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ABSTRACT

This report describes activities and accomplishments of the Oregon Project for Services to Children and Youth with Deaf-Blindness, a 3-year federally supported project to ensure effective educational services for this population and provide support for families and service providers. The project focused on: (1) identifying additional children with deaf-blindness and providing support, counseling, and training to families of all children who are deaf-blind; (2) providing technical assistance and training for the service providers involved in the education of these children; (3) coordinating the activities of regional consulting teachers who provide consultation and inservice training to families and teachers; (4) coordinating and collaborating with other agencies; and (5) maintaining the state count of children and youth who are deaf-blind. The project served an average of 90 to 110 families and 300 professionals per project year. Individual sections of the report describe the project's purpose, goals, objectives, accomplishments, problems and resolutions, and products developed. Appendices include samples of products developed (project brochures in both English and Spanish versions, and a pamphlet about Usher Syndrome), advisory committee meeting agendas, training agendas, and publicity materials. (DB)

PROGRAM FOR CHILDREN WHO ARE DEAF-BLIND
CFDA-84.025A - STATE AND MULTI-STATE PROJECTS

FINAL PERFORMANCE REPORT

PROJECT TITLE: Oregon Project for Services to Children and Youth with Deaf-Blindness
GRANT CONTRACT #: H025A20014

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

GEOGRAPHICAL AREA : State of Oregon

PROJECT DIRECTOR: Maurine Otos
MAILING ADDRESS: Oregon Department of Education
Public Service Building
255 NE Capitol Street
Salem, OR

TELEPHONE NUMBER: (503) 378-3598

DIRECT SERVICE OFFERED BY PROJECT:
No direct service offered

TECHNICAL ASSISTANCE OFFERED BY PROJECT:
No. of families: 90 - 110 per project year
No. of professionals: 300 average per project year

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I. EXECUTIVE SUMMARY

The purpose of the Oregon Project for Services to Children and Youth with Deaf-Blindness was to ensure appropriate, effective educational services for children and youth who are deaf-blind, and provide support for their families and the many service providers who work with them. This purpose was accomplished by completing the activities associated with the three project goals:

1. Provide services to children for whom Oregon is not obligated to make available a free appropriate public education (FAPE).
2. Provide technical assistance to those who provide special education and specialized services to children with deaf-blindness.
3. Coordinate and manage educational services for children with deaf-blindness.

The State of Oregon, in 1991, mandated that a free appropriate public education (FAPE) be provided for children birth through age twenty-one. Direct services for all of Oregon's children and youth who are deaf-blind were provided by various state and local agencies:

- Children birth through two received early intervention services through six regional agencies which contracted with the Oregon Department of Education to provide services for children with disabilities birth through age two.
- Children birth through age five received special education services in public or private day care centers or preschools and in public kindergartens. The Oregon Department of Education contracted with regional entities who then subcontracted with local service providers.
- Children and youth six through twenty-one received special education services through Oregon's public education system. Educational services were provided in public schools, state operated schools, and other public or private facilities.

Because educational services were mandated for all children, the funds provided through this grant were used for technical assistance across the following goals:

Goal 1. To identify additional children who are deaf-blind and provide support, counseling and training to the families of all children who are deaf-blind.

Goal 2. To provide technical assistance and training for the service providers involved in the education of children who are deaf-blind.

Goal 3. To coordinate the activities of the consulting teachers in each of the six regional programs who provide consultation and inservice training to families and teachers of children who are deaf-blind. To coordinate and collaborate with other national, state, and local agencies. To maintain the state count of children and youth who are deaf-blind.

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II. TABLE OF CONTENTS

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III. PURPOSE, GOALS AND OBJECTIVES OF THE PROJECT

The purpose of this project was to provide appropriate, effective services for children and youth who are deaf-blind in the State of Oregon. The objectives and activities proposed for this project included two priority areas: 1) services to children with deaf-blindness for whom Oregon is not obligated to provide a free appropriate education (FAPE); and 2) technical assistance to those who provide special education and specialized services to children with deaf-blindness.

The project goals and objectives follow:

Goal 1: Services to children for whom Oregon is not obligated to make available FAPE.

Objective 1.1: Provide early intervention, including related services, to children who are deaf-blind from the point of identification through age two.

Goal 2: Technical assistance to providers of education, support staff and families, thereby increasing their capacity to provide appropriate education and related services.

Objective 2.1: Provide consultation to classroom staff and support staff who provide educational services to children with deaf-blindness.

Objective 2.2: Provide local, regional and/or statewide in service training to classroom staff, related service staff and support staff who provide services to students with deaf-blindness.

Objective 2.3: Provide training to early intervention interveners.

Objective 2.4: Provide assistance for developing supported education (inclusion) programs for students with deaf-blindness.

Objective 2.5: Provide technical assistance on needed transition services for students with deaf-blindness.

Objective 2.6: Provide family training and support.

Goal 3: Coordinate and manage educational services for children with deaf-blindness.

Objective 3.1: Coordinate special education and related services and activities required to provide an appropriate educational program for each student who is deaf-blind from point of identification through age 21.

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IV. PROJECT ACCOMPLISHMENTS

Goal 1: Services to children for whom Oregon is not obligated to make available FAPE.

Objective 1.1: Provide early intervention, including related services, to children who are deaf-blind from point of identification up through age two.

Activities and related accomplishments include:

Activity 1.1.1: Identification of all children through age two.
Children under age two were referred by doctors, nurses, mental health agency personnel and families to a primary contact agency within each county. This agency acted as the "fixed point of referral" and was responsible for coordinating evaluations for eligibility determination. When a child with suspected deaf-blindness was referred, the fixed point of referral agency contacted a consulting teacher for deaf-blindness through the regional program for low incidence disabilities.

Activity 1.1.2: Provision of early intervention and related services to children from the time of identification through age two.
Children under age two received early intervention services through six regional agencies that contracted with the Oregon Department of Education to provide services to children with disabilities birth through age two.

Consultation on the effect of deaf-blindness on the early education of children was provided to the early intervention service providers by regional consulting teachers with expertise in deaf-blindness. Early intervention providers and early childhood special education providers were invited to participate in all trainings offered by the project and the Oregon Department of Education.

The project did not receive adequate funding to implement activity 1.1.2 as stated in the original grant proposal. Due to cuts in the original budget, direct services from early intervention interveners was deleted.

Activity 1.1.3: Evaluate the effectiveness of services to children.
The project staff worked with the Oregon Department of Education Early Intervention staff to locate documents that identify quality indicators for young children with disabilities.

Activity 1.1.4: Provide family training and support.
Families received training designed specifically for families through the early intervention service provided by the six regional agencies. An annual needs assessment was conducted by the regional agencies to determine the needs of the families in their immediate regions, as well as across the state. The project provided input into ways to meet these needs for the families of children with deaf-blindness. This collaborative effort increased the fiscal and personnel resources available for training to families.

Two families attended the "Wagonwheel" parent/professional conference held in April 1993.

One family (mother, father, and daughter who has Usher Syndrome) attended a three day Usher Syndrome Family Retreat held in Seattle, WA in September 1995. The retreat was hosted by the Washington 307.11 Project.

Goal 2: Technical assistance to providers of education, support staff and families, thereby increasing their capacity to provide appropriate education and related services

Objective 2.1: Provide consultation to classroom staff and support staff who provide educational services to children with deaf-blindness.

Activities and related accomplishments include:

Activity 2.1.1: Consultation to classroom staff and support staff provided by regional and state operated regional program consulting teachers.
Consulting teachers from each of the six Regional Programs were identified. These teachers were selected because of their experience in working with children with deaf-blindness. The consulting teachers, with the assistance of the project staff, continually shared information with local school district personnel regarding the availability of consultation services for students with deaf-blindness. Each of these teachers maintained a close working relationship with other educational staff (local and regional) who provided services to children with vision and hearing impairments, providing consultation on an as needed basis for teachers, families and students with deaf-blindness. Several of the consulting teachers provided awareness level training to other specialists (e.g., vision, hearing, speech-language) and school personnel on the characteristics of students with deaf-blindness. One of the consulting teachers formed a networking group for professionals within her region to problem solve issues concerning students with deaf-blindness.

Activity 2.1.2: Participation of regional consulting teachers in inservice training designed to update and improve their skills.
The regional consulting teachers were provided many opportunities to increase their knowledge and skills in the area of deaf-blindness. The project staff utilized a variety of resources to accomplish this. Project funds were specifically used to host training activities and provide funding for travel and registration to attend trainings offered by other organizations such as the Oregon Department of Education and the TRACES Project.

In addition to the following trainings, the regional consulting teachers received inservice training on a regular basis through the bi-annual advisory committee meetings. At these meetings a one to two hour block of time was scheduled for training on various relevant topics. Dissemination of current literature was also a priority on each meeting agenda.

In April 1993 a workshop was held for the regional consulting teachers and others (at their invitation) within their regions. Topics included teaching orientation and mobility, teaching communication skills, facilitating meetings and consulting skills. The workshop format and topics were planned by the consulting teachers at their Fall 1992 meeting. All of the regional consulting teachers attended the training.

A two day training was held in May 1995 for the regional consulting teachers and other service providers from the state. The training, conducted by Jo Moscarro from Texas, provided training on "Behavior as Communication." The training was attended by the six regional consulting teachers and an additional twenty service providers.

In collaboration with the TRACES Project, a two day training was held for the regional consulting teachers on the "Hand in Hand Deaf-Blind Curriculum" which was recently developed by the American Foundation for the Blind. Jeanne Prickett, one of the principal authors, conducted the training.

The regional consulting teachers attended the following state, regional or national trainings offered by other organizations:

- One regional consulting teacher attended the "Developing Individualized Transition Plans for Students with Deaf-Blindness" workshop sponsored by Helen Keller National Center Technical Assistance Center in Summer 1993.
- Two regional consulting teachers attended a one-week training on transdisciplinary assessment and programming put on by the TEAM Project in California during the summer of 1993.
- Two regional consulting teachers attended a Jan van Dyke training in California in April 1995.
- One regional consulting teacher and a vision specialist from one of the Regional

Programs attended a three day class on "Communication of Learners who are Deaf-Blind" which was held at the 1995 Oregon Supported Education Summer Institute. Kathleen Stremel from the Mississippi 307.11 Project was the instructor for this class.

- One regional consulting teacher and one parent/service provider attended a one week summer institute focused on communication issues for children and youth who are deaf-blind. The institute was conducted by the Perkins National Deaf-Blind Training Project and was held in Seattle, WA.

Activity 2.1.3: Dissemination of successful innovative educational approaches to regional consulting teachers.
Materials regarding successful educational approaches were disseminated at each of the bi-annual advisory committee meeting. Regional consulting teachers who had received financial support to attend trainings were expected to copy and disseminate notes and handouts from the training to the other regional consulting teachers. The project coordinator also collected current information regarding effective practices, available training opportunities, the activities of other relevant organizations (i.e., TRACES; DB-Link; Helen Keller National Center - Technical Assistance Center), and other germane information and disseminated this on a quarterly basis. Copies of some materials were handed out while other materials were made available for check out from the State Deaf-Blind Resource Library.

Objective 2.2: Provide local, regional and/or statewide inservice training to classroom staff, related service staff and support staff who provide services to students with deaf-blindness.

Activities and related accomplishments include:

Activity 2.1.1: Generation of inservice needs assessment data.
A technical assistance request form was developed and implemented by the regional consulting teachers in the fall of 1992. Requests came from school staff and families back to the regional consulting teachers. If the consulting teacher or others within the region was unable to provide the requested assistance, then the request was forwarded to the project coordinator and the Regional Program Advisory Council. If the project could not meet the technical assistance request from sources within the state of Oregon, the project coordinator contacted other technical assistance agencies (TRACES, Helen Keller TAC, American Foundation for the Blind, etc.) for ideas or assistance.

In addition to the project's technical assistance request form, further needs assessment data regarding the needs of families and school staff serving students with deaf-blindness was collected from needs assessments done by other state or regional agencies such as the

Early Intervention regional providers and the State CSPD team. The project provided input into ways to meet the needs related to children with deaf-blindness.

Activity 2.1.3: Implementation of the yearly inservice training plan.
Two workshops on teaching students with deaf-blindness were presented at the annual conference of the Association for Education and Rehabilitation of Visually Handicapped in October 1992. One workshop focused on teaching communication skills and the other on integrating students with deaf-blindness in general education settings. Both workshops received high ratings (9's and 10's on a 10 point scale) from participants and were well attended.

. workshop for consulting teachers and their guests (teachers and/or parents of children with deaf-blindness) was held in April 1993. Topics included teaching orientation and mobility, teaching communication skills, facilitating meetings and consulting skills. The workshop format and topics were planned by the consulting teachers at their Fall 1992 meeting. All of the regional consulting teachers attended the training.

Few technical assistance requests via the request form were received by the project coordinator. Technical assistance needs and the process used to gather information regarding needs at the local, regional and state level will be reviewed during the first year of the 1995 - 1999 grant cycle.

Objective 2.3: Provide training to early intervention interveners.

Activities and related accomplishments include:
Activity 2.3.1: Development of training content; and
Activity 2.3.2: Implementation of training.
The project did not receive enough funding to implement the activities related to direct services from interveners (see activity 1.1.2). Therefore, the training activities for interveners was deleted.

Objective 2.4: Provide assistance for developing supported education (inclusion) programs for students with deaf-blindness.

Activities and related accomplishments include:
Activity 2.4.1: Assistance to LEA's to develop district and building level teams for supported education.
The project coordinator worked with LEA's to develop district and building level teams for including students with disabilities in general education settings or in community settings.

Activity 2.4.2: Consultation to consulting teachers, classroom staff, support staff and families regarding supported education.
The project coordinator consulted on an ongoing basis with staff and families of students with deaf-blindness regarding inclusion in general education settings or in community settings with nondisabled peers.

Objective 2.5: Provide technical assistance on needed transition services for students with deaf-blindness.

Activities and related accomplishments include:
Activity 2.5.1: Assistance from regional consulting teachers to each student's transition team.
Consulting teachers provided assistance with transition, as requested, from teachers of the visually impaired or teachers of the hearing impaired who work with students 14 to 21 who are deaf-blind. Each student's transition team ensured that a) the student is referred to the county mental health case management program and the Oregon Commission for the Blind; and b) the student's IEP addressed transition activities related to instruction, community experiences, the development of employment and other post school living options. Transition teams ensured that representatives from agencies providing transition services, including mental health case management and Oregon Commission for the Blind attended the student's IEP meeting.

Objective 2.6: Provide family training and support.

Activities and related accomplishments include:
Activity 2.6.1: Consultation to families from consulting teachers.
Regional consulting teachers were assigned from each regional program. These teachers were the regional contacts for consultation with families.

Activity 2.6.2: Participation of families in a state-wide family workshop.
Two families attended the "Wagonwheel" parent/professional conference for families of children who are disabled held in April 1993.

One family (mother, father, and daughter who has Usher Syndrome) attended a three day Usher Syndrome Family Retreat held in Seattle, WA and hosted by the Washington 307.11 Project. Sharee Ferree, the mother in this family, is a member of the project's advisory committee.

Activity 2.6.3: Participation of families in relevant inservice opportunities.
Regional consulting teachers and the project coordinator invited parents to the April

workshop, as well as all other project sponsored inservice activities.

Activity 2.6.4: Provision of information or resource materials as requested by families.
The regional consulting teachers continuously provided information and resources to families. The project coordinator provided resources relevant to families to the regional consulting teachers who then disseminated this information to the families in their respective regions.

Activity 2.6.5: Referral of parents and families to other agencies for services beyond educational services.
Parents and families are referred to other agencies by the regional consulting teachers.

Goal 3: Coordinate and manage educational services for children with deaf-blindness.

Objective 3.1: Coordinate special education and related services and activities required to provide an appropriate educational program for each student who is deaf-blind from point of identification through age 21.

Activities and related accomplishments include:

Activity 3.1.1: Preparation of grant applications and reports.
All required applications and reports were completed and submitted in a timely manner.

Activity 3.1.2: Authorization of funding to regional programs providing consulting services to children with deaf-blindness.
Funding for project activities was authorized and project funds were allocated to the six regional programs so that they could provide technical assistance services.

Activity 3.1.3: Monitoring the implementation of grant objectives and activities.
Activity 3.1.4: Evaluation of services provided to students with deaf-blindness.
Monitoring of project activities has been described in this report.

94-142 compliance monitoring teams from ODE review records and IEP's of students with deaf-blindness served in LEA's and through regional programs. The project director and the project coordinator participated in compliance monitoring of districts.

Satisfaction survey data were collected for trainings organized by the project. Satisfaction levels consistently rated high (averaging 6 - 7 on a 7 point scale) for the majority of the trainings held. The survey rated the quality of the instruction, the applicability of the content related, and the organization and planning of the workshop or class.

Activity 3.1.5: Coordination and implementation of technical assistance activities.
Coordination and implementation of technical assistance activities has been described in this report.

Activity 3.1.6: Provision of consultative services to state and local agencies.
The project director worked with LEA and ESD staff to improve services through the regional program.

The project director collaborated with the State Public Health, School Nurses Association and the Board of Nursing to improve services to students with deaf-blindness who have severe health needs.

The project director consulted with statewide working groups (deaf-blind, visually impaired, severe orthopedically impaired, autism, hearing impaired and consulting nurses) to improve services through regional programs.

The project director is the director of Oregon School for the Deaf and Oregon School for the Blind. In this capacity she directed and coordinated services, as well as provided consultation to staff.

The project coordinator consulted with LEA, ESD and regional staff to improve services for students with deaf-blindness.

Activity 3.1.7: Coordination of the State Regional Advisory Council for Regional Services.
The council meets monthly and assisted in implementing technical assistance plans and identifying additional needs. The project director is the state coordinator of the State Regional Advisory Council and coordinates all meetings.

Activity 3.1.8: Coordination of the State Advisory Committee for Services to Children with Deaf-Blindness.
The project's advisory committee met two times per year. The project coordinator and the chair of the committee, with input from the regional consulting teachers, developed the agenda and facilitated all of the advisory committee meetings.

Activity 3.1.9: Maintenance of the state count for children with deaf-blindness.
The state count of children who are deaf-blind was conducted by December 1 of each year. The project coordinator worked with the Oregon Department of Education data management specialist to reconcile the count with the 94-142 and 89-313 annual census.

The count was reported to Teaching Research for inclusion in the National Deaf-Blind Census in March of each year.

The Oregon count of children who are deaf-blind has been diminishing for each of the past four years. This is recognized as a problem and will be a high priority during the first year of the next grant cycle.

Activity 3.2.0: Dissemination of information.
The Deaf-Blind Resource Library was housed at the Oregon Department of Education. In 1993 the project coordinator reviewed all of the available resources, disposing of outdated materials and adding resources as funding allowed. A system was put in place for teachers, support staff and families to borrow videotapes, books, and assessment tools.

Regional consulting teachers listed all of the materials on deaf-blindness that are available in each of their regional libraries. These lists were reviewed at the Spring 1993 advisory committee meeting and used to update regional libraries and gather needed or missing materials.

With the assistance of the regional consulting teachers and DB-Link, an extensive list of current, desired resources was developed. Most of these resources were purchased and added to the Deaf-Blind Resource Library.

The regional consulting teachers developed a packet of basic information concerning deaf-blindness to give to teachers new to teaching students with this type of disability.

The regional consulting teachers compiled information on Ushers screening to disseminate to parents of children who are deaf. The project coordinator developed a brochure regarding Usher Syndrome to disseminate via hearing specialists, the Oregon School for the Deaf, Audiologists, Speech and Language therapists, and school district and public health nurses.

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V. PROBLEMS AND RESOLUTIONS

1. Identification

The identification of children who are deaf-blind remains a problem in the State of Oregon. The term "deaf-blind" is confusing to many. To many school district personnel and regional program personnel, the term is much more narrowly confined than it is intended to be. In addition, the Oregon Administrative Rules (OARs) stated a relatively narrow, medically based definition for the disability, rather than a broader functional definition. Therefore, many children which have both a vision and hearing loss were not reported because their test results did not fall within the established range. However, the combination of their losses do cause significant difficulties in communication and learning. The project has attempted to make school district and regional program staff more aware of the functional definition of the disability, the process for referral of children suspected of being deaf-blind, and the services available through the project. Project brochures have been disseminated to all of the state's school districts and regional consulting teachers use personal interactions to inform related service providers and educators of the functional characteristics of the disability. The topics of identification and functional assessment of children will be a major focus in the next grant cycle.

2. Technical Assistance to Service Providers and Families

The Regional Program structure in Oregon has many benefits; however, it also has drawbacks. Contracting the delivery of technical assistance to the six regions in the state insures a quick response to requests within designated geographical areas. The six regional consulting teachers are familiar with the children, families and service providers within their regions. However, inherent in the design of the Regional Program is the decentralization of deaf-blind services in the state. Few service providers or families are aware of the state deaf-blind project or the project's efforts to provide technical assistance across the state. Because of this, there is often a duplication of efforts while meeting regional needs. Meeting needs at a broader statewide level may sometimes prove to be more effective and cost efficient. For instance, communication strategies continue to be a technical assistance need in many of the regions. Regional consulting teachers continue to expend dollars and time to meet these needs locally when it would be more efficient to develop an inservice training which could be offered to several regions at one time. The project is in the process of developing a statewide needs assessment process to identify the needs of service providers and families. These needs will be analyzed across all of the regions and the most common needs will be met through the delivery of statewide technical assistance.

3. Family Support

The families of children who are deaf-blind in Oregon have not had available to them a forum for meeting with other parents of children who are deaf-blind. In the past, families were encouraged and supported to participate in statewide activities such as the Wagonwheel Parent/Professional conference designed for families of children with disabilities. Families are always invited to participate in project trainings. Because funding an activity such as a family weekend was cost prohibitive, the project has made an effort to promote activities in neighboring states and financially support families to participate. The project coordinator has worked collaboratively with the coordinator of Washington state's deaf-blind project to include Oregon families in that project's annual Usher Family Weekend. Information and invitations regarding California, Idaho and Washington's family activities are actively disseminated through the regional consulting teachers.

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VI. PRODUCTS DEVELOPED

Product	Intended Audience	Date Produced	Available	Dissemination
Project Brochure (English, Large Print and Braille)	Families, educators, related service providers, medical professionals	Spring 1993	Yes (to be revised in 1995)	Distributed widely through Regional Program, school districts, conferences, and in-service trainings on an ongoing basis
Project Brochure (Spanish Language)	Spanish speaking families and professionals	September 1995	Yes	Distributed widely through Regional Program, school districts, conferences, and in-service trainings on an ongoing basis
Usher Brochure	Families and Professionals	Summer 1995	Yes	Will be distributed through Regional Program, related service providers, school nurses and psychologists, audiologists, medical clinics, Oregon School for the Deaf
Detailed Participant Notes from State, Regional or National Trainings	Regional consulting teachers	Throughout grant cycle	No	Regional consulting teachers at each advisory committee meeting
Training Video of inservice trainings	Families and Professionals	Spring 1995	No	Used for followup training by regional consulting teachers

Samples are provided in Appendix A.

VII. FURTHER INFORMATION

Further information regarding the Oregon Project for Children and Youth with Deaf-Blindness (Grant Contract Number HO25A20014) can be obtained from the following sources:

Project Director:
Maurine Otos
Oregon School for the Deaf
999 Locust St NE
Salem, OR 97303-5254

Project Coordinator:
Don Thomson
Teaching Research
Western Oregon State College
345 N. Monmouth Avenue
Monmouth, OR 97361

State Department Liaison to the Project:
Nancy Anderson
Oregon Department of Education
Office of Special Education
255 Capitol Street NE
Salem, OR 97310

A copy of this Final Performance Report has been submitted to the Educational Resources Information Center (ERIC) Clearinghouse at:

ERIC/OSEP Special Projects
ERIC Clearinghouse
Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

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VIII. APPENDICES

A. Samples of Products Developed
  - Project Brochure in English
  - Project Brochure in Spanish
  - Usher Syndrome Brochure
  - Participant notes from Jan van Dyke training

B. Sample Agenda from Advisory Committee Meeting (Deaf-Blind Working Group)

C. Sample of Training Agenda and Publicity

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APPENDIX A

Samples of Products Developed

- Project Brochure in English
- Project Brochure in Spanish
- Usher Syndrome Brochure
- Participant notes from Jan van Dyke training

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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 Oregon Project for Services to Children and Youth with Deaf-Blindness for further information and referral. You may contact the project through the regional program serving the area in which you reside (see insert).

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 Oregon Services to Children with Deaf-Blindness (Grant Contract No HO25A20015) with funding from the U S Department of Education

It is the policy of the Oregon Department of Education that discrimination based on race, color, religion, sex, age, national origin, or disability shall not exist in the institution. This policy embodies and is intended to implement explicit requirements of state and federal law and executive orders of the President in regard to discrimination. It applies to all operations that are part of the Oregon Department Of Education Project facilities will meet full requirements of Section 504 of the Rehabilitation Act.

Norma Paulus
State Superintendent
of Public Instruction

Oregon Department of Education
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Oregon Project for Services to
Children and Youth with Deaf-Blindness
Office of Special Education
Oregon Department of Education
225 Capitol Street N.E.
Salem, OR 97310

OREGON
Project for Services to Children and Youth with Deaf-Blindness

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 9,000 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 Oregon Project for Services to Children and Youth with Deaf-Blindness is the first step to securing assistance.

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* *The federal definition of deaf-blindness is: "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 Oregon Project for Services to Children and Youth with Deaf-Blindness 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 Oregon Project for Services to Children and Youth with Deaf-Blindness

- 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 informacion...

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 los Servicios de Oregon para Niños Sordos y Ciegos para más información y referencias.

Oregon Services to Children with Deaf-Blindness
Nancy Anderson
Public Service Building
225 Capitol Street N.E.
Salem, OR 97310

Ph. (503) 378-3598
Fax (503) 378-4926

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 Inpedimentos Sensoriales (Contrato Cooperativo Número H025C00001) y los Servicios de Oregon para Niños Sordos y Ciegos (Contrato de Subvención Número H025A20015) patrocinado por el Departamento de Educación de los Estados Unidos.

Todos los Empleados del proyecto son empleados por el Departamento de Educación de Oregon asegura que selecciona a su personal sin tomar en cuenta raza, color, origen nacional, sexo,edad o condición de incapacidad..

Oregon Services to Children with Deaf-Blindness
Public Service Building
225 Capitol Street NE
Salem, OR 97310

Servicios de OREGON *para Niños Sordos y Ciegos*

Información y Asistencia para los Individuos Sordo y Ciegos

ué Significa Ser Sordo y Ciego?

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 in 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 occurrir 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 comfirmar las pérdidas sensoriales. Este folleto provee información general sobre ser sordo y ciego. La primera etapa para conseguir la asistencia es comunicarse con los Servicios de Oregon para Niños Sordos y Ciegos.

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* *La definición federal de ser sordo 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 sin la educación especial y los servicios relacionados además de los que se suministrarían solamente para los niños con impedimentos del óido impedimentos visuales o deshabilidades severas, para tratar sus necesidades educativas **debidas a estas deshabilidades** concurrentes."*

Los Comportamientos que 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 perdida 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 analisis de la vista y del oido. Los Servicios de Oregon para Niños Sordos y Ciegos pueden 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 facilmente cuando está haciendo tareas de cerca?
- generalmente voltea hacia una fuente de luz?
- no reconoce y responde a las caras conocidas?
- tiene dificultad en seguir con los ojos los objetos en movimiento?
- [redacted] de claros?

Los Comportamientos que Pueden Indicar un Impedimento del Oido

¿El niño o estudiante...

- no reacciona a los ruídos fuertes?
- pide a menudo que le repita so 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 ien 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)?
- entiento mejor cuando mira directamente al orador?

Servicos Suministrados por los Servicios de Oregon para Niños Sordos y Ciegos

- Asistencia en la diagnosis
- Asistencia técnica (por ejemplo, entrenamiento, consulta individual, talleras 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.

INFORMATION
ABOUT
USHER SYNDROME

Oregon Project for Services to Children and Youth with Deaf-Blindness

Usher Syndrome is a leading cause of deaf-blindness. It is a genetic disorder which involves *both* a loss of hearing, *and* a progressive loss of vision. While the hearing loss is usually present at birth, or occurring shortly thereafter, the vision loss begins later in life. There is no way of determining the exact age of onset or rapidity of the vision loss.

The vision loss is caused by retinitis pigmentosa (RP), or the degeneration of the eye's retina. Early symptoms of RP include difficulty seeing at night or in dimly lit places (night blindness) and a loss of side (peripheral) vision. The vision loss may be gradual and barely noticeable at first, but most people with RP will eventually be considered "legally blind."

A person can have Usher Syndrome even though his or her parents or siblings do not. If each parent is a carrier of an Usher gene and genetically passes this along to a child, the child receives two of the 'recessive' or weak Usher genes and the effects (hearing loss and RP) will be present.

What is Usher Syndrome?

Over ninety percent of people diagnosed with Usher Syndrome have one of two main types:

Type I	Born with a profound hearing loss
	May experience balance problems
	Retinitis Pigmentosa (RP) is present
Type II	Born with or develop shortly after a mild to severe hearing loss
	Do not experience balance problems
	Retinitis Pigmentosa (RP) is present

It is estimated that three to six percent of all children who are deaf have Usher Syndrome. An equal percentage of children who are hard-of-hearing may also have Usher Syndrome. Usher Syndrome is the cause of more than fifty percent of the cases of deaf-blindness in the United States, with at least 10,000 people currently diagnosed.

While only 4 people per 100,000 in the general population are currently diagnosed with Usher Syndrome, physicians and researchers involved with Usher Syndrome claim the incidence is likely to be 9 to 10 people per 100,000. Given the United States' current population, this estimate predicts 25,000 people are affected by Usher Syndrome.

There are no treatments or cures to restore or halt an individual's hearing loss or vision loss caused by Retinitis Pigmentosa. Intensive research is being conducted at several research facilities in the country to determine the causes, means of prevention, and treatments for Usher Syndrome, as well as other retinal degenerative diseases.

Even though there are no treatments or cures; there is still a lot that can be done for individuals with Usher Syndrome. With an early diagnosis, individuals and their families have the opportunity to make psychological, emotional, educational, and physical adjustments which will help them adapt and pursue a full and satisfying life.

Is There a Cure for Usher Syndrome?

The first noticeable symptom of Usher Syndrome is a sensorineural hearing loss at birth or shortly after birth. If the hearing loss is a result of any of the conditions listed below, the person is at **low risk** for Usher Syndrome. There is always a small chance that Usher Syndrome is a secondary cause of the hearing loss, but this is extremely rare.

Causes of hearing losses which place an individual at low risk for Usher Syndrome

Conductive loss

Kidney disease

Trauma/accident

Genetic deafness [1]

Auditory neuritis

Diabetes

Disease (i.e., Meningitis, Mumps, Scarlet Fever, Measles, Chicken Pox, Encephalitis)

Rubella (German Measles)

Otitis Media (ear infections)

Scarring of the eardrum

Noise-induced loss

Ototoxic drug therapy

Viral infection

Other known syndromes (please name___________________)

While individuals who have a hearing loss due to any of the above conditions are at **low risk** for Usher Syndrome, they may suffer a vision loss for other reasons. This makes it especially important to have regular, comprehensive eye exams.

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[1] *The genes for genetic deafness and for Usher Syndrome are different. An individual at risk for Usher Syndrome will probably not have another family member who is deaf, unless they too have Usher Syndrome*

Those at risk for Usher Syndrome are usually born with a hearing loss. This loss is sensorineural, or "nerve deafness." A vision loss due to Retinitis Pigmentosa (RP) occurs later in the individual's life. Vestibular problems, such as poor balance, may also be present. By screening for a vision loss, Usher Syndrome can be diagnosed as early as possible. RP manifests itself through increasing difficulty seeing in the dark or to the side (peripheral vision).

Following are some behavioral symptoms which may indicate Usher Syndrome and can be used for initial screening purposes.

Night Blindness

- Has difficulty seeing when coming in from bright sunlight
- Trips over things when light changes or light is dim
- Stays near light in a dark room or at night
- Positions self so light falls on the face of a speaker
- Has difficulty seeing seats or people inside a darkened room (e.g., movie theater)
- Avoids conversations in darkened areas
- Staggers or loses balance after an oncoming car has passed at night
- Has problems reading under some lights or in dimly lit areas

What Symptoms Suggest Usher Syndrome?

Restricted Visual Field

- Has difficulty detecting drop-offs (e.g., stairs, curbs, ramps)
- Bumps into people, tables, chairs, etc.
- Has accidents at mealtime with objects placed to the side (spilled glasses)
- Startles easily, "jumpy"
- Eyes seem to focus in different directions when looking at some things
- Turns head while reading across a page
- Uses fingers to mark place while reading
- Shows difficulty finding small objects that have been dropped
- Doesn't acknowledge another person's hand wave from the side
- Is quiet or edges to one side when in a large group
- Frequently misses of fails to understand group instruction

Glare Sensitivity

- Squints and shades eyes in bright lights or fluorescent lighting
- Likes to wear sunglasses inside or outside, but especially in bright sunlight
- Appears awkward when leaving a building with bright lights immediately inside or outside the point of exit

Need for Contrast

- Has difficulty reading light copies or ditto copies
- Can't see stars at night
- Often spills when pouring liquids

Acuity Problems

- Holds book close to eyes, or bends forward to read
- Sits close to blackboard

Balance Problems

- Learned to walk late (past 15 months)
- Considered clumsy
- Loses balance easily in the dark
- Can't ride a bicycle or required a long time to learn

Other

- Exhibits anxiety in new places
- Doesn't participate fully in group activities associated with new situations in the dark or dimly lit areas (parties, dances, outdoor games)
- Avoids walking or running in unfamiliar areas, especially in the bright sunlight or darkened areas
- Constantly appears to be visually scanning a group

Early identification of Usher Syndrome is crucial for the individual and his or her family for many reasons:

1. The individual and his or her parents and teachers will want to consider the eventual vision difficulties while making educational and vocational plans.
2. The individual and family will have the time necessary to gain skills and experience in communication techniques which will enable him or her to continue to communicate with others even if a severe visual impairment occurs.
3. The gradual decrease in vision may go unnoticed by the individual, who may continue activities (such as driving or working in hazardous conditions) which cannot be continued safely.
4. The individual and family may choose to seek counseling and support to cope with the present and prepare for the future.
5. A diagnosis of Usher Syndrome may encourage family members (parents and children) to seek genetic counseling and testing. Usher Syndrome runs in families. Genetic counseling and testing may reduce the risk of parents having other affected children, and the risk of an individual with Usher Syndrome having affected children.

Why is Early Identification Crucial?

If an individual has a hearing loss and Usher Syndrome is suspected, there are several tests used to determine whether that individual has Retinitis Pigmentosa (RP). Some tests may be completed by an eye specialist during a regular exam.

- **Visual Field Test** - measures side vision using a machine called a Goldman perimeter. It will indicate the field of vision (normal fields = 180 degrees).
- **Psycho-Physical Test** - indicates which colors, if any, an individual can distinguish and the amount of contrast needed to see.
- **Dark Adaptation Test** - determines an individual's ability to see in the dark and how long it takes to adjust to the dark.

The definitive test for RP, however, is the electroretinogram (ERG), which has been found to be 95 percent accurate. This test must be administered by an ophthalmologist. To learn more about ERG testing in Oregon, turn to the "Resources" section.

An ERG measures the electricity given off by nerve impulses in the retina of the eye. The patient sits in a dark room until the eyes adjust to the darkness. One eye is then patched and the other fitted with a special contact lens. The test, which is painless, measures the electrical response of the uncovered eye as it is exposed to a flashing light.

An ERG is necessary only once in a person's lifetime.

All children with congenital deafness should be screened for Usher Syndrome—preferably between the ages of 9 and 12.

Vision—the ability to see—is particularly important to all individuals who are deaf or hard-of-hearing. Children and youth who have a hearing loss, regardless of whether they are considered at risk for Usher Syndrome, should have regular, comprehensive eye exams by an optometrist or ophthalmologist. If the individual exhibits symptoms of vision difficulties as discussed earlier, it is particularly critical that testing be done.

While many optometrists or ophthalmologists can perform preliminary screening, they will need to refer the individual to a retinal specialist for more definitive testing with the ERG. The eye doctor may not routinely test for field loss. This screening and others should be included in the basic exam. Always request that the following tests be given during the complete eye exam:

- Dilated eye exam
- Visual field test
- Color sensitivity and contrast test
- Dark adaptation test

In addition to requesting the above tests, provide the eye doctor with any information you have regarding: 1) the individual's history of vision or hearing problems and the testing which has been done in the past; 2) the family's history of vision or hearing problems; and 3) symptoms you or others have observed which might suggest vision problems.

Once Usher Syndrome has been diagnosed, the individual and his or her family can begin planning for the present and the future. For more information on Usher Syndrome, ERG testing, and resources available to assist individuals with Usher Syndrome, contact your ophthalmologist or any of the agencies listed on the next two pages.

Local Resources

Oregon Project for Services to Children and Youth with Deaf-Blindness

(Contact may be made through the following Regional Programs)

Eastern Oregon Regional Program
(Serves: Baker, Grant, Malheur, Morrow, Umatilla, Union, and Wallowa counties)

Union ESD
10100 N. McAlister Road
Island City, OR 97850
(503) 963-4106 (V)

Central Oregon Regional Program
(Serves: Crook, Deschutes, Gilliam, Harney, Jefferson, Sherman, and Wheeler counties)

Bend School District 1
520 NW Wall Street
Bend, OR 97701
(503) 383-6345 (V/TTY)

Southern Oregon Regional Program
(Serves: Curry, Douglas, Jackson, Josephine, Klamath, and Lake counties)

Jackson ESD
101 N. Grape Street
Medford, OR 97501
(503) 776-8555 (V/TTY)

Cascade Regional Program
(Serves: Benton, Coos, Lincoln, and Linn counties)

Linn-Benton ESD
905 Fourth Avenue SE
Albany, OR 97321
(503) 967-8822 (V/TTY)

Mid Oregon Regional Program
(Serves: Marion, Polk, Tillamook, and Yamhill counties)

Marion ESD
3400 Portland Road NE
Salem, OR 97303
(503) 588-6677 (V/TTY)

Columbia Regional Program
(Serves: Clackamas, Clatsop, Columbia, Hood River, Multnomah, and Washington counties)

Child Services Center
531 SE 14th Street
Portland, OR 97214
(503) 280-5840 x. 263 (V)
(503) 280-5675 (TTY)

Lane Regional Program
(Serves: Lane county)

Lane ESD
Educational Support Services
200 N. Monroe
Eugene, OR 97402
(503) 687-3339 (V)
(503) 687-3508 (TTY)

State Resources

Casey Eye Institute (*performs all ERG testing for Oregon*)

Oregon Health Sciences University
3375 SW Terwilliger Boulevard
Portland, OR 97201-4196
(503)494-8386 Pediatric Eye Clinic
(503) 494-7672 Adult Eye Clinic

Oregon Commission for the Blind

535 SE 12th Avenue
Portland, OR 97214
(503) 731-3221

Oregon School for the Blind

700 Church Street SE
Salem, OR 97301
(503) 378-3820

Oregon School for the Deaf

999 Locust Street NE
Salem, OR 97303-5254
(503) 378-3826

National Resources

Due to space limitation, the following is only a partial list of the many service and information resources available.

American Association of the Deaf-Blind (AADB)

814 Thayer Avenue
Silver Spring, MD 20910
(301) 588-6545 (V)

Boys Town National Research Hospital
Usher Syndrome Project

555 North 30th street
Omaha, NE 68131
(402) 498-6556 (V)
(402) 498-6631 (TTY)
(800) 835-1468 (V/TTY)

DB-LINK
The National Information Clearinghouse On Children Who Are Deaf-Blind

345 N. Monmouth Avenue
Monmouth, OR 97361
(800) 438-9376 (V)
(800) 854-7013 (TTY)
Internet: leslieg@fsa.wosc.osshe.edu

Helen Keller National Center for Youths and Adults who are Deaf-Blind
Northwest Regional Office

2366 Eastlake Avenue, Suite 209
Seattle, WA 98102
(206) 324-9120 (V)
(206) 324-1133 (TTY)

NFADB
National Family Association for Deaf-Blind

111 Middle Neck Road
Sands Point, NY 11050
(800) 255-0411, ext. 275 (V)
(516) 944-8637 (TTY)

NICD
National Information Center on Deafness
Gallaudet University

800 Florida Avenue NE
Washington, DC 20002-3695
(202) 651-5051 (V)
(202) 651-5052 (TTY)
Internet: nicd@gallau.gallaudet.edu

RP Foundation Fighting Blindness

1401 Mt. Royal Avenue, 4th Floor
Baltimore, MD 21217
(410) 225-9400 (V)
(800) 683-5555 (V)
(410) 225-9409 (TTY)

TRACES
Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments
Teaching Research Division/WOSC

345 N. Monmouth Avenue
Monmouth, OR 97361
(503) 838-8778 (V)
(503) 838-8773 (V)
(503) 838-8821 (TTY)

Usher Family Support
(A newsletter for families of people with Usher Syndrome)

c/o Helen Anderson
4918 42nd Avenue South
Minneapolis, MN 55417

This brochure was adapted from two brochures previously developed by the Illinois Usher Syndrome Screening Project and the Alaska Services for Children and Youth with Dual Sensory Impairments Project.

Additional information was taken from the following articles and resources; all of which are available from DB-LINK (see National Resources section).

Davenport, S., (1992). Usher syndrome needs document. Bloomington, MN.

Davenport, S., (1994). Usher syndrome: vision and hearing loss. Hereditary Deafness Newsletter of America, vol. 4 no. 1, Summer 1994 1–4.

Walters, J., Quintero, S., & Perrigin, D., (1982). Vision: its assessment in school-age deaf children. American Annals for the Deaf. August 1982, 418–341.

This brochure is available in large print or grade 2 braille. Please contact:

Project Coordinator
Oregon Services to Children with Deaf-Blindness

(503) 838-8778 (V)
(503) 838-8821 (TTY)

Funding for Oregon's Usher Syndrome Project is through a joint agreement between the Oregon Services to Children with Deaf-Blindness Project (Grant Contract No. HO25A50013) and TRACES (Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments, Cooperative Agreement No. HO25C00001).

MEMOMEMOMEMOMEMOMEMOMEMOMEMOMEMOMEMOMEMOMEMO
MEMOMEMOMEMOMEMOMEMOMEMOMEMOMEMOMEMOMEMOMEMO

TO: MORS Vision Specialists / Hearing Specialists
FROM: Jay Gense
RE: Jan Van Dijk Workshop - May 28, 29, 30/1995

I attended a conference presented by Jan Van Dijk a couple of weeks ago. Dr. Van Dijk, as many of you know, has worked in the field of "deaf-blind" since the 1960's, and his theories has served as a foundation for many of the models in existence today. He is the director of a specialized school for deaf children in Holland. In particular, he was the creator of the "coactive movement" strategies: (please note, however, that he never meant for the coactive "stuff" to continue as it has...)

There was a lot of valuable information shared over the course of the three days. Rather than hand out all my notes, I tried to summarize the "key" points he emphasized. If you want more complete notes, or want to discuss any of these issues in more depth, please let me know.

It is interesting that many of the "key ingredients" Van Dijk feels to be important for educating kids who are deaf-blind and/or multi-impaired are very difficult for us to implement in our country, given the current emphasis on the mainstream model. He discussed this as a problem area.

KEY POINTS FROM THE CONFERENCE

- Van Dijk wants people to discontinue only associating him with the "coactive movement" strategies; he is purporting an educational model based on "attachment" and "bonding". His new coin phrase is "from hands-on, to hands-off...let kids do more on their own"

- We all know about the "resonance phenomenon" level of the Van Dijk strategies...simple movement with a kid, stop, wait for a signal to continue, then continue. He spent quite a bit of time again emphasizing the importance of this sequence, creating the "mismatch" for the student so they learn that they must do "something" to communicate their wishes.

- Some new research is being released that shows that some forms of stimulation on light sources is not simply self-stimulatory behavior nor autistic behavior, but rather is neurologically linked to the deprivation of sight.

- Head balance and vision are "brother and sister". We must be more aware of providing appropriate activities to encourage upright posture and upper trunk control for kids who are blind.

- Teachers must constantly pursue strategies that allow the child to make more decisions.

- Some new research (take this for what it's worth):
  65% of non-disabled kids attach or bond with their parents
  27% of disabled kids attach or bond with their parents.

- It is imperative that 1 or 2 people completely bond with a student; they must feel for, care, communicate with and fully understand the child.

- Teachers and parents must always be asking "how can the program be designed to build upon the child's memory skills"?. They must have something to help them organize their memory; i.e. calendar systems, memory books, etc.

- There actually is a **weak** correlation between intellect and communication ability.

- Van Dijk jokes about a good teacher sometimes being a "lazy" teacher...meaning don't rush, don't force...wait the student out. Sometimes we think too much in the medical model, assuming that we can "fix" it.

- Van Dijk believes that the primary goal of any early intervention program should be to encourage appropriate bonding between child and parents. Bonding occurs most often because parents respond appropriately with their children. But this appropriate response is VERY difficult with a child who is blind or deaf-blind, because the cues they give are very subtle.

- In Holland, a complete functional vision assessment includes:
  - visual history
  - measurement of visual acuity
  - measurement of visual fields (particularly use the Goldman)
  - microscopic inspection
  - assessment of ocular motility
  - assessment of color vision (a new test is being developed in Finland presently)
  - referral to a Low Vision Clinic if necessary

- By the age of 5, the glasses should be comfortable to wear.

- You don't see with your eyes, but with your brain. Sometimes kids are happy with a "blurred" picture, and we must help change that.

- Van Dijk feels that good teachers and parents simply have "IT"...have the natural ability to teach, to respond appropriately with kids. And to know when to demand a little "more" . When working with students, always look for the people who have "IT", and help them to better understand the student.

- "Mismatch" stimulates the brain to work. They are anticipating one thing, but something else happens.

APPENDIX B

Sample Agenda from Deaf-Blind Working Group Meeting (Advisory Committee)

❖ ❖ ❖ ❖ ❖ ❖ ❖ ❖ ❖ ❖

Oregon Project for Services to Children and Youth with Deaf-Blindness

Deaf-Blind Working Group Meeting
April 25, 1995
9:00 am - 4:00 pm
Oregon School for the Deaf
Directors Conference Room, Nutrition Services Building

9:00	**Greetings!** ▸ Introductions ▸ Stories about Kids (or other news from your region)	**Terry**
9:45	**What are we doing from 1995 to 1999?** ▸ Review final copy of the new grant application ▸ Update on federal action on grants ▸ New directions for services in Oregon ▸ A quick look at the Evaluation section of the grant application	**Paddi** **Terry**
10:30	**How many kiddos do we have in Oregon?** ▸ Final numbers on 1994 Child Count ▸ Where are the changes?	**Paddi**
11:00	**Break**	
11:15	**What's happening on the training scene?** ▸ Information on upcoming trainings (Oregon, TRACES Western Region, national) ▸ Brief reports on training recently attended	**Paddi**
11:45	**The Oregon Deaf-Blind brochure unvieled** ▸ Identify target locations for dissemination of brochures	**Paddi**
12:00	**Lunch** (at OSD, tickets will be sold for $2.75 during morning break)	

Oregon Project for Services to Children and Youth with Deaf-Blindness

Deaf-Blind Working Group Meeting
April 25, 1995
9:00 am - 4:00 pm
Oregon School for the Deaf
Directors Conference Room, Nutrition Services Building

1:00	**They're baaaaack...revisiting the Regional Program Resources lists** ▸ Look through resources brought and recommended by WG members ▸ Make & prioritize "wish list" of new resources	**Terry**
1:45	**Update on Usher Syndrome activities** ▸ Progress on the Oregon Usher brochure ▸ News about a TRACES Usher Syndrome workshop	**Jay** **Paddi**
2:00	**Who should we send to the Perkins Summer Institute?** ▸ Select the two Perkins funded participants ▸ Discussion and selection of additional participants funded by the project	**Paddi** **Terry**
2:45	Break	
3:00	**1st Oregon viewing of "You and Me" video** ▸ Meet Riley Ford, his mom, peers, teachers, and staff at his neighborhood school	**Paddi**
3:30	**Other items we really should talk about...** ▸ ▸ ▸ ▸	**Terry**
4:00	**We've put in a hard day -- let's call it quits!**	**Terry**

APPENDIX C

Sample of Training Agenda and Publicity

❖ ❖ ❖ ❖ ❖ ❖ ❖ ❖ ❖ ❖

TRAINING OPPORTUNITIES FOR OREGON PROFESSIONALS AND FAMILIES

ARRANGED THROUGH THE

OREGON PROJECT FOR SERVICES TO CHILDREN AND YOUTH WITH DEAF-BLINDNESS

SPRING - SUMMER 1995

Date and Location	Training Activity	Participants	Follow-up Activities
April 27 - 28 Tucson, AZ AZ School for the Deaf and the Blind	**"From Grief to Growth"** A two-day workshop presentation by Gwen Whiting in association with Kenneth Moses. An exploration of issues related to grief and coping specifically related to families and professionals involved in the care of children with special needs. Participation will be very interactive with presenter and the other 120 parents, teachers and service providers in attendance.	Family members and service providers Project will pay stipends for one family member and one professional	Participants will disseminate materials and provide 30 - 45 minute presentation to Deaf-Blind Working Group; Working Group will brainstorm ideas for infusing content into current services.
April 28 - 30 San Diego, CA Clarion Hotel	**"Assessment and Development of Communication Skills for Individuals who are Deaf-Blind"** Jan van Dijk will present during a two-day workshop. An additional half day workshop will focus on rare genetic syndromes and advanced assessment techniques.	Family members, teachers, service providers Project will pay stipends for two individuals	Participants will develop action plans outlining their plans for implementing the training content; follow-up needs, and the expected impact the training will have on children. Participants will disseminate materials and provide 30 - 45 minute presentation to Deaf-Blind Working Group; Working Group will brainstorm ideas for infusing content into current services.
May 4 - 5 Portland, OR Child Services Center	**"Behavior as Communication"** Jc Mascorro will present strategies to assist service providers as they work with individuals who are deaf-blind and demonstrate behaviors which appear to interfere with the learning process.	Forty - fifty teachers, family members, service providers from Oregon, Washington, California, Idaho Project will pay stipends for ten individuals	Participants will: 1. Identify three strategies learned during the workshop 2. Develop a plan for implementing these three strategies 3. Identify areas of need (i.e., follow-up assistance) for implementation 4. List their preferred method of follow-up (i.e., site visit, phone consultation, video)

Date and Location	Training Activity	Participants	Follow-up Activities
May 5 - 6 Salt Lake City UT John A. Moran Eye Center	**"Usher Syndrome Screening Workshop"** Dr. Sandra Davenport will present during a two-day workshop on the genetic causes of Usher Syndrome, the symptoms and educational implications, and statewide Usher Syndrome screening systems.	State or private agencies/ representatives affiliated with Usher Syndrome TRACES will pay stipend for one individual	Participants will develop an action plan for the dissemination of the workshop information and written materials. The action plan will also identify steps for further investigation into the need for or feasibility of a statewide screening process.
July 21 - 23 Portland, OR Lewis and Clark College	**"Second Annual International CHARGE Syndrome Conference for Families and Professionals"** This three day conference will include information on CHARGE Syndrome, behavioral and management issues, educational planning, and many pertinent workshops.	Families of children who have CHARGE Syndrome and interested professionals Project will pay stipend for one family	TBD
July 23 - 27 Seattle, WA University of Washington	**"Communication with Learners who are Deaf-Blind"** **Perkins Nat'l Deaf-Blind Training Project** This five-day summer institute will provide a comprehensive analysis of the communication needs of learners who are deaf-blind.	Seven teachers and service providers from Oregon 2 paid by Perkins 5 paid by project (2 grad credits)	TBD with the Perkins Project
July 31 - August 2 Bend, OR	**"Increasing Peer Interactions and Social Networks"** **Oregon Supported Education Summer Institute** Kathleen Stremel will present during this three day workshop on inclusive instructional design for students with severe needs.	Teachers, service providers Project will pay stipends for ten individuals	TBD
Sept 29 - Oct 1 Seattle, WA Location: TBD	**"Usher Syndrome Family Retreat"** For two and a half days, children who have Usher Syndrome and their families will learn and laugh together. Activities will be informational, include formal and informal networking opportunities, and be interspersed with fun and games. Members of Seattle's adult deaf-blind community will also be involved as friends, supporters, and role models for the children and families.	Families of children who have Usher Syndrome Project will pay stipends for three families	TBD

The Oregon Project for Services to Children
and Youth with Deaf-Blindness
presents a two day workshop

BEHAVIOR AS COMMUNICATION:

Strategies to Assist Direct Service Providers when Challenged to Teach Children who Experience Deaf-Blindness

Presented by:
Jo Mascorro, M.Ed.
Consultant for Education
San Antonio, Texas

May 4th and 5th, 1995
Child Service Center
Portland, Oregon

Consultant's summary of workshop

This presentation will provide the direct service provider with strategies to assist individuals who are deaf-blind and demonstrate behaviors that appear to interfere with learning. Given the unique challenges presented by the dual sensory impairment, staff must be acutely aware of how their behaviors may in fact, contribute to the crisis of an excalating behavior demonstration.

This two-day workshop will address the following issues:

- *Where to begin*
- *Behavior as communication*
- *Role-modeling appropriate intervention strategies*
- *Developing schedules and routines*
- *Developing an appropriate behavior management plan*

It is critical we recognize that behavior is most often learned based on our experiences in relating to our environment and interacting with others. The ability to make someone change their behavior is extremely difficult, if not impossible! We do, however, have the ability to influence change in behavior based on how we qualify our expectiations and teach appropriate alternatives to inappropriate behavior demonstrations.

DATES AND TIMES

May 4 and 5, 1995
9:00 am - 4:00 pm

LOCATION

Room C-121
Child Service Center
531 SE 14th Street
Portland, OR 97214
503.280.5840 ext. 263

PARKING

Free parking available at the Child Services Center or on nearby streets

OTHER DETAILS

- *Morning and afternoon refreshments provided*
- *Several restaurants are located nearby for lunch*
- *Assistance with hotel accommodations gladly provided*

CONTACT

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BEHAVIOR AS COMMUNICATION:

Strategies to Assist Direct Service Providers when Challenged to Teach Children who Experience Deaf-Blindness

INSTRUCTOR: Jo Mascorro, M.Ed.

Thursday, May 4th

AGENDA

- Introduction
- Pre-test
- Where do we begin?
  - *yourself*
  - *environment*
  - *instructional strategies/expectations*
  - *behaviors*

BREAK

- Things to consider
- Activity
- What's the point?

LUNCH

- Behavior as communication
- Schedules and routines
- Making it connect!
- Questions...attempts at responses
- Prepare for tomorrow

Friday, May 5th

AGENDA

- Where were we?
- Applying the format
- Avenue to experience
- Meaningful programs...how do we know?

BREAK

- Taking a risk
- Behavior management plans
- Video

LUNCH

- Working with the family
- Taking another risk!
- Quality of life issues
- Community experiences
- Questions...attempts at responses
- Post-test