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ABSTRACT

This final report describes activities and accomplishments of the South Dakota Deaf-Blind Project, a 4-year federally funded project designed to raise awareness of the need for early identification of children who are deaf-blind and reside on Native American reservation lands. To this end, the states of Montana, Minnesota, North Dakota, Nebraska, Wyoming, and South Dakota joined together as the Great Plans Regional Alliance. Using strategies utilized successfully on reservations in South Dakota, the member states began making connections with Native American families. A major goal of the project was to increase the number of Native American children on the deaf-blind census. Every state increased the number of Native American children on their census, and each state reported a significant increase in the number of referrals received from reservation areas. Specific activities of the project are described, and include: public service announcements using Lakota people and language; culturally based posters and brochures; videos highlighting the deaf-blind clinic and other training issues for children who are deaf-blind; the initiation of a tracking system to ensure that families crossing state borders are able to access services; and training opportunities for children who are deaf-blind and their families. Publications developed by the project are attached. (CR)

Expanding the Circle
South Dakota Deaf-Blind Project
H025A00026

Final Report
10-1-98 through 9-30-99

South Dakota
Department of Education and Cultural Affairs
Pierre, SD 57501

Expanding the Circle
South Dakota Deaf-Blind Project
H025A00026

Highlights:

The fourth and final quarter of this project has been as successful as all of the prior quarters. The impact on Native American families with children who are deaf-blind has been significant. From the beginning the goal of the project has been to raise the awareness of the need for early identification and identification of children who are deaf-blind and reside on reservation lands. To this end the states of Montana, Minnesota, North Dakota, Nebraska, Wyoming and South Dakota joined together as the Great Plains Regional Alliance. Using strategies utilized successfully on reservations in South Dakota, the member states began making connections with Native American families in their respective states. A major goal of the project was to increase the number of Native American children on the deaf-blind census. Every single state increased the number of Native American children on their census – most by 100%! More importantly, each state reported a significant increase in the number of referrals they are receiving from reservation areas. These contacts are critical as the new millennium and the new projects roll around.

Many, many great materials were developed from this four-year project. To name a few:

South Dakota – video public service announcements using Lakota people and language.
- Audio public service announcement using Lakota people and language.
- Culturally based posters and brochures
- Resource packet of informational materials on vision, hearing and deaf-blindness
- Draft replication guide for the development of culturally appropriate materials

North Dakota – video public service announcements focused on the Ft. Berthold reservation
- Audio public service announcements.
- Culturally appropriate posters and brochures

Wyoming	- Three videos highlighting the deaf-blind clinic and other training issues for children who are deaf-blind
Nebraska	- the beginnings of a tracking system to ensure families crossing state borders are able to access appropriate services.
Montana	-in the development stages of a public service announcement -informational 'give-away' items for pow-wows and local fairs.
Minnesota	-informational brochure of available services in Minnesota for children who are deaf-blind -specific training opportunities for children who are deaf-blind and their families.

The success of the last four years has led the Great Plains Regional Alliance to conclude that it must continue it's efforts in this area. To this end each of the Alliance states – Montana, Minnesota, Nebraska, North Dakota, Wyoming and South Dakota – wrote a collaborative plan that was included in each individual grant proposal. Future plans are already underway for a jointly sponsored regional training on deaf-blind issues. Each year a different state proposes to "host" the event and the other states financially support the training.

Specific information on each goal, objective and activity follows:

South Dakota State/Multi-State Project
Expanding the Circle of Services
H025A50026

GOAL 1: Children with deaf-blindness and their families will have enhanced skills and abilities through a high quality responsive statewide system of early identification and intervention.

OBJECTIVE 1.1: Given appropriate training and supports, children birth to 21 years of age with deaf-blindness will be identified through the Local Interagency Network System in South Dakota at an incidence rate consistent with national norms.

OBJECTIVE 1.2: Given training and supports, all children identified with deaf-blindness and their families will receive appropriate intervention assistance from local education, health, medical and interagency network systems.

Activity 1.1: Provide on-going training for project staff in all areas of deaf-blindness--which may include: identification, definition of deaf-blindness, unique needs, intervention techniques, transition planning, conflict resolution, group processes, cultural sensitivity and awareness of tradition, values, and child rearing practices of American Indians.

Progress: Dr. June Downing once again provided outstanding training for educators across the state of South Dakota. Dr. Downing presented two outstanding sessions for educators on effective strategies to include students with disabilities into regular education classrooms and activities. Dr. Downing presented to a crowd of nearly 70 people at the Howard Johnson Hotel in Rapid City on November 19, 1998. The following day she did the same presentation at the Holiday Inn in Sioux Falls to a similar crowd. Dr. Downing is always well received and her information is down to earth, easy to replicate in the classroom and incredibly effective with students with disabilities especially those who are deaf-blind.

The System Change and Deaf-Blind Projects participated on the planning committee for the Native American Indian Summit for three years. The 1999 Native American Indian Summit was held in Pierre for the first time. A small crowd was in attendance but the participant's felt the information was extremely valuable and hoped the Summits would continue in the future. The conference provides an opportunity for members of all nine Indian nations to come together to discuss issues surrounding individuals with disabilities in their communities. Issues that surfaced were: accessible transportation, ramps for homes, basic services such as medication, nursing care, crutches, wheelchairs, etc. These were very similar issues brought forth at the previous two summits. A continuing challenge has been "how to engage tribal leaders" in the discussion of the needs of individuals with disabilities. Future plans for the next summit will look at this issue as well as those from the participants.

The Office of Special Education Summer Institute was held July 19-24, 1999. The SD Deaf-Blind Project, SD Statewide Systems Change Project and the Office of Special Education co-sponsored Robi Kronberg who conducted a 2 1/2 day training on integrated curriculum.

Personnel also participated in the Colorado Deaf-Blind Training Institute in Breckenridge, Colorado in August 1999. The training was outstanding and a similar training for South Dakota is being discussed.

Activity 1.2: Solicit appropriate membership and convene project advisory council to provide direction and oversight to the implementation of the Expanding the Circle Project.

Progress: The project continues to struggle with an active advisory board. First there was a delay in assembling the board because an attempt was being made to coordinate several project advisory boards into one Advisory Board. This was suggested in an attempt to provide consistency across projects as well as to save on costs. The attempt was partially successful as the Deaf Blind Project and the South Dakota Statewide Systems Change Project share an Advisory Board. A board meeting was pulled together, but the very first meeting was shortened due to extreme weather conditions. Since then several members have moved from the state and replacements as of yet not found. Even though this is the fourth and final year the project will continue to solicit advisory board input and membership. In the interim the Office of Special Education Advisory Panel and the East Dakota Educational Cooperative Board provide input and direction.

Activity 1.3: In collaboration with the Birth to Three local interagency networks, identify specific need requirements for students with deaf-blindness; their families and the service providers working with them; establish a work plan for on-going training and technical assistance based on identified needs.

Progress: Several training opportunities were offered to educators, parents and service providers including those with the Local Interagencies during 1998-99. The project supported the annual Three Rivers Interagency spring training. This training continually brings in educators, parents, and other service providers on the Rosebud Reservation and the surrounding areas to learn new strategies and techniques for serving children with disabilities. The Three Rivers Interagency was also instrumental in developing the Great Plains Regional Alliance public service announcements and the Resource Packet.

Activity 1.4: Identify concentrated technical assistance sites serving predominantly rural and American Indian families to identify the most effective strategies, encourage families and seek out and utilize intervention services.

Progress: The Deaf-blind Project is currently linked to several sites - all of them through the local interagency networks. The current technical assistance sites are:

Three Rivers Interagency - this interagency serves the Rosebud Reservation area, as well as the surrounding rural communities. This is an extremely active interagency and generates incredible participation from community members, tribal members, Headstart, school districts, hospitals, clinics and church groups. This interagency is also linked to the University of South Dakota: University Affiliated Program. The UAP provides support personnel once a month at the local Rosebud Clinic to assist in screening young children. This UAP also participates in all training opportunities offered through the interagency. The Interagency holds an annual Spring training opportunity for providers and parents within the area and the SD Deaf-Blind Project offers support for this training whenever possible, as well as disseminates information during the event. It is extremely well attended and provides an opportunity to get critical information to families and providers.

Yamni Interagency - this interagency serves the Pine Ridge Reservation area along with the surrounding rural communities. This area of the state is the most isolated and remote and presents great challenges in meeting the needs of families. Families are scattered in small tribal communities that offer few, if any services. Meeting most service needs for children with disabilities requires significant travel to communities such as Rapid City (as much as a 4 hour drive for some families) or Chadron, Nebraska which is again a significant distance, not to mention requires crossing state lines and entering another whole set of regulations, and policies.

Activity 1.5: Develop and execute a public awareness campaign to include the use of brochures, posters, public service announcements (PSAs), and a video to communicate an awareness of the project's activities, the services available, the need for identification and early intervention, the importance and necessity to evaluate vision and hearing deficits as part of a comprehensive interdisciplinary evaluation techniques when multiple disabilities are present, how to access the project's services, and the benefits children with deaf-blindness and their families can receive from the project.

Progress: Originally a sampler of 10 examples of Public Service Announcements was completed. The PSA samples included a male version, a female version, an English version and a Lakota version. These examples were then shown to the Advisory Council, the Three Rivers Interagency sub-committee, the Office of Special Education, the Three Rivers Interagency membership and the Great Plains Regional Alliance members. Comments and suggestions for necessary changes were collected and referred on to the producer. A final product was completed May 31, 1997. The sub-committee also recommended producing a poster from one of the clips of the video PSA and exploring the option of creating a radio PSA spot. Samples of these two products were completed and presented to the Three Rivers Interagency and the Great Plains Regional Alliance members. Along with the samples, Brent Bailey offered ideas and suggestions for other ways of 'marketing' our information. Currently the products have been completed and the next step will be to determine the best and most effective way to disseminate them.

Activity 1.6: Develop a computerized listing of all public, private, Bureau of Indian Affairs (BIA) and tribal contract schools, state and private agencies serving children with deaf-blindness, tribal leaders, medical providers, local interagency network system contact persons, and health agencies within each local interagency network.

Progress: A comprehensive compilation of all reservation schools and agencies within the Great Plains Region has been completed and disseminated to the surrounding states. The report is on file in the Pierre office. Additionally, each local Interagency Network has developed a resource listing of services and supports within their coverage area. These resource listing will be gathered and kept on file for reference as activities are implemented within local reservation areas.

Activity 1.7: Maintain and update required census information on all identified children who are deaf blind in South Dakota.

Progress: Census information is collected throughout the year, as well as with the annual state 94-142 child counts process. The project works closely with the state department in the development of census/child count documents to ensure that every opportunity is utilized to provide information on identification of children who are deaf-blind. Information on identification is also provided on an on-going basis to the local Interagency Networks across the state.

Activity 1.8: Update current materials and create new materials to include training strategies considerate of the unique cultural practices of American Indian families within the two model project sites serving predominantly American Indian families. Materials may include existing parent videotapes, strategy guides, informational material and in-depth training seminars.

Progress: Products under development or available at the present time are:

1. Video Public Service Announcements: this product was developed specifically to address the Native American families and features several Lakota tribe members. The finished products feature one PSA in English and one in Lakota. These were distributed to all of the television stations in South Dakota. In addition each of the member states of the Great Plains Regional Alliance received copies. Some of these states chose to use the PSAs in their states as well.

2. Audio/Radio Public Service Announcements: based upon the visual PSA's, a selection of CD's was developed specifically to address the Native American families and features several Lakota tribe members. The finished products feature one PSA in English and one in Lakota. These were distributed to the larger radio stations in South Dakota and in particular those whose coverage included reservation areas.

3. Effective Education: Adapting to Include All Students: this is a video product completed in collaboration with the South Dakota Statewide Systems Change Project, the Indiana Deaf-blind Project and the Utah Deaf-blind Project. The video highlights best practices for including children with disabilities in regular classroom activities. A major feature of the video includes activities filmed on location at the Loneman School on the Pine Ridge Reservation.

4. Essential Characteristics: Schools for the Real World: the second in this series highlights effective teaching strategies for high school and middle school students. Based on the essential characteristics defined by South Dakota administrators and educators, this video outlines 'what it takes to make inclusion happen in real schools'. Outstanding interviews with educators and administrators make this video tape a powerful training tool.

5. Vision-Hearing Resource Packet. This packet has been developed specifically for the local interagency staff serving children birth to 3. The Regional Interagency Facilitators and the Single Point of Contact needed a "toolkit" that provided them with some information, check lists, resources and census data readily at hand. The packet is assembled in a divided folder and can be easily carried with the staff as they visit families. Feedback from the Facilitators and Single Points will be gathered and additional information added to the packets.

Activity 1.9: Coordinate with national technical assistance projects: NTAC, as well as both Part H and Special Education Part B of IDEA, the UAP Rosebud Project, the South Dakota Statewide Systems Change Project and other related projects to increase awareness, skills and knowledge of educators, medical personnel, and other service providers to meet the needs of children who are deaf-blind in general education and community settings.

Progress: An exciting partnership activity developed with Part H in South Dakota. From the state level, a heavy emphasis was placed on screening for vision and hearing. Through the Deaf-blind Project, a training opportunity for all Single Points of Contact and Regional Interagency Facilitators was conducted to strengthen existing screening techniques used by these local interagency personnel. The state director of Part H brings all interagency staff together annually to provide information on current issues and to provide new training opportunities. At the fall 1999 meeting, Resource Packets were distributed to all of the Part H personnel. June Downing conducted a training November 19-20, 1998. The training was provided in two locations – Rapid City in the western part of the state and Watertown on the eastern side. With approximately 70 people in attendance in both locations, the training was a success. The Deaf-Blind Project and the South Dakota Statewide Systems Change Project coordinate all activities and training. Materials prepared through the Systems Change Project always include information or strategies to include children with deaf-blindness. Project staff also participates with the Office of Special Education Compliance monitoring activities to ensure consistency between school districts and project activities in meeting the needs of children who are deaf-blind.

Activity 1.10: Initiate contact with all higher education institutions in South Dakota including Universities, Native American Colleges, private colleges and technical institutes to discern those institutions interested in entering into a working relationship with the Deaf-Blind Project.

Progress: Project staff has been persistent in persuading higher education to become partners with the project. Currently, Sinte Gleske University on the Rosebud Reservation, and Lower Brule University, have become interested, active partners in working toward meeting the needs of kids with vision and hearing disabilities. Both of the small, private colleges are linked to the University of South Dakota, University Affiliated Program as well as to each other. These links provide great strength and a good deal of creativity to students who attend these very rural universities. Currently collaboration has been focused on developing paraeducator training programs, as well as how to incorporate the philosophy of Alfie Kohn into inclusive classrooms on the reservation. The University of South Dakota - University Affiliated Program, the Rosebud Sioux Tribe and the South Dakota Deaf-Blind Project have been working collaboratively to strengthen vision and hearing screening techniques through the Rosebud Clinic. The clinic is held every month for families residing on the Rosebud Reservation and provides a comprehensive evaluation for young children. A team of professionals from the hospital, the local school district and the UAP provide the evaluations for families. Working relationships continue to be strengthened with Black Hills State University, South Dakota State University, Oglalla Indian College, and Sinte Gleske College. Project staff continues to provide information to the other higher education institutions as well.

GOAL 2: Upon completion of the project, children and youth who are identified as deaf-blind will have increased opportunities to participate with their non-disabled peers in general education and community settings.

OBJECTIVE 2.1: Given the resources, training and supports, all children identified as deaf-blind will expand educational and developmental skills necessary for inclusion with typical peers as measured by increased time in general education settings.

OBJECTIVE 2.2: Given appropriate training and supports, all students age 16-21 identified as deaf-blind will expand transition related skills allowing successful transition as measured by increased time with typical peers in work and community settings.

Activity 2.1: Based on 'best practices' in effective teaching, inclusion, and deaf-blindness, collaborate with higher education institutions to develop a "strategy packet" for prospective 'new teachers'. The packet would include:

a. Information on effective teaching and inclusive education techniques
b. Strategies for building partnerships between regular and special educators
c. Ideas for curriculum modifications and adaptations
d. Resources on effective teaching and inclusion practices
e. Methods for involving parents in active, positive relationships with educators.

Progress: All of the pieces for the "strategy packet" have been completed. A video titled "Effective Education: Adapting to Include All Children" has been completed. The video was a collaborative effort between the South Dakota Deaf-Blind Project, the South Dakota Statewide Systems Change Project, the Indiana Deaf-Blind Project and the Utah Deaf-Blind Project. The video features several classrooms and teachers implementing effective education strategies that allow children with severe disabilities, including those who are deaf-blind, to be included in typical regular class activities. Footage from Indiana, Utah and South Dakota, including Native American children from the Pine Ridge Reservation was used to highlight specific strategies. This video will form the nucleus for a strategy 'packet' for educators, families, higher education and other service providers. A second piece of the packet The Primer: A Closer Look At Inclusion is a booklet of strategies originally produced by the Systems Change Project in 1986. It was updated in 1998 and still remains highly valued by South Dakota educators. A second video Essential Characteristics: Schools for the Real World has also been completed. This video is focused on including students with disabilities at the middle and high school level and outlines the essential characteristics of an effective school. These materials along with Issues Briefs and other supporting documents make up the strategy packet. The packets will be used for inservice training but the final goal with these products is to work with higher education to assemble the packages for teacher 'study groups' and offer credit opportunities.

Activity 2.2: Collaborate with local interagency networks, parent support centers Pathways (ND) and EPICS (NM) to identify training needs among American Indian families and service providers (both public & tribal) and create or update training materials to incorporate the unique differences among Anglo and American Indian family training approaches.

Progress: As part of the planning committee and a participant of the Native American Indian Summit, the project was able to incorporate ideas and strategies related to children who are deaf-blind. The 1999 Native American Indian Summit was held in Pierre for the first time. A small crowd was in attendance but the participant's felt the information was extremely valuable and hoped the Summits would continue in the future. The conference provides an opportunity for members of all nine Indian nations to come together to discuss issues surrounding individuals with disabilities in their communities. Issues that surfaced were: accessible transportation, ramps for homes, basic services such as medication, nursing care, crutches, wheelchairs, etc. These were very similar issues brought forth at the previous two summits. A continuing challenge has been "how to engage tribal leaders" in the discussion of the needs of individuals with disabilities. Future plans for the next summit will look at this issue as well as those from the participants. As part of the Great Plains Regional Alliance, training needs of families across the plains area were discussed. As a result all of the states agreed to continue support for this priority in the next grant application. A specific plan was developed to provide training on a regional basis for rural, reservation areas. The first training is tentatively planned for Spring 2000 in Montana.

Activity 2.3: Research educational service strategies to meet identified training needs in coordination with national technical assistance, NTAC, Part H, Special Education, Part B, Rosebud Project, and all related local, state, and national programs having the potential to impact children with deaf-blindness.

Progress: The Deaf-Blind Project has worked closely with all agencies to coordinate technical assistance. Some of the highlights of this collaboration are:

The Deaf-Blind Project collaborated with the SD Statewide Systems Change Project on the Effective Education Summit held in Pierre October 12 and 13, 1998. Teams from each of the Systems Change initiative sites as well as several agencies were invited to attend. Teams from the districts included an administrator, regular educator, special educator and, in some cases a related service provider. Participants included: Arlington School District, McCook Central School, Todd County Schools, Chamberlain School

District, SD Education Association, CASE and the Office of Special Education. The purpose of the summit was to identify those characteristics and strategies that must be in place in order for a school to be "inclusive".

As this was the final year of this Deaf-Blind grant cycle, scheduled to end September 31, 1999, the Request for Proposals for new awards was due in April 1999. Through the federally funded technical assistance project, NTAC, grant writing and support workshops were held around the country. South Dakota attended the workshop held in San Diego, California, February 17-19, 1999. As the South Dakota University Affiliated Program was writing the grant, two members of their staff also attended. The new grant will be implemented through the SD UAP starting October 1, 1999.

OSEP Compliance Monitoring was a major focus of the Office of Special Education this past year. The Systems Change Project and the Deaf-Blind Project served on the steering committee for the OSEP monitoring. Several meetings were held to assemble the state's self-assessment document, pull together necessary data documents for support materials and one on-site visit. The on-site visit was originally scheduled the entire week of March 15-19, 1999 but due to some unforeseen emergencies most of the visit was postponed until April 1999. However, one on-site visit was held in Kyle, SD. A large number of both public, tribe and BIA individuals were in attendance for the Part C portion of the visit, but no public school representatives were in attendance for the afternoon session on Part B.

Activity 2.4: Continue to foster relationships with other organizations providing service or technical assistance to children with severe disabilities including those who are deaf-blind and their families. These organizations may include South Dakota Advocacy; South Dakota Extension Services, South Dakota Hearing & Speech Association, South Dakota Nursing Association, South Dakota Guardianship Program, South Dakota Medical Association, etc.

Progress: Past activities have relied on the Family Support Roundtable to bring these groups together. However, in the past year the Roundtable has not met. Concern was raised as to whether the Roundtable had outlived it's usefulness and that while it still served a purpose for members to "get together and network", no one felt the need for one more meeting to be added to their calendars if there were not specific target items or a general focus. The Roundtable Resource Poster and Brochure have been updated and it is anticipated that the members will come together to disseminate these materials as well as discuss the future of the Roundtable.

Activity 2.5: In collaboration with the South Dakota Statewide Systems Change Project create an "Inclusion Strategies" guide for school districts and communities on "how to" ideas that facilitate including children who are deaf-blind.

Progress: The Deaf-Blind Project and the South Dakota Statewide Systems Change Project already have in place a document titled, "The Systems Change Primer: A Closer Look At Inclusion". This booklet includes strategies for children who are deaf-blind as well as those with other significant disabilities. A collaborative effort with Indiana and Utah in the development of a training video for educators was developed. "Effective Education: Adapting to Include All Children" provides a real-life look into classrooms in the three states on how to include children who are deaf blind. Much of the footage was shot on location in South Dakota and includes some excellent examples from the Loneman School District on the Pine Ridge Reservation. The video also includes a small booklet with additional strategies for inclusion. A direct link between The Primer and the video will offer opportunities for development of credit granting packages. A second video focusing on middle school and high school inclusion strategies titled "Essential Characteristics: Schools for the Real World was also developed. This video provides an inside look at what it takes to implement inclusion in real schools – putting the theories to work. The Deaf-Blind Project is also working as a partner with the South Dakota Statewide Systems Change Project in identified initiative sites. These sites have been selected to address issues of including children with severe disabilities (including Deaf-Blind) into secondary settings. As one of the sites includes a young middle school student who is Deaf-Blind, it is critical that we work closely to ensure strategies address her needs as well as those of other students. Each site has assembled a local team that includes regular and special educators, administrators, parents and community members. Both the Systems Change and Deaf-Blind Projects provide technical assistance and training to these teams. This provides consistency in information and support. At the core of these initiative sites is the development of innovative strategies for including students with disabilities in regular classroom activities and also the measurement of the impact of these changes. Several tools have been developed to assist the sites in

identifying starting points as well as measure progress and impact. Data has been collected and will be available for analysis soon.

April 14th, 1999 saw the second Effective Education Summit take place. Held at the South Dakota Education Association building, the Summit brought together 37 superintendents, principals, university personnel, teachers and state department personnel to discuss the issues of school reform and restructuring. Starting with the information from the first Summit, the group again reviewed the issues of "Essential Characteristics" and Effective Strategies" necessary to effect true *systems change* within a school district. Rhonda Tyree again facilitated the group. The daylong session kept participants busy and by the end of the day a set of South Dakota Essential Characteristics and Effective Strategies was drafted. (Attached). These will provide a foundation for several future activities as the grant moves into its fifth and final year. The Summit was hosted by both the Systems Change Project and the Deaf-Blind Project.

ACTIVITY 2.6: Develop an "Inclusion Readiness" process to assist school districts in planning and implementing inclusion strategies. The process will include the following elements:

a. Identification of "Effective Teaching" strategies that facilitate inclusion of children with severe disabilities, including those who are Deaf-Blind
b. Elements specific to elementary, middle school and high school
c. A template to help sites with "school/community identified success" for including children with deaf-blindness and their families
d. A process to evaluate school/community identified success and the impact on current systems
e. Collection of "baseline" information on current district status in including children with severe disabilities including those who are Deaf-Blind.
f. Identification of strategies to support the transition of students with deaf-blindness from secondary programs into post-secondary programs or employment opportunities.

Progress: Several consultants; Brent Bailey, Alice Udvari-Solner and David Mank assisted in the development of this process. Staff met once with Dr. Mank around issues of 'systems change'. Project personnel reviewed and compiled available information on effective schools and effective teaching practices that could be used as part of the process. Several activities were completed:

a.) "Toolkit" - the toolkit was developed in coordination with the Systems Change Project and consultant Dr. David Mank. The instruments developed will assist districts and communities in identifying where they are in the "inclusion process", areas of needed change and evaluation of progress and impact. Several instruments were developed

Middle School/High School Initiative Information Sheet

Provides basic information on the project goals and objectives, as well as expectations for prototype sites.

Middle School/High School Initiative Profile & District Data Profile

Gathers pertinent information from initiative sites. Assists in identifying sites that have met criteria to become a "site" and also begins to build baseline information for the project.

Student Data Profile

Tool developed specifically to show student movement within and across placements. Completed within selected sites on children with severe disabilities, it is anticipated that data will show not only movement by placement, but will identify curriculum changes, instructor and supports within these placements

Needs Assessment Form

A simple needs assessment form relative to effective teaching strategies that lead to inclusion of children with severe disabilities. This form was developed specifically at the request of some of the initiative sites.

Classroom Observation

This form was developed to assist educators in identifying issues relative to a specific child. Again this form was developed based on requests from educators and parents in selected sites. The form is NOT used in all sites and is intended only to provide beginning information on what is currently in place within a child's program and what may need to be looked at as areas to be changed or strengthened.

School & Community Survey

This form was developed to assist selected school sites in addressing community involvement in the education process. Again this form will NOT be used in all sites and is used only if the school district determines it as a need. Several of the sites have their own tools or survey data.

Post School Accomplishments

An effort to collect post school data for students with severe disabilities led to the development of this form. In collaboration with School to Work and Transition projects, this data may provide insight into "where" students with disabilities go upon completion of secondary programs. It is hoped it will also assist in identifying gaps between education and adult services.

b.) Effective Education Video - shows examples of elementary classrooms that have utilized unique, effective teaching strategies to include students with disabilities. The video has a companion booklet that provides additional teaching strategies and processes to include children with disabilities. This video has become the nucleus of much of the training and technical assistance provided to school districts.

c.) Valuing Parents Video – this video was developed specifically to explain the new IDEA reauthorization to parents. Since many regular educators are not familiar with IDEA it will be helpful in many areas of training.

d.) Essential Characteristics:Schools for the Real World Video – second in the video series. This video highlights the essential characteristics and the "people" who are critical when implementing inclusion. The video is based on the national set of essential characteristics for effective schools.

e.) Essential Answer: a newsletter providing continued information related to effective teaching practices. Highlights outstanding strategies, encourages educators to "look beyond" the basics, provides information on upcoming events and in general continues to "push educators to the next level of teaching".

Activity 2.7: Collaborate with other federally funded 'systems change' projects within South Dakota to assist youth with disabilities and their parents as they transition from school to the world of work. These projects include South Dakota Transition Project; Dakota Link (assistive technology); Dakota Works (supported employment) and South Dakota Systems Change Project. Efforts of these projects will focus on:

a. Coordinated inservice and training opportunities.
b. Shared materials and resources.
c. An inter-communication system between project personnel.
d. Cross-training between project staff.

Progress: Although no formal efforts currently exist to coordinate efforts, all project staff interact and network with these projects when needed. The Dakota Link project has completed it's federal funding and is now coordinated through the Department of Rehab. Services.

Activity 2.8: Based on recommendations from research of existing "community guides" create a new "Community Template" which will facilitate community action in implementing strategies to identify and meet the needs of individuals with disabilities in their schools, businesses, recreational and social settings. The template will be designed to meet the individual unique needs identified by each community, including rural vs. urban issues, remote access, cultural issues, economic development issues, etc. This template will place emphasis on:

a. A community self-study designed for local communities to measure their current attitudes and commitment to inclusion of individuals with disabilities.
b. A technical assistance guide for community leaders, complete with strategies designed to build inclusive recreational, social and economic disabilities.
c. A community leadership planning guide designed to help community leaders build coalitions for change in their communities.

Progress: A community packet was developed to be disseminated to community organizations. This packet contained basic information on individuals with disabilities, as well as ideas for community activities to support individuals with disabilities. This packet will be disseminated through the South Dakota Systems Change Project in 2000. A "School & Community Survey" has been developed to assist selected school sites in addressing community involvement in the education process. This form will NOT be used in all sites and is used only if the school district determines it as a need. Several of the sites have their own tools or survey data

Activity 2.9: Collaborate with the South Dakota Transition Project to provide training and technical assistance to families, service providers, and relevant parties in planning and implementing transition services for students age 14-21.

Progress: Although no formal efforts currently exist to coordinate efforts, all project staff interact and network with the Transition project when needed. Efforts will continue to be made to ensure training and materials are supportive of the other 'systems change' projects and include information on children who are deaf-blind.

South Dakota
Optional Pilot Project
Goals & Objectives

GOAL 1: The Expanding the Circle to the Great Plains project will provide a comprehensive set of strategies, materials, and products designed to promote awareness, identification, and service coordination for children with deaf-blindness and their families residing in American Indian communities across the Great Plains and nationally.

OBJECTIVE 1.1: By the end of the project the states of Montana, Wyoming, North Dakota, South Dakota, Nebraska and Minnesota will have in place a collaborative alliance of communication, shared training and expertise to support children identified as deaf-blind who reside on American Indian reservation land.

OBJECTIVE 1.2: By the end of the project each member state of the alliance will increase by 80% the number of American Indian children identified as deaf-blind who live on American Indian reservation lands using materials and products specifically designed to meet tribal needs identified in their area.

OBJECTIVE 1.3: By the end of the project, using products specifically designed to promote awareness and coordination of services and supports, each member state will initiate a system of coordinated local, tribal and governmental services to meet the unique needs of children identified as deaf blind residing on American Indian reservation land.

Activity 1.1: Develop ongoing communications network with Great Plains Regional Alliance state coordinators.

Progress: Members of the Alliance communicate on a regular basis either by telephone or e-mail. The relationship between the Great Plains states seems to have been strengthened through this grant effort. Even though there is no set schedule for communication, member states probably touch base at least on a monthly basis, some even more often. The group developed a collaborative brochure, which provides contact information for each of the member states. Each state received 1,000 copies of the brochure plus a camera-ready copy to duplicate additional copies. The group historically meets twice a year to discuss progress; once during the project director's meeting and once in the spring. These meetings have proved to be invaluable in sharing information and planning future direction.

Activity 1.2: Discuss the development of a regional tracking system of American Indian families of children who are deaf-blind, birth through 21 years of age and their service providers to assure consistency of service delivery as families move from one reservation/state to another.

Progress: Discussion between South Dakota, Nebraska and North Dakota has been initiated, specifically targeting the reservation areas that cross state lines. Service providers and project staff from Nebraska and South Dakota met June 3-4, 1998 to discuss issues surrounding families crossing state lines to receive services. Tentative plans were developed but further meetings will need to be held to provide more detail to the plan. North Dakota and South Dakota met May 27, 1998 to discuss options for residents of the Ft. Berthold Reservation. The workgroup were looking at developing some public awareness products and activities as well as discussing the availability of services to families who move across state borders. This continues to be an area of need.

Activity 1.3: Build on existing efforts and materials to expand and support current skills of families and service providers (both public and tribal) to meet the needs of children who are deaf blind and that all activities and materials acknowledge the unique differences among Anglo and American Indian family training approaches.

Progress: South Dakota: From a sampler of 10 examples, two Public Service Announcements have been completed. The PSA includes a male version, a female version, an English version and a Lakota version. Along with the PSA, the sub-committee recommended producing a poster from one of the clips of the video PSA. An audio/radio public service announcement has also been completed. These were distributed to stations providing service to reservation areas. Each of the Great Plains Regional Alliance received copies of the posters, video and audio PSAs to use as 'samples' in their reservation areas as well as to show workgroups what they might wish to produce. A Resource Packet was also developed and disseminated to all Part H personnel. The packet contains basic information on vision, hearing and deaf-blindness. The intent was to produce quick, easy to read documents that provide basic information to families and service providers.

Minnesota: Minnesota developed and disseminated a brochure highlighting services available within their state. Since much of the Native American population in Minnesota is the same as South Dakota, many of the materials developed in South Dakota were used in Minnesota.

Montana: Montana working with a local group on the Northern Cheyenne Reservation, decided to produce their own public service announcement. They are currently looking for a producer and developing a script. Montana also is in the process of developing "give-away" items such as key rings, refrigerator magnets, etc. that have information on services available to families. These items would be given during pow-wows and fairs across the state.

Wyoming: Wyoming really took the bull by the horns and developed several videos for their state. Wyoming conducts a semi-annual clinic for families who have children who are deaf-blind. In order to ensure that Native American families knew about the clinic and felt comfortable bringing their children there for evaluation, Wyoming developed a video showing the clinic and the value of brining children to the clinic. Utilizing footage taken during the development of the first video, Wyoming also created two other videos. These videos were targeted at other audiences, such as the medical community and service providers in Wyoming. All of the videos were widely accepted and were very successful.

Nebraska: Although Nebraska does not have many reservation areas, a strong focus for the state was the Native American families who reside in South Dakota and cross the state line for services in Nebraska. Nebraska borders both the Rosebud and the Pine Ridge Reservations in South Dakota. All of the materials produced in South Dakota were used in Nebraska with minimal changes. Nebraska and South Dakota continue to work on the issue of tracking families across state borders to ensure that services are readily available on either side.

North Dakota: North Dakota was another state that made incredible progress in meeting the goals of the grant. Working with a local group from the Ft. Berthold Reservation, North Dakota produced it's own set of public service announcements, posters and supporting materials. Using replication materials from South Dakota they easily assembled their videos and produced some outstanding posters. The materials have been widely disseminated and embraced by the people of the Ft. Berthold Reservation.

Activity 1.4: Develop and share a collaborative regional listing of available resource materials within the Great Plains Alliance states that can be used to meet the needs of children who are deaf-blind and their families.

Progress: The members have a shared brochure and resource listing. As materials were developed by individual states they were shared with the other members. Each state received copies of public service announcements developed by North Dakota and South Dakota. Wyoming shared their videos developed for their reservation area. Brochures, training opportunities, all were shared across states.

Activity 1.5: Establish a plan for Great Plains Regional Alliance states to meet on at least an annual basis to discuss issues, concerns and progress.

Progress: The Alliance states met annually at the project directors meeting and typically held a spring meeting in St. Paul, Minnesota. These meetings along with frequent phone calls met the needs of the states.

Activity 1.6: Analyze existing state census information to develop a baseline of number of American Indian children identified as deaf blind currently being served by each individual Alliance state.

Progress: Following is the census data from 1995 and 1998 for each of the member states.

	1995	1998
South Dakota	8 children	9 children
North Dakota	3 children	8 children
Wyoming	2 children	2 children
Minnesota	unknown	1 child
Montana	7 children	6 children
Nebraska	unknown	2 children

At the beginning of the project the states of Minnesota and Nebraska were unable to identify children by ethnic group. They both were able to identify ethnic group in the 1997 census. This was the first time that all of the member states were able to identify Native American children who are dual sensory impaired. All states saw an increase in the number of children identified and more importantly all states reported a significant increase in the number of referrals of children who have hearing or vision impairments.

Activity 1.7: Solicit local contacts within designated reservation sites to support and participate in project activities.

Progress: Following is a summary of activity from each state:

Montana: The first pilot site lost two key people; therefore they had to begin the process of locating other people. Progress continues, however with the original group of people, who have provided ideas on how to access and give information to families on the reservation. They have identified community activities as the vehicle to build on. For example, they have a Harvest Days festival that would provide the Montana project an opportunity to have a booth that would offer both "fun" activities as well as "information". Montana is currently working on putting together a public service announcement for the area. Montana staff also continues to build a strong relationship with Part C. These activities and the information provided have assisted in the identification of two additional children residing on the Lame Deer Reservation.

Wyoming: Video production was a major focus of activities for Wyoming. Since a major emphasis of the Wyoming Deaf-Blind Clinic, there was a need to "show" families the benefits of referring their children to the clinic for evaluation purposes. Additionally the videos will be utilized as training tools for educators and service providers across Wyoming. Because Wyoming is one of our more sparsely populated states, creative options for training become critical in building awareness and skills. Prior to development, careful planning ensured the end product would have multiple uses as well as multiple audiences. The Wyoming Deaf-Blind project has been very effective in developing partnerships with other agencies in getting these videos off the ground. Through grant writing efforts and support of the Optional Pilot Project, several videos, with multiple uses have been completed and are now available. It is anticipated this will increase the number of children identified with vision and hearing disabilities in Wyoming, as well as improve services to those already identified on the census.

North Dakota: Several activities have taken place in North Dakota. The project worked in their designated site to identify a core work group. This group was charged with the task of providing direction to grant activities and to identify what a public awareness package might look like for their area. South Dakota met with this workgroup May 27, 1998 to discuss strategies that had been successful. From this discussion the group decided to develop a Public Service Announcement for the area. Contacts were made to a local station and from this contact the station agreed to work with the team in the development of their PSA and an INCREDIBLY low cost! The PSA with supporting posters was ready by late Fall, 1998. The 307.11 project changed to a new person and the members welcomed her and offered any assistance necessary to aid in the transition of duties. North Dakota now has a Web site up and active. The web site was developed with the assistance of a person with Ushers so that the backgrounds are not visually distracting and utilized a inimum of graphics. Minot University has a person available to assist in the development of web pages if

needed. The project has also been actively involved with the STAT teams and a copy of the new STAT manual was shared with members of the Alliance and NTAC.

Nebraska: Nebraska is developing an active linkage with Part C activities. Three school districts in the eastern part of the state have been identified and are working closely with the project. The project has been focused on providing information to early childhood programs and providers. Based on this emphasis, the project has seen a marked increase in requests from early childhood providers. Nebraska also has an operational web site, which is linked through the Department of Education. Another focus has been on the development of competencies for all personnel working with children birth to 3. These competencies address deaf-blind. This information was shared with approximately 400 educators in March 1998. On June 3-4, 1998, the 307.11 coordinators from both Nebraska and South Dakota met to discuss the availability of services to families living along the border areas who cross over into Nebraska for services. This has been an issue for many years and a preliminary plan was developed to address this need. A follow-up meeting will be scheduled.

Minnesota: Minnesota developed and disseminated a brochure highlighting services available within their state. Since much of the Native American population in Minnesota is the same as South Dakota, many of the materials developed in South Dakota were used in Minnesota.

South Dakota: From a sampler of 10 examples, two Public Service Announcements have been completed. The PSA includes a male version, a female version, an English version and a Lakota version. Along with the PSA, the sub-committee recommended producing a poster from one of the clips of the video PSA. An audio/radio public service announcement has also been completed. These were distributed to stations providing service to reservation areas. Each of the Great Plains Regional Alliance received copies of the posters, video and audio PSAs to use as 'samples' in their reservation areas as well as to show workgroups what they might wish to produce. A Resource Packet was also developed and disseminated to all Part H personnel. The packet contains basic information on vision, hearing and deaf-blindness. The intent was to produce quick, easy to read documents that provide basic information to families and service providers.

Activity 1.8: Review current child count census procedures and provide recommendations for necessary changes to appropriate policy makers.

Progress: Alliance members have made changes on individual state census forms to more accurately reflect Bureau of Indian Affairs and Tribal enrolled children. Discussion has been held with Dr. Vic Baldwin on possibilities for change at the federal level, but to date no change has occurred.

Activity 1.9: Provide information and technical assistance to the medical community, tribal college system, tribal community, tribal health care and other resource networks to build capacity to support children who are deaf blind and their families.

Progress: Each of the member states conducted training within their states, either bringing in consultants with specific expertise or utilizing their own talents. Future plans include conducting a regional training, which would be supported by all of the Alliance members. Plans include that each year a different state would host the event thus providing opportunities for more service providers and families in rural and remote areas to participate in training. Additionally all materials mentioned above have been disseminated to the medical community, college systems, tribal community and service providers.

Activity 1.10: Develop a process to identify and contact existing service providers in tribal communities and on reservation land that can be utilized by other states in establishing linkages with reservation service providers.

Progress: A comprehensive listing of all public, private, tribal and BIA schools, agencies and organizations has been compiled from available information and disseminated to all member states. This information will provide a nucleus for a "linkage" process. Parent training centers Pathways and EPICS will also provide information in the development of this process.

What is Deaf-Blindness

The term deaf-blindness (also known as dual sensory impairment), would seem to imply that the individual has no functional use of ***any*** vision or hearing. Yet there are very diverse descriptors for children and young adults who are vision and hearing impaired. Individuals with deaf-blindness may have ***some*** functional vision or hearing; they may be losing vision or hearing slowly; they may have ***additional*** disabilities; or they may be profoundly deaf and totally blind. Children with deaf-blindness are singled out educationally because impairments of both sight and hearing require thoughtful and unique educational approaches in order to ensure that children with this disability have the opportunity to reach their full potential.

A person who is deaf-blind has a unique experience of the world. For people who can see and hear, the world extends outward as far as his or her eyes and ears can reach. For the young child who is deaf-blind, the world is initially much narrower. If the child is profoundly deaf and totally blind, his or her experience of the world extends only as far as the fingertips can reach. Such children are effectively alone if no one is touching them. Their concepts of the world depend upon what or whom they have had the opportunity to physically contact.

If a child who is deaf-blind has some usable vision and/or hearing, as many do, their world will be enlarged. Man children called deaf-blind have enough vision to be able to move about in their environments, recognize familiar people, see sign language at close distances, and perhaps read large print. Others have sufficient hearing to recognize familiar sounds, understand some speech, or develop speech themselves. The range of sensory impairments included in the term "deaf-blindness" is great.

Basic Principles

Few generalizations can be made about deaf-blindness because "deaf-blind" refers to combined hearing and vision losses, and there are as many possible combinations of hearing and visual impairments as there are individuals who are deaf-blind. However, here are a number of key principles that are useful to follow:

- There is no single profile of a deaf-blind student
- Most deaf-blind students have and make use of some hearing and vision.
- Deaf-blind students can participate in almost any activity.
- Deaf-blind students communicate in a variety of ways.
- Many deaf-blind students can get around their communities independently.
- Deaf-blind students can be included in every teaching environment.
- Educational teams are essential for the design and delivery of educational programs for deaf-blind students.
- The families of deaf-blind students are key players on the educational team.

Hand in Hand, AFB Press, New York, NY and DB Link, February 1999.

Causes of Deaf-Blindness

Syndromes

- Down
- Trisomy 13
- Usher

Multiple Congenital Anomalies

- CHARGE Association
- Fetal alcohol syndrome
- Hydrocephaly
- Maternal drug abuse
- Microcephaly

Prenatal Dysfunction

- AIDS
- Herpes
- Rubella
- Syphilis
- Toxoplasmosis

Post-Natal Causes

- Asphyxia
- Encephalitis
- Head injury/trauma
- Meningitis
- Stroke

Prematurity Congenital

Adapted from Etiologies and Characteristics of Deaf-Blindness, Heller & Kennedy, (1994)

Forms of **Deaf-Blindness**

Early Deaf-Blindness

People tend to think of early onset when they hear the term "deaf-blind." This is the most obvious form, since it is the most extreme, although it is not the most frequent. People with early deaf-blindness

- Have both visual and hearing losses at birth or by age 2.
- Have severe to profound losses of both vision and hearing.
- Lack access to much environmental information, except within arm's reach.

Strategies to facilitate development

- Parents and teachers can interact with the child using movement, physical closeness, and touch to promote the development of communication.
- One-to-one interaction promotes the development of relationships with significant people and can easily be expanded to include siblings, extended family members and neighbors.
- Information from smell and taste can supplement information from touch and movement.
- Parents and teachers can introduce concepts with hands-on demonstrations and repetition.

Early, Less Severe Hearing and Visual Impairments

Most people who are identified as deaf-blind have some useful residual vision, residual hearing, or both. People in this category

- Have the combined partial impairments from birth or early childhood.
- Have mild to moderate losses of both senses.
- Usually receive incomplete or indistinct visual and auditory information (blurry, vague, muffled)
- Can learn to interpret even minimal visual and auditory information meaningfully with training and assistive devices.
- Can use this information for developing language, communication, mobility, and conceptual skills.
- Are likely to have gaps in concept development because of the reduced information available to them.
- Can benefit from multisensory input to fill in the gaps in concept development.

Strategies to facilitate development

- Check the child's perceptions of what is occurring in the environment and his or her general concept development. Ask the child: "What just happened here? What did you see [or hear]?"
- Check the child's comprehension of a message, have the child retell what you described or demonstrate something you have just shown and explained.
- Repeat and rephrase what you have previously explained for more clarity.
- Provide multisensory information with each new experience or concept; adapt information for touch, movement (together or by imitation), smell, or taste if appropriate.

Early Hearing Disability with Later Vision Loss

Some children have been deaf or have had significant hearing impairments from birth or early childhood and use vision for most information gathering and learning. A number of them may have significant vision losses later in life and become deaf-blind. A child who is deaf or hard of hearing and later loses vision

- Has the hearing impairment at birth or by age 2.
- Has a mild to profound hearing loss that may contribute to delayed language and speech development
- Has subsequent delays in learning reading and writing skills, as well as delays in developing related academic skills because of delays in language development.
- Can generally master daily living activities through visual imitation without major difficulty.

Early Visual Disability with Later Hearing Loss

An individual who has been blind or visually impaired from birth may acquire a hearing loss later and become deaf-blind. Some cause of this form of deaf-blindness include

- Damage to the ears from accidents or infections
- The use of medicines, such as mycin drugs, that can damage hearing
- Syndromes like Leber's amaurosis (in which the hearing loss, if there is one, may occur in childhood.

Children with this form of deaf-blindness

- Have mild to significant visual impairment or are blind at birth or by age 2.
- Have access to auditory information, especially language, and their parents tend to rely on spoken language, movement, and tactile information to support their concept and mobility development.
- Learn to read and write using Braille or regular or large print, depending on the degree of vision loss and the amount of remaining useful vision, with spoken language as the basis for reading.
- Probably will not need an adapted reading method (Braille or large print) if the visual impairment is mild and stable because a later hearing loss will not affect already developed reading skills.
- Can learn academic subjects normally in elementary and secondary school if their hearing loss does not occur until adulthood and they have no additional disabilities.
- Have already learned to perform daily living activities (such as selecting clothing, brushing teeth, or crossing streets safely) that would typically be learned through visual imitation using adaptations and demonstrations involving movement and tactile information combined with auditory information, including spoken descriptions
- Will need to learn new ways to obtain auditory information, for example, by reading news in Braille, rather than listening to television or radio, or by having a person read mail with fingerspelling.

Later Sensory Losses

People who lose both vision and hearing either as young adults or later in life also may be considered deaf-blind. Those whose sensory losses occur when they are young adults

- Have already mastered essential movement and communication skills using vision and hearing.
- Can learn new adaptive life skills for movement and communication based on previously learned concepts and skills.
- May have additional disabilities resulting from the same diseases or conditions that caused their visual and hearing losses, such as accidents, brain tumors, stroke, or spinal meningitis.
- May find counseling helpful for psychological-emotional issues that are sometimes associated with the sudden or gradual loss of vision and hearing that interferes with long-established ways of communicating and performing daily routines.
- May need to relearn academic or job skills without visual and auditory information or may need to train for different types of work entirely.

Hand in Hand, AFB Press, New York, NY and DB Link, February 1999.

Challenges Of Deaf-Blindness

A person who is deaf-blind must somehow make sense of the world using the limited information available to them. If the person's sensory disabilities are great, and if people in the environment have not made an effort to order the world for them in a way that make it easier to understand, this challenge may be overwhelming. Behavioral and emotional difficulties often accompany deaf-blindness and are the natural outcomes of the child's or adult's inability to understand and communicate.

People who can see and hear often take for granted the information that those senses provide. Events such as the approach of another person, an upcoming meal, the decision to go out, a change in routine are all signaled by sights and sounds that allow a person to prepare for them. The child or adult who misses these cues because of limited sight an/or hearing may come to experience the world as an unpredictable, and possibly threatening, place. To a great extent, persons who are deaf-blind must depend upon the good will and sensitivity of those around them to make their world safe and understandable.

The challenge of learning language is perhaps the greatest on those children who are deaf-blind face. It is also the greatest opportunity, since language holds the power to make their thoughts, needs, and desires known. The ability to use words can also open up worlds beyond the reach of their fingertips through the use of interpreters, books, and an ever-increasing array of electronic communication devices. In order to learn language, children who are deaf-blind must depend upon others to make language accessible to them. Given that accessibility, children who are deaf-blind face the challenges of engaging in interactions to the best of their abilities and of availing themselves of the language opportunities provided for them.

A person who is deaf-blind also faces the challenge of learning to move about in the world as freely and independently as possible. Adult individuals also must eventually find adult living and work situations that allow them to use their talents and abilities in the best way possible. Many adults who are deaf-blind lead independent or semi-independent lives and have productive work and enjoyable social lives. The achievement of such success depends in large part no only on the severity of their impairments but also upon the education they have received since childhood, and particularly upon the communication with others that they have been able to develop.

Hand in Hand, AFB Press, New York, NY and DB Link, February 1999.

Tips For Early Communication

Strategies

To develop emotional bonds, an infant who is deaf-blind needs contact with caregivers that is consistent and predictable.

Although the capacity to communicate is inborn, the skills that infants need to communicate are acquired with the assistance of other people. Therefore, the primary goal of early intervention with infants who are deaf-blind is to encourage the growth of their bonds with their parents and other caregivers because attachment and bonding can promote the development of essential communication skills.

- When possible ***hold*** the infant in a secure and comfortable position for caregiving routines, such as bottle feeding, and identify other routines in which holding is possible.

- ***Touch*** the infant during play and other interactions. Identify the types of touching that the baby enjoys, such as patting, stroking, kissing, tickling, cuddling, and bouncing.

- Respond quickly to ***comfort*** an infant who is crying, fussy, or frightened. Identify ways to calm the baby, such as rocking, providing opportunities for sucking, or gently patting the baby's chest.

- Give as much ***attention*** as possible to the infant by maintaining eye contact (at close range for infants who are visually impaired), smiling, talking, touching, and so on. Encourage the caregivers to identify how they pay attention to their infant.

- ***Engage*** the infant's attention by making faces, cooing or babbling, humming and singing, tickling, blowing on the baby's stomach, and so forth. (Encourage the infant to touch the caregiver's throat and feel vibrations of sound, especially when an infant has significant hearing loss.) Encourage the caregivers to identify how they engage the attention of their infant.

- ***Respond*** to the infant's behavior, such as by vocalizing when the baby makes a sound or shifting the baby's position when he or she begins to fidget. Observe the baby's body language and identify what gets the caregiver to respond.

Hand in Hand, AFB Press, Eleven Penn Plaza, New York , NY 10001

Communication Systems

For Persons Who Are Deaf Blind

- **Touch cues**
  Communication prompts that are made on a child's body, such as a light touch on the lips for eating. Touch cues encourage the child to anticipate the next activity and to begin to respond appropriately.
- **Gestures**
  Mutually understood natural movements or signals, such as pointing or waving good-bye, that are used to communicate specific ideas consistently. Gestures can be used to prepare a child for the use of signs as symbols.
- **Object cues**
  Communication prompts that are made with objects that touch the child's body or are presented visibly to the child. For example, a washcloth touched to the face can indicate the activity of washing the face. An object cue encourages the child to anticipate an activity and can be the precursor for using objects as symbols.
- **Sign language**
  A formal language that uses hand and arm movements, natural gestures, body and facial movements, and expressions symbolically.
- **Tactile sign language**
  Sign language that is used with touch. Both the person signing and the receiver may use touch or the receiver alone may use touch and then sign back visibly or speak.
- **Finger spelling**
  Hand shapes that symbolize alphabet letters that can be read visibly or through touch.
- **Tangible Symbols**
  Items such as objects (either partial or whole), pictures, or textured materials, that can be used to represent a concept or activity. Their use does not require the cognitive ability that formal language does, and they can be readily manipulated to convey an idea.
- **Vocalizations**
  Sounds made with the voice that can be used to get attention, make wants and needs known, and communicate specific things to others. Vocalizations may precede speech.
- **Spoken language**
  The use of speech to articulate concepts.
- **Braille**
  Written language that is embossed, so it can be read by touch.
- **Print-on-palm**
  "Writing" on a person's palm with the index finger.
- **Large print**
  Writing that is made large for persons who are visually impaired, so they can read more easily.

DB-Link, February 1999, Hand In Hand, AFB Press, New York, 1995.

Challenges Facing Families, Teachers and Caregivers

Communication

The disability of deaf-blindness places unique demands upon families, teachers, and caregivers who must make sure that the person who is deaf-blind has access to the world beyond the limited reach of their eyes, ears, and fingertips. The people in the environment of children or adults who are deaf-blind must seek to include them – moment –by-moment – in the flow of life and in the physical environments that surround them. If they do not, the child will be isolated and will not have the opportunity to grow and to learn. If they do, the child will be afforded the opportunity to develo0p to his or her fullest potential.

The most important challenge for parents, caregivers, and teachers is to communicate meaningfully with the child who is deaf-blind. Continual good communication will help foster their healthy development. Communication involves much more than mere language. Good communication can best be thought of as conversation. Conversations employ body language and gestures, as well as both signed and spoken words. A conversation with a child who is deaf-blind can begin with a partner who simply notices what the child is paying attention to at the moment and finds a way to let the child know that their interest is shared.

This shared interest, once established, can become a topic around which a conversation can be built. Mutual conversational topics are typically established between a parent and a sighted or hearing child by making eye contact and y gestures such as pointing or nodding, or by exchanges of sounds and facial expressions. Lacking significant amounts of sight and hearing, children who are deaf-blind will often need touch in order for them to be sure that their partner shares their focus of attention. The parent or teacher many, for example, touch an interesting object along with the child in a nondirective way. Or, the mother may imitate a child's movements, allowing the child tactual access to that imitation, if necessary. (This is the tactual equivalent of the actions of a mother who instinctively imitates her child's babbling sounds.) Establishing a mutual interest like this will open up the possibility for conversational interaction.

Teachers and parents can continue conversations with children who are deaf-blind by learning to pause after the initial topic has been established. These children frequently have very slow response times. Respecting the child's own timing is crucial to establishing successful interactions. Pausing long enough to allow the child to take another turn in the interaction, then responding to that turn, pausing again, and so on – this back-and-forth exchange becomes a conversation. Such conversations, repeated consistently, build relationships and become the eventual basis for language learning.

As the child who is deaf-blind becomes comfortable interacting nonverbally with others, she or he becomes ready to receive some form of symbolic communication as part of those interactions. Often it is necessary to precede the introduction of words with the use of simple gestures and/or objects, which serve as symbols or representations for activities. Doing so may help a child develop the understanding that one thing can stand for another.

Think of the many thousands of words and sentences that most children hear before they speak their own first words. A child who is deaf-blind needs comparable language stimulation, adjusted to his or her ability to receive and make sense of it. Parents, caregivers, and teachers face the challenge of providing an environment rich in language that is meaningful and accessible to the child who is deaf-blind. Only with such a rich language environment will the child have the opportunity to acquire language herself or himself. Those around the child can create a rich language environment by continually commenting on the child's own experience using sign language, speech, or whatever symbol system is accessible to the child. These comments are best made during conversational interactions. A teacher or a parent may, for example, use gesture or sign language to name the object that they and the child are both touching, or name the movement that they share. This naming of objects and actions, done many, many times, may begin to give the child who is deaf-blind a similar opportunity afforded to the hearing child – that of making meaningful connections between words and the things for which they stand.

Usher Syndrome

- **Usher syndrome** involves both a genetic hearing loss and a genetic vision loss that is due to retinitis pigmentosa (RP). Although the hearing loss is usually obvious from firth or early childhood, the vision loss is often more gradual. Two visual problems that children with Usher syndrome develop early are night blindness and the loss of peripheral vision. Central vision is affected later, and because children with User syndrome may have sharp acuity for reading print and for daily living activities, the diagnosis of Usher syndrome may not be made until adolescence or adulthood.

There are three types of Usher Syndrome

Usher Syndrome, Type I: born profoundly deaf, retinitis pigmentosa (RP), and balance problems. Night blindness in infancy or early childhood. Can be legally blind by early adulthood.
Seven different genes have been identified so far that cause Usher syndrome Type I, Usher IA through Usher 1F.

Usher Syndrome, Type II: has moderate stable hearing loss, RP, and normal balance; blind spots by late childhood or teens. Can be legally blind by early adulthood. There are at least 2 genes that cause Usher Syndrome, Type II, Usher IIA and Usher IIB.

Usher Syndrome, Type III: has progressive hearing loss, RP, and the status of the balance system is still being determined, night blindness in childhood or teens, can be legally blind by early to mid adulthood. There are at least 2 genes that cause Usher Syndrome, Type III, Usher IIIA and Usher IIIB. More genes are still being identified.

Because only peripheral vision is lost in childhood, and Usher syndrome is usually not diagnosed in childhood, children may experience difficult social and emotional circumstances as a result of misunderstandings. For example, they may be labeled clumsy because they bump into or stumble over objects or be considered inattentive or stuck-up because they cannot detect people or objects from the side.

In addition, children with Usher syndrome are often educated with other children who are deaf and hard-of-hearing and grow up participating in recreational activities in the deaf culture. Therefore, when their vision losses become severe in young adulthood, they may be unable to participate in these activities or to use sign language or speech-reading and hence may feel isolated from the close knit, supportive deaf community. Furthermore, their communication with their families can become limited, and family members often become over-protective. Therefore, counseling is important especially for deaf teenagers with RP to help them cope with the gradual and anticipated changes in their vision; to deal with possible comments and teasing from peers and others; and to make decisions about a number of issues, including driving and letting others know what visual adaptations they need.

Hand in Hand, AFB Press, New York, NY and DB Link, February 1999.

Things to Remember

For Children Who Are Visually Impaired/Blind

- Access to toys that are colorful, interesting to touch and have sound and/or vibration.
- Close physical proximity to others – teachers and classmates.
- Safe, predictable environment in which to explore.
- Structured environment and routines.
- Sufficient lighting on task and in play area.
- Clear verbal directions and physical prompts as needed.
- Tactual materials to replace visual activities (e.g., textured collage vs. drawing).
- Emphasis on active and interactive play.
- Good contrast when providing visual information (e.g., foreground information clear from background).
- Concrete REAL items to introduce concepts.
- Exposure to Braille and/or large print (e.g., labels on items in room, books).

Normal Visual Development

Vision is one of your baby's most important ways to learn about the world. The first three years of life is a critical time for your baby to be visually alert and learning about objects, people and events.

Your baby sees some things from the moment of birth because much of the visual system has already developed. Vision develops in a predictable way; here's what happens before and after birth. The ages are averages; every baby is a little different.

Before birth

- **16 weeks fetal age: Eye movements occur.**
- **25 weeks fetal age: The light-sensitive cells in the eye can be seen.**
- **28 weeks fetal age: The muscles that control the pupils have developed.**
- **32 weeks fetal age: The cornea—covering the lens—appears. The optic nerves—the visual pathways that connect the eyes and the brain—are in place.**

Your baby is able to visually learn about the world, but the visual systems are not fully developed. Here are some of the changes that should occur in your baby's visual behavior during the first three years.

At birth

- **The cornea becomes fully transparent.**
- **Can tell colors apart, but the ability is not mature for all colors until 2 to 3 months.**
- **Until about 3 months, sees things to the side better than to the front.**

Your baby's ability to notice details and differences quickly increases, but attention to different nearby areas may be limited. The ability to shift attention rapidly increases during the first 2 months.

3 months

- **The shape of the cornea makes close objects a little out of focus. Sees best at a distance of eight to ten inches.**
- **The way the pupil reacts to light continues to develop.**
- **Begins to recognize your face. At first, baby scans the angles, shapes, and outline of the face. By 3 months, scans the eyes and mouth, unless there is an unusual feature—such as glasses, glitter, or paint—added to the face.**

4 months

- **Sees detail and color. Probably knows your face from a stranger's and prefers yours.**
- **Can accommodate—shift focus from one distance to another—from eight to thirty inches away and converge—turn the eyes inward—with good precision to look at a target at close range.**
- **Binocular vision—the ability to focus both eyes on one object and see one image—is fairly well developed and is closely linked to accommodation and convergence. Should respond to horizontal and vertical lines, and black-and-white checkerboard and bull's eye patterns.**

6 months

- **Watches everything that is nearby.**
- **At a slightly earlier age, baby gazed at hands, batted and swiped at hanging objects, and tried to grasp objects. Now baby stretches both arms out to grasp an interesting-looking object or to touch your face. This shows that some depth perception—the ability to see the three-dimensional relationship between objects—is developing.**
- **Reaching skills continue to develop until 12 months. Baby watches the activities of others, looks at pictures in books, and dumps and fills containers.**

12 to 18 months

- **Practices visual-motor skills: Scribbles, builds a tower with cubes, attempts to imitate strokes, places a circle in a one-piece puzzle and pegs into a pegboard.**
- **Is interested in simple picture books and in touching bold colors.**

2 Years

- **Sees detail in pictures.**
- **Works on matching things that are the same and different.**
- **Matches objects to pictures.**
- **Recognizes detail in pictures.**
- **Becomes aware of upside down and right side up.**
- **Continues to draw and place square and triangle shapes in puzzles.**

3 years

- **Matches and sorts by color and shape.**
- **Matches objects to pictures that are not identical.**
- **May be able to sort pictures of common objects and draw a person with a head and one or two other features.**

Many of these "visual behaviors" involve the use of eyes and hands together. During the first three years, eye and hand development cannot be separated.

Hand and eye development is closely linked during the first three years. By the toys you give and the kind of play your encourage, your can help your child's vision develop normally.

What You Should Know About Blindness and Visual Impairment in Children

- The development of the child who is blind or visually impaired is highly individual, as it is with all children.
- Vision is the primary learning modality and source of information for most children.
- No other sense can stimulate curiosity, integrate information or invite exploration in the same way, or as efficiently and fully, as vision does.
- The child who is blind or visually impaired has many needs in common with all children. Among these are the needs for a sense of worth and accomplishment.
- Children who are blind cannot learn to do things by visual imitation. Children who are blind or visually impaired often require more "hands-on" experience, time, practice, and guidance in order to learn skills.
- More efficient hearing and a finer sense of touch, smell or taste do not develop ***automatically*** in an infant who is blind or visually impaired.
- Specialized training in the effective and efficient use of vision, hearing, touch, smell and taste can bring about increased skill in their use.
- Because most parents have not had the opportunity to know a child who is blind or visually impaired, they can often benefit from the assistance provided by trained professionals and other parents who have had such an experience, and adults who are blind or visually impaired.
- Many children who are blind or visually impaired have other disabilities.
- The relationship between blindness and other disabilities is complex. Assessment and programming become complicated and may require the services of a variety of disciplines.

Facts

The Visual System

The visual system is complex. The process of seeing involves a sequence of events—the reception of light and sensory stimuli through the eye, the transmission of electrical impulses along the optic nerve and the interpretation of these impulses as an image in the visual cortex of the brain. The anatomic structures involved are interrelated and very complex.

What Can Go Wrong

Low vision and blindness limit the quality and quantity of a person's experiences. Difficulties may originate in the cornea, lens, retina, optic nerve, brain stem and/or other parts of the visual pathway up to an including the visual cortex.

Common visual impairments include:

Nearsightedness	Can focus up close, but vision is blurred at a distance.
Farsightedness	Can focus at a distance, but vision is blurred up close.
Astigmatism	Visual image is distorted. Usually accompanied by nearsightedness or farsightedness.
Cataracts	Lens becomes opaque, obstructing part or all of view.
Glaucoma	Peripheral vision diminishes. Can cause total loss of vision.
Detached retina	Retina comes loose causing blindness or blind spots.
Macular degeneration	Failure of the small region in center of retina causing blind spots. Can interfere with fine discrimination need for reading and using graphic symbols.
Strabismus	Convergence and muscle imbalance resulting in poor focus or double vision makes focusing, fixing and tracking more difficult. Binocularity occurs in many children with cerebral palsy.
Amblyopia	Reduced vision from lack of use or lack of clarity of vision during early childhood. A consequence of strabismus.
Hemianopia	Lack of peripheral vision on one side of the visual field of both eyes. Requires active scanning of visual information.
Visual field defects	Blind spots, which result in a lack of awareness (neglect) of objects. Requires active scanning of visual information.
Nystagmus	Oscillations or tremors of the eyes occurring independently of normal eye movements.

Indicators of Cortical Visual Impairment

Appearance

- Absence of sensory nystagmus
- Absence of deep set orbits
- Expressionless face
- Eye movements slow but aimless
- Visually inattentive
- Tend to look away from people, events
- Diminished visual communication
- Visual self-stimulation rare

Visual Perception

- Appears unable to recognize stationary objects
- May not recognize faces
- Needs wide spaces between objects/stimuli
- Focuses only on one toy among several
- Depth perception is poor
- Reach is inaccurate
- Identifies color more easily than objects or shapes

Visual Functioning

- Visual abilities fluctuate day to day, hour to hour
- Peripheral fields often more functional
- Tunnel vision, hemianopias common
- Attends optimally to movement, sees best when moving
- Sees better in familiar environments
- Depending on site of lesion: 1) aware of distant objects, cannot identify them or, 2) has difficulty spotting distant objects, can identify
- Functions better when told where to look and for what to look
- Often needs to touch to identify although object can be seen at distance
- Lacks visual curiosity
- Spontaneously uses vision only for short periods of time
- Tires easily during visual learning
- Holds objects close to see
- May jerk head from side to side
- On reaching, turns head to side; exhibits downward gaze
- Vision may be better one side; field restrictions apparent
- Uses saccadic eye movements to localize objects
- Encounters difficulty identifying pictures but locates small details when given labels

Sensory Modalities

- Tactile cues used to supplement vision
- Uses hand-searching to locate objects
- Appears to listen better when eyes closed

Posture and Movement

- Rarely bump into objects during travel
- Balance better, eyes closed
- Vestibular input improves visual function
- Use of vision correlated with head control
- When moving, may see stationary objects
- Usually holds head up except when reaching
- Depth perception poor when moving; cannot judge distances
- Because of decreased spatial perception, use of dog and cane travel may be ineffective

Risk Factors

- Asphyxia
- Shunt failure
- Cerebral bleeding
- Trauma
- Brain malformation

Diagnostic Indicators

- Bilaterally reactive alpha rhythms
- Disturbance of posterior visual pathway and/or cortex
- Loss of vision not attributed to other severe ocular defects
- Optic atrophy minimal
- Preservation of pupillary response
- Absence of sensory nystagmus
- Blink to threat may be present

Communication Systems And Vision

Finding Solutions

More than one type of visual problem can occur so it can take years to figure out the functional vision of individuals who have multiple disabilities who are unable to speak. Between 75 and 90% of school aged children with severe/profound cognitive disabilities and approximately 40% of those with cerebral palsy have visual problems. People who have severe speech/language problems, developmental disabilities and neurologic problems often have visual impairments. Vision has a profound impact on the selection and use of augmentative and alternative communication symbols, devices, techniques and strategies.

Some considerations:

Component	Effect	Accommodation
Visual acuity	Impaired acuity, with a variety of etiologies, is the most common visual problem. Visual acuity allows us to discriminate details close up and far away. Acuity impairment classifications vary from partially sighted to totally blind and include visual field defects	Consider the size, position and type of symbols being used, how they are presented and how the individual will select the. Color and contrast (i.e., figure/ground) can greatly enhance acuity. Lighting also is important.
Visual fields	Mapping visual fields to determine the location of blind spots is helpful. Central fields discriminate color and shape in daylight conditions. Peripheral fields are sensitive to motion, contrasts and low light conditions. People who lack central vision depend on peripheral vision and may turn away from an object/person in order to see it with peripheral vision. Be careful. This may be confused as a positioning rather than a visual problem.	Just because you have a good map of a person's visual fields doesn't mean you know about functional vision. Check to see how "blind spots" affect function. Adjustments in positioning of symbols and displays and in mounting devices may be necessary.
Oculomotor functioning	Eye muscles allow people to scan, locate, fixate and track moving objects. People may need to shift their bodies to make accommodations. If motor problems or positioning constraints interfere, seeing can be difficult.	Pay attention to the design of displays. Adjust the positioning of a person and/or equipment. Sometimes the angle of a display is critical. How the person tilts his/her head also can make a difference.
Light and color sensitivity	Color and illumination factors can vary with the type of visual impairment. For example, as we age and presbyopia occurs, more light is required to see. Sensitivity to certain colors may be depressed depending on the visual impairment, but color blindness is rare.	Appropriate use of color and lighting enhances acuity and makes perception easier. Illumination on a display or device screen must be adequate and without glare. Sunny days can be a problem. Backlighting is important. Color provides contrast. Yellow backgrounds are often better than white.

Component	Effect	Accommodation
Cortical vision	Cortical visual impairment occurs with damage to visual pathways leading to and including the visual cortex. It is generally caused by a lack of oxygen to the brain. Prematurity is a major etiology of cortical visual impairment as more fragile babies are surviving. Cortical visual impairment also occurs following anoxic events associated with head trauma, hydrocephalus, meningitis and encephalitis. Studies suggest a gradual visual recovery extended over several months to years in people who acquire cortical visual impairments. Those who have congenital cortical visual impairments have more difficulty because learning is so dependent on vision and other problems associated with brain damage are often present. Clinical symptoms of cortical visual impairments include visual inattentiveness and a lack of visual acuity. Because eye movements are not affected, individuals may not appear to have impaired vision.	Individuals who are unable to attach meaning to visual information remain severely compromised in learning, language development and communication. Cortical visual impairments will interfere with the use of augmentative and/or alternate communication system components. Children with cortical visual impairments often benefit from auditory scanning and motor experiences that allow them to interact with and learn the meaning of objects, events and people. Motor memory (i.e., the mental map we use to carry out our rote movements) may be critical to an individual with cortical blindness to establish meaning.

Conditions and Diseases

Astigmatism	A defect in the curvature of the cornea; light rays cannot focus on a single point on the retina. May be hereditary.
Buphthalmos (Infantile glaucoma)	A form of glaucoma that has its onset at birth or within the first three years of life. Surgery may be necessary. May be acquired through autosomal recessive inheritance.
Cataracts	Opacity or cloudiness of the lens which restricts the passage of light, usually bilateral. Immature or incipient cataracts are only slightly opaque; while mature cataracts are so opaque that the fundus cannot be seen and the pupil may be white. Surgical removal is usually recommended when the cataract becomes mature. Intraocular lens (IOL) implants or corneal contact lenses may be used after surgery.
Coloboma	A birth defect, which causes a notch or cleft in the pupil, iris, ciliary body, lens, retina, choroid or optic nerve which, occurs during fetal development. A "keyhole pupil" often occurs. Hereditary: autosomal dominant.
Color deficiency	Cone malformation, macular deficiency, partial or total absence of cones. Hereditary: sex-linked or caused by retinal disease or poisoning.
Cortical visual impairment	Damage to the visual cortex or the posterior visual pathways. Pervasive neurological disorders such as cerebral palsy, epilepsy, hydrocephalus, learning disabilities, or deafness may be present. Occasionally optic nerve atrophy, optic nerve hypoplasia, retinal abnormalities and other ocular lesions occur. Spatial confusion is common. Caused by anoxia at birth, a head injury, infections to the central nervous system (such as encephalitis, and meningitis) shunt failure, or a genetic malformation.
Hyperopia (Farsightedness)	A refractive error in which the focal point for light rays is behind the retina; shortness of the eyeball. If not corrected, close work may cause nausea, headache, dizziness, and eye rubbing.
Leber's Congenital Amaurosis	A form of retinitis pigmentosa causing degeneration of the macula occurring at or shortly after birth, progressive central field loss; abnormal corneas and cataracts may be present. Hereditary: autosomal recessive.
Microphthalmos	A congenital birth defect that causes one or both eyes to be abnormally small. May occur with other congenital abnormalities such as clubfoot, additional fingers, toes, webbed fingers or toes, polycystic kidneys, and cystic liver. Hereditary: most frequently recessive, sometimes dominant.
Myopia(simple), Degenerative Myopia (Farsightedness)	A refractive error where the image of a distant object is formed in front of the retina and cannot be see distinctly; elongation of the eyeball. Surgery is experimental, but may be helpful in some cases. Screen for glaucoma. Hereditary: autosomal recessive.
Nystagmus	Involuntary eye movements which can be horizontal, vertical, circular or mixed. Can be elicited when someone watches certain kinds of moving objects. Muscle surgery may be helpful. Causes are often unknown but can be hereditary (autosomal recessive) or caused by neurological or inner ear disturbances.
Optic Atrophy, Optic Nerve Atrophy	Dysfunction of the optic nerve resulting in the inability to conduct electrical impulses to the brain causing loss of vision. The optic disc becomes pale and there is a loss of pupillary reaction. Caused by disease, pressure on the optic nerve, trauma, glaucoma, toxicity or heredity; if inherited: dominant.

Optic Nerve Hypoplasia	A congenital non-progressive anomaly, in which the optic nerve head appears small and gray or pale and is often surrounded by a mottled yellow halo bordered by a dark ring of pigment, called the "double ring sign". There is often indication of abnormalities of the midline structures of the visual system, such as the corpus callosum, causing midline deficiencies. There is often a dramatic asymmetry between the two optic heads. Central nervous system and endocrine anomalies, cerebral palsy and mental retardation also can occur. An insult to the prenatal central nervous system. Commonly found with fetal alcohol syndrome, frequently found in first born children of very young mothers. May be genetic and can be caused by trauma.
Ptosis	Drooping of the eyelid may be unilateral or bilateral, constant or intermittent. Medication may be called for with abnormality of nerve-muscle junction; leads to excessive muscle fatigability. Caused by heredity, damage to the muscle or nerves, swelling or tumors.
Retinoblastoma	A malignancy of the retina in early childhood which usually requires enucleation and can occur in one or both eyes. Surgery, radiotherapy, chemotherapy, cryotherapy or photocoagulation may be helpful. Bilateral reinoblastoma has increased risk of developing other tumors. Regular physical examinations are encouraged. Hereditary: autosomal dominant.
Retinopathy of Prematurity (RPO)	A curtailment of retinal blood vessel development in premature infants, which can lead to bleeding, scarring, and retinal detachment. Can range from minimal damage to complete blindness. Treatments include vitamin E therapy, photocoagulation procedures, cryotherapy, scleral buckling procedures, and vitrectomy, but none is totally successful. Some cases resolve themselves without intervention. Causes are low birth weight, early gestational age, and duration and administration of oxygen.
Strabismus	The inability of both eyes to look directly at an object at the same time, a muscle imbalance, often secondary to other visual impairments. With young children, eye exercises, occlusion or patching of the good eye or surgery may help. Hereditary is multifactorial.

10 Tips

To Good Mobility Skills

1. **Allow** children to explore and learn on their own. Falling, bumping into objects and crying are a normal part of childhood and your child should be allowed to experience them.
2. **Use** sounds your child likes, such as your voice or a musical toy, to stimulate movement. For example instead of placing a rattle in your child's hand, shake it to one side and help them reach for it.
3. **Tell** your child where they are as they move or are carried from place to place.
4. **Help** your child learn about the sources of sounds by saying who or what is making the noise when the doorbell rings, when a guest comes into your home or when the water is running.
5. **Discuss** textures, smells, colors and other properties of objects and incorporate this discussion into the daily routine.
6. **Encourage** your child to play with other children.
7. **Promote** mobility in your child that is similar to other children the same age—crawling for infants or riding a tricycle for older children.
8. **Teach** your child how to look for or explore objects in an organized way. For example, if your child drops a toy they should listen for the sound of the toy hitting the floor, then look for it in that direction.
9. **Have** your child take part in household chores.
10. **Keep** things in the home in a designated place and be consistent. Knowing where objects are located in the house will help.

Factors Associated with Visual Impairments in Very Young Children

Vision Loss Factors

- Family History
- Prenatal exposure to maternal infections (toxoplasmosis, syphilis, rubella, cytomegalovirus, herpes, chick pox, HIV)
- Abnormal prenatal brain development
- Prematurity
- Hypoxia
- Certain syndromes (e.g., CHARGE, cri du chat, Down, Fetal Alcohol, Goldenhar, Hurler, Lowe, Marfan, Norrie, Refsum, Trisomy 13)
- Other congenital ophthalmological syndromes (optic nerve hypoplasia, Leber's)
- Bacterial meningitis
- Head trauma
- Cerebral palsy
- Certain neurodegenerative disorders (e.g., neurofibromatosis, Tay Sachs)

Northern & Downs, 1991; Teplin, 1995

High Risk Signs of Vision Impairment

Atypical Appearance of the eyes:

- Drooping eyelid which obscures the pupil
- Obvious abnormalities in the shape or structure of eyes
- Absence of a clear, black pupil
- Persistent redness of conjunctiva (normally white)
- Persistent tearing without crying
- High sensitivity to bright light indicated by squinting, closing eyes, or turning head away

Unusual Eye Movements:

- Jerky eye movements (nystagmus)
- Absence of eyes moving together or sustained eye turn after 4 to 6 months of age

Unusual Gaze or Head Positions:

- Tilts or turns head in certain positions when looking at an object
- Holds object close to eyes
- Averts gaze or seems to be looking beside, under, or above the object of focus

Absence of Visually Directed Behaviors:

- Eye contact by 3 months
- Visual Fixation or following by 3 months
- Accurate reaching for objects by 6 months

Calvello, 1990; Fewel, 1983; Teplin, 1995

Classroom Check List

If ANY of these are checked, refer for further evaluation.

Eye Condition

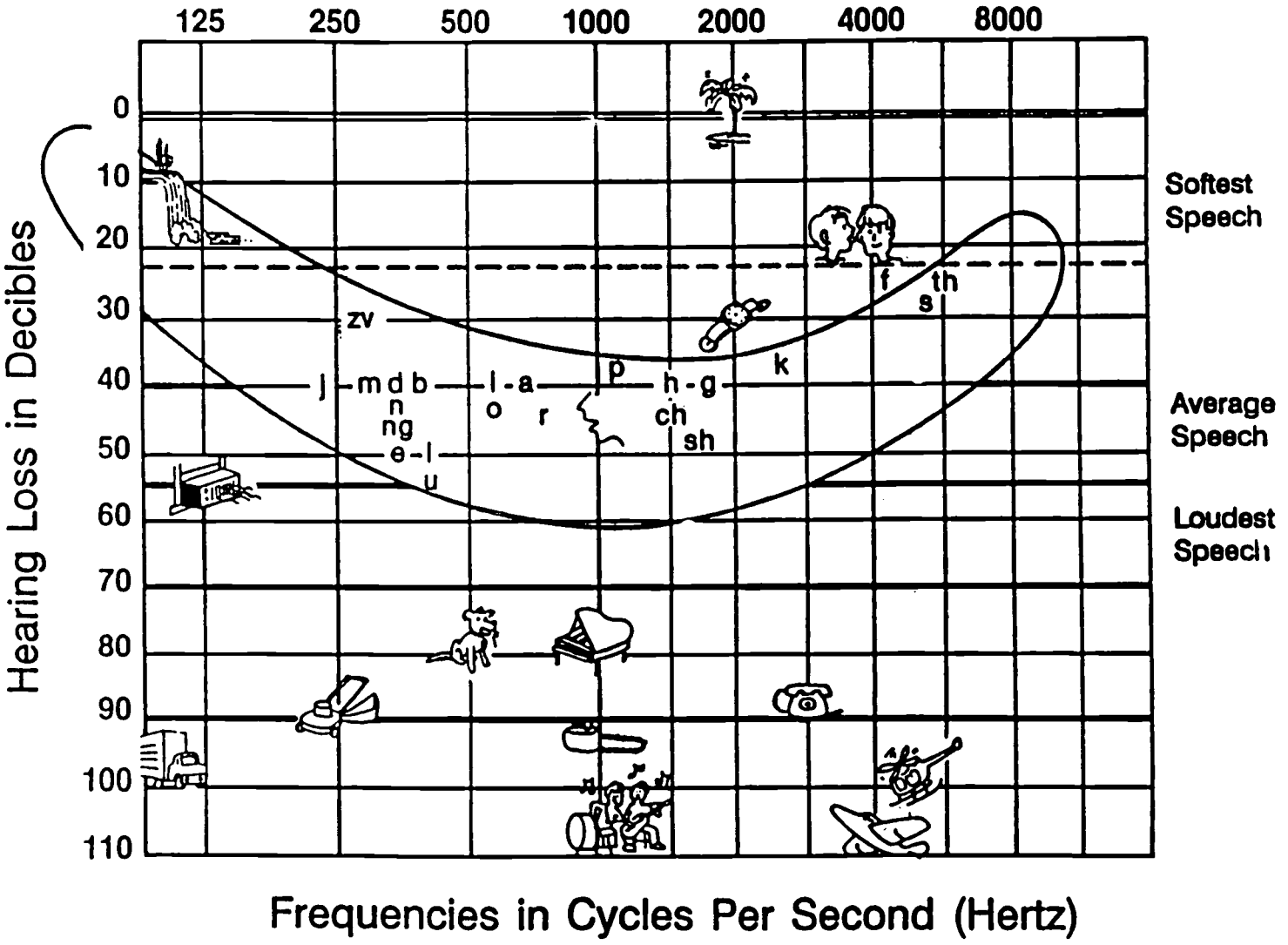
☐ Crusts on lids, among lashes	☐ Red rimmed eyelids
☐ Recurring sties (small boil on eyelid)	☐ Swollen eyelids
☐ One or both eyes crossed	☐ One eye turns in or out at any time
☐ Inflamed or watery eyes or discharges	☐ Lack of coordination in directing gaze of both eyes
☐ Reddened conjunctiva (white part of eye)	☐ Sensitivity to light

Behaviors Observed

☐ Rubs eyes frequently	☐ Frequent squinting
☐ Attempts to brush away blur	☐ Has dizziness, headaches, or nausea following close work
☐ Is inattentive in chalkboard, wall chart, or map lessons	☐ Has difficulty in reading or in other work requiring close use of eyes
☐ Blinks continually or excessively when reading or doing desk work	☐ Holds book too far from face or face too far from desk work
☐ Holds book too close to face or face too close to desk work	☐ Makes frequent change in distance at which book is held
☐ Is inattentive during lessons	☐ Works only brief periods
☐ Shuts or covers one eye	☐ Tilts head to one side
☐ Tends to reverse words or syllables	☐ Tends to look cross-eyed
☐ Tends to lose place on page; needs finger on marker to keep place	☐ Confuses the following in reading or spelling: **o** and **a**; **n** and **m**; **h** and **n**; **f** and **t**
☐ Omits small words repeatedly	☐ Rereads or skips lines unknowingly
☐ Has difficulty with glare on work surfaces	☐ Has difficulty identifying pictures
Does not write legibly ☐ Writing is spaced incorrectly and not on the line ☐ Writing size is unacceptable ☐ Is unable to read own writing ☐ Needs extra time for copying ☐ Skips letters or words when copying	When looking at distant objects: ☐ Holds body tense ☐ Contorts face in attempt to see clearly ☐ Thrusts head forward ☐ Squints eyes excessively ☐ Asks to move closer to chalkboard or display ☐ Has difficulty seeing projected images (overhead)
☐ Misses visual cues during classroom activities	☐ Often feels things to assist in verbal interpretation
☐ Unusual awkwardness; frequent tripping	☐ Frequent bumping into people and objects
☐ Hesitancy at down steps, curbs, stairs	☐ Inaccurate reach and grasp
☐ Problems with color identification	☐ Complains that eyes itch, burn or feel scratchy

Hearing Loss in Decibels

Comparison of the Frequency and Intensity of Various Environmental and Speech Sounds



Interview/Observations

Refer for Hearing Evaluation when Any One is Checked

Non-Verbal and Verbal Children

— Does the child respond inappropriately, especially to loud noises that cause reactions in other children?

— Does the child respond the same to voices of men, women, and other children? If not, when do responses to voices most often occur?

— Does the child respond to the dial tone on the telephone?

— Does the child consistently turn one ear toward you?

— Does the child show strain in trying to hear?

— Does the child watch and concentrate on the parent/teacher's lips?

— Does the child become frantic when parent/caregiver is out of sight, even in the same room?

— Do other people think your child is hyperactive (too active)?

— Do other people think your child is spoiled, because he or she will only pay attention if the child is held in their lap?

— Has the child stopped babbling?

— Does the child fail to learn to stop misbehaving when told "no"?

Verbal Children

— Does the child often ask for statements, directions, or questions to be repeated?

— Does the child respond inappropriately, e.g., make mistakes in following directions, make unusual mistakes in taking directions?

— Does the child complain of other people mumbling?

— Does the child seem to have a speech problem?

— Does the child complain of hearing difficulty in noisy situations such as classrooms, playgrounds, and stores?

— Does the child show signs of withdrawal from social situations or signs of depression, which may be reactions to hearing impairment?

— Do high-pitched sounds such as women's and children's voices and telephone dial tones "disappear"?

— Does the child speak too softly or too loudly? Inappropriate voice volume can signal hearing loss.

— Does the child need to turn up the volume of the TV, radio, or stereo when others in the family who have good hearing seem to have no problem hearing it?

— Has the child experienced academic failure following a severe illness?

— Does the child display any of the following physical symptoms of a possible hearing problem:

  — Mouth breathing

  — Draining ears

  — Ear aches

  — Dizziness

  — Reports of ringing, buzzing, or roaring in ears (tinnitus)

From Hear News, Vol. I, Published by the Texas Department of Health

Possible Causes of Sensorineural Hearing Loss

Antenatal and Neonatal Maternal Infections (e.g.), Rubella (German Measles) Congenital syphilis Asian flu Cytomegalic Inclusion Disease	A number of maternal bacterial and viral diseases may result in varying degrees of sensorineural loss. Effects may vary, mainly depending upon when during pregnancy the infection is contracted. Some viruses, such as the cytomegalovirus may be asymptomatic in the mother but can be passed on to the infant with severe effects upon the central nervous system. These viruses may result solely in hearing loss or can cause multiple disorders.
Rh Incompatibility	This condition results in the destruction of Rh positive blood cells in the fetus and may cause a number of complications in the newborn, including retardation, cerebral palsy, and epilepsy. Associated hearing loss may range from mild to profound.
Maternal Ingestion of Ototoxic Drugs (e.g.), Salicytes Quinine Streptomycin "Mycin" Drugs	Ototoxic drugs are those which may permanently injure, destroy or retard development of the inner ear, including hair cell damage in the cochlea and absence of auditory nerves. The result is sensorineural loss; however, ingestion of such drugs during the first trimester of pregnancy may also contribute to conductive losses due to malformation of the auditory ossicles. Ototoxic drugs may also produce a number of other congenital abnormalities.
Genetic Disorders (e.g.), Waardenburg's Syndrome Jervel and Lange-Nielsen Disease Usher's Syndrome	These genetic disorders typically result in failure of some portion of the inner ear to reach full development. In the case of the syndromes listed here, for example, membranes within the cochlea do not reach full development and degeneration of the Organ of Corti may be observed.
Acquired Bacterial and Viral Diseases (e.g.), Meningitis Measles Mumps Chicken Pox	Sensorineural losses ranging from mild to profound may occur because of direct infiltration of the bacteria or virus to the inner ear. Effects may include destruction of the Organ of Corti, destruction of neural pathways, or damage to other parts of the inner ear.
Ingestion of Ototoxic Drugs (e.g.), Kanamycin Neomycin Gentamycin	Considerable individual variability exists in susceptibility to the ototoxic effects of these drugs. As in the case of maternal ingestion, these drugs affect hearing by destruction of the hair cells in the cochlea.
Head Trauma	Hearing loss due to a concussion may show recovery; however, hearing loss caused by a fracture line through the cochlea, which may result in total deafness, is irreversible.
Noise Induced	Although susceptibility is apparently highly individual, exposure to intense sounds can damage the inner ear and cause hearing loss, which may be either temporary or permanent. Firecrackers, noisy machinery, and toy firearms are examples of sounds, which may result in sensorineural loss, typically for sounds in the high frequency range.
Acoustic Neuroma	This condition refers to tumors of the auditory nerve. It has rarely been reported in children.

Listening Checklist

The trouble with listening, you'd think, is that it's an invisible act. You can't see if a child's ears are shut, even though the consequences of not listening, in terms of self-esteem, happiness and achievement may be devastating.

To help parents and teachers identify children with a listening problem; we've devised the following checklist.

RECEPTIVE LISTENING/LANGUAGE

This is the listening which focuses outside, on what another is saying, or what is going on in the home or school environment.

- ☐ Has short attention span
- ☐ Is easily distractible, especially by peripheral noises
- ☐ Is oversensitive to certain sounds
- ☐ Misinterprets questions or requests
- ☐ Has difficulty with auditory discrimination (confuses similar-sounding words or consonants),
- ☐ Often asks for repetition
- ☐ Is able to follow only one or at most two instructions in sequence

EXPRESSIVE LISTENING/LANGUAGE

The listening which focuses inside, which monitors and reproduces correctly what one hears, especially one's own voice.

- ☐ Voice quality (flat, monotonous)
- ☐ Speech lacks fluency, rhythm, is hesitant
- ☐ Vocabulary is weak
- ☐ Sentence structure is poor or stereotyped
- ☐ Singing is out of tune
- ☐ Confuses or reverses letters
- ☐ Has difficulty with reading (dyslexia), especially out loud
- ☐ Poor spelling

MOTOR SKILLS

"Listening to the body." These skills are intimately related to the vestibular system of the ear, which controls balance, co-ordination and body image.

- ☐ Poor posture; slouching and slumping
- ☐ Uncoordinated body movement, fidgeting, clumsiness
- ☐ Poor sense of rhythm
- ☐ Messy handwriting
- ☐ A hard time with organization structure
- ☐ Confusion of left and right, mixed dominance

BEHAVIOURAL AND SOCIAL ADJUSTMENT

A listening problem is often accompanied by the following;

- ☐ Low tolerance of frustration
- ☐ Poor self-image, self-confidence
- ☐ Difficulty in making friends, relating with peers
- ☐ Withdrawal/avoidance
- ☐ Irritability
- ☐ Hyperactive tendencies
- ☐ Is inordinately tired at the end of the school day
- ☐ Low motivation, loss of interest in work
- ☐ Immaturity (indicates lack of desire to grow up)

DEVELOPMENTAL HISTORY

Listening difficulties usually develop well before school age. If you've noted any of the signs above, you can trace the problem further by checking into the following:

- ☐ A stressful pregnancy
- ☐ Difficult birth
- ☐ Adoption
- ☐ Early separation from the mother
- ☐ Delay in motor development
- ☐ Delay in language development
- ☐ Recurring ear infections

There is not "score" on this checklist; it is only a guide to identification.

Possible Cause of Conductive Hearing Loss

Antenatal and Neonatal Genetic Disorders (e.g. Pierre-Robin Syndrome Treacher Collins Syndrome Apert's Syndrome Klippel-Fell Syndrome Crouzon's Disease	Conductive losses due to genetic disorders typically involve middle ear anomalies such as deformation in the auditory ossicles. Many of these deformities are surgically correctable.
Cleft Lip and Palate	The incidence of recurring middle ear diseases in children with cleft palate is quite high. Middle ear disease such as otitis media affects the air conduction pathway and may cause conductive losses. Because the associated middle ear disease may have variable effects upon hearing, the hearing of individuals with cleft palate requires regular monitoring.
Acquired Tympanic Membrane Perforation	A perforation of the tympanic membrane may result in a conductive loss. Traumas such as blows to the head, or middle ear disease, may cause the perforation. The degree of loss is dependent upon the size and location of the perforations(s). Perforations occasionally heal spontaneously, but often require medical intervention. In all instances, a physician should be alerted.
Otitis Media	Otitis media is a pathological condition of the middle ear and is differentiated into several types. Serous otitis media occurs when the Eustachian tube is blocked, causing negative pressure and the appearance of fluid in the middle ear cavity. Supprative otitis media may be accompanied by sudden ear pain; the pain may subside upon the rupture of the tympanic membrane. In this condition, the fluid in the middle ear cavity is infected. Chronic otitis media is a recurrent disease in which middle ear tissues may undergo a repeated cycle of deterioration, healing, and scarring. Discharge from the ear can occur in some states of otitis media. Medical intervention may involve inserting tubes into the ear canal to facilitate drainage and ventilation. The presence of such tubes precludes the use of any hearing aids requiring closed ear molds, as such molds fill the pinna and block ventilation.
Cholesteatoma	Cholesteatoma occurs when skin from the ear canal grows into the middle ear cavity or mastoid through a perforation in the tympanic membrane. The Cholesteatoma is susceptible to bacteria and moisture, which may cause erosion of bone tissue and other complications.
Impacted Cerumen	Cerumen is earwax, which may be either west (yellow to dark brown in color) or dry (powdery whitish scales). Typically, ears are self-cleaning, in that the build up of Cerumen migrates outward into the outer ear canal where it can be easily wiped away with a washcloth. If too much accumulates in the canal, however, it can cause hearing loss. A physician must always remove impacted Cerumen, as improper attempts may result in damage to the ear canal and/or eardrum. Similarly, removal of foreign objects from the ear canal requires a medical specialist.
Head Trauma	Skull fractures may disrupt the ossicular chain, resulting in a conductive hearing loss; blows to the head may also result in perforation of the tympanic membrane as discussed above.

Auditory Screening Tool

Directions: Circle yes or no for each response depending upon the specific item.

1 . **Response to noises in the home. Ask parent, "how does baby respond to:**

Yes	No	doorbell,
Yes	No	telephone,
Yes	No	vacuum cleaner,
Yes	No	door slam,
Yes	No	Other

Have parent describe ways in which child responds to different sounds.

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2. **Response to verbalization. Speaker is approximately 3 feet to either side and/or in front of child. Stimulus "Hi there" is given at a time when the child is not looking at the examiner. Attempt a second time if there is no response the first time.**

	Right Ear	**Left Ear**	**Bilateral**
Soft voice	Yes No	Yes No	Yes No
Normal Voice	Yes No	Yes No	Yes No
Loud Voice	Yes No	Yes No	Yes No
Amplified Voice	Yes No	Yes No	Yes No

3. **Turns to "Look her" spoken at approximately 3 feet, 90 degree angle from child.**

Yes	No	**Right Ear**	- turns to localize
Yes	No	**Left Ear**	- turns to localize

4. **Response to non-speech sounds initiated at approximately 3 feet, 135 degree angle from child. Random presentations.**

Right Ear

Yes	No	a)	cellophane	-	turns to localize
Yes	No	b)	rattle	-	turns to localize

Left Ear

Yes	No	a)	cellophane	-	turns to localize
Yes	No	b)	rattle	-	turns to localize

5. **Response to familiar and unfamiliar voice. Parent and examiner alternate in calling child's name while child is engrossed with a toy.**

Yes	No	a)	Examiner's voice	-	turns to localize
Yes	No	b)	Parent's voice	-	turns to localize

If several items are checked NO, an audiologist should check the child.

Of Hearing Loss

Hearing Level In Decibels	Severity of Disability	Potential Effects
0 to 10 dB	Normal	
16 to 25 dB	Slight	Can hear faint speech within a close range. May experience no appreciable difficulty with communication. Speech not likely to be affected. May be of educational significance
26-35 dB	Mild	May have difficulty hearing faint or distant speech. A child with mild loss may miss up to 10% of speech signal when the speaker is at a distance greater than three feet, or if the environment is noisy. Likely to experience some difficulty in communication and education settings. May benefit from amplification.
36-50 dB	Moderate	Understands conversational speech at a distance of 3-5 feet. Amplification may enable listener to hear and discriminate all sounds. Without amplification, 50% to 100% of speech signal may be missed. Speech may be affected unless optimally amplified.
51-70 dB	Moderate/Severe	May hear loud voice at about one foot; may identify environmental noises; may distinguish vowels but not consonants. A 55 dB loss can mean 100% of the speech signal is missed. Delays in spoken language and reduced speech intelligibility expected without intervention and amplification.
71-90 dB	Severe	If loss is pre-lingual, spoken language and speech may not develop spontaneously, or could be severely delayed unless modifications and interventions are taken. With optimal amplification, should be able to detect all the sounds of speech and identify environmental sounds. Without amplification, is aware of loud voices about one foot from ear and likely to rely on vision for communication.
91 dB or greater	Profound	Aware of vibrations more than tonal pattern. Many rely on vision rather than hearing as the primary avenue for communication and learning. Speech and oral language will not develop spontaneously without modifications and intervention. Speech intelligibility often greatly reduced and atonal voice quality likely. Residual hearing can benefit from amplification.

Winter 1999 Edition, Newsletter of Colorado Services for Children Who Are Deaf-Blind

Facts about Hearing Loss

Identifying a Hearing Loss

Hearing loss is defined by the **degree** of loss and the **type** of loss. These two factors are decided through audiological testing, which is testing of the ear. The person who does the testing is usually an **audiologist.** Testing is done using earphones placed over a person's ears. The audiologist sends **tones** (sounds) through the earphones to one ear at a time. These tones are different **frequencies** (high or low) and **intensities** (loud or soft). Frequency is measure in **Hertz** (Hz), and intensity is measured in **Decibels** (dB). The quietest sound the person can hear at each frequency is marked on a graph called an **audiogram**. Tones are normally presented at 250, 500, 1,000, 2,000, 4,000, and sometimes 8,000 Hz. The normal threshold of hearing (the intensity at which a tone is heard) is between 0 dB and 15dB. Usually, 0 dB is the quietest a person can hear a tone of 1,000 Hz. If the tone is not heard, the intensity (loudness) is increased until the person either hears the tone or feels the tone (if it is really loud). Marks are made on the audiogram for both ears.

Deciding What Kind of Hearing Loss a Person Has

After audiological testing has been completed, the audiogram is read by the audiologist, who will define both the **type** of loss and the **degree** of loss.

Type of Hearing Loss

The **type** of hearing loss refers to the cause of the loss. The audiogram will indicate which part of the ear is damaged. Some hearing losses can be fixed by surgery or helped by a hearing aid, but not all people can be helped. There are three types of hearing loss: conductive, sensorineural, and mixed.

- A **conductive** loss means that the loss is caused by problems in the outer or middle ear. Sometimes, this type of loss can be corrected by surgery. Sometimes people with conductive losses can hear themselves but not other people. Ear infections and fluid in the middle ear can cause a temporary conductive hearing loss.

- A **sensorineural** loss means that the hearing loss was caused by problems in the inner ear or auditory nerve. This type of hearing loss cannot be fixed. With this type of loss, a person may not be able to hear his or her own voice or other sounds.

- A **mixed** loss means that the hearing loss is conductive and sensorineural. This type of loss is different from person to person.

The Nature of Hearing Loss

The **nature** of a hearing loss means how long it will last and the cause. A hearing loss can be temporary, permanent, fluctuating, or degenerative (it get worse over time).

- You can get a **temporary** hearing loss at any time. It can last a day or a few years. These hearing losses are caused by blows to the head, being around loud noises, sickness, or ear infections.

- You can be born with a **permanent** hearing loss or get one during your life. This type of loss never goes away. You can inherit a permanent loss or an accident can cause one.

- **Fluctuating** hearing losses change from day to day. You can get them at any time. A person who has a fluctuating hearing loss will not be able to hear the same thing from day to day.

- A **degenerative** hearing loss gets worse over time. Sometimes the change is fast and sometimes it is slow. This type of hearing loss can also be hereditary or caused by an illness or accident.

Age of Onset

The **age of onset** refers to when the loss happed. There are three categories describing the age of onset: congenital, acquired/adventitious, and presbycusis.

- A **congenital** hearing loss means a person's hearing loss was present at birth. People who have a congenital loss have the hardest time learning speech and spoken language.

- An **acquired/adventitious** hearing loss can happen or develop at any time during a person's life. Some people lose their hearing as young children, some as teenagers, and many as adults. This type of hearing loss can be caused by heredity, illness, or accident. The extent to which the hearing loss affects the person depends on age, stage of development, and personality. In most cases, younger people have more difficulties than older people.

- **Presbycusis** is the word used to describe a hearing loss that occurs as people grow old. Sometimes it is hard for older people to accept that they have lost their hearing and to wear hearing aids.

Adapted from: Bridges Beyond Sound, Jensema, Corinne K., 1996.

Degree of Hearing Loss

The **degree** (severity) of hearing loss means how loud a sound has to be for a person to hear it. The **hearing threshold** is the quietest sound a person can hear at the frequencies measured by the audiogram. There are six categories of severity of loss: normal, slight, mild, moderate, severe, and profound.

- People who have **normal** hearing have a hearing threshold (loudness level) of 0 dB-15 dB. At this level, an individual can hear all speech sounds.

- People with a **slight** hearing loss have a hearing threshold of 15 dB-25 dB. At this level, an individual can hear all vowel sounds but may not hear some unvoiced consonants, such as *f, t, p, k, ch, h,* and/or *s.* Children with this amount of loss may have some problems learning to speak.

- People with a **mild** hearing loss have a hearing threshold of 25dB-40 dB. At this level, a person can hear only some vowel sounds and loud voiced consonants, such as l, m, and/or n. This amount of loss can cause problems learning speech and language, paying attention, and understanding what other people say.

- People with a **moderate** hearing loss have a hearing threshold of 40 dB-65 dB. At this level, a person cannot hear most speech sounds at a normal conversational level. This amount of loss also can cause problems with learning speech and language, paying attention, and understanding what other people say.

- People with a **severe** hearing loss have a hearing threshold of 65 dB-95 dB. At this level, an individual can hear no speech sounds without a hearing aid. This kind of hearing loss may cause severe problems with learning language, doing well in school, and paying attention.

- People with a **profound** hearing loss have a hearing threshold of 95 dB or higher. (The threshold of pain is 130 dB; and sound at this level is painful to a person with normal hearing.) At this level, a person hears no speech sounds and few environmental sounds. This kind of loss may cause serious problems with learning language, doing schoolwork, and paying attention.

Effects of Hearing Loss

Hearing impairments are not easy to understand. People who have hearing impairments have complicated problems when communicating. The most important thing to remember is that having a hearing loss makes understanding spoken language very difficult. Many people who have hearing impairments cannot hear others speak or hear their own voices.

A hearing loss also affects a person's ability to learn spoken language. A baby with a hearing loss will have more problems learning language than an adult who becomes deaf.

Factors Associated with Hearing Loss in Very Young Children

Hearing Loss Factors

- Family history
- Prenatal exposure to maternal infections (toxoplasmosis, syphilis, rubella, cytomegalovirus, herpes)
- Prematurity
- Hypoxia
- Cleft lip and palate
- Craniofacial anomalies (malformations of pinna, ear canal, absent philtrum, low hairline)
- Hyperbilirubinemia level requiring transfusion
- APGAR score of 3 or less at 5 minutes after birth
- Prolonged use of ototoxic medications
- Prolonged medical ventilation (>10 days)
- Certain syndromes (e.g., CHARGE, Down, Fetal Alcohol, Goldenhar, Hurler, Norrie, Refsum, Trisomy 13, Waardenburg)
- Childhood infections (bacterial meningitis, mumps, measles)
- Head trauma
- Cerebral palsy
- Certain neurodegenerative disorders (e.g., neurofibromatosis, Tay-Sach, Niemann-Pick disease)

Joint Committee on Infant Hearing, 1991; Northern & Downs, 1991

High Risk Signs of Hearing Loss

Atypical appearance of the face or ears:

- ❑ Cleft lip and palate
- ❑ Malformations of the head or neck
- ❑ Malformations of the ears including lack of opening at ear canal (atresia)
- ❑ Frequent earaches or ear infections (otitis media)
- ❑ Discharge from the ears

Atypical Listening Behaviors:

- ❑ Has few or inconsistent responses to sounds
- ❑ Does not seem to listen
- ❑ Does not respond to caregivers calling his name
- ❑ Shows a preference for certain types of sounds

Atypical Vocal Development:

- ❑ Has limited vocalizations
- ❑ Has abnormalities in voice, intonation, or articulation
- ❑ Shows a delay in language development

Other Behaviors:

- ❑ Pulls on ears or puts hands over ears
- ❑ Breathes through mouth
- ❑ Cocks head to one side

Chen, 1990; Gatty, 1996; Fewell, 1983; Joint Committee on Infant Hearing, 1991

Otitis Media

What it is, What Causes it, It's Effects, and Treatment

What it is

Otitis media is one of the most common problems for which a child is seen by a physician. It is an inflammation of the middle ear space and is usually accompanied by fluid build-up. This fluid may or may not be infected. This buildup of fluid in the middle ear space restricts the movement of the eardrum. If the eardrum does not move freely, a hearing loss occurs. This can be compared to plugging your ear with your finger. The child with otitis media does not always show signs such as fever, irritability, tender ears, reddened ears, etc.

There are three general categories of otitis media:

1. **Otitis media without effusion (fluid)**
2. **Otitis media with effusion**
3. **Otitis media with perforation (hole in eardrum)**

What causes it?

The eustachian tube is the tube connecting the middle ear and the upper part of the nasal passages. Eustachian tube dysfunction is a significant factor in the development of otitis media. The purpose of the Eustachian tube is to equalize the pressure on both sides of the eardrum and provide ventilation to the middle ear space. When it does not work properly, the air is trapped in the middle ear space. This air is absorbed and fluid results.

Age plays a factor in the development of otitis media. At birth, the eustachian tube is in a horizontal position and it is wider and shorter. During the first few years of life it begins to extend downward allowing for easier drainage. Therefore, otitis media is most common during the first 2 years of life. Inflammation of the nasal end of the eustachian tube may produce swelling, thus impairing its function. Such inflammation may result from viral or bacterial infection (a cold) or chemical irritation (tobacco smoke, chlorinated pool water).

Allergies have also been known to cause otitis media. Some foods that commonly cause allergic reactions in young children include milk, wheat, eggs, corn, yeast peanuts, soybean, sugar and citrus.

Skeletal changes play an important part in the development of otitis media. Children with Down syndrome, cranial base anomalies (cleft palate, atresia, adenoid problems, etc.) and craniofacial syndromes (Treacher-Collins, Crouzon's or CHARGE) have a high incidence of otitis media. Children with upper respiratory problems are also more prone to develop otitis media. Family history, climate, and dietary reasons have also been linked to recurring otitis media.

Otitis Media

What the effects are

Recurring otitis media has been shown to have a direct impact on a child's speech, language, and academic development. If a hearing loss is present due to otitis media, a child will experience difficulties in attending and following both formal communication (classroom instruction), and incidental communication (conversation that is ongoing though out the day).

Amplification is not prescribed for the child with otitis media because in the majority of cases, the child's hearing returns to normal after the otitis media is cleared. However, more severe cases, especially when prolonged or left untreated, may result in a perforated eardrum, scar tissue on the eardrum and even a permanent hearing loss. Other, more serious, complications that could occur include facial nerve paralysis, meningitis or brain abscess.

Children that have a known sensorineural hearing loss may experience a decrease in their usable hearing and in some cases, these children may not be able to wear their hearing aids during an episode of otitis media. The ear must be allowed to breathe and drain. If an earmold or hearing aid is in the ear, increased condensation may occur or the fluid may drain into the hearing aid causing internal damage to the amplifier. Some children may experience such pain that they cannot tolerate the earmold or hearing aid in their ear.

Treatment

Treatment for otitis media varies according to the severity, the occurrence, and the age of the child. If the otitis media is found to be infectious, antibiotics are usually recommended. Clearance of the liquid is imperative. If the child has a history of recurring otitis media the doctor may choose to perform a myringotomy and place a tympanostomy tube in the ear drum. This is a common procedure in young children, which entails the doctor making an incision in the eardrum to drain the fluid. A small tube is then placed in the incision. This tube allows for the air pressure to be equalized on both sides. It also assists in keeping the middle ear space well ventilated.

If you suspect your child may be prone to otitis media consult your physician, pediatrician, or ear, nose and throat specialist.

From California Deaf-Blind Services, Fact Sheet 4-10-97

Issues Brief

Effective Education Summit II

April 14, 1999

Pierre, South Dakota

South Dakota Statewide Systems Change

Roots and Wings

All children deserve an education that is firmly rooted in natural learning environments and inclusive schooling practices. All children deserve a future that is propelled under wings sprouted from effective education. To give our children both roots and wings, all individuals with an interest in the education of our children must embrace a shared vision of effective education in inclusive schools and a shared commitment to achieve it.

"There are only two lasting bequests we can hope to give our children. One of these is roots; the other wings."
~Hodding Carter

"What are the essential characteristics of effective education in inclusive schools?" and "How do we make effective education in inclusive schools a statewide reality in South Dakota?" During the last three years, these questions and their answers have evolved over two national and two state dialogues. Initial conversations occurred among representatives of all statewide systems change projects and the US Department of Education. Based on systems change in over two-thirds of our states, essential characteristics of inclusive schooling and effective strategies for inclusive school reform were identified. In October, 1998, South Dakota's Statewide Systems Change and Deaf/Blind Project brought this dialogue to South Dakota in "Effective Education Summit I." A critical assumption embraced by participants of "Summit I" was that inclusive schooling is an important but shortsighted goal. For broad scale reform to occur, effective education in inclusive schools by all educators for all students must become a reality.

In April, 1999, participants of "Summit II" broadened the responsibility for effective education in inclusive schools from educators to "the education community" – that is, all individuals with an interest in the education of our children. This includes families, students, educators, administrators, related service providers, paraprofessionals, school boards, agencies, organizations, institutes of higher education, businesses, churches, elders, and others.

Secondly, participants refined and prioritized the framework of essential characteristics for effective education in inclusive schools. Overall, it was agreed that philosophical commitment, and not resources, is what it takes to realize effective education in inclusive schools. More specifically, "belief in inclusive education as a critical component of effective education" was prioritized as the most essential characteristic.

Finally, participants of "Effective Education Summit II" created an action plan for statewide systems change that will promote effective education in inclusive schools in South Dakota. Thirty-one action steps are advanced. Agents of change and possible methods are proposed. A more detailed explanation of each action step as originally proposed by individual participants is available in the "Proceedings Document for Effective Education Summit II." Again, one notes that philosophy and commitment are at the core of the change agenda. Out of our hearts and minds must flow action.

"He who would leap high must take a long run."
~Proverb

Essential Characteristics that Promote Inclusive Schooling Practices

The mission and vision statement expresses a belief that inclusive education is a critical component of effective education.

A philosophy of inclusion exists that is student centered in all decisions.

Effective education, through the use of inclusive practices, strives for increased student achievement measured by a variety of assessments.

Rationale: Consensus emerging around the need for and/or benefit of inclusion

Diversity is honored with the understanding that all students can learn.

Learner diversity is accommodated with appropriate resources and instructional practices.

Programmatic consistency exists for all students transitioning from one setting to another.

The role of educators is to work cohesively to support all students.

Students with disabilities are members of their age-appropriate classrooms.

A common planning time to collaborate and network is established for teachers.

Scope: Structures, policies and/or are practices becoming more inclusive; supports and resources follow or are part of policies and/or practices

Systemic school reform is ongoing and dynamic.

Strategic action planning is an continuos and dynamic process to guide the systems change.

Pace: Rate and process of change fit the context

Professional development is viewed as an ongoing need and time is available for all staff to meet on a regular basis.

A clearly defined vision exists for ongoing professional development at all levels and sustains systems systematic reform.

Sufficient and common planning time is established for all instructional staff.

Resources: Adequate resources (e.g., release time, technical assistance time) exist to support inclusion

Essential Characteristics, continued

Commitment: Commitment to inclusion is broad based

The community assumes responsibility for individual needs of all students.

The education community wants for and advocates for involvement in the academic planning for all students.

Everyone builds on positive success stories.

Families & Students: Families and students involved in discussions and planning

The education community actively supports practices, policies, and procedures that foster inclusive education.

Meaningful partnerships with students and families involve taking responsibility for planning, decision making, problem solving of school and classroom issues.

Families and students are actively involved in local school restructuring teams or task forces.

District and building-based decision making teams directly involve students and families.

Leadership: Evidence exists of administrative support at the building, district, and/or state levelfor restructuring, reform and inclusive practices

School leadership sets expectations, supplies support, and assesses whether expectations are met.

Skills that enhance an inclusive approach to education (e.g., flexibility, multiple areas of endorsement) are emphasized when hiring staff.

There is a sense of trust between all staff, and members of the education community.

Photos courtesy of SSD Coalition

Essential Characteristics, continued

The community is involved in professional development partnerships that merge general and special education at the preservice and inservice levels.

The education community supports and models reform initiatives which ensure that best practices are a high priority.

Schools engage in a continuous comprehensive planning and improvement process.

Relationship to Other Initiatives: Inclusion viewed within the context of other instructional and organizational agendas of the school

Collaboration occurs between the state education agency and institutes of higher education preservice and accreditation standards.

The education community collaborates to meet all the needs of all students in all settings.

The community works collaboratively to develop the vision for effective education for all students.

Ongoing communication among all staff facilitates a better understanding and more successful implementation of changes that promote effective practices.

Schools promote teaming and collaboration to enable adults to see their role in the change process.

Professional Staff Collaboration: Structures, time and attitudes promote learning

Promising Strategies that Promote Effective Education in Inclusive Schools

Philosophy

- Develop a state mission statement that honors diversity and promotes effective education in inclusive settings.
- Develop a local mission statement that honors diversity, is positive, and sets high expectations for all students.
- Promote the philosophy of inclusion.
- Promote teaching and learning philosophies that promote effective education in inclusive settings.

Commitment

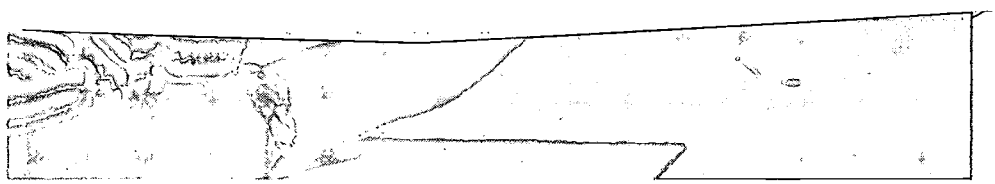
- Assure commitment and understanding for educators in serving all students.
- Assure equality in educational opportunities for all students.

Leadership

- Provide financial, human and moral support for leadership teams to implement inclusionary practices.
- Express clear expectations from state and local leadership. Follow-up is performed, not just intended.
- Engage the educational community in decision making at the local level.
- Encourage state and local educational leaders to support inclusive education.
- Adopt ongoing staff evaluation procedures that assess the staff's incorporation of effective inclusionary practices for all, based on assessment of staff needs.

Community

- Ensure leadership in the educational community that promotes inclusive education.
- Educate communities on the characteristics of effective schools.
- Take the fear out of inclusion.



Photos courtesy of SD Tourism

Promising Strategies, continued

Restructuring

- Incorporate effective schools/inclusion in a revised state monitoring/accountability system.
- Develop local plans of action for effective change.
- Align state and local school standards.
- Promote interagency involvement at all levels ages and agencies statewide.
- Restructure the bureaucracy of the South Dakota system of education so that change is enabled that reflects the powerful thought and accurate research of summits. Replace inertia with "future choice" practices and strategies.
- Merge general and special education systems into one system for kid's education. Staff support each other and kids.

Professional Development

- Provide preservice training for all educators that addresses effective education in inclusive settings.
- Develop state standards that address recertification requirements to include courses that promote effective education in inclusive settings.
- Promote/encourage school districts to provide inservice activities each year on inclusionary practices.
- Create a menu of opportunities which provide professional development and support effective education with inclusive practices.
- Provide intensive training for school boards with built-in accountability (through qualifications, recall or censure as some options) to ensure support for school change/ restructuring.

Implementation

- Plan and schedule time for common professional staff collaboration.
- Restructure school schedule/calendar to support staff development and collaboration.
- Promote increased student achievement and high expectations.
- Accommodate learning styles of all students.
- Promote communication about best practices.
- Focus technology availability, training, accentuation and support at both local and state levels.

South Dakota Systems Change and
Deaf/Blind Project
121 West Dakota
Pierre, SD 57501

Hosted by:
South Dakota Statewide Systems Change
South Dakota Deaf/Blind Project
Phylis Graney
1-800-873-3493
Graney@dtgnet.com

Facilitated by:
The Compact
Interactive Management & Design Consultants
Facilitating solutions to contemporary problems
Rhonda Beach Tyree, Senior Partner
569 Presidential Way
Delaware, Ohio 43015
740-363-0126

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