpreting communicative abilities. Respond to her current signals, while attempting to gently expand, refine and elevate communication to a broader, higher level.

√ Establish a predictable routine with clear transition activities. Create a rhythm of activities. Emphasize a clear beginning and ending to an activity. Use a sensory, verbal and/or an action cue to signal the onset and the closing of the activity. For example, feeding time can be announced by placing the child in his high chair and giving the child a spoon. The closing of this activity can be signalled by giving the child a damp cloth to wipe his face, then putting the cloth back in the adult's hand to indicate "finished". Whenever possible, use established communication cues with the child throughout the routine to let her know what is coming next in the sequence.

Each child will have different needs for being prepared to transition from one activity to the next. Pay attention to these needs so that adequate cuing can occur in advance to prepare the child for the closing of one activity and the beginning of the next.

√ Implement a spatially consistent environment. Whenever possible, reinforce a play setting that has established spatial boundaries and content. Allow the child to have time to explore the area around him on *his own initiative* before presenting yourself into the setting. Also, rather than offering a new item and then removing it completely from the setting, return it to a set place which is within reach of the child. It may be in a container or out in the open next to the child.

√ Systematically learn about the child's individual learning style. Gather information from the people who know the child as to what the best type and level of stimulation is for her. If this information is not known, be careful to monitor the level of stimulation presented to the child until more information is gathered about the child's learning style.

Children who are deaf-blind often benefit from movement arousal activities such as bouncing and swinging. This vestibular input helps to alert the overall sensory systems for interaction. The type and level of vestibular input should be reviewed with the family and the motor therapists involved with the child.

Look for patterns of responsiveness to sensory information. Two examples include: the child responds the most favorably to items that have a vibratory feature and only becomes visually interested in an object after she has touched it.

√ Be patient. Wait time may be much longer than you normally might wait for other children. Parents can be an excellent guide for how much wait time is needed. If this is an unknown variable, make it a practice to wait at least one to two minutes between trials.

It is common that a child may initially need a longer wait period until he has become familiar with the activity. Repeated experience with the object and/or activity may result in reduced wait time between responses.

√ Avoid guiding the child's hands. First invite his response through other means. If the child is able to use his vision and/or hearing to learn from a visual or sound demonstration of the toy, try this first. If these are not viable learning avenues, present the toy near the child's hands and encourage his voluntary touching of the toy. You may also want to activate the toy at this time, so that he can feel its action. Another approach is to put your hands under the child's so that he can feel your actions on the toy.

If it is necessary to guide the child's hands through a particular action, be sure to give him a verbal and/or tactual cue first. A helpful tactual cue might be to place your hands on his upper arm as a signal that hand-over-

(See Guidelines)

(See Guidelines)

hand guidance is coming. With firm patting motions, move down his arm to his hands. If he resists, respect the refusal. If he accepts your touch, continue with the hand-over-hand guidance. You may want to give the child's hands a squeeze to indicate when you are finished.

Use sensory stimulating objects. Objects that have potent sensory features, especially vibratory, seem to promote the best level of interaction. Objects that have been identified as being especially successful in promoting play interaction include: mylar pom poms, florescent colored slinkies, vibrators, musical keyboards, shiny beads, cellophane paper, Rocket Marble™ ball, color capped flashlights, objects with real smells and tin cans as containers.

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### "Share Your Ideas"

Many of you who are parents and teachers of children with deaf-blindness may feel isolated because the children and you are spread across the state. One purpose of the newsletter is to keep in touch. Do you have information to share with service providers or with parents? Do you have a particular idea that has worked? Do you know of a resource that others should know about? What have you found to be a particularly helpful technique? We would like to know! Send in your ideas or items you run across that we can share in one of the three newsletters that come out each year.

*Reminder:* We are here for you. Our purpose is to provide technical assistance and training to school districts, other service providers and families at no charge.

~~~~~

## Arizona Deaf-Blind Project New Staff Member

As the newest member of the staff on the Arizona Deaf-Blind Project, I'd like to introduce myself. I'm Cindi Robinson, and my job is the-Educational-Transition Specialist on the Project. This means I will be working primarily with school districts and families who have children with deaf-blindness in the 14-22 year age group who will be transitioning to adult environments in the not too distant future.

I have over 15 years experience in the areas of deaf-blindness, severe handicaps, visual impairments, and developmental disabilities. I have been the state consultant for deaf-blind in the states of both Kansas and Missouri, wrote and coordinated an in-service training grant in the areas of community-based instruction and integration of students with severe handicaps and deaf-blindness, and been the dormitory director at the Kansas School for the Blind. My masters degree is in the area of deaf-blind multihandicapped education from Boston College, and my bachelors degree is in mental retardation and elementary education from Michigan State University.

The types of services that have thus far been offered through the grant include: identification, referral, dissemination of information, evaluation, and in-services. With the addition of my position it means that we can expand on the services that we have been able to provide to you. I'd like to visit the classrooms and get to know all of the students with dual-sensory impairments who fall into the transitional age range, help districts in forming transitional teams for those students, and assist with the development of transition plans for them. I will also be able to provide input and answer questions for them. I will also be able to provide input and answer questions that teachers and other may have on educational practices for students with deaf-blindness. In short, my job is to be a support and a resource to districts, teachers, parents, and students. Services I can provide might include technical assistance, consultation, and in-service as they relate to educational and transitional issues.

I have just moved to Tucson from Kansas City where I have been for the past 17 years. I'm really impressed with the friendliness and helpfulness of the people here, and I'm continuously struck with the beauty that I see all around me in the mountains, the desert landscape, and the magnificent sunsets! I'm delighted to be here and I look forward to meeting and working with all of you. ■

## INFORMATION

### RP Foundation Fighting Blindness

*Taken from the National Association for Parents of the Visually Impaired, Inc., Summer Issue, 1993.*

#### STUDY SHOWS VITAMIN A SLOWS BLINDNESS

RP Foundation Institutes

Telephone Hotline for Eye Care Professionals and Patients

*NAPVI Editor's Note:* NAPVI is pleased to share this exciting news with you. Please contact RP Foundation at 800-683-5555 for more information

The Baltimore-based RP Foundation Fighting Blindness has launched an international education campaign to alert people with progressive, blinding retinitis pigmentosa (RP) to the first useful treatment that may help them prolong their vision. Taking a 15,000 IU vitamin A supplement (palmitate form) and avoiding high dose vitamin E supplements may save years of sight, according to the results of a study primarily funded by the federal government's National Eye Institute, National Institutes of Health and the RP Foundation. The results were reported in the June issue of Archives of Ophthalmology by Eliot L. Berson, M.D. of Harvard, Medical School and the Massachusetts Eye and Ear Infirmary, and six co-investigators. The RP Foundation has set up a toll free, 24-hour informational hotline at 800-683-5555 to respond to treatment-related inquiries from RP patients and eye care professionals.

Alan M. Laties, M.D., chairman of the RP Foundation's Scientific Advisory Board said of Dr. Berson's findings, "This treatment can be a benefit, a very real one, for people who have RP. Although not a cure, it will improve quality of life, potentially adding many years of useful vision. The discovery that vitamin E was of no use and in fact potentially harmful is not only important on its own, but further justifies this extensive study." Dr. Laties is Professor of Ophthalmology at the Scheie Eye Institute, University of Pennsylvania School of Medicine.

RP is a group of inherited diseases initially manifesting as night blindness, followed by progressive loss of peripheral vision. Over a period of years this results in "tunnel vision," and may lead to total blindness. The majority of people with RP are legally blind by the age of 40, with a central visual field less than 20 degrees in diameter. An estimated 1.5 million people worldwide are affected by RP.

The carefully designed and monitored clinical trial involved 600 patients with RP between the age of 18 and 49, who were at different levels of visual function. The six year study was conducted at the Berman-Gund Laboratory for the Study of Retinal Degenerations of Harvard Medical School at a cost of \$5 million.

According to Gordon Gund, chairman of the Baltimore-based RP Foundation, "The Foundation investment as part of our overall research program is money well spent. We have now bought more time to find the cure for people who are going blind." Until that cure is found, the general guidelines should be adhered to based upon the results of this study.

o Patients and health care professionals are encouraged to call the RP Foundation Fighting Blindness at 800-683-5555 for the complete information packet before starting treatment. ■

### Assistive Technology

*Taken from the National Parents Network Newsletter, Winter, 1992-1993.*

The National Parent Network (NPN) often receives requests for resource information about various topics. In each issue, we will present one question, and ask you, the parents, the experts, to send in your answers. We hope to get a lot of practical advice, to learn from the mistakes and successes of others, to provide support and to help each other avoid unnecessary frustrations.

In the last issue, the following question was posed by Kim and Lynbda Unruh of Tacoma, Washington:

*"How can parents 'tap into' resources to get equipment and other special needs that insurance and state programs do not offer?"*

(See Assistive)

(Assistive)

> IBM reports that it operates a National Support Center for Persons with Disabilities. This information and referral center is located in Atlanta, Georgia and has provided information to thousands of people. In 1990, IBM established the Disabilities Assistance Network (D.A.N.) which loaned equipment to local groups. D.A.N.'s purpose is to provide information about services and assistive technology at a local level. The Center refers people to the D.A.N. or other agency in their state most able to help them. Call toll free 800-426-4832 (voice) or 800-426-4833 (TDD) for more information.

> The American Foundation for the Blind (AFB) recently published Designing a Program for Financing Assistive Technology: The AFB Loan Program Model. This book is intended to provide guidance to all those persons, agencies and organizations who are interested in solving the financial problem of getting expensive assistive technology into the hands of people with disabilities. The cost of the book is \$25.00. Anyone interested in more information, or in ordering a copy, can call the AFB toll free hotline, 1-800-AFB-LINE, or write: Mark Uslan, National Technology Center, American Foundation for the Blind, 15 West 16th Street, New York, NY 10011.

> The Summer/Fall 1992 issue of *Parent Education News*, a publication of Pennsylvania's Parent Education Network, reported the following information regarding assistive technology:

"A recent policy letter from the U.S. Office of Special Education Programs (OSEP) clarifies that if the IEP team determines that a particular assistive technology item is required for home use in order for a child to be provided a free and appropriate public education, the technology must be provided to implement the IEP."

The article went on to clarify that OSEP may consider assistive technology as special education, related services necessary to maintain a child with a disability in regular classes.

> The New York State Office of Advocate for the Disabled was awarded a grant from the National Institute on Disability and Rehabilitation Research (NIDRR) to provide Technology-Related Assistance to Individuals with Disabilities (TRAID). This will include: a statewide information network on

assistive technology services and devices; an affiliation of service providers in the state, linked by technology resource centers; and outreach workshops for dissemination of information and device demonstrations. The project will also operate TRADE-IN Project, a database of used assistive devices available at no or low cost.

For more information, contact: **TRAID Project, NYS Office of Advocate for the Disabled, One Empire State Plaza, Tenth Floor, Albany, NY 1223-0001.**

> Residents of Maryland may want to get in touch with an organization called ACT--Advocates for Communication Technology for Deaf-Blind People, Inc. Incorporated in 1988, ACT provides financial assistance to individuals who are deaf-blind for the purpose of purchasing assistive technology. In their fall '92 newsletter, they reported two recent financial awards: one to a woman who would be using the money toward the purchase of a computer and Braille output device, and another to a man who received assistance in getting a special guide dog trained to work with a deaf-blind person.

Although ACT cannot presently offer financial assistance outside of the Maryland/DC area, they can offer other types of support, and they do hope to expand in the future to become a national organization with local chapters. For more information, contact: **Advocates for Communication Technology for Deaf-Blind People, Inc., P.O. Box 652, Columbia, MD 21045, or call them at (410) 381-3377.**

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#### Please note: Further Resources

##### Newsletter on Assistive Technology

The National Easter Seal Society publishes the quarterly *Computer-Disability News*, which provides information on products designed to assist people with disabilities. An annual subscription can be obtained for \$15.

To order, contact National Easter Seal Society, 70 Lake St., Chicago, IL 60601-5907; 312-551-7147.

#### In Arizona

##### Assistive Technology Support Program (ATSP)

ATSP is a cooperative project between the Arizona Department of Education, the Arizona Easter Seals Society, and the Institute for Human Development--Project TECH located at Northern Arizona University. The ATSP program

(See ATSI

( ATSP)

designed to provide statewide awareness training and technical assistance to school personnel in issues related to assistive technology. ATSP services are provided at no cost to local educational agencies and are available upon request on first come first serve basis.

Institute for Human Dev.  
AZ University  
Affiliated Program  
P.O. Box 5630  
Flagstaff, AZ 85601-5630  
1-800-553-0714  
Contact: Larry Gallagher

AZ Easter Seals Society  
903 N. 2nd St.  
Phoenix, AZ  
(602) 252-6061  
Contact: Sue LeHew

**ANNOUNCEMENTS**

**Directory of Sign  
Language/Oral Certified Interpreters**

The Arizona Council for the Hearing Impaired has recently published a Directory of Sign Language/ Oral Certified Interpreters and Interpreter Services Listing in Arizona, 1993-1994.

This directory serves as a reference for businesses, organizations, institutions, agencies and service providers needing interpreter services to communicate with persons who are deaf/hard of hearing and may be involved in legal matters, medical emergencies or other situations.

This directory will assist the user by:

1. Defining deafness
2. Identifying where interpreting services can be obtained
3. Listing qualifications and levels of Certification
4. Referencing state and federal laws

This directory is compiled, published and distributed free by the Arizona Council for the Hearing Impaired, an information and referral agency according to A.R.S. 36-1943 to 36-1945.

For a copy contact:

**Arizona Council for the Hearing Impaired**  
1400 West Washington  
Phoenix, AZ 85007  
(602) 542-3323  
1-800-352-8161  
*In Arizona only*

**D-B LINK**  
**The National Information Clearinghouse  
on Children Who Are Deaf-Blind**

DB-LINK (The National Information Clearinghouse on Children Who Are Deaf-Blind) is a federally funded information and referral service that identifies, coordinates, and disseminates information related to children and youth who are deaf-blind (ages 0 to 21 years).

DB LINK is a collaborative effort utilizing the expertise and resources of:

- American Association of the Deaf-Blind (AADB)
- American Foundation for the Blind (AFB)
- Helen Keller National Center (HKNC)
- Perkins School for the Blind (Perkins)
- Teaching Research (TR), Western Oregon State College

These organizations have pooled their expertise into a consortium-based clearinghouse charged with meeting the information needs of a broad cross section of consumers.

DB-LINK responds to questions related to topics including:

- *Early Intervention*
  - *General education*
  - *Health*
  - *Legal issues*
  - *Transition*
  - *IFSPs, IEPs, ITPs*
  - *Special Education*
  - *Medical*
  - *Social services*
  - *Employment*
  - *Technology*
  - *Inclusion*
- (See Clearinghouse)

**(Clearinghouse)**

- Orientation and mobility
- Post-secondary education
- Parents and families
- Independent living
- Recreational services
- Communication
- Syndromes

DB-LINK provides referrals to other organizations.  
DB-LINK is available to everyone--

- Parents
- Employers
- Teachers
- Other professionals
- Researcher
- Other information consumers

**Deaf-Blind Perspectives**

A new journal-like newsletter will make its debut. Deaf-Blind Perspective builds on the success of the TRACES Newsletter, which ceased publication with the Spring, 1993 issue.

Deaf-Blind Perspectives will serve as a forum for presentation and exchange of information related to all people who are deaf-blind. Information previously covered in the TRACES Newsletter will be included in Deaf-Blind Perspectives as well as solicited and unsolicited articles from projects, agencies, consumer groups--anyone with an interest in sharing information in this field. Regular features will include articles by representatives from TRACES, DB-LINK (The National Information Clearinghouse On Children Who Are Deaf-Blind), parent groups, professionals, service agencies, and consumer groups.

Deaf-Blind Perspectives will be published quarterly by Teaching Research Publications. There is no charge for the newsletter. For more information, please contact:

Deaf-Blind Perspective  
Teaching Research Division  
345 N. Monmouth Ave.  
Monmouth. OR 97361  
or call  
(503) 838-8391



**CHECK IT OUT**

**Federally Funded  
Organization Established for Dads**

*Taken from the National Parent Network  
Newsletter, Summer 1993.*

The National Father's Network puts fathers of children with special needs in contact with support groups in different locations around the country. There is a free quarterly newsletter written for and by dads. For more information contact:

James May, Project Director  
National Father's Network  
The Merrywood School, 16120 N.E. Eighth Street  
Bellevue, WA 98008  
or call  
(206) 747-4004 or (206) 282-1334

**... And Also From AFB**

Does your child's braille teacher need some professional support? The Teacher/Mentor Network: Access Braille Literacy may be for her or him. The database is a result of AFB's National Braille Literacy Project, recently renamed Braille DOTS (Development of Training Systems). It acts as a bridge connecting educators with experts around the country who are willing to act as mentors. There is also help available from the entire network through requests for SOS--Strategy for Success.

**Do You Know About APSE?**

The Association for Persons in Supported Employment (APSE) is a membership organization formed to improve and expand integrated employment opportunities, services and outcomes for persons with severe disabilities. It accomplishes this by providing advocacy and education to customers of supported employment, addressing issues and barriers to integrated employment services, improving supported employment practices, promoting national, state, and local policy development, and public education. There is a quarterly newsletter and annual conference. Contact: APSE, 5001 W. Broad St., Ste 34, Richmond, VA 23230

# Calendar of Events

## November

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- November 4, 5, & 6, 1993

**Usher Syndrome: Transitions for the Future Conference** will be held in Seattle, Washington and topics include are: Communication, Orientation & Mobility, Current Technology; Vocational Assessments/Career Exploration; and Supports & Resource Development for Families and Persons with Usher Syndrome. Sponsored by Helen Keller National Center--Technical Assistance Center. Contact: JoAnn Enos, 2366 Eastlake Ave. E., Suite 209, Seattle, WA 98102, (206) 324-9120.

- November 4, 5, & 6, 1993

The Arizona Department of Education, Special Education Section is sponsoring The Fourth Annual Transition Conference on Students with Disabilities in Phoenix at the Arizona State University--West Campus on November 4, 5, and 6, 1993. Mark your calendar!

- November 4, 5, & 6, 1993

"It's About Justice" is the theme for The National TASH conference which will be held in Chicago. On November 3, 1993, choose one of ten TASH-TECH workshops. For more information contact: The Association For Persons With Severe Handicaps, 11201 Greenwood Ave. N., Seattle, WA 98133, (206) 361-8870.

- November 5-7, 1993

The National Association for Parents of the Visually Impaired is sponsoring a conference in Seattle, Washington from Friday, November 5, 1993 through Sunday, November 7, 1993. The theme of conference is "The Challenge Continues." A series of concurrent workshops will be offered, including such topics as: movement for young children, finding sources, recreation, resources for parent leaders, socialization and sex education, technology, making toys, stress management, and cortical visual impairments. Joyce Ford and Steve Perreault will be addressing the topics of national resources for families and personal future planning for families of children who are deaf-blind. For more information, contact NAPVI at 800-562-6265.

- November 18, 1993

Advocates for the Disabled, Inc., and Social Security Advocates want to alert you to an opportunity to become more familiar with the way in which the Social Security Administration determine children's disability for SSI purposes. You might want to make a notice of this event now, knowing that subsequent information will be forthcoming later in the fall. This event will be held at the Embassy Suites Hotel, 1515 North 44th Street, Phoenix, Arizona from 1:00 to 5:00 p.m. If you desire further information, please contact either Sue Schaafsma, Director of Advocates for the Disabled, 1314 North Third Street, Suite 116, Phoenix, AZ 85004, at (602) 256-9673 or Mark Caldwell, Chairperson of Social Security Advocates, 3737 North 7th Street, Suite 100, Phoenix, Arizona 85014, at (602) 277-1745 or toll free (800) 572-6222.



## Calendar of Events

### December

- December 2-5, 1993

"Joining Forces with Infants, Toddlers and Their Families," National Training Institute, sponsored by Zero to Three/National Center for Clinical Infant Programs. Washington Hilton Hotel, Washington D.C. Contact: Zero to Three, P.O. Box 7270, McLean, VA 22106-7270; 703-356-8300; Fax 703-790-7237.

- December 11-15, 1993

International Early Childhood Conference on Children with Special Needs, San Diego Marriott Hotel and Marina, San Diego, California. Contact: DEC Conference (410) 269-6801.

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## Upcoming Events

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### Summer 1995

- July 9-14, 1995

The next International Association for the Education of Deaf-Blind People 11th World Conference will be held in CORDOBA, Argentina. The 1995 conference is entitled "Working and Growing Together." Plenary sessions will cover the nature of deaf-blindness in children and adults; values of society and ethical dilemmas; principles of integrated services for children, young adults and adults. *Full details of this conference will be announced in September, 1994.*

Dear Reader:

Please give us your opinion. We'd like to know if you find the *Arizona Deaf-Blind Project Newsletter* interesting and informative. With your input we can make it more valuable. Please mail or FAX your responses to us.

Thank you!

1. Circle the number beside the title that best describes you: (circle only one)

- 1. Student
- 2. Parent
- 3. Legal Advocate
- 4. Person experiencing disabilities
- 5. Educator (University/College)
- 3. Teacher (Direct Service) \_\_\_\_\_
- 4. School Administrator \_\_\_\_\_
- 5. Therapist \_\_\_\_\_
- 6. Human Service Provider
- 7. Social Worker/Psychologist
- 10. State/Federal Government Personnel
- 14. Teacher Trainer
- 15. Other: \_\_\_\_\_

2. Rate your interest in the following sections in the Newsletter.

Great    Some    Slight    None

a) Front page article				
b) Communication				
c) Information				
d) Announcements				
e) Conferences/ Workshops				

4. Rate the *Newsletter* on each of the following attributes:

Great    Some    Slight    None

a) Your overall opinion				
b) Writing Style				
c) Ease of reading/ appearance				
d) Variety of articles				

5. Is the newsletter informative?

Very    Somewhat    Not too    Not at all

6. Is the newsletter relevant to you?

Very    Somewhat    Not too    Not at all

7. Articles are generally:

too long    too short    just right

8. Please list topics you would like to see in future issues.

9. What suggestions do you have to improve the *Newsletter*?

Return surveys to:  
**Emma Wiseley**  
**Arizona Deaf-Blind Project**  
**Arizona State Schools for the Deaf and the Blind**  
**P.O. Box 5545**  
**Tucson, AZ 85703**  
**(602) 770-3677**  
**or FAX to (602) 770-3759**

Watch for the next  
**Arizona**  
**Deaf-Blind Project**  
**Newsletter**

**ARIZONA DEAF-BLIND PROJECT NEWSLETTER**

**Vol 1, No. 4**

*This newsletter has been provided by the Arizona Deaf-Blind Project located at the Arizona State Schools for the Deaf and the Blind with support from the U.S. Department of Education, Division of Special Education Programs, under cooperative agreement #H025A20036. The views expressed in this newsletter do not necessarily reflect the opinions of either the U.S. Department of Education, or the Arizona State Schools for the Deaf and the Blind, and no official endorsement should be inferred.*

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**P.O. Box 5545**  
**Tucson, AZ 85703-0545**  
**(602) 770-3700**  
**FAX (602) 770-3759**



# ARIZONA DEAF-BLIND PROJECT NEWSLETTER

Arizona State Schools for the Deaf and the Blind  
Vol. 2, Number 6

## Arizona Child Count for Deaf-Blindness

Thank you to everyone who helped with the 1993-1994 Child Count for Deaf-Blindness. We realize the child count creates an extra step in your already busy schedule, and we want to express our appreciation to those of you who helped gather the required information. Below is a summary of a part of the student count information.

### Summary of Children by Age Groups on the Arizona Child Count for Deaf-Blindness

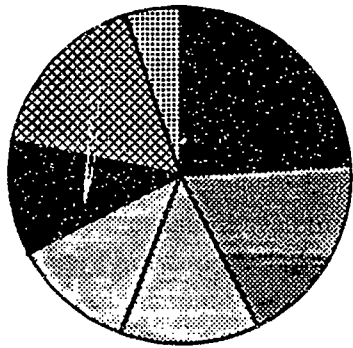
Age Group	1992-1993	1993-1994
0-2 yrs.	12	7
3-5 yrs.	22	12
6-13 yrs.	28	47
14-21 yrs.	30	35
<b>Total</b>	<b>92</b>	<b>101</b>

Number of increase from 1992-1993 = 9

### Category of Disability Reported

	Multiple Dis.	Hrng. Loss	Vision Loss	Preschool	Severe Mental Retardation	Speech/Lang. Delay
Title/Chapt. 1	15	12	9	--	--	--
94-142 Part B	32	4	5	6	1	2
Part H	7	--	--	--	--	--
Graduated/Not in Sch. Prgm.	8	--	--	--	--	--
<b>Total = 101</b>						

### Causes of Deaf-Blindness in Arizona



■	Syndromes	24	23.8%
■	Post Natal Causes	19	18.8%
■	Congenital Prenatal Disfunction	13	12.9%
■	Prematurity (Only)	12	11.9%
■	Multiple Congenital Disabilities	11	10.9%
■	Unknown Causes	17	16.8%
■	Other Known Causes	5	5%

### Distribution of Children with Deaf-Blindness by County and by Age

County (represented on Count)	Birth - 2 yrs.	3 - 5 yrs.	6 - 13 yrs.	14 - 21 yrs.	Total
Apache	0	0	3	3	6
Cochise	0	1	3	0	4
Coconino	1	1	2	4	8
Gila	1	1	0	0	2
Graham	0	0	1	0	1
La Paz	0	1	0	0	1
Maricopa	1	3	19	12	35
Navajo	0	2	2	2	6
Pima	1	3	10	12	26
Pinal	1	0	1	2	4
Santa Cruz	0	0	2	0	2
Yavapai	1	0	0	0	1
Yuma	1	0	4	0	5
<b>Total</b>	<b>7</b>	<b>12</b>	<b>47</b>	<b>35</b>	<b>101</b>

## TRANSITION

The following two articles were taken from "Transition Summary," a yearly publication from the National Information Center for Children and Youth with Disabilities (NICHCY, Number 7, September 1991). For a copy of this entire document and to get on NICHCY's mailing list, you may call toll free 1-800-695-0285.

### Employment Options

A major transition issue for young people with disabilities is securing and maintaining employment. The disturbing truth is that two-thirds of the people with disabilities in our society are not working (Harris & Associates, 1986). Reasons for this high unemployment rate include such factors as: the nature of the disability an individual has, lack of appropriate education, employer perceptions and attitudes, lack of social skills, transportation, economic and benefit disincentives, family beliefs and concerns, lack of appropriate jobs, and lack of needed devices or aids to help in job performance (Kierman & Brinkman, 1985; Harris & Associates, 1986). Many of these factors can be and are being addressed by training programs, adult service providers, and technological advances. There is also a growing awareness that self-sufficiency, employment, and independent or semi-independent living are attainable and desirable goals for individuals with disabilities. Indeed, research shows that working makes an enormous qualitative difference in the lives of people with disabilities, in terms of their self-perception and satisfaction with life (Harris & Associates, 1986).

What employment options, then, are available to young people with disabilities who are making the transition from school to the world of work? Basically, there are three options: competitive employment, supported employment, and sheltered employment. Which employment option is most suitable for an individual will depend largely on the nature and severity of his or her disability and the amount of support needed by the person to maintain employment.

(Page 3)

### Other Disability Categories

Autism	2
Emotionally Disturbed	3
Learning Disabled	3
Mental Retardation	33
Orthopedic Disability	37
Other Health Impairment	8
Speech/Language Impairment	7
Other	5

The updated information on the child count will serve as our guideline of "Who is in what community". "How can we keep in contact", "What are the needs." We want to help team members to best meet the needs of their child with deaf-blindness, their parents and their teachers. As you conclude this school year and prepare for next year, please contact us at the Arizona Deaf-Blind Project as your needs arise. Emma Wiseley and Cindi Robinson are available at 770-3677 (collect calls are accepted). ■

## Competitive Employment

Competitive employment can be defined as full-time or part-time jobs in the open labor market with competitive wages and responsibilities. Competitive employment is employment that the individual maintains with no more outside support than a co-worker without a disability would receive. The key word here is *maintains*. Although a student may make use of transition services available in the community in order to prepare for and find competitive employment, these services are temporary. Once the individual has the job, support from outside agencies is terminated, and the individual maintains, or does, the job on his or her own.

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*"Research shows that working makes an enormous qualitative difference in the lives of people with disabilities ..."*

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The types of jobs that are normally considered competitive employment are as vast in number as they are varied. Waitresses, service station attendants, clerks, secretaries, mechanics, professional drivers, factory workers, computer programmers and managers, teacher's aides, teachers, health care workers, lawyers, scientists, and engineers are just some examples of people who are competitively employed. As can be seen by these examples, the amount of training an individual needs varies considerably from job to job. Some jobs are entry-level and require little or no specific training. Other jobs require vocational preparation and training, while still others require extensive academic schooling.

The traditional route to obtaining competitive employment is that, upon leaving the public school system, a vocational training program, or higher education, job seekers look in the Help Wanted ads in the newspaper or use contacts to locate a job opening. Interviews are scheduled, resumes are sometimes presented, and, with luck and an adequate background of vocational, academic, and/or social skills, competitive employment is obtained.

Youth with disabilities sometimes follow this traditional path, but more often they need assistance in securing a competitive job. The amount of assistance a youth needs may vary, depending upon his or her disability, the particular career in which he or she is interested, the amount of training the job requires, and the type of training

the youth obtained during the public school years or thereafter. Many youth with disabilities leave secondary school with sufficient academic or vocational preparation to maintain competitive employment without help from an outside agency. These individuals may only need assistance from a human services agency in order to *locate* an appropriate job. Other students may exit school without the training necessary to secure and maintain competitive employment. These students generally need support from a human services agency in order to receive adequate vocational skills training or to explore academic opportunities that will prepare them for the career of their choice.

Recently, a training model known as *transitional employment* has been useful in helping many youth and adults with disabilities prepare for competitive employment. "Transitional employment is designed for those who cannot enter on their own into competitive work, but who are able to handle an independent full-wage job after training and support" (Norman, 1987, p. 7). In demonstration projects funded by the U.S. Department of Labor, transition employment consists of three phases. In Phase 1, participants receive initial training and support services in a low-stress work environment. Phase 2 involves a period of on-the-job training in local firms and agencies, "emphasizing job performance and

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*"Which employment option is most suitable for an individual will depend largely on the nature and severity of his or her disability and the amount of support needed by the person to maintain employment."*

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work stress to resemble the demands faced by nondisabled workers in the same types of jobs" (Kerachsky & Thornton, 1987, p. 516). Phase 3 consists of up to six months of follow-up services. Among those who have benefited from transitional employment are individuals who are mentally retarded, individuals with developmental disabilities and learning disabilities, and persons with hearing impairments. Through the transitional employment model, workers have received the training, supervision, and support services they needed to prepare for and secure competitive employment.

The important thing to remember about competitive employment, however, is that the assistance, and supports offered by a human services agency are *time-limited in nature and end once the person has secured employment*.

(Page 4)

## Supported Employment

Supported employment is competitive work in integrated settings for individuals with severe disabilities. It is specifically targeted for individuals who, because of their severe disability, need ongoing support services to perform such work (U.S. Congress, 1986 Amendments to the Rehabilitation Act). The provision of ongoing support, in fact, is one of the features of supported employment which distinguishes it from other services. Support is provided to enable the individual with a disability to learn and maintain the job, and continues to be provided as long as the individual holds the job. Thus, supported employment offers individuals with severe mental or physical disabilities the opportunity to earn wages in job sites in their community while working alongside their nondisabled peers.

There are four models of supported employment. **Individual placement** is one in which individuals receive intensive one-on-one job training from a job coach until they demonstrate proficiency at the job. Once this occurs, training and support from the job coach are gradually reduced, although the job coach will continue to provide follow-up services to the individual and the employer. In the **enclave model**, several individuals with disabilities are trained and supervised in a small group and work alongside nondisabled employees. A trained human services professional or an employee of the host company provides continuous, long-term supervision at the job site (Wehman, Moon, Everson, Wood, & Barcus, 1988). The **mobile crew model** is one in which four to six individuals with severe disabilities move from business to business providing a variety of services as a team. The **mobile crew** is accompanied by a training supervisor or manager who is responsible for training and supervising members and for seeing that the work is completed according to required standards. Janitorial services and groundskeeping are examples of the types of work done by mobile crews. In the **benchwork model**, eight to fifteen workers with disabilities perform contract work procured from electronics firms and related industries. A small number of highly qualified staff provides intensive training and supervision in the work tasks and, additionally, helps workers to develop appropriate work behaviors.

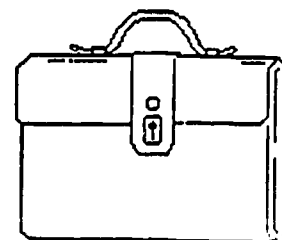
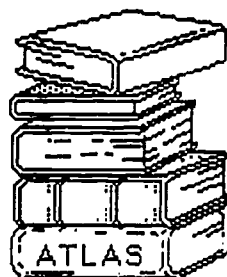
It is important to remember that these are generalizations about the types of models of supported employment. Many communities have agencies providing innovative models of supported employ-

ment which combine elements of the different models described above.

## Sheltered Employment

Sheltered employment options are ones in which individuals with disabilities work in a self-contained unit, without integration with nondisabled workers. Sheltered employment options typically range along a continuum from adult day programs to work activity centers to sheltered workshops. In **adult day programs**, individuals generally receive training in daily living skills, social skills, recreational skills, and prevocational skills. **Work activity centers** offer individuals similar training but may also include training in vocational skills. In **sheltered workshops**, individuals perform subcontracted tasks such as sewing, packaging, collating, or machine assembly and are usually paid on a piece-rate basis. Typically, people do not advance to the workshop until they have demonstrated mastery in the level(s) below. Sheltered employment options are generally supported by federal and/or state funds and are operated by private, non-profit corporations governed by a volunteer board of directors.

Traditionally, sheltered employment options were thought to be the only ones available for individuals with severe disabilities. There is now evidence from supported employment models that individuals with severe disabilities can work in community settings if provided with adequate supports ("Supported Employment," 1989). With the emergence of supported employment, many facilities have begun to modify their sheltered employment programs to provide workers with integrated options (Wehman & Moon, 1988). Advocates of this trend away from sheltered employment point to the advantages of supported employment, which include higher wages, more meaningful work, and integration with workers who do not have disabilities. ■





## Adult Systems

When young people with disabilities exit the public school system, they --and their families-- must learn how to pursue and coordinate many needed educational and related services for themselves. Up to this point, students with special needs have received needed services primarily from one service provider, namely the school system. These services are generally provided in a relatively organized fashion, with school personnel serving as coordinators or case managers for the educational and vocational programs of students with disabilities. Upon exiting the school system, however, students become responsible for managing their own educational and/or vocational programs. They and their families are faced with a baffling array of service providers and differing eligibility requirements. Moreover, the agencies and organizations that can help youth with disabilities make the transition from school to work are no longer conveniently located under one roof, but may be spread out all over the town, county, or state.

Needless to say, assuming total responsibility for locating and coordinating needed services may be a new and challenging task to many youth with disabilities and their families. This article, then, gives an overview of the two adult systems most like to be of assistance to youth with disabilities. These are the Vocational Rehabilitation System and the Social Security Administration.

### Vocational Rehabilitation (VR)

VR is the nationwide federal-state program for assisting eligible people with disabilities to define a suitable employment goal and become employed. Each state capital has a central VR agency, and there are local offices throughout the state that can be located in the telephone directory under the STATE listing for Rehabilitation Services or Vocational Rehabilitation Services. In some states, there is only one VR office that serves all eligible persons with disabilities. Other state may maintain two offices, one which serves persons with visual impairments and another which serves all other individuals with disabilities.

The VR is an excellent place for a youth with a disability to begin exploring available training and

support service options. Typically, a person begins his or her interaction with VR by completing an application form and being assigned to a VR counselor. Generally, the counselor will ask the individual to have a medical examination or provide reports of such an examination if a recent one exists. This step is necessary so that the counselor can determine whether or not the applicant is eligible to receive services. It is important to know that the Vocational Rehabilitation System is an eligibility program, not an entitlement program. Eligibility for services is determined on the basis of three criteria: The person must have a physical or mental disability; the disability must create or cause a substantial obstacle to employment; and a reasonable expectation must exist that the provision of vocational rehabilitation services can make the individual employable.

Section 103(a) of the Rehabilitation Act of 1973, as amended by P.L. 99-506, enumerates a wide array of vocational rehabilitation services that can be provided to eligible individuals. These services are listed in Table 1, along with a brief description of each service. Although "the scope of services provided by local state offices of the Division of Vocational Rehabilitation ... varies in both quantity and quality," for those individuals who are found to be eligible for services, "there is usually a variety of opportunities available" (Skyer & Skyer, 1986, p. 2).

The extensive nature of the services that VR can provide to an individual inevitably raises the question of how these services are funded. How much fiscal responsibility does the individual receiving the services have? The answer is: It varies from individual to individual. VR must pay for all activities needed to determine an applicant's eligibility, including the medical examination. However, when an individual is determined to be eligible, the cost of the services provided thereafter may or may not be fully assumed by VR. The individual with the disability must supply income and expense information to the VR. Depending upon the person's financial status, VR may pay for all services or may require that the person assume a portion of the costs.

Clearly, VR can be of considerable help to young people with disabilities who are exiting school and who are eligible to receive services. An important part of the process is the development of an **Individualized Written Rehabilitation Program (IWRP)**. This document is similar to the IEP developed during the public school years for students with disabilities. As part of the IWRP, long-range and short-term goals for rehabilitation and employment are determined and

(Page 6)

serve as a guide for the provision and monitoring of services. However, it is important to note that rehabilitative services "are time-limited in duration, as opposed to long-term services typically provided or purchased by departments of mental retardation or mental health" (Everson & Moon, 1987, p. 90).

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*Recent legislation ... has made major changes in both the SSI and SSDI programs to encourage people receiving these benefits to try to work and become independent."*

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VR services stop when the client is successfully rehabilitated or it is determined that goals established by the VR counselor and the individual with a disability cannot be achieved.

### Social Security Administration

The Social Security Administration (SSA) directs two programs that can be of financial benefit to eligible individuals with disabilities throughout the transition process. These programs are: the Supplemental Security Insurance (SSI) program and the Social Security Disability Insurance (SSDI) program. Because the Social Security Administration considers many variables before determining if a person is eligible for SSI or SSDI benefits, the discussion here is intended only as an overview to the benefits of these programs. Ultimately, an individual's eligibility can only be determined by contacting the Social Security Administration and filing an application.

The SSI program is targeted for individuals who are both (a) in financial need, and (b) blind or disabled. The evaluation process to determine eligibility varies depending upon whether the applicant is under the age of 18 or over. Recently, there have been many significant changes in how SSA determines the SSI eligibility of individuals under the age of 18. These changes are expected to make it easier for children and youth with disabilities to qualify for SSI benefits (Mental Health Law Project, 1991). More information about these changes and the specific evaluation process the SSA now uses for individuals under the age of 18 is available by contacting the Social Security Administration directly.

When a child reaches the age of 18, the Social Security Administration no longer considers the income and resources of parents when determining

if the youth is eligible for benefits. Under the SSI program, individuals over the age of 18 are eligible to receive monthly payments if they: (a) have little or no income or resources such as savings accounts; (b) are considered medically disabled or blind; and (c) do not work or earn less than a certain amount, defined by the Social Security Administration as **Substantial Gainful Activity (SGA)**. Individuals who are eligible to receive SSI benefits are eligible in most states for food stamps and Medicaid benefits as well (U.S.) Department of Health and Human Services, 1990, July).

The SSDI program is a bit different, because it considers the employment status of the applicant's *parents*. "SSDI benefits are paid to persons who become disabled before the age of 22 if at least one of their parents had worked a certain amount of time under Social Security but is now disabled, retired, and/or deceased" (National Association of State Directors of Special Education, 1990, p. 9). As with SSI, eligibility for SSDI generally makes an individual eligible for food stamps and Medicaid benefits as well.

In the past, the amount of benefits an individual might receive from either or both of these programs would be substantially reduced or even eliminated by income earned at a job (Krebs, 1990). Recent legislation, however, has made major changes in both the SSI and SSDI programs to encourage people receiving these benefits to try to work and become independent. These changes are called *work incentives*, because they make it possible for individuals with disabilities to work without an immediate loss of benefits. To find out more about the work incentives, refer to the article entitled "Work Incentives in SSI and SSDI," found on page 14 in this **TRANSITION SUMMARY**.

**Table 1**  
**Vocational Rehabilitation Services Enumerated in Section 103 (a) of**  
**The Rehabilitation Act of 1973**

Service	Description of Service
Evaluation	To determine a person's interests, capabilities, aptitudes, and limitations, and the range of services needed to prepare the individual for employment.
Counseling & guidance	To help the person aim for a job in keeping with his or her interests, capabilities, aptitudes, and limitations.
Medical & hospital care	To attend, if needed, to mental or physical problems that are obstacles to job preparation.
Job training	To provide training that fits the person's needs and that leads to a definite work goal. Can include personal adjustment training, prevocational training, vocational training, on-the-job training, and training in a sheltered workshop.
Maintenance payments	To cover increases in a person's basic living expenses because of participation in vocational rehabilitation.
Transportation	To support and maximize the benefits of other services being received.
Services to family members	To help the person achieve the maximum benefit from other services being provided
Interpreter services	To assist persons with hearing impairments.
Reader services	To assist persons with visual impairments, including note-taking services and orientation and mobility services.
Aids and devices	To provide the person with needed aids and devices, such as telecommunication devices, sensory aids, artificial limbs, braces, wheelchairs, etc.
Tools and equipment	To provide the person with tools and equipment needed to perform the job.
Recruitment & training svcs.	To provide new work opportunities in public service employment.
Job placement	To help the person find a job, taking into consideration the person's abilities and training; includes placement into supported employment.
Job follow-up	To help the person make whatever adjustments are needed to succeed at the job into which he or she has been placed.
Occupational licenses or permits	To provide the person with the occupational licenses or permits that the law requires a person to have before entering an occupation.
Other	To provide other services that an individual may need to become employable.

## Sources of Information

For more information about the vocational rehabilitation process: Call your State Office of Vocational Rehabilitation and make an appointment to talk with a rehabilitation counselor. You can also contact HEATH for a free copy of Vocational Rehabilitation Services: *A Postsecondary Student Consumer's Guide* (1989).

For specific information about the benefits provided through SSDI and SSI: Contact your local Social Security Office (listed in the telephone directory under Social Security Administration) and request a copy of the publications addressing SSI and SSDI. Single copies are free. You can also contact the SSA through its toll-free number: 1-800-772-1213 (voice) or 1-800-325-0778 (TDD) which is available 24 hours a day. Due to the volume of inquiries that SSA receives, it is best to call early in the morning or late in the afternoon. SSA also recommends calling later in the week.

For a discussion of recent changes to SSI eligibility criteria for individuals under the age of 18, you can contact the Mental Health Law Project, 1101 Fifteenth Street N.W., Suite 1212, Washington, DC 20005, (202) 467-5730.

Another source of information about SSI and SSDI is the Clearinghouse on Disability Information at the Office of Special Education and Rehabilitative Services, U.S. Department of Education, Room 3132, Switzer Building, Washington, DC 20202-2524, (202) 732-1723. Ask for the *Pocket Guide to Federal Help for Individuals with Disabilities* (1989). ■

## INFORMATION

### Anophthalmia Link With Pesticide

*Taken from the VIP Newsletter, Vol. 9, No. 4.*

Doctors in England investigating a mystery condition where children are born with no eyes are to widen their inquiry to examine the role of pesticides, after discovery of an abnormally high cluster of eyeless infants in rural Lincolnshire.

Within a 64 km radius of Louth village in North Lincs, nine children in the past twelve years have been born, either without eyes at all--the condition known as anophthalmia--or with related syndromes, including microscopic eyes and blindness due to severe damage to the optic stem.

Previously, surgeons thought anophthalmia was caused by a genetic deficiency in the parents but, because there are only between 80 and 120 cases of the condition a year, the high concentration in Lincolnshire is causing concern that some external factor could be to blame. Consultants based at London's Moorfields Hospital, the country's premier eye clinic, who have been examining the phenomenon of eyeless children for five years, will investigate potential links between anophthalmia and a chemical compound called Benomyl, widely used in agricultural fungicides.

Experiments with animals in Sweden (1982) and the U.S. (1991) have indicated a link between Benomyl and severe ocular anomalies, including anophthalmia.

*From the PRETORIA NEWS as reported in INFAMA June, 1993.*

### PRIME TIME USA

On October 21, 1993 Prime Time, a USA TV program also carried a report on Anophthalmic children and the dangers of Benomyl. A parents support group called I CAN (International Children's Anophthalmic Network) has been initiated. For more information write or call:

NAPVI, P.O. Box 317, Watertown, MA 02272  
(800) 562-6265

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## ABC Prime Time Live Program on Anophthalmia

*Taken from the National Association for Parents of the Visually Impaired, Inc. Newsletter Awareness, 1994, Winter Issue.*

*NAPVI Works Behind the Scenes  
By Susan Laventure*

Producers from ABC Prime Time Live called the NAPVI office this summer looking for information on Anophthalmia. Their interest in this rare congenital condition was triggered by a previous program aired in England about children with Anophthalmia. Prime Time Live wanted to know what was going on in the United States. ABC Producer Penny Flemming and Assistant Producer Joyce Riley said they had called governmental, private, and medical organizations all over the country looking for any information or families and were not able to find any until they reached the National Association for Parents of the Visually Impaired.

We were very familiar with Anophthalmia and Microphthalmia because NAPVI has many parent members from all over the country who have a child with this condition.

Anophthalmia (born without eyes) and Microphthalmia (born with small eyes) are rare, as most causes of childhood blindness are. There is a variation of incidence rate statistics from medical professionals and institutions because there is no central data base in this country for childhood diseases of the eye. NAPVI is the only organization that has been attentive to this population and has kept a national data base of our members.

When children with Anophthalmia/Microphthalmia are born, parents are devastated and are given very few answers as to the causes and effects. Often times because the condition is rare, the local pediatrician and community are unfamiliar with this condition. You could say that Anophthalmia has been an orphan. There has not been much specific attention given to Anophthalmia until the publicity of the ABC Prime Time Live Program aired on national television October 21, 1993.

This shows the lack of information on Anophthalmia that is provided by governmental agencies. The story also gave a strong impression that there could be an environmental link to the

causes of Anophthalmia. There was a good focus on the Gomberg family and their new support group called I CAN (International Children's Anophthalmia Network) from Pennsylvania. NAPVI was mentioned in the credits and transcripts for our work. There was a tremendous response after the program was aired. ABC in New York referred all of their inquiries to the NAPVI office. We received 100+ phone calls for isolated families from all around the United States who had never corresponded with other parents who had a child with Anophthalmia or Microphthalmia. The letters and calls came in like a flood. Parents were overjoyed to find NAPVI's wealth of resources and network of families.

There has been no specific or significant national study on children born with Anophthalmia/Microphthalmia and their families ever published. NAPVI has begun to gather and compile the information that we have found from the families themselves. We are hoping to further study depending upon research funding that becomes available to us.

### NAPVI's Preliminary Findings:

Based on 100 children born with Anophthalmia/  
Microphthalmia

#### OTHER CONDITIONS

- 54% Had other developmental or physical disabilities that included:  
heart defects, structural abnormalities of the brain, seizure disorders, hearing impairment, hypothalamus, other body parts not developed fully, autism, spasms, cerebral palsy, cysts, mental retardation, and eating disorders
- 20% Had no other developmental or physical disorders
- 26% Unknown

#### FAMILY HISTORY

- 79% No known family history
- 5% Known family history
- 16% Unknown

## ANNOUNCEMENTS

### Fifth Annual Family Learning Weekend

The Fifth Annual Family Learning Weekend for families of children with both hearing and vision impairments is being organized for the weekend of July 29 to 31, 1994. Activities during this weekend will include information, teaching strategies, and support for parents, siblings, and other family members in emphasizing the dignity, rights, and skills of people with deaf-blindness even if severe multiple disabilities are present.

The Arizona Advisory Committee on Deaf-Blindness (AACDB) is coordinating this weekend. The AACDB includes representatives from the Arizona Department of Education; Arizona State Schools for the Deaf and the Blind; Arizona Deaf-Blind Project; Services for the Blind and Visually Impaired; the Community Outreach Program for the Deaf, and other state/national agencies serving the deaf-blind.

We will hold the Family Learning Weekend at Camp Shadow Pines in Heber, Arizona. This is a cool, comfortable dormitory setting where each family is provided with a private room. Separate men's and women's restroom facilities are located in each dorm. The camp kitchen staff will prepare meals.

Supervised recreational and learning activities will be provided by experienced staff for children with deaf-blindness together with their non-disabled brothers and sisters. This is a camping experience for the whole family to share with family members with dual sensory impairments. There is no required skill level for attendance at this weekend.

Topics suggested for the parent discussion groups at the Family Learning Weekend in the past have been: Identifying ways to prepare for and get your input into the IEP process; Job opportunities; Strategies to deal with stress; How to help siblings; Discussions with adults who are sensory impaired; and Sharing information and resources. A schedule for both the parent and the children's groups will be based on parents' input. There will also be ample

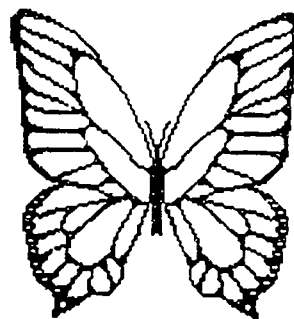
opportunities for families to get to know each other and relax in an informal setting.

Registration may be limited, and total cost is \$10 per family for registration fees. Some funds are available to assist families with the registration fees as needed.

Please share this information with your son's or daughter's DDD case manager, teacher or other school staff, or vocational program. School or work personnel who support your family may be able to attend the weekend with you.

If you and your family would like to attend or have any questions about the Family Learning Weekend, please contact:

Cindi Robinson  
AZ State Schools for the Deaf and the Blind  
P.O. Box 5545  
Tucson, AZ 85703  
(602) 770-3677



#### *Parent Comments from Last Year's Family Learning Weekend*

*Which of your own experiences did you value the most?*

*"Sharing with other parents."*

*"The Parent workshops, especially the relaxation exercises."*

*"The family round table, and talking and getting to know other families and their experiences."*

*"Getting to meet people who have similar problems and hear about the difficult days and how they cope with them plus the joy of their children."*

*"Able to spend wonderful time alone while kids were well taken care of."*

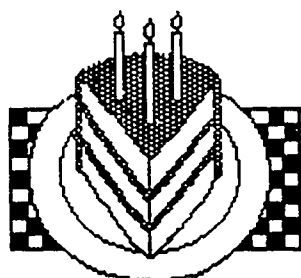
*"Talking with other parents and hearing of their frustrations and experiences."*

(Page 11)

## National Parent Network Changes Its Name

On June 27, 1994, the anniversary of Helen Keller's birthday, the National Parent Network will become the National Family Association for Deaf-Blind: supporting persons who are deaf-blind and their families.

The National Family Association for Deaf-Blind is founded on the belief that individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community. ■



## Recycling Eyeglasses to Help Others

Don't throw out your old eyeglasses. Instead, send them to one of these ongoing programs:

### √ New Eyes for the Needy

549 Milburn Ave., P.O. Box 337  
Short Hills, NJ 07078

Accepts: Metal frames in any condition (broken frames bring cash as scrap metal to buy new glasses for U.S. needy.) All other frames should be in reusable condition for distribution overseas.

### √ VOSH

(Volunteer Optometric Services to  
Humanity)

505 S. Clay St.  
Taylorville, IL 62568

Accepts: Glasses in any condition for distribution in Eastern Europe, Africa, Asia, South and Central America.

### √ SightFirst

Lions Clubs Intl.

(check phone book for local office)

Accepts: Eyeglasses in any condition.

### √ Help the World See

34 W. Spain St.  
Sonoma, CA 95476

Accepts: Eyeglasses in any condition for distribution at overseas clinics.

These programs collect all types of eyeglasses: children's frames, bifocals, even nonprescription sunglasses (for postcataract-surgery patients). Wrap glasses in tissue or toilet paper to protect them when mailing; better yet, ship in an old eyeglass case.

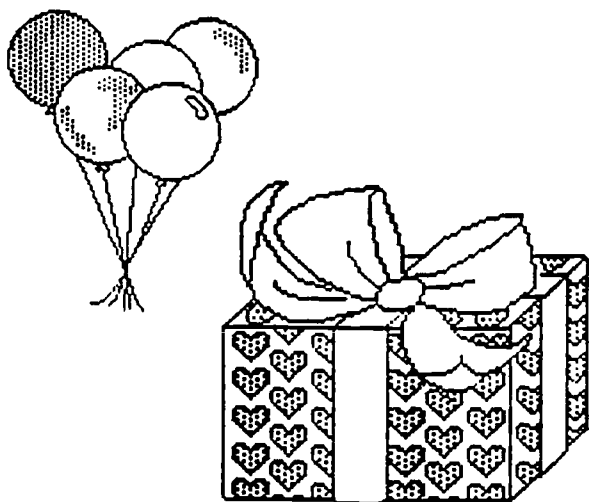


## Gift Ideas

*Taken from the Usher Family Support Newsletter,  
Vol. 1, No. 3, Fall, 1993*

Here are some gift ideas for a person with Usher Syndrome:

- Cane Holder
- Desk, table, or floor lamps with halogen lights
- Hand lotion
- Large-dial or tactile watch/clock
- Large Print or braille reading material and subscriptions
- Set of felt-tip markers
- Set of large print or braille greeting cards
- Tactile signaling equipment
- Unbreakable dishes and kitchenware
- Vibrating wake-up alarm



## Choices for Children

Choices for children is a campaign to inform policymakers, legislators, and others of the unique educational needs of children who are blind or visually impaired.

*What is this campaign?*

Organizations and individuals representing parents, persons with visual impairments, and professionals have joined together in order to promote choices for children who are blind and visually impaired by:

- △ *Supporting* efforts to assure that all federal education legislation adequately addresses the needs of children who are blind and visually impaired. In particular, we are working on the reauthorization of IDEA to ensure that much-needed specialized services and programs will be available to meet the educational needs of these children.
- △ *Assuring* that educational reform efforts offer the opportunity for an array of learning opportunities, including inclusion, for children who are visually impaired.
- △ *Promoting* equal opportunities for, and assuring the civil rights of every child who is visually impaired.

For further information contact either:



Kathleen Huebner  
American Foundation for the Blind  
15 West 16th St.  
New York, NY 10011  
Telephone: (202) 620-2045  
or  
Herb Miller  
St. Joseph's School for the Blind  
253 Baldwin Ave.  
Jersey City, NJ 07306  
Telephone: (201) 653-0578



# Calendar of Events

## May

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### ■ May 31, 1994

International TASH-TECH Workshops Pre-Conference, Reykjavik, Iceland. Topics include:

Facilitated Communication presented by Doug Biklen  
Inclusive Schools presented by Diane Ferguson  
Inclusive Communities presented by Jay Klein

For more information contact: *International Conference Beyond Normalization  
Towards One Society for All  
c/o Iceland Tourist Bureau  
Congress Department  
Skogarhlid 18, 101 Reykjavik, Iceland*

## June

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### ■ June 6 - 24, 1994

New Mexico Summer Institute 1994, Santa Fe, is offering a series of courses in new and emerging topics of value to special and general education teachers, instructional aides, parents, related service personnel, administrators, and state agency personnel. The following courses will be offered:

- June 6 - 7 Tactile Signals and Cues
- June 7 - 8 Adaptive/Compensatory Skills for Students with Visual Impairments
- June 9 - 10 Current Trends in Educating Students Who Are Deaf and Hard of Hearing
- June 12 - 15 Hints for Survival! Community -Based Instruction and the Management of Challenging Behaviors
- June 16 - 17 Personal Futures Planning: A Different Way to Think About Planning
- June 19 - 24 Models for Inclusion (COACH/MAPS) including the Integration

### ■ June 11 - 17, 1994

Eighteenth Annual Open Convention of the American Association of the Deaf-Blind will be held June 11 - 17, 1994 on the campus of the University of North Carolina, Greensboro, North Carolina. The theme for this year's Convention will be "Caring For Ourselves: Facing Changes and Challenges." For more information contact: American Association of the Deaf-Blind, 814 Thayer Avenue, Suite 302, Silver Spring, MD 20910-4500. (301) 588-6545 TTY/(301) 588-8705 Voice.

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# *Calendar of Events*

## **June**

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### ■ June 13 - 17, 1994

The Arizona SCCSC Summer Institute will be presenting a five-day workshop on **Best Practices for Educating Individuals with Severe Disabilities**. The workshop will be held in Casa Grande, 8:30 a.m. to 4:30 p.m. The cost is just \$10 for registration. Two hours of credit are available from the University of Arizona. For more information contact: Judy Croswell, Department of Education/Special Education, 1535 W. Jefferson, Phoenix, AZ 85007, (602) 542-3184.

## **July**

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### ■ July 2, 1994

**Meeting for Parents and Educators of Blind Children, Detroit.** For more information contact: Mrs. Barbara Cheadle, President of the Parents of Blind Children Division of the National Federation of the Blind, 1800 Johnson Street, Baltimore, MD 21230, (41) 659-9314

### ■ July 2 - 8 1994

**National Federation of the Blind Convention, Detroit, 1994.** For more information contact: Mr. Marc Maurer, President, National Federation of the Blind, 1800 Johnson Street, Baltimore, MD 21230, (410) 659-9314.

### ■ July 9 - 13, 1994

**Association for Education and Rehabilitation of the Blind and Visually Impaired (AER) International Conference.** For more information contact: AER, 206 N. Washington St., Suite 320, Alexandria, Virginia 22314.

### ■ July 9 - 14, 1994

**11th World Conference of the International Association for the Education of Deaf-Blind People, Cordoba, Argentina, "Working and Growing Together."** For more information contact: Lucia Piccione, Chairperson, IAEBD Conference, Perkins School for the Blind, Hilton Perkins Program, 175 North Beacon Street, Watertown, MA 02172. FAX (617) 923-8076.

# Calendar of Events

## July

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### ■ July 25 - 29, 1994

The Colorado Department of Education and the University of Northern Colorado are co-sponsoring a second Kephart Symposium graduate course on deaf-blindness entitled, "Assessment into Intervention: Effective Strategies for Students with Deaf-Blindness" in Vail, Colorado. The course instructor will be Dr. Kay Alicyn Ferrel and presentation topics will include:

- "Psychological Views of Deaf-Blindness" by Dr. Harvey Mar
- "The Infant, Toddler, and Preschool Child" by the Colorado Hilton-Perkins Early Intervention Assessment Team
- "The School Aged Child" by Dr. Barbara McLetchie
- "Social Interaction/Inclusion/intervention" by Madeline Milian-Perrone and Nancy Sall
- "What Professionals Need to Know" by a panel of parents and consumers

For more information contact: Tanni Anthony

Colorado Department of Ed. or  
201 E. Colfax Avenue  
Denver, Colorado 80203  
(303) 866-6681

Marsha Woodruff

University of Northern Colorado  
Division of Special Education  
Greeley, CO 80639  
(303) 351-2893

### ■ July 29 - 31, 1994

Fifth Annual Family Learning Weekend in Heber, AZ. For more information call Cindi Robinson at 770-3677 (Collect calls accepted).



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### *Share Helen Keller's Vision Helen Keller Deaf-Blind Awareness Week June 26 - July 2, 1994*

#### *Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC)*

HKNC, Headquartered in Sands Point, NY, provides diagnostic evaluation, short-term comprehensive rehabilitation and personal adjustment training, work experience and placement. Services in the field include 10 regional offices, over 80 affiliate agencies, a National Training Team and Services for Older Adults Who are Deaf-Blind. Special programs include a Technical Assistance Center and a National Parent Network. The role of the Center is to ensure that people who are deaf-blind receive the skills training and supports necessary to enable them to live and work in the community of their choice.

If you know someone who could use the skills and support of Helen Keller National Center call 1-800-255-0411.

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Dear Reader:

Please give us your opinion. We'd like to know if you find the *Arizona Deaf-Blind Project Newsletter* interesting and informative. With your input we can make it more valuable. Please mail or FAX your responses to us.

Thank you!

1. Circle the number beside the title that best describes you: (circle only one)

- 1. Student
- 2. Parent
- 3. Legal Advocate
- 4. Person experiencing disabilities
- 5. Educator (University/College)
- 3. Teacher (Direct Service) \_\_\_\_\_
- 4. School Administrator \_\_\_\_\_
- 5. Therapist/ \_\_\_\_\_
- 6. Human Service Provider
- 7. Social Worker/Psychologist
- 10. State/Federal Government Personnel
- 14. Teacher Trainer
- 15. Other: \_\_\_\_\_

2. Rate your interest in the following sections in the Newsletter.

Great    Some    Slight    None

a) Front page article				
b) Communication				
c) Information				
d) Announcements				
e) Conferences/ Workshops				

4. Rate the *Newsletter* on each of the following attributes:

Great    Some    Slight    None

a) Your overall opinion				
b) Writing Style				
c) Ease of reading/ appearance				
d) Variety of articles				

5. Is the newsletter informative?

Very    Somewhat    Not too    Not at all

6. Is the newsletter relevant to you?

Very    Somewhat    Not too    Not at all

7. Articles are generally:

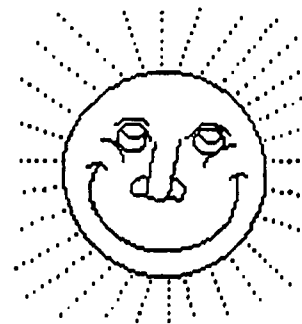
too long    too short    just right

8. Please list topics you would like to see in future issues.

9. What suggestions do you have to improve the *Newsletter*?

**Return surveys to:**  
**Emma Wiseley**  
**Arizona Deaf-Blind Project**  
**Arizona State Schools for the Deaf and the Blind**  
**P.O. Box 5545**  
**Tucson, AZ 85703**  
**(602) 770-3677**  
**or FAX to (602) 770-3711**

Watch for the next  
 Arizona  
 Deaf-Blind Project  
 Newsletter



**ARIZONA DEAF-BLIND PROJECT NEWSLETTER**

**Vol. 2, No. 6**

*This newsletter has been provided by the Arizona Deaf-Blind Project located at the Arizona State Schools for the Deaf and the Blind with support from the U.S. Department of Education, Division of Special Education Programs, under cooperative agreement #H025A20036. The views expressed in this newsletter do not necessarily reflect the opinions of either the U.S. Department of Education, or the Arizona State Schools for the Deaf and the Blind, and no official endorsement should be inferred.*

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**Editor/Project Manager: Emma Wiseley**

**Education-Transition Specialist: Cindi Robinson**

**Administrative Secretary: Sarah Molina**

**Arizona State Schools for the Deaf and the Blind**

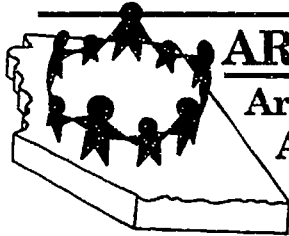
**P.O. Box 5545**

**Tucson, AZ 85703-0545**

**(602) 770-3700**

**FAX (602) 770-3711**

**BEST COPY AVAILABLE**



# ARIZONA DEAF-BLIND PROJECT NEWSLETTER

Arizona Deaf-Blind Project

Arizona State Schools for the Deaf and the Blind

Volume 3, Number 7

Winter/Spring 1995

## Parent Workshop on Transition

On October 27-29, 1994, the Helen Keller National Center's Technical Assistance Center offered a national workshop for parents of transition aged young adults who are deaf-blind. This workshop focused on best practices and real life issues faced by these young adults and their families. Four parents from Arizona were funded to attend this conference in St. Louis, Missouri. We asked two of the parents to share their experiences with us in this newsletter. Their experiences follow:

**from Linda Carpenter, whose son is 20 years old**

'I had a most wonderful experience attending the workshop "Best Practices and Real Life Issues: A National Workshop for Parents of Transition-Age Young Adults Who Are Deaf-Blind" sponsored by the Helen Keller National Center on October 27-29, 1994 in St. Louis, MO.

The agenda of the workshop permitted time for small group interaction and response following each presentation. This was especially beneficial to me as it allowed a way to process the information we had just heard into concrete ideas as to how we could best use it in our own individual situations. The information presented and discussions were very motivating and encouraging to me.

Another benefit of the workshop was the strong networking that took place. I met families who were farther along in the transition process than myself and they were inspirations to me. There were also families just starting to think of transition issues and I was able to share my progress with them. The level of support and understanding in such a setting is amazing.

If you ever have an opportunity to attend such a workshop, please don't hesitate to do so. The experience will be wonderful!

**from Phyllis Grossman, whose daughter is 17 years old**

'I had the privilege to attend the Helen Keller Workshop in St. Louis in October on "Best Practices and Real Life Issues: A National Workshop for Parents of Transition-Age Young Adults Who Are Deaf-Blind". It was both exciting and reassuring to meet with other parents from across the country who had similar concerns. A major emphasis of the conference was developing natural supports for our deaf-blind children. These can be a co-worker, a peer buddy, neighbors, and just about anybody. As parents we need to observe social opportunities to see how our children might fit in and who to connect with. One way to do this is to meet with a circle of concerned individuals and friends, including peers of our children to do a lifestyle inventory and identify choices and opportunities. In social situations our children should not be just "receivers" in activities, but we need to determine how they can also become "providers" and share information about themselves in order to change their image and increase the number of social interactions and length of interactions they have. In order to make a friend, it's necessary to meet a lot of people and have repeated contacts with them over a period of time and it is important to have some way of sharing yourself as a person. As Parents we need to make sure that our children have these opportunities to develop friendships. We can promote success by making sure communication is accessible, preparing our children for participation by making them familiar with what they will be doing, making sure the activity is something our children want to do now and that they feel secure in doing, and modifying the environment if necessary to assist participation. We all came away inspired to make positive changes today to help change the tomorrows for our children.'

## ARIZONA DEAF -BLIND PROJECT



has changed its  
POST OFFICE BOX ADDRESS  
and TELEPHONE AREA CODE NUMBER  
effective MARCH 19, 1995

*new mailing address*

*new area code*

P.O. BOX 85000  
Tucson, AZ 85754

(520) 770-3677 (voice/tdd)  
(520) 770-3759 FAX

# ARIZONA PARENT GROUP



Come join in the discussion, family support  
and information sharing at the  
Arizona Parent Group  
Sponsored by the  
Community Outreach Program for the Deaf  
(COPD).

Saturday March 18, 1995  
10:00 a.m. - 2:00 p.m.  
COPD Conference Room  
268 W Adams  
-Lunch will be provided-



If you would like to attend the meeting, request more information about the meeting,  
and inquire about possible on-site activities for your child during the meeting, contact:

**Jim Schiller at (602) 792-1906**

If you would like assistance in attending this meeting, or would like minutes from the meeting, contact:

**Emma Wiseley at (602) 770-3677**

## Arizona Transition Team on Deaf-Blindness (ATTDB)

### State & Local Team Partnership Project

The ATTDB is a statewide interagency group which is working with Local Community Transition Teams to improve transition outcomes for students who are deaf-blind. The team is using a three tiered approach to developing transition services which work simultaneously from the state level down and the local, individual level up.

**Level 1:** Is working on statewide systems change through interagency planning, collaboration, and problem solving at the state level with the State Transition Team (ATTDB).

**Level 2:** Is working on local systems change and problem solving through interagency planning and collaboration with Local Community Transition Teams (LCTTs).

**Level 3:** Is working on planning and problem solving for deaf-blind individuals at local sites with direct service providers, families, and interested friends.

Participation in the ATTDB State and Local Team Partnership Project was open to all communities serving students with deaf-blindness. Each community making application was required to already have, or be willing to develop, a Local Community Transition Team (LCTT) in cooperation with the Arizona Department of Education. In addition, each team had to identify in its community at least two students with both a vision and hearing loss to transition plan for. Four community teams were selected to participate. Two of the teams are brand new, (Little Colorado and Paradise Valley) and two have been working with ADE for more than a year (West Yavapai and Tempe).

The project is receiving technical support from the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) whose staff is working on similar projects in eleven states. HKNC has assisted the ATTDB in developing its value and mission statements, identifying local team participation requirements, developing materials for soliciting teams to apply, developing a needs assessment questionnaire, and planning the trainings for the local teams.

On February 8-9-10, 1995, the ATTDB in collaboration with HKNC held the first of three Local Team Training workshops. Topics covered included transition services nationally and locally, person centered planning, best educational practices for individuals who are deaf-blind, adult service options in Arizona, team building and interagency collaboration, and identifying values and missions. Participants had an opportunity to experience a simulation of a combined vision and hearing loss, and each team had time to work together to develop their values and mission statements as well as to action plan for the transition of their identified students.

# Sixth Annual Family Learning Weekend

The Sixth Annual Family Learning Weekend for families of children with both hearing and vision impairments is being organized for the weekend of June 16-18, 1995. Parent activities during this weekend will include roundtable discussions, sharing sessions, presentations, and resources for parents and other family members of children with deaf-blindness, even if severe multiple disabilities are present. The Family Learning Weekend will again be held at Camp Shadow Pines in Heber, Arizona, amidst the beautiful White Mountains. It is a cool, comfortable dormitory setting where each family is provided with a private room. Meals are prepared by kitchen staff. Families may bring close relatives or friends who provide support in their lives.

Recreational and learning activities will be provided by experienced staff for children with deaf-blindness together with their non-disabled brothers and sisters. This is a camping experience for the whole family to share. There is no required skill level for attendance at the weekend. Discussion topics at previous Family Learning Weekends have included: Stress Management; Transition Planning; Participating in the IEP Process; Job Opportunities for Your Child; How to Help Siblings; and Resources for Families. The agendas for both the parent and the children's groups will be based on parents' input.

The Arizona Advisory Committee on Deaf-Blindness and the Arizona Deaf-Blind Project are coordinating this weekend. Sponsors include the Arizona Department of Education; Arizona State Schools for the Deaf and the Blind; Arizona Deaf-Blind Project; Community Outreach Program for the Deaf, and other state/national agencies serving the deaf-blind. There will be ample opportunities for families to get to know each other and relax in an informal setting. Registration may be limited, and total cost is \$10 per family for registration fees. Some funds are available to assist families with the registration fees as needed. Please share this information with your son's or daughter's DDD case manager, teacher, other school staff, or vocational program. School or work personnel who support your family may be able to attend the weekend with you.

If you and your family would like to attend or have any questions about the Family Learning Weekend, please contact: Cindi Robinson AZ State Schools for the Deaf and the Blind P.O. Box 5545 Tucson, AZ 85703 (602) 770-3677

## Parent Comments from Last Year's Family Learning Weekend When Asked Which Experiences Were Most Valuable

*"Sharing with other parents."*

*"The Parent workshops, especially the relaxation exercises."*

*"The family round table, and talking and getting to know other families and their experiences."*

*"Getting to meet people who have similar problems and hear about the difficult days and how they cope with them"*

*"Hearing about the joys of their children."*

*"Able to spend wonderful time alone while kids were well taken care of."*

*"Talking with other parents and hearing of their frustrations and experiences."*





# NEW PUBLICATIONS

These books are available for review by contacting : Emma Wiseley at (602) 770-3677 (collect calls accepted).

## **Etiologies and Characteristics of Deaf-Blindness,**

by Kathryn Wolf Heller, R.N., Ph. D. and Cheryl Kennedy

This monograph looks at anatomy and disorders of the visual and auditory systems, and the possible causes of deaf-blindness.

If you would like to obtain a copy contact: Teaching Research Publications, Western Oregon State College, 345 Monmouth, OR 97361 (503) 838- 8792 (voice) (503) 838-8150 (fax)

## **Inclusive Instructional Design: Facilitating Informed and Active Learning for Individuals with Deaf-Blindness In Inclusive Schools,**

by Kathleen Gee, Morgan Alwell, Nan Graham, and Lori Goetz

This manual looks at issues in service delivery, friendship building, teaming, and appropriate curriculum organization.

To obtain a copy contact: California Research Institute, San Francisco State University, San Francisco, CA 94132 (415) 338-7847

## **Profiles: Individuals with Deaf-Blindness,**

by Lisa E. Edwards, B.S., Karen S. Goehl, M.S., Larry A. Gordon, M.S., and Ed. Joan Houghton, M.S.

This monograph presents information about some causes of deaf-blindness with biographical sketches of individuals who have deaf-blindness due to those causes.

Copies can be obtained by contacting: Indiana State University, Blumberg Center School of Education, 502 Terre Haute, Indiana 47809-5501 (801) 237-2830

## **Choosing Options and Accommodations for Children: A Guide To Planning Inclusive Education,**

by Michael F. Giangreco, Chigee I. Cloninger, Virginia Salce Iverson.

This manual provides information on incorporating the valued outcomes of the family into the student's educational program, and building cooperative teams to insure the inclusion of students in the typical classroom.

To obtain a copy contact: Paul H. Brookes Publishers, P.O. Box 10624, Baltimore, MD 21285-0624



**INFO WORTH ASKING FOR**

# PARENT ADVOCACY TIPS

The following article and TIPS were taken from the Winter 1994/95 issue of "HORIZONS," the newsletter of the Blind Babies Foundation headquartered in California.

One of the most important skills a parent can develop is becoming an effective advocate. Being a child's advocate is the best way to ensure that she or he receives the most appropriate medical and educational services. Judith L., who has a visually impaired son, has become a parent advocate extraordinaire. The following are pointers she shared with other parents at the BBF Parent Workshop last June:

**1.**

**Share your "vision" of who your child is and is capable of becoming with every professional working with him or her.**

**2.**

**Filter all goals, therapies, etc. through your "vision".**

**3.**

**Remember that you know the "whole" child best; others will only know more about part of your child's condition.**

**4.**

**Be proactive! Don't wait for things to go wrong before getting involved. Stay informed and know your child's care providers.**

**5.**

**Consider yourself a full-fledged member of all teams that care for your child. Attend all team meetings and bring written reports for other team members.**

**6.**

**Follow through with all agreements you make about working with your child.**

**7.**

**Prioritize your demands.  
Be selective about what you can give up and what you can't.**

**8.**

**Get emotional support from friends, family, and other parents facing similar struggles.**

**9.**

**Don't accept that something is impossible just because someone says it is. You might be able to convince the person who makes or enforces the rule or regulation creating the "impossibility" to meet your demands.**

**10.**

**Remember that government agencies mandated to serve your child have to provide that care. Solving their financial problems is not your concern.**

**11.**

**Recognize that you will occasionally have to devote time to things other than caring for your child.**

**12.**

**Always remember, there are no perfect parents, and there are no perfect programs.**



## Homemade Materials

### PLAYDOUGH

Mix 1 cup of flour with 1 cup of salt - Add water to mix and one tablespoon vegetable oil - Take the clump and knead it with your hands until it feels like smooth playdough - Store in tight container

Note: the clay has a tendency to dry out. If you keep it in a tight container it should stay pliable. Just work in more water to reconstitute.

### DIAPER WIPES

Materials Needed: - Rubbermaid Size 9 food container (the tall, deep ones) - Paper towels - 2 to 2 1/2 cups water - 2 Tbsp. baby oil - 2 Tbsp. liquid baby soap - a splash of distilled vinegar

Cut the roll of paper towels in half and remove the cardboard tube. Place one of the halves in the food container, add the other ingredients.

To use: pull paper towels from center of the roll. Keep covered when not in use.

(from Horizons Winter 1994/95 issue)



## ANNOUNCEMENTS

### TWELFTH ANNUAL INTEGRATION CONFERENCE ON INDIVIDUALS WITH SEVERE DISABILITIES "BUILDING BRIDGES" ARIZONA'S EFFORTS TO INCLUDE EVERYONE MARCH 2 1995

At the AZ-TASH conference there will be many presentations and information on delivering services to individuals who are multiply disabled and severely sensory impaired. The Arizona Deaf-Blind Project is sponsoring the following presenter: Fran Maiuri, Pilot Project Director, Project Pals, Alaska Services for Children with Dual Sensory Impairments.

TOPIC: Team collaboration strategies and supports to facilitate the education of children who are deaf-blind and multiply disabled in urban and rural inclusive schools.

WHERE: YWCA Leadership Development Center, 9440 N 25TH AVE, Phoenix, AZ.

To register and for further information call: The U of A Extended University at 1-800-955-8632

### STATEWIDE TRANSITION CONFERENCE MARCH 29-30-31, 1995

Sponsored by the AZ Department of Education. Topics include IDEA: What it Means; Determining Post School Outcomes; Assessing Student Preferences and Interests; Making Transition Work In AZ Schools; The IEP: What Transition Looks Like On Paper; and, Planning Is the Key. For more information, call Laura Love or Gay McLaughlin at (602) 542-2805

### UNIVERSITY COURSES NORTHERN ARIZONA

The Institute for Human Development at Northern Arizona University offers two graduate level courses on assistive technology (AT) for persons with disabilities. The first course, UAP 505 - "Disabilities & Technology in the Lifespan: An Introduction" presents an overview of the range of AT options for persons with a variety of disabilities. The second course, UAP 525 - "Applications of Assistive Technology" reviews and critically analyzes available AT devices.

In order to meet the needs of administrators, direct instruction, and related service personnel, NAU has added a section to each course which will meet three weekends during the semester (Friday 6-10p and Saturday 8-4p). Each course will be offered for three graduate credits. This Spring, the introductory class UAP 505 will be offered. Prerequisites: Senior standing, admissions to the Graduate College, or instructor approval. For more information contact: Larry Gallagher, Institute for Human Development, Northern Arizona University, Box 5630, Flagstaff, AZ 86011-5630 (602) 523-5083

### UNIVERSITY OF ARIZONA COURSES

Two courses from the Teacher Preparation Program on Visual Impairments which will be offered this summer are: Low Vision and Visual Functioning which is offered on June 5 through the 23, 1995 from 1:00 p.m. to 3:50 p.m., and Methods of Teaching Children with Visual Impairments offered on June 5 through the 23, 1995 from 9:00 a.m. to 11:50 a.m. For further information contact: Jane Erin at (602) 621-0945.

## CONFERENCE

The California Deaf-Blind Services and Project Needs present: Dr. Jan van Dijk professor, researcher, and international lecturer Sint-Michielsgestel Institute, The Netherlands April 28-29, 1995, Clarion Bay view Hotel, San Diego, CA. Topic: "Assessment and the Development of Communication Skills for Individuals Who are Deaf-Blind." For information contact: Project Needs (619) 225-3800

## FREE RECONDITIONED HEARING AIDS

Behind-the-ear hearing aids are provided free by the National Hearing Aid Bank (NHAB) to individuals who are financially unable to purchase new hearing aids. NHAB accepts donations of used hearing aids, reconditions them, and makes them available. Each donated hearing aid entitles the donor to a \$100 tax receipt. For more information, call 1-800-648-HEAR.

## HOUSING CONCERNS

If you are having trouble finding accessible housing for yourself or your family member with a disability, the National Accessible Apartment Clearinghouse (NAAC) may be able to help. Call them toll free at 1-800-421-1221

## DEAF HISPANIC NEWSLETTER

Did you know? The Hispanic Deaf Newsletter is published three times a year for parents, teachers and others interested in services for Spanish-speaking students who are hearing impaired. To get the newsletter write Dr. Barbara Luetke-Stahlman, Dept. of Special Education, Northern Illinois University, DeKalb, IL 60115.

## NEW FROM NICHCY!!!!

The National Information Center for Children and Youth with Disabilities (NICHCY) is pleased to announce the availability of these free new publications:

- Parenting a Child with Special Needs: A Guide to Reading and Resources
- A Parent's Guide to Accessing Parent Groups
- Directory of Organizations
- Transition Services in the IEP
- Questions and Answers about the Individuals with Disabilities Education Act
- Updated fact sheets, and a new fact sheet on Traumatic Brain Injury

NICHY'S TOLL-FREE NUMBER IS NEW  
1-800-695-0285 (voice/TTY)

## "TOYS"R"US TOY GUIDE FOR DIFFERENTLY-ABLED KIDS

Toy R"Us and the National Parent Network on Disabilities have put together the "Toys"R"Us Toy Guide For Differently-Abled Kids. To get your copy of this toy catalog which indicates toys that are or can be adapted for specific disabilities and are educational and entertaining to children, write to: Toys"R"Us Guide for Differently-Abled Kids, P.O. BOX 8501, Nevada, IA 50201-9968

## THE GUIDE TO TOYS FOR CHILDREN WHO ARE BLIND OR VISUALLY IMPAIRED

Is a joint initiative of the Toy Manufacturers of America and the American Foundation for the Blind. The 20 page guide provides full color pictures, descriptions, and age ranges for 70 commercially available toys that are appropriate for children with visual impairments. To receive a free copy, send a postcard to: Toy Manufacturers America, 200 5TH AVE., Suite 740, New York, NY 10011.



## AIN'T MISBEHAVIN'

"Ain't Misbehavin': Strategies for Improving the Life of Students who are Deaf-Blind and Present Challenging Behavior" produced by the Outreach Department of Texas School for the Blind and Visually Impaired, Austin: 1995. This video tape offers practical strategies for proactively avoiding interactions which challenge relationships. It is valuable to families, educators, educational support staff, in-home and residential support providers, friends, community members, and anyone else who regularly interacts with a child who is deaf-blind. The crucial links between behavior and the issues of communication, control, and quality of life are examined. A copy of the script accompanies the video and is available in braille upon request.

Length: 16 min. Cost: none. Send a blank VHS tape (30 min., minimum) and request to: Outreach Department Texas School for the Blind and Visually Impaired, 1100 West 45TH Street, Austin, TX 78756 (512) 454-8631

## PARENT ADVOCACY COALITION FOR EDUCATIONAL RIGHTS (PACER)

PACER is an educational advocacy organization providing parent education and training to help parents understand the special laws and information on how to obtain special education school programs for their children and young adults. PACER offers workshops and programs on a variety of topics as well as inservice training, interpreter, service, computer resource center, transition planning, newsletters, booklets, videos, and other materials. Contact: PACER, 4826 Chicago Avenue South, Minneapolis, MN 55417-1055 (612) 827-2966

## **COLLABORATION AMONG PARENTS AND HEALTH PROFESSIONALS (CAPP)**

CAPP is a parent-run resource system for children with special health needs and their families. The purpose of the project is to develop a parent organized, nationally coordinated system that will maintain and strengthen parent and family involvement in health care. The project is built upon the recognition that understanding the needs of families is central to achieving this nation's agenda for family-centered, community based, coordinated care. CAPP provides written materials, training packages, workshops, and presentations for families and professionals. CAPP, 95 Berkeley Street, Suite 104, Boston, MA 02116 (800) 331-0688

## **SIBLING SUPPORT PROJECT**

The goal of the Sibling Support Project is to facilitate the creation of statewide systems of peer support and education programs for brothers and sisters of children with special needs. This is accomplished by providing training, demonstration and technical assistance to projects and agencies, disseminating written materials and presentations, and developing and refining products related to peer support and education programs. For more information contact: Sibling Support Project, Children's Hospital and Medical Center, 4800 Sand Point Way NE, Seattle, WA 98105 Phone (206) 368-4911

## **NATIONAL CENTER ON EDUCATIONAL RESTRUCTURING AND INCLUSION (NCERI)**

NCERI is concerned with inclusion of students with disabilities in the context of broad educational restructuring. Toward this goal, NCERI addresses issues of national and local policy; disseminates information about programs; provides technical assistance to school district and state departments of education; builds a network of inclusion districts; identifies individuals with expertise in inclusion; and conducts research. For more information contact: NCERI Graduate School and University, Center City University of New York, 33 West 42 Street, New York, NY 10036-8009 Phone (212) 642-2656

## **NATHHAN**

The NATIONAL CHALLENGED HOMESCHOOLERS ASSOCIATED NETWORK (NATHHAN) is a, non-profit, organization for families home-educating their special needs children. Among the 2,000 families in the organization there are several hundred families teaching their blind or visually impaired child at home who are eager to share resources and encouragement with others doing likewise. Contact: NATHHAN, 5383 Alpine Road S.E., Olalla, WA 98359 Phone (206) 857-4257

## **SYMPOSIUM ON DEAF-BLINDNESS**

Texas Services for the Blind and Visually Impaired will host A Symposium on Deaf-Blindness on June 23-24, 1995 in Austin, Texas. If you are interested in more information contact: Beth Sanchez (512) 454-8631, EXT. 103

## **"YOU & ME".**

Teaching Research Division has produced the first video in a five-part video series about educating children who are deaf-blind. The video is entitled "You & Me". The price of each video is \$15.00. Videos with open captioning are available upon request. For more information contact: Teaching Research Division, 345 N Monmouth Ave., Monmouth, OR 97361 Phone (503) 838-8792 (voice) (503) 838-8821 (TTY)

## **INTERNATIONAL CHARGE SYNDROME CONFERENCE**

The Second International CHARGE Syndrome Conference for Families and Professionals will be held July 21- 23, 1995 at Lewis and Clark College, in Portland, Oregon. For more information contact: CHARGE Syndrome Foundation Inc., 2004 Parkade Blvd., Columbia, MO 65202-3121 Phone (800) 442-7604

## **KIDS 'N SIBS**

Kids 'N Sibs is a newsletter for kids with and without disabilities - for children who have to cope with chronic illnesses, physical disabilities, and learning disabilities, and for their brothers, sisters and friends. For more information, write to: Kids 'N Sibs, c/o Elizabeth Fogg, 191 Whittier Road, Rochester, NY 14626

## **MUMS**

Mothers United for Moral Support (MUMS) is a nationwide support group for parents and foster parents of a child with any disability. MUMS networks systems match parents with other parents whose children have the same or similar disability. Write to: MUMS, c/o Julie Gordon, 150 Custer Court, Green Bay, WI 54301

## **LILLI NIELSEN CONFERENCE**

The Blind Children's Fund will host the "National Conference for Active Learning: Turning Latent Potential into Dynamic Ability for Infant, Preschool, and Multi-Impaired Blind and Visually Impaired Children" presented by Lilli Nielsen, Ph.D. of Denmark on June 19-23, 1995 in Novi, MI. For more information call: Sherry Raynor (517) 333-1725

## **CANES!CANES!CANES!**

The Foundation for Blind Children will soon be offering the CANES FOR KIDS program to families throughout the Phoenix area (and surrounding communities). Canes for Kids is both a clearinghouse for used canes and a supplier of new canes and cane parts. Any child, in need of a new cane, or parts for their current one, can easily purchase them through this program for a reasonable price. Old canes can also be exchanged for new ones for 25% off the base price of the new cane. Financial assistance is available. For more information contact: The Foundation for Blind Children, O&M Dept. (331-1470 EXT.163).

# CALENDAR OF EVENTS

## MARCH 1995

- 2 The AZ-TASH Conference, YWCA Leadership Development Center, Phoenix, AZ  
Contact: U of A Extended University 1-800-955-8632
- 9-10 Sixth Annual CHILD FIND Conference, ASU West  
Contact: Deanna Bigar or Rita Kenison (602) 542-3852
- 14-18 Technology and Persons With Disabilities 10TH Annual International Conference,  
sponsored by California State University, Northridge, Los Angeles.  
Contact: Dr. Harry Murphy, Center on Disabilities,  
California State University, Northridge, 18111 Nordhoff Street, Northridge, CA 91330-8340,  
(818) 885-2578
- 15-18 American Council on Rural Special Education Conference,  
"Reaching to the Future: Boldly Facing Challenges in Rural Communities", Las Vegas, NV  
Contact: Dr. Dianne Montgomery (405) 744-6036 or Dr. Joan Sebastian (801) 585-5659
- 29-31 Fifth Annual School to Adult Life Transition Conference, Phoenix, AZ  
Contact: Laura Love/Gay McLaughlin/Kathy Dacey, (602) 542-2805
- 

## APRIL

- 1 AER Division 9 (O&M) Workshop, Dr. Sandra Rosen, ASDB in Tucson  
9:00 a.m. - 4:00 p.m. Contact Eileen Sifferman (602) 770-3721
- 5-9 Council for Exceptional Children (CEC) Annual Convention, Indianapolis  
Contact: CEC, 1920 Association Drive, Reston, VA 22091, (703) 620-3660
- 

## JUNE

- 16-18 Deaf-Blind Family Learning Weekend, Heber, AZ Contact: Cindi Robinson (602) 770-3677
- 

## JULY

- 9-14 International Association for the Education of the Deaf-Blind  
11TH World Conference, Cordoba, Argentina  
Contact: Graciela Ferioli, Calle Lima, 1443, 2nd piso, Barrio General Paz,  
Apartado 16, Cordoba, Argentina
- 

## OCTOBER

- 12-14 Discovery '95 The Third Low Vision Conference Chicago, Illinois  
Contact: Derrald Taylor, O.D., Illinois College of Optometry,  
3241 S. Michigan AVE., Chicago, IL 60616  
Phone (312) 225-1700 EXT 540
- 26-27 AER State Chapter Annual Meeting (Tentative Date)

**Newsletter Staff**  
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**Education-Transition Specialist:** Cindi Robinson  
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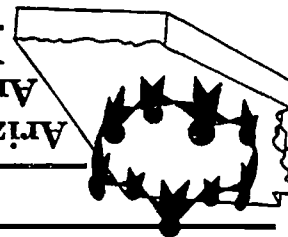
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*Winter/Spring 1995*

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**Arizona State Schools for the Deaf and the Blind**  
**Volume 3, Number 7**

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**Arizona State Schools for the Deaf and the Blind**  
**P.O. Box 5545**  
**Tucson, Arizona 85703-0545**

PROGRAM STANDARDS

FOR

STUDENTS WITH

DEAF-BLINDNESS

Revised  
April 1993

June Downing  
Rod Ferrell  
Matt Franz  
Don Welch, Facilitator  
Emma Wiseley

100



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## INTRODUCTION

### What Is the Role of the Student and Parents?

Students and parents play a critical role in the planning and provision of educational services. Research studies show that with a close working relationship between staff and family, students who are deaf-blind will make more progress.

The deaf-blind student has the responsibility to provide information about his needs, interests, likes and dislikes to the extent possible. Parents and staff may be expected to interpret these patterns through knowledge and understanding of expressions and behaviors.

The roles and responsibilities of parents include the following:

1. To participate actively on the transdisciplinary team and in the IEP process.
2. To provide appropriate information regarding health and early developmental history and ongoing student growth.
3. To seek appropriate medical intervention and services.
4. To provide appropriate individual amplification and visual aids.
5. To provide carry over experiences at home, in skill acquisition.
6. To communicate on a regular basis with the teacher and other service providers.
7. To learn and use the communication system/systems required by their child.
8. To participate in the IEP process.
9. To register with adult service agencies in preparation for transitioning into adult living.

### Are There Specialists in Deaf-Blindness Available?

It is desirable that each regional program and state-operated school identify a specialist/consultant knowledgeable about the education of students who are deaf-blind.

**What Are the  
Qualifications  
for a Specialist  
in Deaf-Blindness?**

This specialist would possess all of the competencies for teachers of students who are deaf-blind, plus have a minimum of three years of direct instruction with students who are deaf-blind including those at all functioning levels. (The specialist should also be knowledgeable about community-based, functional skills instruction.)

This person will be expected to provide consultation to programs and classrooms, assist in the assessment process, participate in IEP development, locate resources, provide inservice and facilitate or assist with program monitoring and review.

## IDENTIFICATION

Who Are Individuals with Deaf-Blindness?

The student who is deaf-blind is one who has concomitant hearing and visual impairments, the combination of which can cause severe communication, developmental, social, emotional, physical and educational problems. The student's impairments may vary from hard-of-hearing and partially sighted to profoundly deaf and totally blind. In general, students identified as deaf-blind have residual hearing and/or vision.

Are There Other Disabilities Associated with Deaf-Blindness?

The presence of additional disabilities is not unusual in this population. Deaf-blindness is often accompanied by one or more of the following: developmental delay, seizures, attention deficit disorder, learning disabilities, autism; mental retardation, orthopedic impairments, social/emotional problems, and disorders of learning. However, the effect of even mild to moderate vision and hearing impairments on the child's development and behavior could easily be underestimated resulting in an inappropriate diagnosis.

## SPECIAL NEEDS OF STUDENTS WHO ARE DEAF-BLIND

Students who are deaf-blind are a diverse population with a variety of special needs. These needs must be considered for each individual student as they will greatly affect his/her educational program.

What Problems  
with Learning  
will Students  
with  
Deaf-Blindness  
Encounter?

The student who is deaf-blind is not to be thought of as a blind person with hearing problems, nor a deaf person with visual problems. Vision and hearing provide the stimulus for interacting with the environment and are the major channels which most people depend upon to receive information. Impaired vision and hearing impose a serious obstacle to the student's development of skills in all areas, and particularly in cognition, communication and social interaction. The effect of a combined visual and auditory impairment is not additive but multiplicative.

Most children have had a variety of auditory and visual experiences by the time they enter school. They have established a foundation of knowledge and learning due to visual and auditory input and are developing concepts and skills necessary to succeed with the academic curriculum of reading, writing and calculating.

Information received by the student with impaired vision and hearing is incomplete and distorted for the following reasons:

1. Subtle cues that most people unconsciously rely on for information and take for granted are missed or misunderstood.
2. Facial expressions, eye contact and body language which provide emotional content and meaning to words used during social interaction are missed.
3. Emotion and purpose of communication which are conveyed by the rate, pitch and intensity of the speaker's voice are not received to assist in the interpretation of the intent of the message.
4. Opportunities for exploration or contact with a variety of environments are limited.

What Are the  
Unique Educational  
Needs of Students  
with Deaf-  
Blindness?

Unique educational needs of students with  
deaf-blindness may include some or all of the  
following:

1. To accommodate for the vision loss it may be necessary to stimulate other senses such as tactile and residual auditory channels. Vision training and low vision aids may be of benefit to enhance residual vision.
2. To accommodate for hearing loss auditory training and hearing aids may be of benefit. These students need to learn how to use residual hearing for language development, as well as the acquisition of other acoustical information which alerts them to their environment, if feasible.
3. The concomitant sensory impairments may also create the need for: a highly individualized/specialized communication system; specially designed programs for sex education, for developing socialization skills, recreation skills, leisure skills, daily living skills, and career-vocational skills; help in dealing with the psychological implications of deaf-blindness; behavior intervention strategies; specialized techniques in developing skills of orientation and mobility.

## ASSESSMENT

Assessment is the first process that must be completed in order to determine eligibility for special education. Ongoing assessment is needed to plan, develop, and implement instructional programming. Special consideration in assessment will result in a more appropriate and beneficial education for students who are deaf-blind.

**What Are the Benefits of Assessment?**

Strengths and limitations will be identified as they relate to educational programming. A measure of the student's present level of performance in significant skill areas will be obtained, followed by the development of goals and objectives and development or selection of individualized instructional strategies. A good assessment will identify critical skills which need to be taught, and where to teach them. Ongoing assessment allows for the monitoring and adjustment of the child's program.

**Are There Appropriate Assessment Tools to Evaluate Students Who Are Deaf-Blind?**

It is difficult to obtain an accurate assessment of a deaf-blind child's potential and level of performance because:

1. The nature of the disability and difficulties experienced by individuals who are deaf-blind affects the administration of most traditional formal assessments. Very few instruments have been standardized on students who are deaf-blind.
2. The category includes students with differing degrees of sensory impairments, differing in age, and differing in age of onset of either or both sensory impairments along with other disabilities.
3. It is difficult for students who are both visually and auditorily impaired to demonstrate their skills and knowledge outside of familiar situations, including testing locations and assessors.

Do Assessment  
Procedures  
Require  
Adaptations?

Persons experienced in assessing students with deaf-blindness will generally be required to select from portions of several formal/standardized tests to obtain useful assessment information. Items within tests will often need to be adapted to accommodate visual, auditory, and communication limitations. Lighting, size of objects and print distance are factors to be considered.

Can Nonstandard-  
ized Assessments  
Be Used to Assess  
Students with  
Deaf-Blindness?

Adaptations of standardized tests invalidate the test and results should be considered accordingly. Interpretations of results from standardized tests must be done cautiously because adaptations of procedures renders the norms invalid.

For the student who is deaf-blind, nonstandardized assessment tools may provide the most accurate measure of the student's typical, spontaneous performance. These tests may either be developmentally-referenced, criterion-referenced or chronologically age referenced (sequenced in order of behaviors and skills exhibited by non-disabled age peers).

A wide variety of survey instruments and nonstandardized assessment tools have been designed and/or adapted for use with deaf-blind populations. See Appendix.

For a large segment of the deaf-blind population, observational assessments should incorporate an appraisal of the students' abilities and performances in their natural environments to include home, school, and community, which in turn lead to assessment of required skills in these critical environments. This information is obtained through interviews with parents, family members, and other persons important in the child's life and through ecological inventories of natural environments (see appendix). Interviews with parents and/or significant others will determine where informal observations and assessments of the student should occur.

What Factors  
Need to Be Con-  
sidered Prior  
to Initiation  
of Assessment?

Prior to the selection and initiation of any assessment procedure, the following questions should be addressed and answered:

1. What current information exists?
2. What additional information is needed?
3. Why is the information needed?
4. How will the information be used in program planning, curriculum selection and/or



- evaluation?
5. What is the most effective means for obtaining the information?
  6. In what environment will the student perform at his/her best?
  7. What motivates the student to perform?
  8. What do family members consider necessary to be assessed?

**Who Should Assess  
the Student with  
Deaf-Blindness?**

The optimal assessment of students who are deaf-blind include the parent as a member of the transdisciplinary team. In addition, a specialist in the area of deaf-blindness, a person skilled in administering, interpreting, and evaluating the validity of assessment methods and tools with students who are deaf-blind, and a person skilled in interview techniques is critical. Evaluators must have communication skills and the ability to use technology to ensure nondiscriminatory assessment.

The following service providers may be involved in the assessment (either directly or through consultation) according to the needs of the student:

1. Certified teacher in the area of sensory impairment, preferably with training specific to deaf-blindness
2. Special educator with experience and training in mental retardation and/or severe/profound impairments.
3. Orientation and mobility specialist
4. Low vision specialist
5. Audiologist
6. Psychologist
7. Speech and language pathologist/communication specialist
8. Occupational therapist
9. Physical therapist
10. Adaptive P.E./recreational specialist
11. Ophthalmologist and/or optometrist
12. Physician and/or nurse
13. Counselor/psychologist
14. Regular education teacher
15. Vocational evaluators
16. Care providers
17. Social Worker

What Areas  
Should Be In-  
cluded in the  
Assessment?

A comprehensive assessment should include information from formal/standardized, and functional assessments and include fine and gross motor development; communication skills; vision and hearing function and acuity; basic skills and functional academics; orientation and mobility; vocational skills; and social/ adaptive behavior skills.

A report of current specialized health needs should be obtained on every student. Special attention should be paid to other conditions, such as orthopedic, neurological, behavioral, and dietary needs that may impact on access to education.

The transdisciplinary team meet to discuss the results of the assessment and to prepare an integrated written report to include impressions, implications and recommendations appropriate to the results of informal and formal assessments. Assessment findings and recommendations for goals and objectives, specialized services, materials and equipment must be included.

How is the  
assessment  
information  
used?

The team uses the assessment information to develop IEP goals and objectives to reflect long-term needs of students. Goals and objectives are age-appropriate, functional, relevant and reflect skills that are to be used in both present and future environments.

How is Student  
Progress  
Assessed?

Data systems are developed and utilized to make decisions about modifications of instructional programs, and to monitor student progress through all aspects of training and education.

The data system includes criteria for determining when a skill has been learned and when the program is not working. The data also provides information about correct, incorrect or inconsistent responses, instructional cues or prompts, and correction and reinforcement to be used.

An ecological assessment of needed skills and a discrepancy analysis of steps required in those meaningful activities provides the framework for effective analysis of student progress and teacher effectiveness. Student progress on skills attained will diminish discrepancies and reflect positive intervention strategies. Lack of progress will signal a need to modify intervention strategies.

## PLACEMENT

Placement of the student who is deaf-blind is the result of a team decision, based on a comprehensive evaluation of a variety of student and program variables. Students who are deaf-blind require the same considerations when placement is being made as other students with disabilities. A continuum of placement options should be available for education of students who are deaf-blind. The goal, as for students with other disabilities, is to place students who are deaf-blind in the least restrictive environment. The least restrictive environment for a student who is deaf-blind is one that maximizes learning, which provides a peer group with whom he/she can interact/communicate.

Another important variable is the qualification of staff to teach students who are deaf-blind. The communication mode used in the classroom must be appropriate to the student's needs and be delivered consistently by all staff. Language/communication should be a major focus of the student's program. Staff should understand effects of deaf-blindness on the student's development and functioning and have the ability to provide necessary adaptations that will allow the student to function. Included in this variable is the availability of support staff from regional programs or other state-operated programs who have knowledge in the area of deaf-blindness. Instructional staff not trained or experienced in teaching students with deaf-blindness must demonstrate an ability and willingness to learn the appropriate skills. Training vehicles are available within the state (see Inservice Training section).

Placement decisions should also consider the needs and preferences of the student's family. A student who is deaf-blind may require continuous intervention both in and out of school. The family and community resources to provide the amount and type of intervention needed must be considered. Placement is to be reviewed annually or more frequently to meet the changing needs of the student and the availability of resources in the community. Vocational training and work experience options are to be considered in the placement decisions for adolescents who are deaf-blind.

What Placement Options are Available for Students Who Are Deaf-Blind?	In Arizona a continuum of options is available. Students may be placed in one of the following settings:  <ol style="list-style-type: none"><li>1. Regular Classroom with supplementary services and/or aids</li><li>2. Regular classroom with itinerant instruction</li><li>3. Regular class/resource room</li><li>4. Special class/self-contained</li><li>5. Separate day school</li><li>6. Private school</li><li>7. Residential school (Institution)</li><li>8. Home</li><li>9. Hospital</li></ol>
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## INSTRUCTION

What Are the Special Curricular Needs of the Deaf-Blind Population?

Educational programs for students with deaf-blindness should emphasize skills that are needed for success immediately and in the future. Teaching methods and educational media will be individualized with appropriate modifications. Basic skills taught in all areas must be made available to those with deaf-blindness, and must be learned in meaningful environments. The individual will not be prohibited from receiving instruction due to mental functioning.

Partial participation is a critical component of functional programming and targets active participation of the student in at least some of the activity steps that a same age (or older) non-disabled peer would perform.

What Curriculum Is Most Appropriate?

Any one approach to the development of a curriculum would not address the multiplicity of needs exhibited by this diverse population.

Curriculum content is developed on an individual basis and reflects student's present and future life needs, including vocational, personal and home management, and social interaction. A few curricula appropriate for students with deaf-blindness are commercially available. More often teachers must adapt these materials to meet individual students' needs or develop their own using a combination of curriculum resources.

Curriculum content is always relevant to the needs of the student and based on activities in situations experienced by the student. Use of curriculum needs to be flexible, include a combination of resources and used as a guide to instructional content.

How Should Instruction Be Organized to Best Meet the Needs of Students with Deaf-Blindness?

The basic skills may best be taught in the following domain areas:

Leisure Time - Many students who are deaf-blind use unstructured time to engage in nonproductive activities. Individuals who are deaf-blind need to learn how to make appropriate use of leisure time in independent and structured group situations in a variety of home and community settings.

Domestic - The concomitant visual and hearing loss affects the student's ability to live independently. The student will need to learn special techniques to function as independently as possible within the home. Domestic skills include self-care skills and activities related to maintaining one's home.

School/Vocational Skills - Students who are deaf-blind require early educational intervention to include observation, assessment, selective training, and community work experience in a variety of age appropriate settings. Introduction of the student and the parents to adult service agencies at an early age is also appropriate.

Community - Students with deaf-blindness will need to learn and practice skills in the community. Early intervention is needed to determine and provide meaningful and optimal instructional objectives within the environments and subenvironments of the individual.

What Specialized Instructional Techniques Can Be Used?

Meaningful and functional activities provide the basis for developing a daily schedule. There must be opportunities for the student to practice the skills in several activities throughout the day.

What Are the Basic Skills Which Must Be Taught to Those with Deaf-Blindness?

Isolated instruction of any basic skill that is not contextually based and has no functional purpose does not represent appropriate programming for this population (e.g., repetitive practice of stringing beads, repetitive dressing/undressing, labelling objects, visually tracking objects).

The following basic skills must be taught in meaningful environments.

Vision - Students who are functioning as totally blind will need to use other senses such as tactile and residual auditory channels. Students with low vision and even light perception may benefit from vision aids and training to enhance their residual vision in appropriate and meaningful settings.

Audition - Students who are hearing impaired may benefit from auditory training and hearing aids. Students need to learn how to use residual hearing for language development, as well as the acquisition of other acoustical information about their environment, if feasible.

Communication - The concomitant sensory impairments create the need for the development of a highly individualized, specialized communication system. Alternative/augmentative equipment/materials may be required. See Appendix

Social/Emotional - Deaf-blindness has a major impact on the social and emotional growth of the individual. Students must develop a feeling of self-worth as they are learning to relate to people. The student who is deaf-blind will have special needs in developing social skills, friendships, recreational skills, and sexuality. Traditional or nontraditional counseling to deal with the psychological implications of deaf-blindness may be needed for the student and the family.

Behavior - Individuals who are deaf-blind often exhibit a variety of atypical behaviors. Positive behavior support strategies may be required to direct these behaviors toward more acceptable patterns.

The student who is deaf-blind will benefit from an educational setting which is as predictable as possible, highly structured, and provides modes of communication for the student. Many so called behavior "problems" exhibited by the students are actually an effort to communicate. With additional support of the Communication Specialist (Speech and Language) appropriate communication skills develop.

A consistent schedule will enable the student to anticipate and understand routines, and to develop a sense of trust. Learning to use a daily schedule will provide students with the opportunity to handle changes in routines.

Orientation and Mobility - The combined sensory loss creates a need for specialized techniques in developing skills of orientation and mobility. Techniques should assist students to move, travel, play and interact independently and safely within the environment.

Motor - The dual sensory loss often inhibits motor development which may adversely affect gross, fine and sensory integrative motor skills. In turn, these motor and sensory-motor limitations affect other areas of development.

What Are Other Considerations Which Might Impact Programs for Students with Deaf-Blindness?

Training - Information and techniques in teaching and communicating with the student should be shared among parents, family, friends, teachers, and others. Information on workshops, and groups dealing with deaf-blindness should be made available to parents.

Materials/Equipment - Technology has changed the way students with deaf-blindness can access and utilize information. Examples include: daily schedules, object schedules; tactile augmentative communication systems; computer programs with touch windows; and telebraille. Students may need assessments, instructional strategies, and opportunities to learn the set of skills required to use these materials and equipment. The family must be involved in the selection and uses of the materials. The student must be allowed the opportunity to use the materials and equipment in all environments.

Peer and social pressure on the student with deaf-blindness should be minimized by providing the student and class placement adequate and on-going counseling opportunities.

How Will the Instructional Methods Be Selected?

Instructional goals, strategies, and procedures will be individualized to meet the educational needs of the student who is deaf-blind. Learning style, physical needs, and communication modes of the student must also be considered when planning teaching strategies. Instructional techniques are always the least intrusive and demonstrate the greatest respect and positive feelings toward the individual student.

How Will Educational and Related Services Be Provided?

Educational and related services will be provided within functional and meaningful activities.

Pull-out models of isolated services (separate rooms/environments) are not appropriate. The daily schedule will provide natural opportunities for learning functional and meaningful skills. The benefit of related services being provided within the daily schedule and activities is that all staff are providing more opportunities of learning for the student.

How Will Scheduling Decisions Be Made?

Scheduling is very important; therefore, a number of factors must be considered to develop an effective class schedule. Students who are deaf-blind will benefit most from instruction when skills are taught in a functional manner. That is, skills are taught in the natural environment and occur at natural times. The schedules can be designed so priority programs are scheduled when the student is most alert and not when he/she is fatigued or influenced by medication. Activities can also be scheduled so active tasks are alternated with quiet tasks or high-preference tasks follow low-preference tasks. Finally, an established daily routine consistently followed allows the student to anticipate activities and develop a sense of time.

How Will Instructional Environments Be Determined?

Where the instruction occurs for each student will reflect individualization considering age, normally accessed environments, interests and future needs. Educational team members with the individual and family as the core will determine the most critical environments for instruction based on present and future needs.

How Will Materials Be Presented?

The Transdisciplinary team must discuss the use of materials. For program effectiveness, the team may need to prioritize or determine the order for the use of materials. Materials must be functional and appropriate for the students' age and degree of vision, hearing, and motor abilities. Placement of the material as well as the physical positioning of the student should facilitate the student's ability to respond. This may include such techniques as placing materials in the best visual field for a low-vision student or positioning the student in side lying to promote arm use and visual attending. For some students, it is also important to allow enough time for the student to process information and to give a response.

Materials and activities may also be selected based on the amount of sensory information they provide. Adaptations can be made to accentuate sensory input as needed.



## COMMUNICATION

Students who are deaf-blind often require an alternative or augmentative system of communication rather than relying upon a verbal system. Intense training in language and communication is frequently necessary to assist the student who is deaf-blind to interact with others in his/her environment.

Why Is Communication Such a Critical Factor?

The greatest disadvantage for the student who is deaf-blind is the lack of ability to communicate. Communication skills are difficult to acquire and require highly specialized instruction. For those who are deaf-blind, competent communication skills are not learned by imitating the communication of those around them, nor is it acquired through incidental learning as it is for many other children. Serious auditory and visual deficits deny these students the experience of hearing and seeing normal conversation, the highly informative nonverbal information given through facial expressions, body language and other nonverbal clues, and opportunities to see how others respond to communicative situations.

Communication is integral to everything that is done with all children and youth and is, therefore, not an area that can be taught in isolation such as during "speech time." Communication instruction must be incorporated into every activity and interaction the child experiences.

Everything that is done with the student is communicative: how the student is held or touched, objects used and activities, manual gestures, facial expressions and vocal intonation. However, the student who is deaf-blind may not receive the full impact of these communicative signals nor understand their meaning.

**How Do Individuals with Deaf-Blindness Communicate?** A variety of communication modes can be used simultaneously and interchangeably with those who are deaf-blind. See Appendix on communication modalities.

**Who Will Determine the Communication Systems Used?** A number of individuals must be consulted when determining the communication system and content. Input from the students, parent(s) or direct care staff, teaching staff, deaf-blind specialist, psychologist or counselor, speech/language pathologist, audiologist, occupational and/or physical therapists and ophthalmologist or optometrist must be considered when identifying efficient and functional communication systems for the student who is deaf-blind.

**How Will Communication Skills Be Assessed?** Communication skills will be assessed using ecologically-based tools and procedures. A standardized test may be inappropriate and may not provide needed information. An ecological procedure and observation identifies the communication demands of meaningful environments, and the needs of the individual in those environments. The discrepancy between environmental demands and the individual student's communication skills provides a functional evaluation of communication strengths and limitations.

**What Are the Critical Factors When Determining Communication Systems?** The student's cognitive level, amount of vision and hearing, motor abilities, and learning disabilities are all considered when determining the most appropriate communication systems. Both the present and future environments in which communication systems will be used must also be identified. The content of the communication instruction should be based on what is required by each environment and what the student is motivated to communicate about. No one communication system will suffice for all communication needs.

How Will  
Communication Be  
Encouraged?

Frequently students who are deaf-blind do not initiate communication. All people, including parents and education staff, must be aware of the individual's communication systems and the skills to be encouraged. They must recognize and consistently acknowledge the student's communicative attempts. In addition, they must provide opportunities for communication and incorporate communication into a variety of settings. These opportunities include a system to provide information to the student about what will happen next, a way to let the student know that the present activity is over, a way to facilitate interactions and spontaneous communication with peers and others and a way to indicate choices and express needs or protests. Both receptive and expressive skills must be taught by all people interacting with the student who is deaf-blind. Isolated "language" training by a speech and language pathologist that focuses on labelling and compliance training is not recommended.

## BEHAVIOR MANAGEMENT

Students who are deaf-blind often display socially unacceptable behaviors. Many variables will influence the students interactive/social skills. Careful assessment and appropriate intervention can frequently reduce behaviors to acceptable standards. Inappropriate behavior may prevent some students who are deaf-blind access to living, working and community-based environments. Severe behavior that is socially unacceptable can also prevent access to less restrictive education environments. However, behavior management issues for students who are deaf-blind may not be different from those of other students with disabilities. Behavior intervention may include a variety of approaches.

**Is Communication a Factor that Influences Behavior?** It is not uncommon for students who are deaf-blind to have communication and interaction skill deficits. Staff, families, and others may have difficulty communicating with the student. The communication deficits of the student may be manifested by tantrums, passivity, aggressiveness, and apparently noncompliant behaviors. Strategies to change behavior of a student who is deaf-blind must go beyond addressing only the target behavior and must include looking at possible contributing environmental influences (both social and physical).

**Does the Environment Affect Behavior?** Before a behavior intervention program is developed, variables in the student's environment must be thoroughly analyzed. A systematic review of the student's environment might identify influences that are contributing to the unacceptable or inappropriate behavior.

**What Are the Environmental Influences?** These influences may be categorized into five groups:

1. Medical/Physical Problems - e.g., hunger, pain, resulting in socially unacceptable behavior
2. Communication - Has an effective communication system been developed? Are all the student's communicative attempts recognized? Do all people interacting with the student have the ability to use the student's mode(s) at the appropriate level?

3. Instruction - Are instructional methods appropriate to the student? Are the materials appropriate? Is the curriculum functional and relevant to the student? Is the reinforcement and delivery schedule effective? Does the student understand the task - how to complete it and why it should be completed?
4. Environmental Pollutants - Is the lighting adequate? Is there ambient noise? Is the environment crowded?
5. Scheduling - Does the student have difficulty during transition between activities or environments? Are there unrelated school events that may be a problem? Does the student have access to a personal schedule to anticipate coming events?

How Will Intervention Occur for a Student with a Severe Problem?

Environmental factors and communicative needs are always considered before more intrusive intervention is applied. Students will always be treated in a positive manner that demonstrates respect and concern. The reasons for the behavior are analyzed for their value (purpose) to the student and alternative behavior(s) taught to replace the socially unacceptable behavior.

## TRANSITION

What Is  
"Transition"?

"Transition" is defined as passage from one state, stage, place, or subject to another. In recent years, education has defined "transition" as a goal-oriented process that assists students in their movement from school to a meaningful adult life. "Transition" is applicable throughout a person's life.

From his/her first interaction with the world, the child seeks a state of satisfaction and equilibrium with a world that is most often unaware of and ill-prepared to interact with a person with dual sensory losses. Although the major thrust of educators has focused on school to work transition, similar standards for successful school to adult transition apply at every stage of the person's life.

When Does Transi-  
tion Begin?

Transition for the student with deaf-blindness happens each time the individual moves from one environment to another.

What Are Major  
Transition Times?

The following list, which is not exhaustive, are examples of "transition" events.

- Hospital to home
- Home to pre-school
- Pre-school to school
- From grade to grade
- Elementary to secondary
- School to work
- Living environment changes
- Job changes

"Transition" also occurs when there is a major change in the personal life of the student with deaf-blindness--e.g., change in the disabling condition--or a change in the family--e.g., death of a family member, addition of a new family member.

Is There a Way to Facilitate the Early Transition Process?

To ensure a successful early transition for the student with deaf-blindness, early intervention by trained parent advisors needs to begin before the child with deaf-blindness leaves the hospital. These trained parent advisors can teach the parents about deaf-blindness, and they can also serve as a link to the next transition step--home to school. As a transition to a new environment is planned, staff will provide opportunities for the student with deaf-blindness to explore and adjust to the future environment. A formal referral process from one educational setting to another is mandatory to pass on all possible information about the child with deaf-blindness.

Who Ought to Be Involved with Long-Planning for Students with Deaf-Blindness?

Parents are the first and greatest continuing caregivers to the child. They must receive Term prominence in the long-term planning for their child with deaf-blindness. Each move to a new service area involves a different set of professionals who become significant people in their child's life.

Educators have primary roles in the early, immediate, and long-range planning for the student with deaf-blindness. It is their responsibility to involve parents in the education process. It is the shared responsibility of parents and educators to begin a comprehensive long-term plan for the student with deaf-blindness.

Others who play important roles in transition for students with deaf-blindness include:

- Family members
- Friends
- Medical personnel
- Social service agencies
- Adult service providers

How Early Does the School to Work Transition Begin?

All IEP's for students with deaf-blindness past the age of 14 will need specific preparation with the parents and must project the student's needs for vocational, living and leisure options and identify appropriate agencies to be contacted.

What Are Suggested Roles and Responsibilities of Those Involved in the Transition Process?

1. Student with Deaf-Blindness participate according to ability in all planning and decision-making.

2. Parents  
Advocate for the special needs of their child within and without the family.  
Involve their child in the family to develop positive self-esteem.  
Become aware of resources of benefit to their child with deaf blindness.
3. Educators  
Facilitate an individualized educational program (IEP) which initiates the transition process, including (but not limited to) objectives regarding:
  - Transition
  - Career education
  - Vocational evaluations
  - Actual job experience
  - Learning about the adult world outside the school systemHelp the student with deaf-blindness access appropriate current and future resources.  
Involve current and future service providers and agencies in transition planning by the student's fourteenth birthday.
4. Agency Professionals  
Become involved in the transition planning for the student with deaf-blindness by that student's fourteenth birthday.  
Inform parents, educators, and the student with deaf-blindness about the services, opportunities, and responsibilities of adult citizenship.  
Provide data on career opportunities for the person with deaf-blindness.  
Advise parents, educators, and students on the appropriateness of IEP services for future living, training, and vocational options.  
Learn about the strengths, weaknesses, and unique characteristics of the student with deaf-blindness.  
Ensure proper linkage of the IEP to the agency's written plan (IWRP, IPP, ITP, etc.).



## QUALIFICATIONS OF STAFF

Who Is Involved  
with the Student  
Who Is Deaf-  
Blind?

Many professionals and paraprofessionals in the education system have a part in the instruction of a student who is deaf-blind. Included are bus drivers, therapists, instructional aides, classroom teachers, itinerant teachers, mobility instructors, physical education teachers, and office, custodial and food service staff. Each has a very important role in the total program of the child. To be effective it is important that all involved individuals communicate well with each other and understand the unique and specialized needs of students who are deaf-blind.

What Certifica-  
tion Is Required  
in Arizona?

Teachers working with deaf-blind students hold various types of teaching certification including "visually impaired," "hearing impaired," "Multiply impaired," and "severely impaired". There is no certification specifically for education of the deaf-blind in Arizona.

What Competen-  
cies Must a  
Teacher Possess  
to Be Effective  
with Students Who  
Are Deaf-Blind?

The many competencies needed by the teacher can be separated into eight areas: communication behavior with students, planning, teaching performance, student management, classroom management, record keeping, and on going assessment.

### Communication Behavior with Students

1. Demonstrates knowledge of language/communication development and systems at both presymbolic and symbolic levels.
2. Gives clear, concise directions and instructions to let student know what is expected.
3. Uses students communication system(s) to interact with the student.
4. Uses objects, pictures, signs, devices, and natural gestures, as needed, to communicate instructions.
5. Allows the student sufficient time to respond.
6. Responds appropriately and consistently to the student's spontaneous communication.
7. Incorporates informal language instruction into all other instructional areas and does not teach in isolation.
8. Elicits appropriate language from the student in meaningful activities/interactions.
9. Reinforces appropriate communication using natural reinforcers.
10. Encourages student initiations by being less directive.

### Planning

1. Places materials within the student's range of motion.
2. Frequently changes the position of nonambulatory students.
3. Makes sure materials used are chronologically age-appropriate and motivating for the student.
4. Provides a definite beginning and an ending to all activities with individual students.
5. Makes an effort to reduce down time and transition time.

### Teaching Performance

1. Demonstrates an ability to adapt instruction to the specific needs of the student considering the dual sensory impairments as well as the demands of the students natural environments.
2. Models or demonstrates the behavior desired of the student.
3. Guides the student's observation to the important aspects of the modeled behavior.
4. Obtains attention before giving instructions with individual students.
5. Maintains student's on-task behavior during activities with individual students.
6. Uses the least intrusive prompts and props to facilitate the desired response.
7. Selects natural cues and reinforcers that have demonstrated functional value to the student.
8. Modifies activity as needed to require active involvement of student versus passive stimulation and handling.
9. Provides contrived reinforcers only when necessary and pairs them with natural events.
10. Uses contingency teaching practices.
11. Reinforces approximations to desired behavior.
12. Reduces the frequency of reinforcement as much as possible and still maintains the level of desired behavior.
13. Keeps students in small and large groups on task with reduced wait time.

### Accommodation for Sensory Impairments

1. Places materials within the student's visual field.
2. Reduces or eliminates outside visual and auditory distractions that interfere with the student's performance.
3. Adapts visual and auditory material into tactual forms.

4. Enhances visual/auditory input of material (increases contrast, decreases background).
5. Presents auditory and visual information at a useable distance to each student.
6. Demonstrates knowledge of the effect of specific vision and hearing impairments on development and functioning.
7. Remediates visual/auditory deficits within age-appropriate and meaningful activities.
8. Demonstrates effective sighted guide technique.
9. Provides opportunities for functional use of residual hearing or vision.
10. Monitors user's sensory aids appropriately for individual children.
11. Manages acoustic environment to decrease noise.

#### Behavior Management

1. Has a clear understanding of the least intrusive management system used in the classroom.
2. Consistently reinforces appropriate behavior immediately following its occurrence.
3. Develops and implements appropriate reinforcement schedules for individual students.
4. Avoids use of aversive control and uses techniques of redirection and reinforcement of other behavior.
5. Recognizes the communicative potential of "aberrant" behavior and responds in a positive and appropriate manner.

#### Classroom Management

1. Outlines the routines (e.g., feeding, toileting, etc.) of individual students in the classroom.
2. Clearly designates each student's "work" space.
3. Arranges a learning environment that facilitates appropriate behaviors.
4. Facilitates daily classroom activities.
5. Develops a daily and weekly classroom schedule that specifies each student's activities and each staff member's responsibilities.
6. Balances individual instruction with group instruction for each student.

#### Record Keeping

1. Uses the prescribed record keeping system in the classroom.
2. Objectively documents each student's performance.

3. Recognizes the importance of systematic data collection.
4. Modifies program/techniques based on data.
5. Designs documentation tools/procedures appropriate for recording each student's performance.

Ongoing Assessment

1. Obtains comprehensive parental and familial information to determine educational program.
2. Chooses appropriate assessment tools that are valid for the target population.
3. Uses observational assessment procedures of natural environments to evaluate student performance.
4. Uses an environmental inventory and discrepancy analysis to evaluate each student's progress.
5. Applies assessment data:
  - a. To design and modify Individualized Education Programs (IEP's).
  - b. To design and modify individualized educational strategies.
6. Describes a student's behavioral strengths and needs based on progress records.

## STATE REGISTRY OF DEAF-BLIND CHILDREN

What Is the Deaf-Blind Registry?

The State Education Agency for each state is required by federal mandate to maintain a registry of all students, 0-21 years of age, who are eligible as deaf-blind. This requirement is found under Section 622 of the Education of the Handicapped Act Amendments of 1983, P.L. 98-199. The administration of this responsibility has been assigned to the Arizona State Schools for the Deaf and the Blind. Registry information is periodically reported to and used by the United States Department of Education to obtain and disperse funding for education to students who are deaf-blind.

Who Should Be Placed on the Registry?

The student who is deaf-blind is one who has concomitant hearing and visual impairments, the combination of which can cause severe communication, developmental, social, emotional, physical and educational problems. Students meeting both the criteria as visually impaired and hearing impaired or having suspected vision and hearing impairments are to be included on the registry. Students may have impairments in addition to both vision and hearing impairments. The individuals may currently be considered multihandicapped, multihandicapped severely sensory impaired, deaf, or visually handicapped and may be placed in a variety of educational settings. Whatever their educational setting and whether or not they have been designated as deaf-blind, if, in your professional judgement there are individuals who have a combination of impairments of both senses that interferes with their ability to function effectively, a referral to the deaf-blind registry is warranted.

A student must be placed on the deaf-blind registry to be eligible for services provided under the Deaf-Blind Project.

How Is a Student  
Placed on the  
Registry?

Registry forms are available from the deaf-blind project supervisor at the Arizona State Schools for the Deaf and the Blind (ASDB). When the multidisciplinary team or its designee determines or suspects a student to be deaf-blind, the referral form will be completed and sent to the deaf-blind project supervisor at ASDB and a copy of the registry referral form will be placed in the student's file. A contact person must be indicated on the form to provide further information or clarification about the data submitted. All information provided to the deaf-blind registry is held in accordance with the requirements for confidentiality as specified in the regulations for the "Privacy Rights of Parents and Students" (CFR 99). The Deaf-Blind Project is eligible to view and maintain confidential and identifying information regarding individuals with exceptional needs.

What Assistance  
May Be Available  
as a Result of  
Registering a  
Student on the  
Deaf-Blind  
Registry?

Upon receipt of the registry referral form, the project's deaf-blind supervisor or coordinator will contact the designated person of the referring program to offer assistance. Information on deaf-blindness and specific topics are available as well as a newsletter and a lending library of books and video tapes. Technical assistance to school districts may include assistance in identification, additional assessment, educational evaluations, inservice training of professionals and parents, and observation of a Community Based/Functional Skills Curriculum Model. Direct services to families with children who are deaf-blind between the ages of 0-5 years may be available in the areas of detection, assessment, educational evaluation, and parent/family education.

What Are the Reporting Requirements for a Student Placed on the Deaf-Blind Registry?

The registry is an ongoing effort updated regularly by the Deaf-Blind Project according to the provisions in CFR 34 Part 307 governing services for children and youth who are deaf-blind. The identified contact person representing the team must contact the ASDB Deaf-Blind Project if any changes occur in the referral information. Through contact by the identified referral person or by periodical written or phone contact initiated by the deaf-blind project codirectors, supervisor or coordinator, a student may be removed from the registry and placed on the inactive listing. Reasons for this action include: the student moved from the state of Arizona; the student is ineligible according to a change in the determined functioning level of vision or audition; or the individual has reached twenty-two years of age.

The designated contact person may also be requested to complete a technical assistance needs survey.

## INSERVICE TRAINING

Research and technology are continually providing educators, adult services, residential providers, and other professionals with new methodology for teaching students who are deaf-blind. Inservice training is needed to keep teachers updated on new developments in the field.

**Is Inservice Training Necessary for Teachers of Students Who Are Deaf-Blind?** There is an intense need for continuous inservice training for staff, parents, and family members who are involved with those who are deaf-blind. Few people have participated in formal training to work with these students. The needs of this low-incidence population are diverse, complex, and continually changing.

**Why Is Inservice Training Important?** Education programs serving students who are deaf-blind often suffer from geographic isolation, staff with minimal training, staff turnover, and burnout. There are limited methods of disseminating new information being developed through research and high technology for low incidence populations. Inservice training is one of the most effective methods of disseminating new information on successful instructional methods, curriculum, and adaptive equipment, and of preventing staff burnout.

**Who Could Benefit from Inservice Training?** All staff, parents, and family members who are responsible for individuals who are deaf-blind can benefit from inservice training.

**How Could Inservice Training Be Delivered?** Inservice training may include a combination of traditional classroom instruction presented information and direct participation with students who are deaf-blind in classroom settings, community based programs, and in domestic living situations. Inservice plans could include plans to provide follow-up and evaluation of student, staff, and family change.



**How Can Teachers and Parents Access Inservice Training?** Inservice training opportunities are provided through school programs and local, state, and national workshops. Information related to Child Find, Early Intervention, Educational Programs, and Supported Employment can be obtained through the Arizona Deaf-Blind Project at the Arizona State School for the Deaf and the Blind (602-629-5698). Related publications and videotapes addressing the topics of Integration, Functional Curriculum, and Parent Advocacy can be accessed through the Arizona Department of Education (602-542-3184). Pre-service and inservice training will be available through the University of Arizona (602-621-3248). The Arizona Early Intervention Program (602-542-5577) for information on early intervention.

**How Can Information Be Disseminated?** Information regarding actual programs and related services in Arizona for students who are deaf-blind is available through resources listed in the appendix.

**Information Be Disseminated?** for students who are deaf-blind and related services is available through resources listed in the appendix.

## PROGRAM EVALUATION

Programs for students who are deaf-blind will be evaluated and modified on a regular basis for both individual student progress and program effectiveness.

What Methods Will Be Used to Ensure Program Effectiveness?

Program evaluation should be an ongoing process to determine the effectiveness of the education and related services to students who are deaf-blind. Program quality indicators (Meyer et al. or Fox et al.) have been developed to assist in the general evaluation of programs. Specific feedback on program effectiveness comes from documentation of student progress at a satisfactory rate that will allow the student to meet established IEP objectives.

## GLOSSARY

**Adaptations:** Adjustments to environmental conditions, including change in sequence of task and additions/changes in materials used to facilitate completion of the task. May include alternative means for communication such as picture/tactile books, electronic devices, tactile/pictorial schedules.

**Chronological Age Appropriateness:** Appropriateness of an activity or environment based on chronological age (not mental age) of a student as compared to a non-handicapped peer.

**Criterion Referenced Tests:** Assessments which address sequences of behaviors defined in terms of some prearranged or predetermined standard of scores without comparison to previous performance of any group or persons.

**Critical Skills:** Skills determined essential to participation which must be completed by another individual should the student not accomplish it or that add to the individual's emotional or physical well-being.

**Developmental/Norm-Referenced Tests:** Standardized measures of a person's performance relative to the performance of others as identified in formal tests, e.g., Brigance.

**Discrepancy Analysis:** An analysis of a student's task performance in relation to a non-handicapped individual's task performance which indicates areas requiring intervention or adaptations to achieve sequence completion.

**Domains:** Curriculum orientation used in functional, integrated and age-appropriate programming consisting of domestic, recreation/leisure, school/vocational, and community activities.

**Domestic Domain:** Curriculum area including self-help skills and encompassing additional home and family skills necessary for participation in all aspects of home life.

**Recreation/Leisure Domain:** Curriculum area utilizing activities which can be incorporated into play, amusement, or relaxation at a time free from responsibilities or engagements.

**School/Vocational Domain:** Curriculum area addressing preparation of students in acquisition, performance, and maintenance of work related skills/behaviors in various integrated environments.

**Community Domain:** Curriculum area including environments and related activities occurring outside the home, school, or work settings requiring student participation within natural integrated environments.

**Ecological Inventory:** A process to determine skills and related factors necessary to function in natural environments, including location, environment, subenvironment, and activities.

**Location:** Specific area which may encompass a one to two block segment within the community.

**Environment:** A site or establishment where a variety of subenvironments or activities may be contained.

**Subenvironment:** More specific areas within a site or establishment in which various activities may occur.

**Activity:** Sequence of skills required to accomplish a task within a subenvironment (e.g., choosing a meal from a menu at a fast food restaurant is one skill within the activity of eating out).

**Functional Skills:** Skills which have high probability of future use and essential to student performance in an environment.

**Individual Education Program (IEP):** A plan for providing specific individualized instruction and services to special education students.

**Infused Basic Skills:** Academic, communication, motor/mobility, cognition, social, auditory, and visual skills integrated into functional activities.

**Integration/Least Restrictive Environment:** A variety of factors must be considered in determining the location of services. These include presence of non-handicapped peers; interaction with non-handicapped peers in schools; naturally proportioned ratio of handicapped to non-handicapped individuals; equal access to education facilities; standard school hours for comparable grade levels; qualified and appropriate personnel; and locations close to home as possible.

**Multidisciplinary Conference (MDC):** A meeting including the diagnostic team and/or education staff with parents/guardians to review evaluations, student needs, and service recommendations.

**Natural Environments:** Available environments typically accessed within a student's home/neighborhood community.

**Positive Behavior Support:** The practice of helping students acquire meaningful skills and display socially appropriate behavior across activities and environments without the use of punitive strategies (overcorrection, response cost, physical and verbal punishment, and time out). Positive intervention strategies are the first option and include techniques of positive reinforcement, token economies, redirection, and prevention.

**Non-Disabled Person Inventory:** Process identifying each component step of a task completed by a non-disabled person.

**Partial Participation:** The right of all students to acquire skills allowing them to function, at least in part, in a variety of least restrictive environments and activities.

**Reinforcement:** An event immediately following a behavior resulting in an increase in performance of that behavior. Reinforcement is highly individualized to be effective for each student.

**Related Services:** Supportive service providing appropriate educational programming (including speech/language, low vision, audiology, occupational/physical therapy, counseling, and orientation and mobility, adaptive physical education).

**Sensory Impairments:** Visual and/or auditory deficits impacting a student's ability to learn.

**Transdisciplinary Approach:** The integration of all support staff and services into a student's total educational program. The family serves as the central focus for the transdisciplinary team with professional members sharing information and intervention techniques to most effectively assist the student achieve meaningful goals and objectives. Intervention is provided cooperatively among service providers and occurs within meaningful activities and environments, not in isolated and specialized settings. Role release is the usual outcome of this approach.

**Transition:** Preparing student for subsequent environments, expectations, and rules via systematic instruction in various settings.

**Vocational Program:** Education plan addressing the vocational domain at three levels.

**Career Awareness:** Educational component for students five to twelve years of age addressing development of work attitudes and behaviors and providing exposure to various careers and jobs in school and community environments.

**Work Exploration:** Educational component for students thirteen to seventeen providing experience and training in various career clusters in school and community environments.

**Work Experience:** Educational component for students over seventeen designed to prepare them for permanent employment in integrated work environments.

APPENDIX

204

# ARIZONA DEAF-BLIND PROJECT

Transdisciplinary Educational Assessment Model

## TEAM

### PURPOSE

The Arizona Deaf-Blind Project will provide training to local education agency personnel in a transdisciplinary contextual assessment process for individuals with deaf-blindness.

### WHAT

Regional Teams throughout Arizona will be identified and provided training and technical assistance to implement the TEAM process in their region.

### WHO

Local Team members may include: psychologists, teachers, parents, audiologists, vision specialists, hearing specialists, speech and language specialists, orientation and mobility specialists, OTs, PTs, transition specialists, and early childhood interventionists.

### HOW

If you or your school district is interested in learning more about the TEAM process, please complete the attached or contact:

Earlene Dykes  
Arizona Deaf-Blind Project Director  
Arizona State Schools for the Deaf and the Blind  
P.O. Box 5545  
Tucson, Arizona 85703-0545  
770-3677 (Tucson)

Yes, I'm interested in learning more about the "TEAM PROCESS".

Name \_\_\_\_\_

Agency \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

Special Education Director \_\_\_\_\_

Phone \_\_\_\_\_ 205 \_\_\_\_\_

BEST COPY AVAILABLE

**Arizona Deaf-Blind Project**  
**Transdisciplinary Educational Assessment Model (TEAM)**

Deaf-Blind Training Agenda  
11/14/94 - 11/17/94

**Monday**

9:30 Transdisciplinary Content  
Buffet Lunch  
1:00 D/B Information: Simulation  
Implications for assessment/sensory diet  
Functional Implications

**Tuesday**

8:30 Team Building  
10:00 Working with Parents: Gail Harris  
12:00-1:00 Lunch  
1:00 Case Presentation  
Design Parent Interview - (Gail participates)  
2:00 Design Assessment Plan - Discipline Framework (Gail participates)

**Wednesday**

8:30-10:00 Parent Interview/Parent (Gail Harris observes)  
10:00 Work with child  
11:30-12:30 Lunch: Replanning of Team Assessment  
1:00-3:00 Team Assessment  
3:00-4:00 Synthesize Information

**Thursday**

8:30 Report Writing  
12:00-1:00 Lunch  
1:00-2:30 Sharing information school/parents (Gail observe or videotape)  
2:30-4:00 Debrief  
Follow-up with new child from Gilbert area