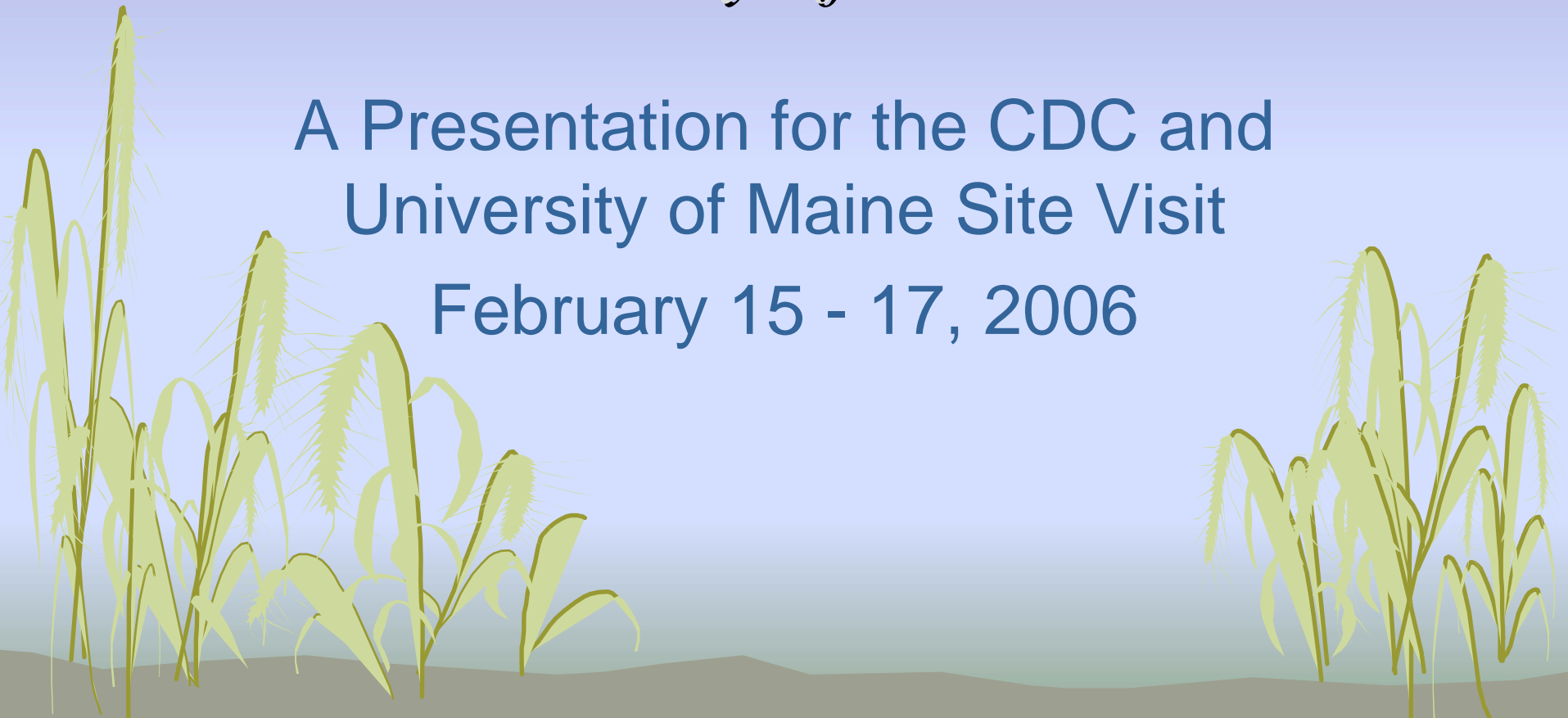


*EHDI Profile for the
Territory of GUAM*

A Presentation for the CDC and
University of Maine Site Visit
February 15 - 17, 2006



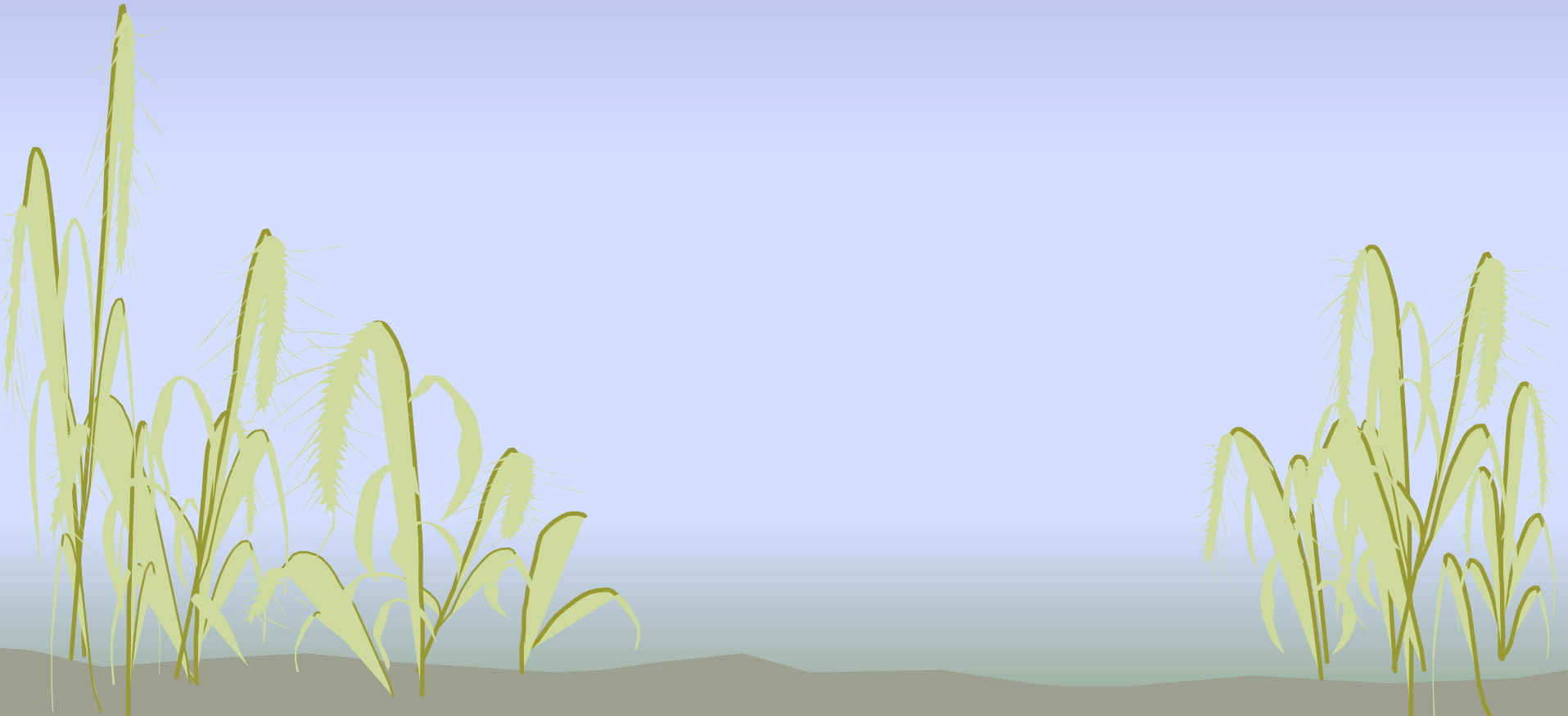
Guam's Early Hearing Detection and Intervention Project

Universal Newborn Hearing Screening
on Guam

Video Presentation



I. Program Information



I. Program Information

In what agency/department is the EHDI program located?

Guam EHDI is located at the University of Guam, Center for Excellence in Developmental Disabilities Education, Research, and Service. (Guam CEDDERS) Dean's Circle. House #24 houses the MCHB initiative for services and resources and House #26 houses the database system.

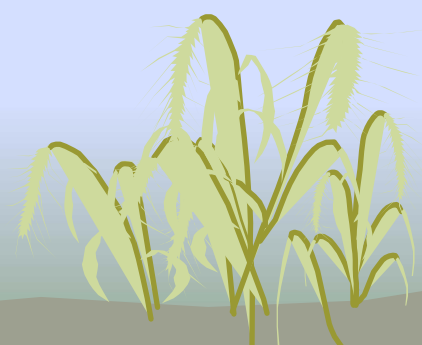


Program Information

Who are the primary contacts? (CDC & HRSA)-
*For CDC, Dr. Velma Sablan and for HRSA,
Elaine Eclavea*

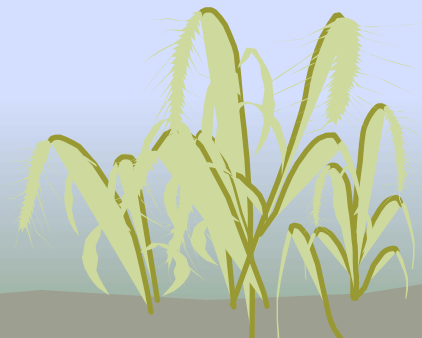
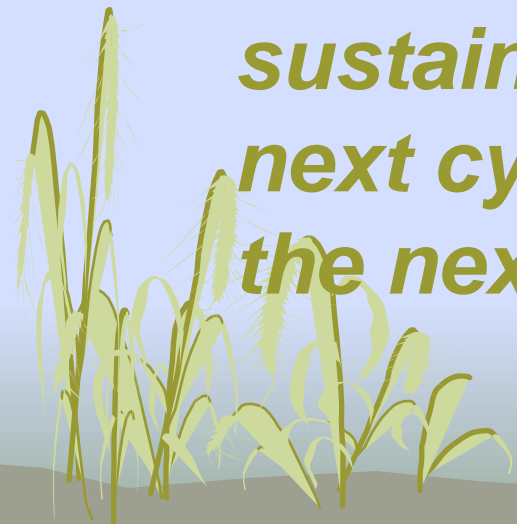
Is there a State EHDI website? No, not yet.
We anticipate having a website by 2007.

Is there a State EHDI Advisory Committee?
*Yes, the Guam EHDI Advisory Council has
23 members which include parents,
representatives from the birthing sites,
physicians, early intervention, and
consumer advocates.*



Program Information

What funding does the Guam EHDI program have in addition to CDC funds?
At present, only the CDC and HRSA grants fund UNHS activities, however Guam is looking into local sustainability plans as part of the next cycle of goals and objectives for the next 3 years.



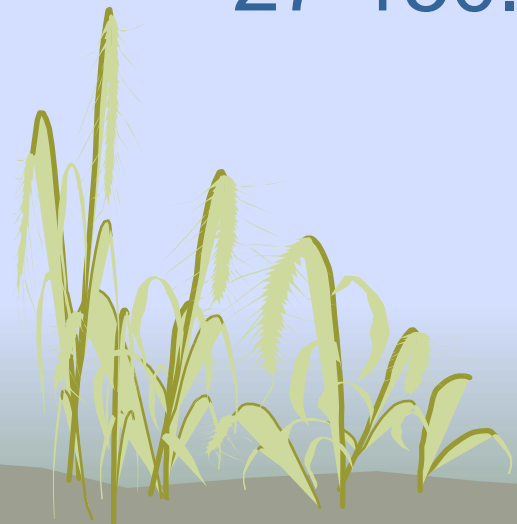
II. Hearing Screening of Newborns

Guam's Progress from 2003-2005



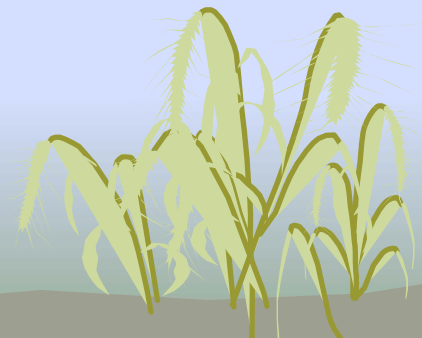
Does Guam have written guidelines/protocols for performing hearing screening?

- Yes, currently Guam has guidelines/protocol. However, we are currently working with DPHSS in promulgating the rules and regulations required by PL 27-150.



Is newborn hearing screening part of the hospital's standard of care package? Is informed consent required?

- Yes, newborn hearing screening is part of the birthing sites' standard of care package.
- Yes, informed consent is required at GMHA until the standard of care is formally approved by the Hospital Board.



What screening technology do you use?

- Guam uses the Grayson-Stadler GSI-70 for OAE screening.



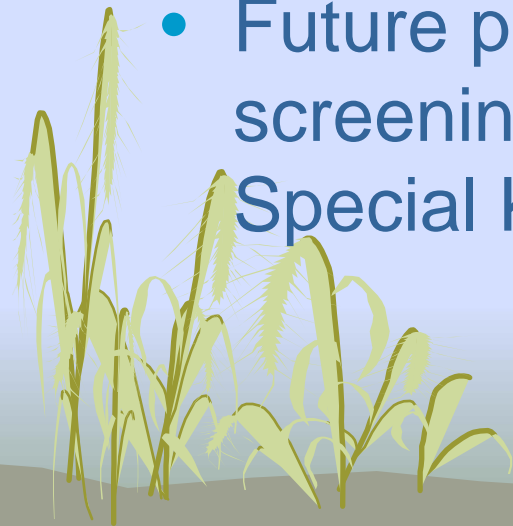
Who does the screening in the hospital?

- Nurses and nurse's aides perform the screening at the birthing sites.



Who does the out-patient screening?

- Out-patient screening is done by the Guam EHDI Facilitator, Bill Toves and Screener, Vicky Ritter.
- At Sagua Managu Birthing Center out-patient is done by nurses and nurse aides.
- Future plans are to conduct out-patient screening at Department of Public Health Special Kids Clinic .

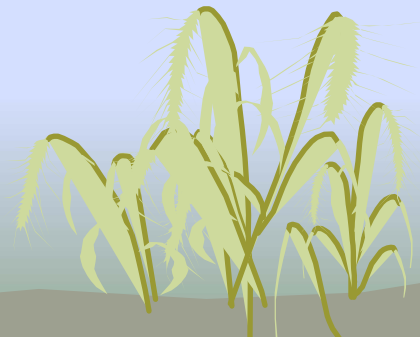
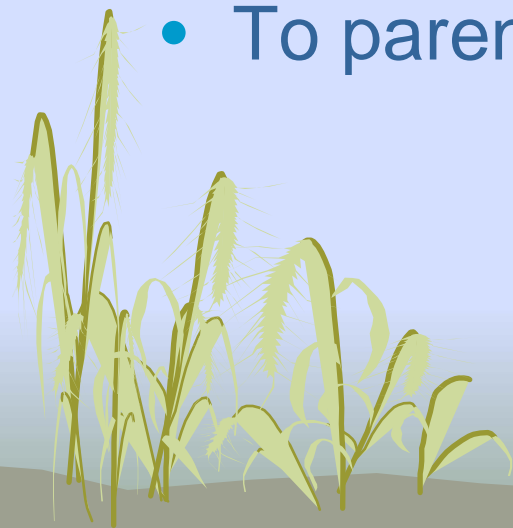


If a baby does not pass the screening, what procedures are followed?

- Prior to discharge, the parents are given a rescreen appointment to return for a 2nd screening at the Sagua Managu Birthing Center or at UOG PEDS.

To whom is it reported?

- To parents and pediatrician.



Who is responsible for setting up the appointment for rescreen?

- Birthing sites schedule the rescreen appointments.

How soon does the baby usually come back?

- Infants usually return for a rescreen in 2 weeks.



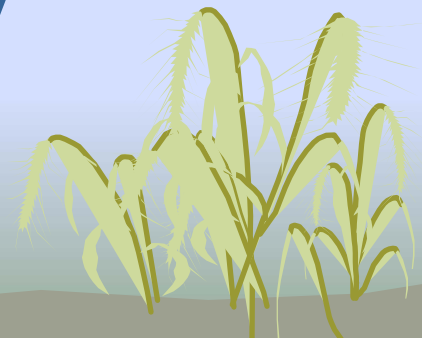
What equipment is used for out-patient screening?

- The Grayson-Stadler GSI-70 is the equipment used for out-patient screening.



Do you have any procedures/policies in place to ensure infants born outside of a hospital receive a hearing screening?

- There have been no incidence of out of hospital births at this time.
- Guam does not have any procedures/policies in place to ensure infants born outside the hospital receive a hearing screening.
- Contact with babies born outside the hospital will come from “Well Baby Clinics” (pediatrician referral) or self referral by parents.



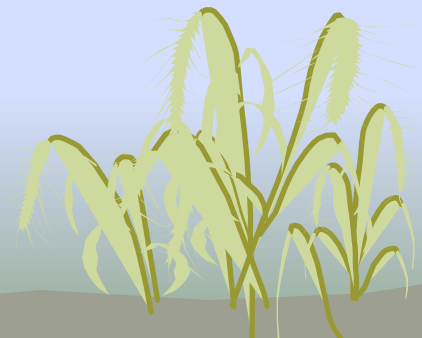
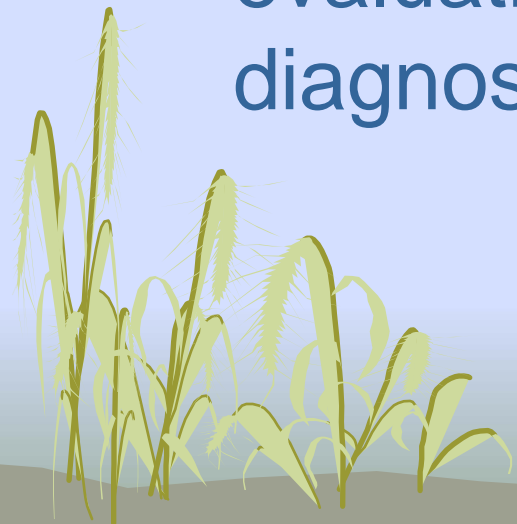
What are the key issues facing your state/territory that affect screening infants for hearing loss?

- High false positive rates prior to discharge (initial screen)
- Loss to follow-up: Return for 2nd screen, return of infants with high risk factors, and return of infants with possible late onset for hearing loss.
- Refusal for early intervention services is another challenge Guam needs to continue to address .



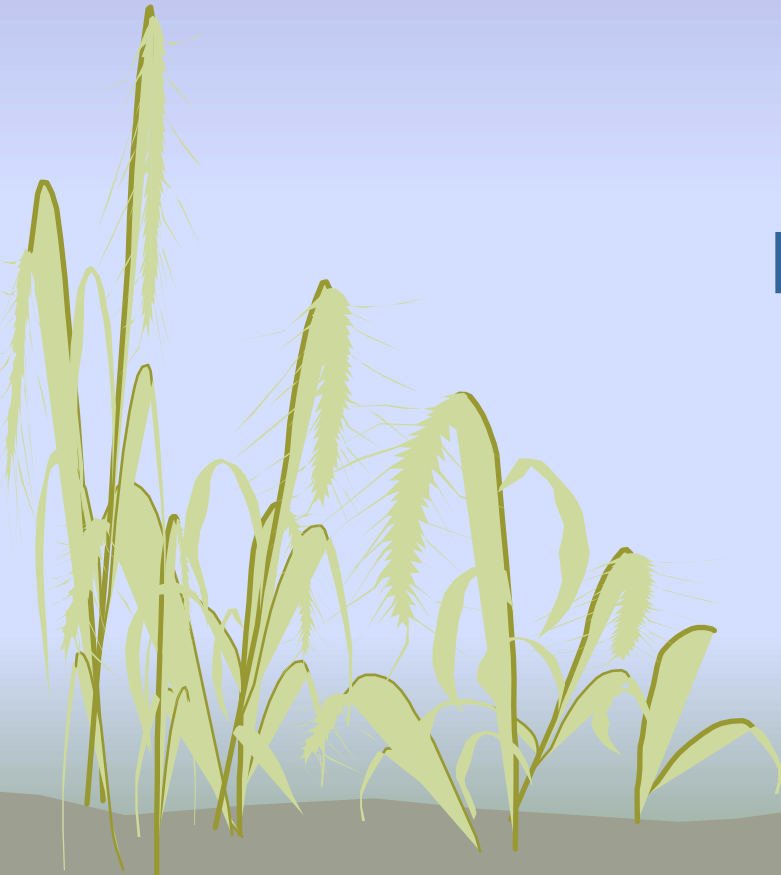
What are the key issues facing Guam that affect screening infants for hearing loss?

- The audiological services (evaluation and follow-up)
- The reluctance of some families in agreeing with the audiological evaluation results or a hearing loss diagnosis of their child is a concern.



III. Diagnostic Evaluations

Follow Up



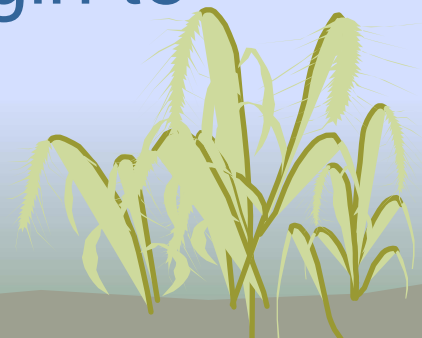
Does the Guam EHDI program have required or recommended audiological assessment protocols or guidelines for personnel, facilities, and equipment?

- Guam EHDI does have required audiological assessment protocol for personnel, facilities, and equipment.



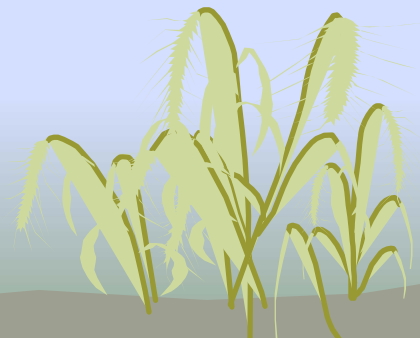
Is there a Guam list of pediatric audiologists or diagnostic centers?

- Guam has no pediatric audiologist on island.
- Diagnosis is done at Audiological Associates, the only available audiologist on Guam for infants 0 to 3 years old. However, GPSS has agreed to have the GPSS Audiologist begin to assess infants and toddlers.



Does the Guam EHDI program have medical assessment protocols or guidelines?

- Currently Guam EHDI does not have medical assessment protocols or guidelines.
- Infants with known medical conditions are referred to the Guam Early Intervention System. If needed, a full medical assessment is conducted as part of the child's Individualized Family Service Plan.

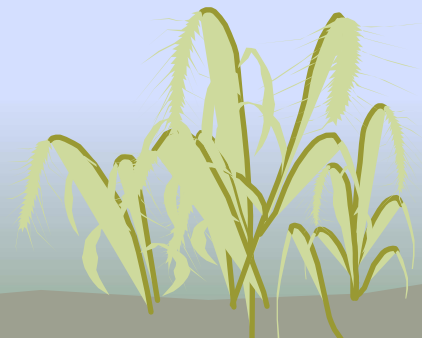


When an infant is identified with a hearing loss, to whom does the audiologist send a report?

- Copies of the audiological report are provided to the family, pediatrician, and the Guam EHDI Project.

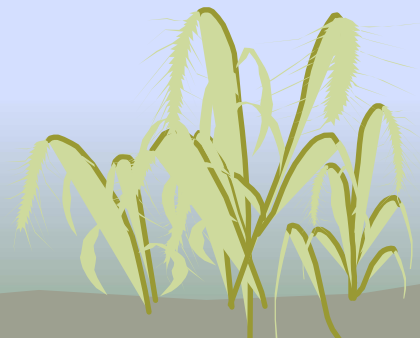
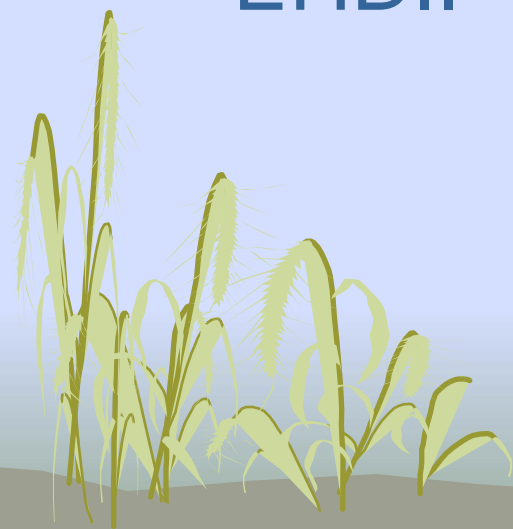
Who makes the referral to Early Intervention?

- Most often the Guam EHDI Project makes the referral.

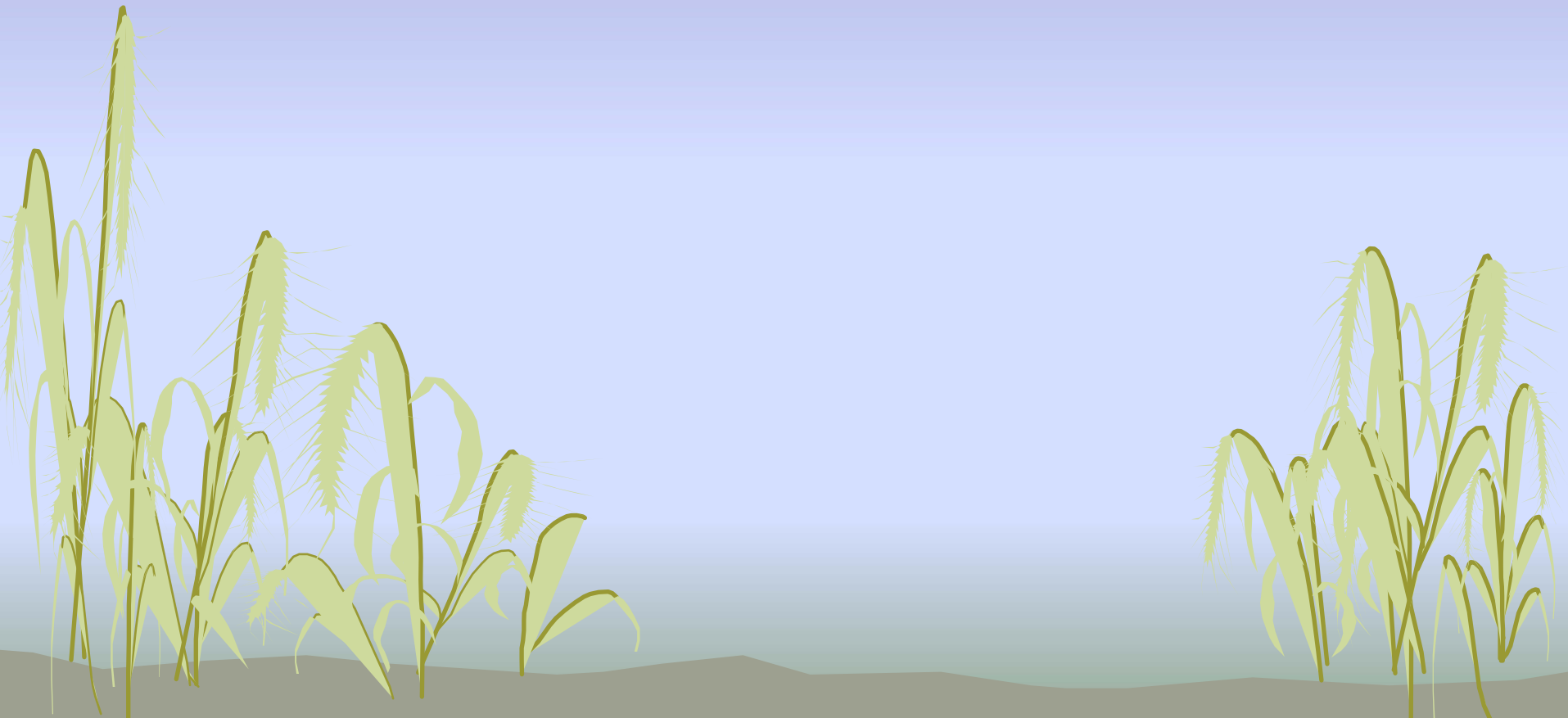


Are reports sent for all infants and children or just those who are identified with a hearing loss? How are these reports sent?

- Audiological reports of infants with hearing loss are sent to the Guam EHDI Project.
- These reports are hand carried to Guam EHDI.



IV. Early Intervention



Who is the lead agency for Early Intervention Services?

- Guam Public School System is currently the Lead Agency for Part C services.
- For active military families services may be provide by the Education and Developmental Intervention Services – under of U.S. Naval Station - Pediatric Clinic (Department Head Dr. Whitfield (Dr. Andrea Rahn Supervisor)



What is the eligibility criteria for children with hearing loss to receive early intervention through Part C?

- **GEIS**

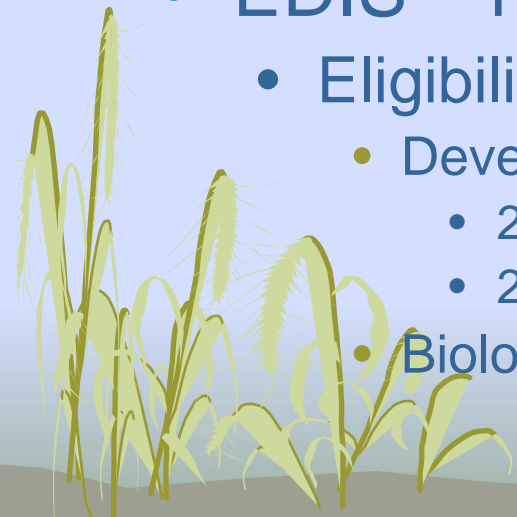
- 4 Eligibility criteria

- Establish Risk (known mental or physical condition)
 - Biological At Risk
 - Environmentally At Risk
 - Developmental Delay

- **EDIS – must qualify under DODEA**

- Eligibility Criteria

- Developmental Delay
 - 20% in 2 areas
 - 25% in one area
 - Biological Risk or Established Condition



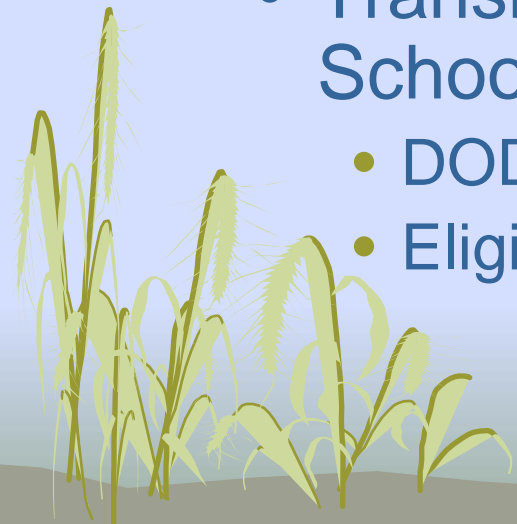
Are infants with mild and unilateral hearing loss eligible?

- Yes, if they have any loss they are eligible for early intervention services.



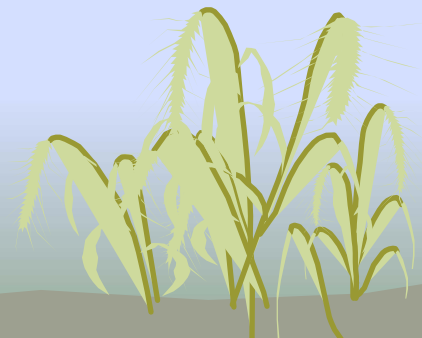
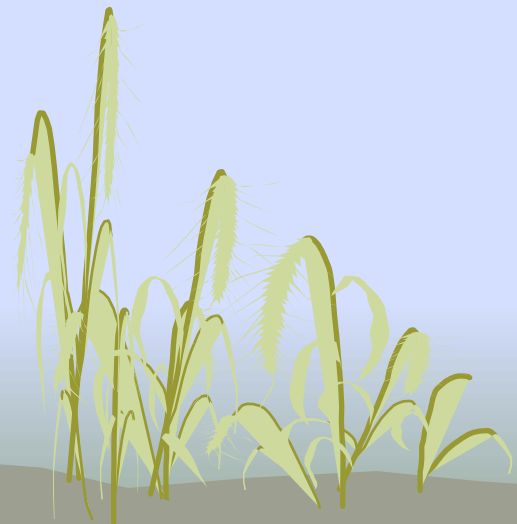
When a child transitions to Preschool, does the eligibility criteria change?

- YES from GPSS Part B to GEIS
 - Child's eligibility is re-determined for Part B services under IDEA and is part of the child's Transition Plan.
- EDIS
 - Transition from Preschool to DODEA Schools
 - DODEA does further evaluation if needed.
 - Eligibility changes to follow Part B.



Does the EI program report enrollment and intervention information back to the Guam EHDI program?

- Collaborative relationships and monthly staffing between both programs have been working.
 - Guam EHDI monitors and tracks all infants referred to GEIS.



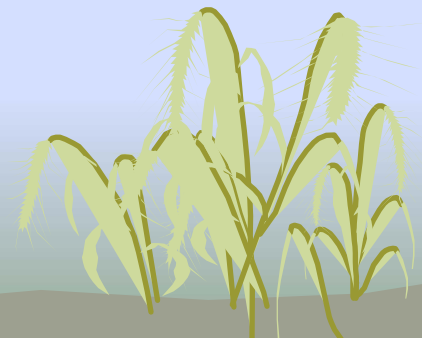
Does the Guam EHDI program receive information/reports from the preschool programs?

- At this point, Guam EHDI does not receive information/reports from the preschool programs.



Does the Guam EHDI program track the type and intensity of EI services received by infants, children, and their families? To what age do you track children identified with hearing loss?

- Guam EHDI tracks the type and intensity of EI services received by infants, children, and their families through the database and periodic meetings with EI.
- Children with hearing loss are tracked by the Guam EHDI project until they transition to Part B at age 3.



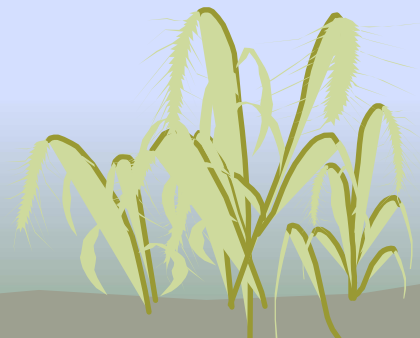
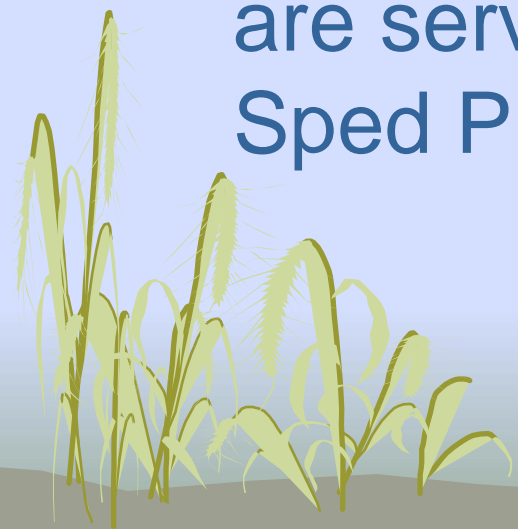
What kind of EI services are available to the families of children, birth to 3, with hearing loss on Guam? Where are the children served? How often?

- Home services may range from 1 x a week to once every 3 months depending on the child.
- EI services may include the following: home visits, audiological services, transportation, family counseling, etc.
- Children are served either at home or in the setting the parent's choose. (grandparents, extended family, child care)



What kind of services are available to preschool children with hearing loss on Guam? Where are the children served?

- Speech and Language Services
- Specially designed instruction
- Preschool Children with hearing loss are served in Head Start Centers or Sped Preschool Classes.

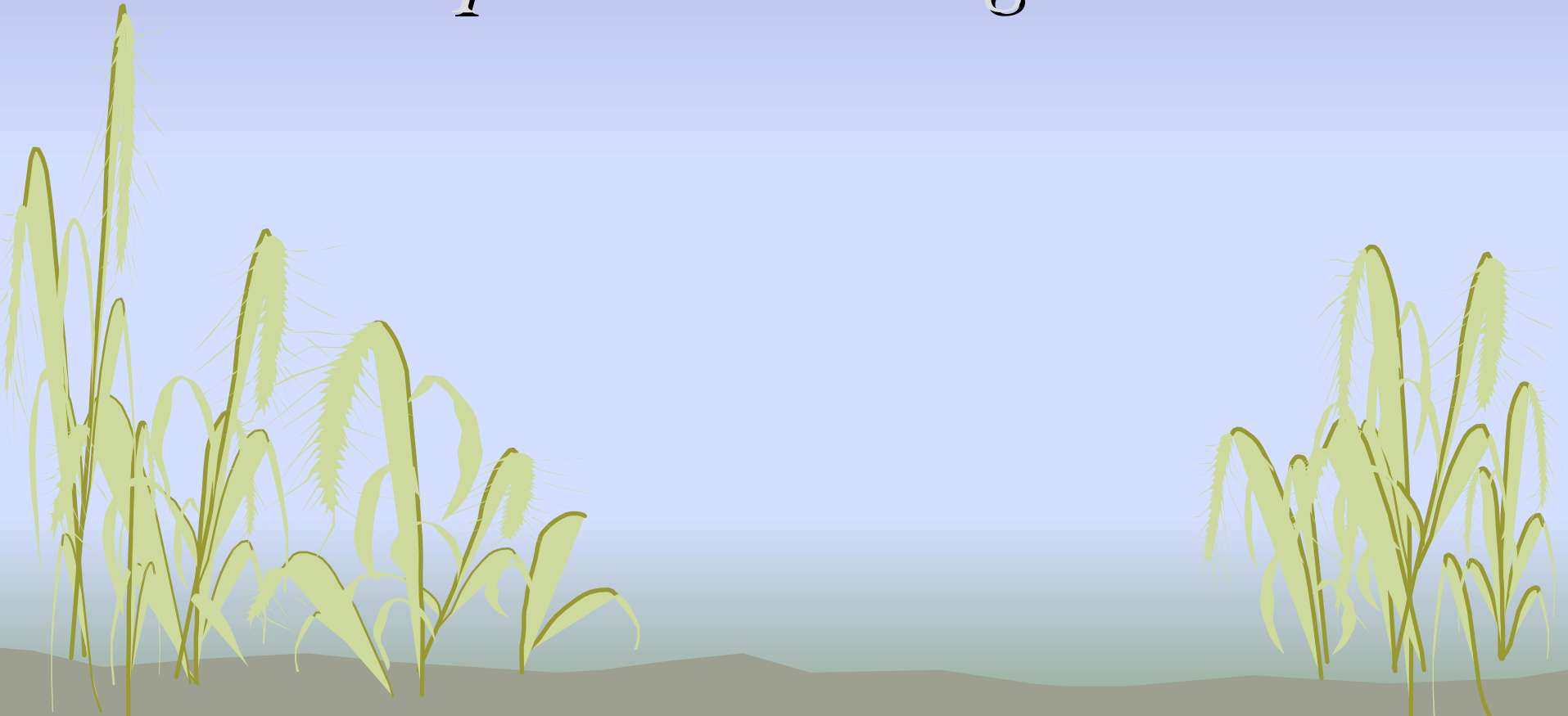


In addition to Part C, what programs are available for infants and children with hearing loss?

- Families may access the Guam EHDI parent to parent support group.
- Resource materials from the Guam EHDI Project.
- Guam Rotary Clubs



*V. Late Onset, Progressive , and
Acquired Hearing Loss*



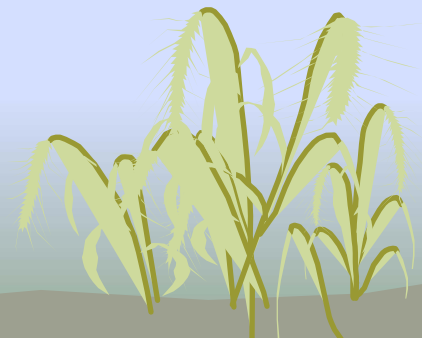
Does the EHDI program on Guam collect data on known risk factors? If yes, are the JCIH risk indicators used?

- Guam does collect data on known risk factors that are similar to the JCIH risk indicators.



What follow-up procedures do you use for infants with risk factors for hearing loss?

- Infants with risk factors are rescreened at 6 months of age.
- If they pass the rescreen, no further screening is required.
- If they fail the rescreen, the infant is referred to Guam Early Intervention System which includes a full audiological evaluation.



Are hearing screening programs available for children between 1 and 6 years of age?

- Yes, there are a variety of mechanisms in place for a child to receive a hearing screening.

If yes, who sponsors these programs?

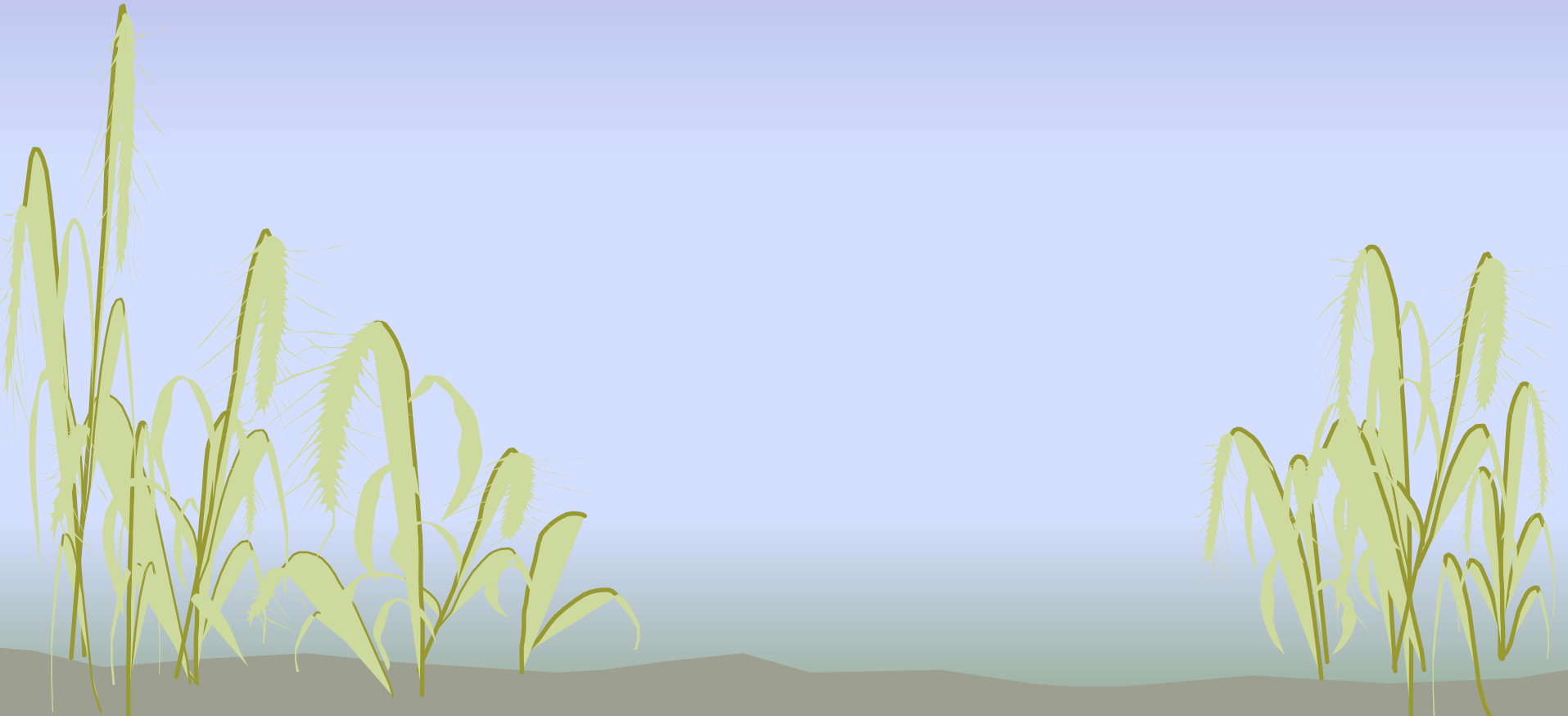
- Guam Public School System, DPHSS, GEIS, Head Start

Are results reported to the EHDI program?

- At the present time, results are not forwarded to the Guam EHDI.

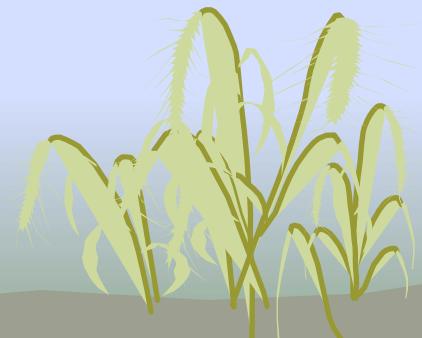


VI. Medical Home



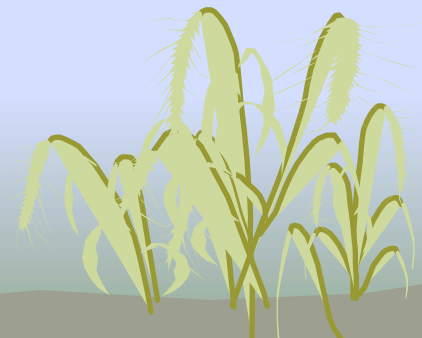
How does Guam's surveillance system integrate with the medical home to ensure tracking and follow-up?

- At the present time, the Guam EHDI surveillance system does not integrate with the medical home. Plans are being developed to expand surveillance to include this integration. Currently, tracking and surveillance is ensured through collaboration with early intervention.

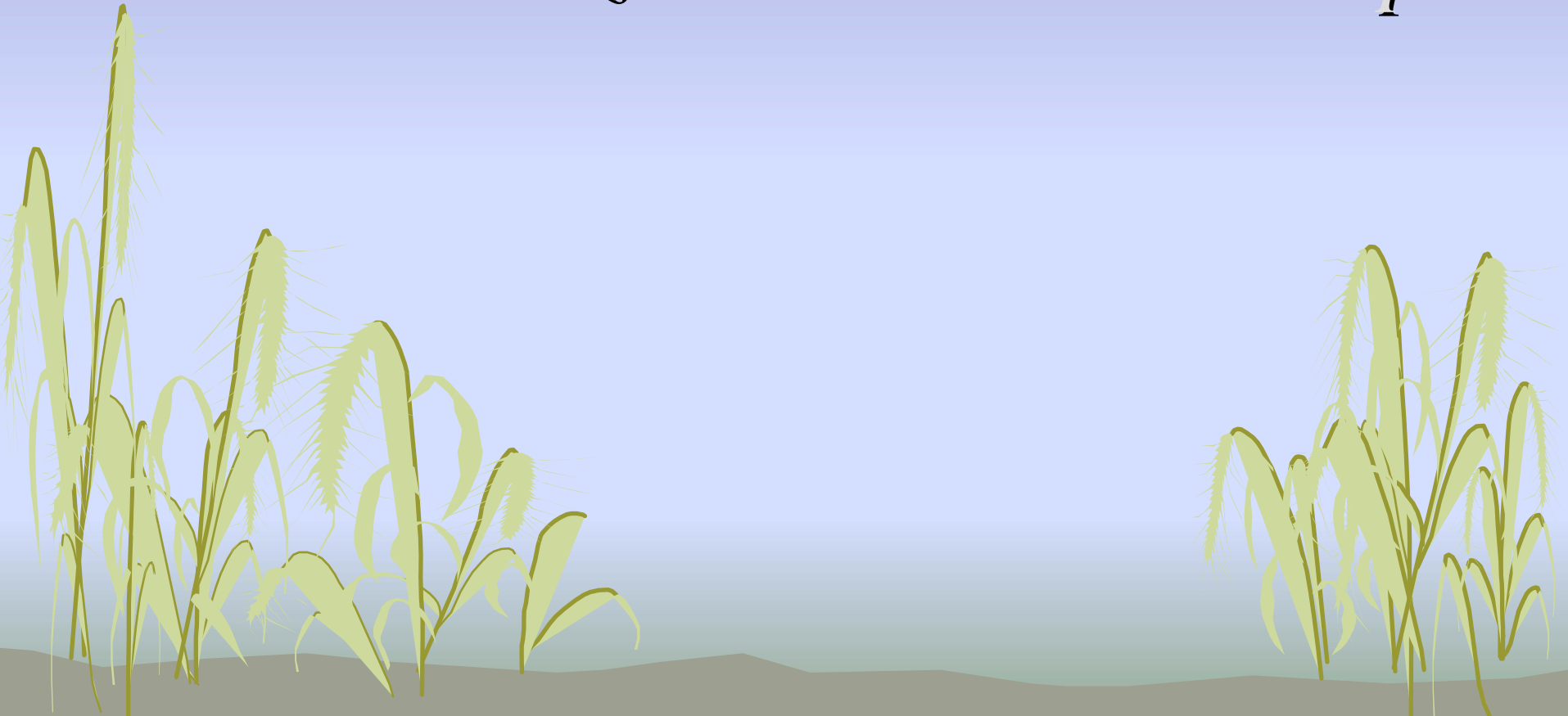


Do you have outreach efforts to make medical homes aware of the Guam EHDI process? If so, what are these efforts and what groups do you target?

- Yes, Guam EHDI provides training on the medical home concept for parents and co-sponsors with other agencies the Medical Home Conference.
- Groups targeted include: physicians, parents, service providers, advocates, and the community at large.

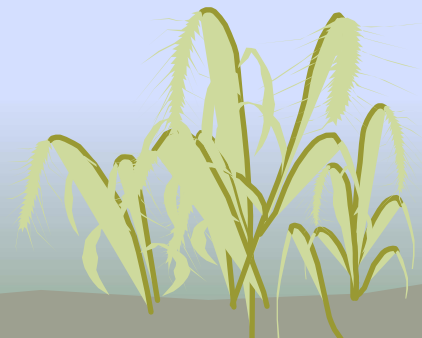


*VII. Tracking & Surveillance
that Minimizes Loss to Follow-up*



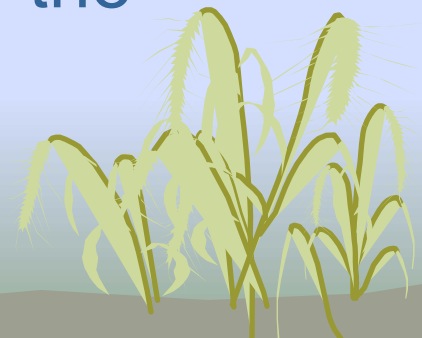
What software and database system does the Guam EHDI program use to track hearing screening, diagnostic and intervention data?

- Guam initiated data collection on FileMaker Pro 7 from the beginning of the UNHS effort to February 2006.
- With CDC support, Guam negotiated with the University of Maine and restructured the database system to collect other data needed and to move to a system that would offer more options for expansion in the future. This system was a revised version of ChildLink, a database developed by the University of Maine.
- Guam now uses Microsoft SQL with a server that will allow the birthing sites the option of downloading their data to a server that is protected with firewalls and accessible only to EHDI users.
- Plans to expand to a web-based system are currently in the planning stages



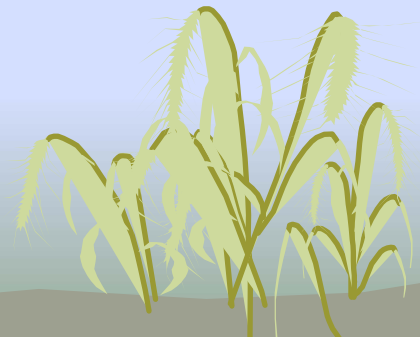
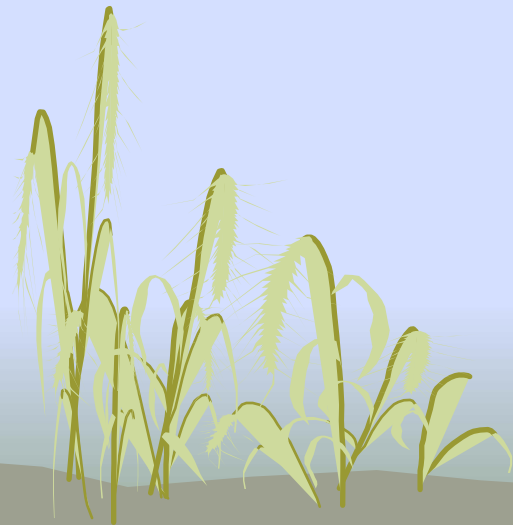
Does the Guam EHDI tracking system reflect/include recommended CDC/EHDI data items?

- The CDC/EHDI data recommendations have 3 levels: Minimum, Core, and Enhanced data items. Guam has insured that all minimum data items are included and most data items from the core and enhanced categories are also included. Some items were not appropriate for an island setting or were not applicable, and these were not included.
- In addition, Guam's system has been developed to meet the ethnic profile of the Pacific island context.



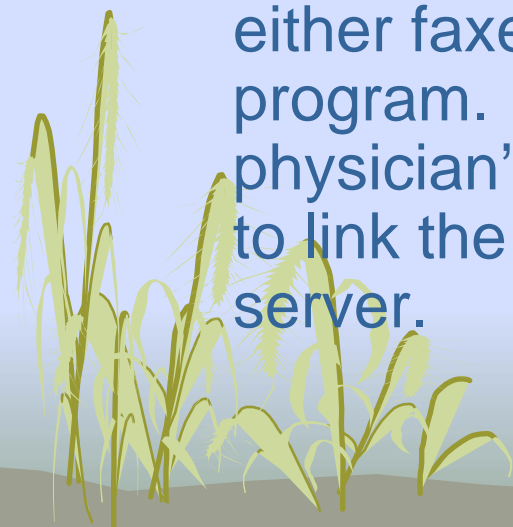
How is an infant uniquely identified in the Guam EHDI tracking system?

- The database has 2 types of numeric identifier:
 - (1) the Guam EHDI numeric string and
 - (2) the hospital or birthing site's unique numeric string



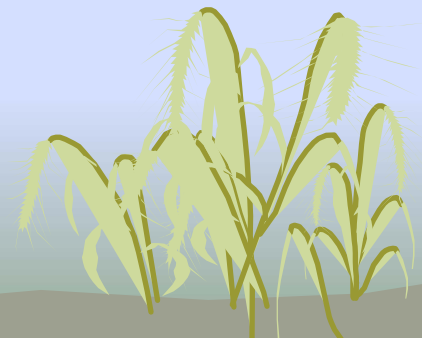
Does the Guam EHDI program receive reports from hospitals, physicians, audiologists, EI? If so, how are these reports received?

- The hearing screening results for each infant is currently on a paper file that is hand carried from the birth site to the EHDI program where the data is entered into the database. This will soon change as the birth sites are linked to the server and data will be transferred electronically.
- Any reports from physicians or the audiologists are either faxed or hand carried from the site to the EHDI program. While there are no plans to link the physician's report to the database, plans are in effect to link the audiologist's reports to the system via the server.



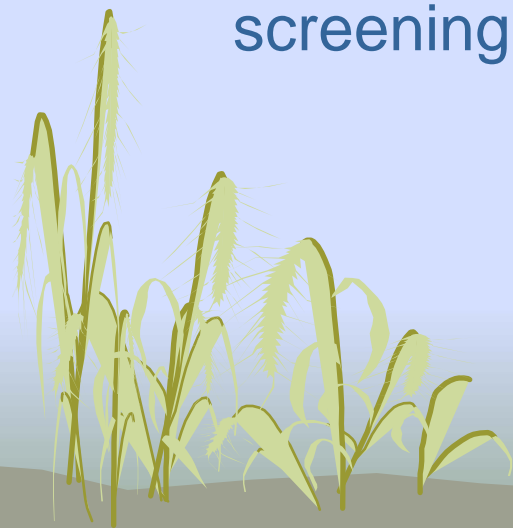
Does Guam maintain a registry of children diagnosed with a hearing loss? If so, up to what age?

- Guam maintains a registry of children with diagnosed hearing loss as a word-document in a desk top computer.
- This file is updated as infants with hearing loss are identified. This file is not currently linked to the database, but the new database now provides reports on all infants with hearing loss.
- In addition, the future plans are to link the early intervention system with the Guam EHDI database so that follow up can be done electronically.



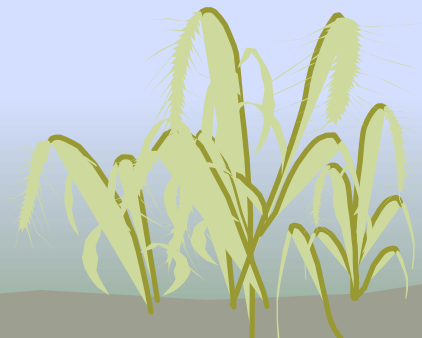
Are children that are identified by means other than the newborn hearing screening program, entered into the Guam EHDI data base?

- Since 2003, there have been no infants identified through other means, such as well-baby clinics.
- In the event an infant is identified (it assumes this infant was missed by the newborn hearing screening program) then, the infant data will be entered into the database and can be flagged to indicate that identification was not done via the newborn hearing screening program.



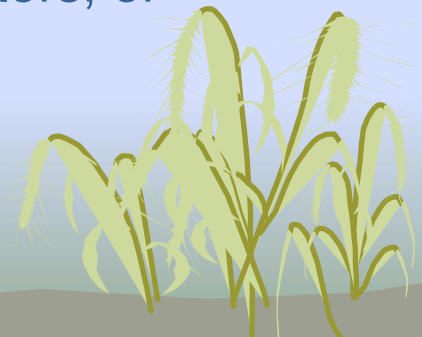
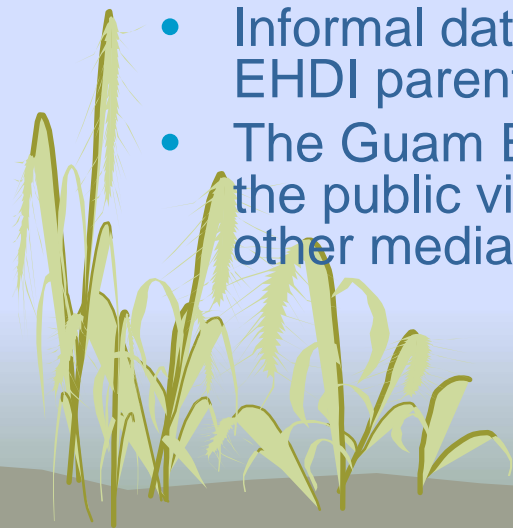
Do you currently integrate with other data systems and if so, which ones? Do you have written policies/agreements for data sharing?

- At the current time, Guam EHDI does not integrate with other data systems
- Plans to link with GMHA's system and the GEIS system are being developed
- There are no formal policies or agreements for data sharing at this time since Guam is still in the developmental phase, however PL 27-150 provides for data collection and management which will involve DPHSS.



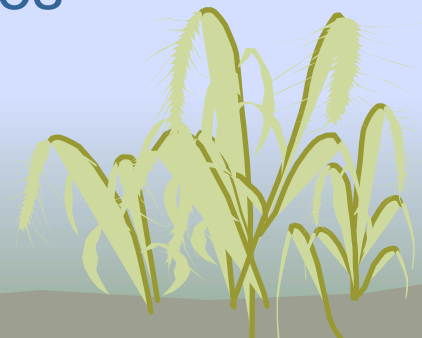
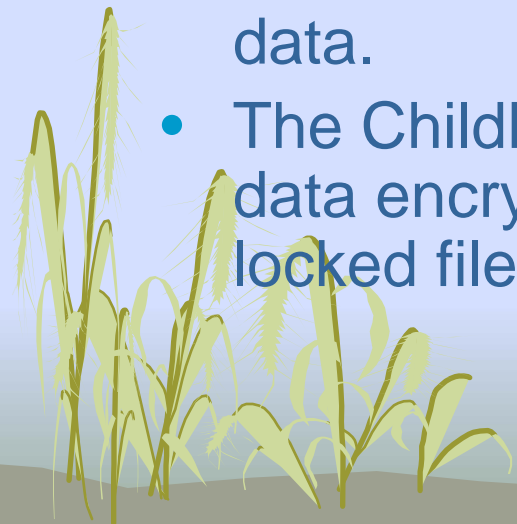
Do you currently prepare data reports or a published report that you share with the hospitals, advisory committee, audiologists, legislature, EI, or the public?

- Yes, formal data reports, usually in the form of a PowerPoint presentation are provided to the Guam EHDI Advisory Council at their quarterly meetings and this report is also shared with the Guam Interagency Coordinating Council.
- No formal reports are made to the birthing sites since stakeholders at these sites are members of the Advisory Council and information is filtered to the hospitals through these members.
- Informal data reports are shared with the GEIS, and the Guam EHDI parent support group.
- The Guam EHDI program periodically provides short reports to the public via public service announcements, newsletters, or other media, when requested.



What security systems are in place to maintain the confidentiality of collected data?

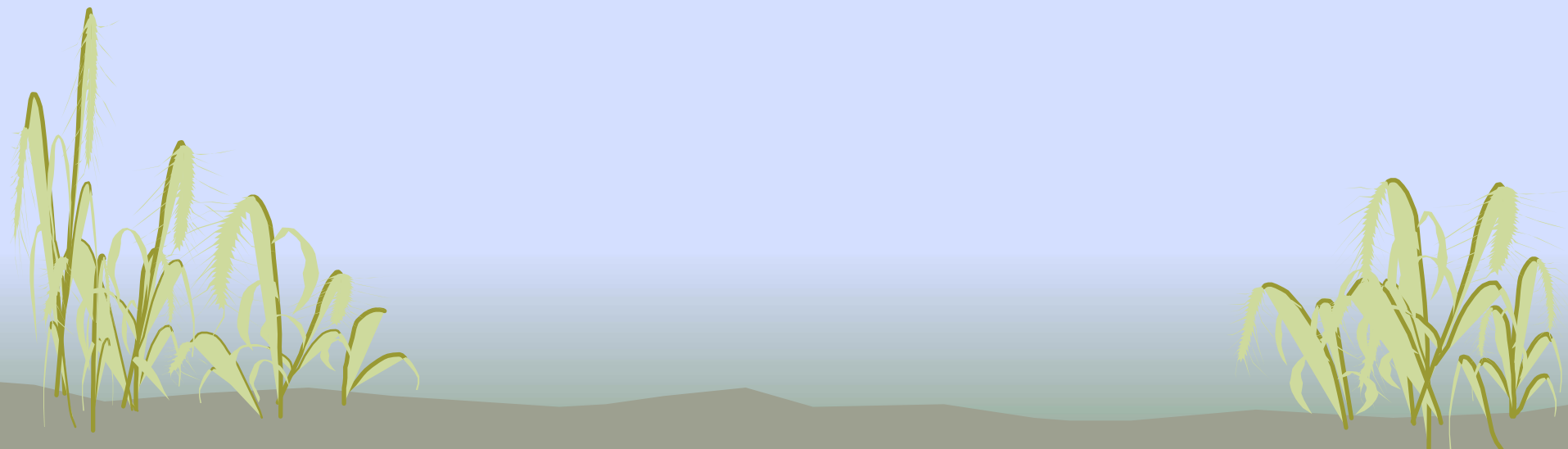
- All HIPPA and FERPA requirements were planned early in the Guam EHDI program. Informed parental consent, using a paper file is currently being used.
- The current data system is not connected to the internet, is password protected, and hardcopy files are double locked in the Guam EHDI office.
- In addition, a dedicated DSL line is used to transfer data.
- The ChildLink data system, has firewall protection, data encryption, password protection and uses locked files.



*VIII. Involving Stakeholders in
Coordination of Care*

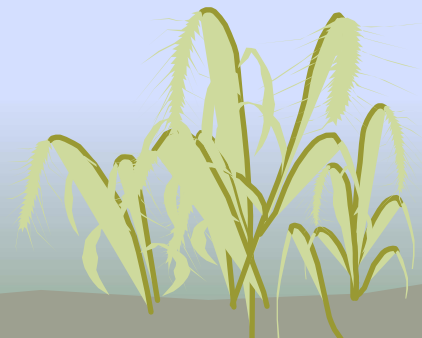


Who are your primary stakeholders / collaborators and what challenges does Guam EHDI face regarding the involvement of stakeholders?



Who are your primary stakeholders / collaborators and what challenges does Guam EHDI face regarding the involvement of stakeholders?

- The primary stakeholders are represented in the Guam EHDI Advisory Council and the Guam Interagency Coordinating Council. (List provided)
- A major challenge is the availability of a pediatric audiologist.

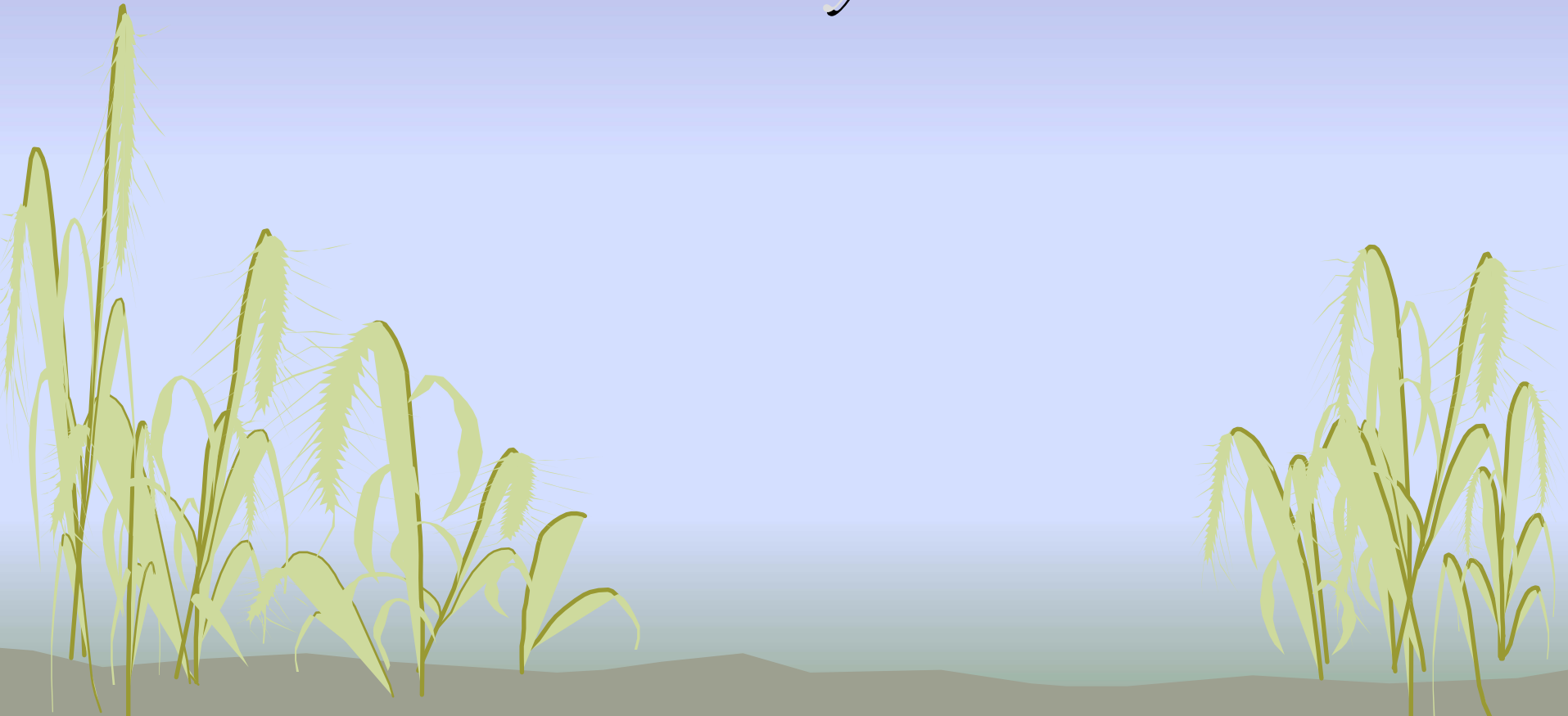


Have your stakeholders help you to achieve the goals of the Guam EHDI Program? If so, please provide an example of how they have support you.

- Yes, the Guam EHDI Advisory Council and the parent to parent support group was instrumental in rallying support for EHDI legislation.
- The parent to parent support group has also assisted other families in working with and advocating for their infants with hearing loss.

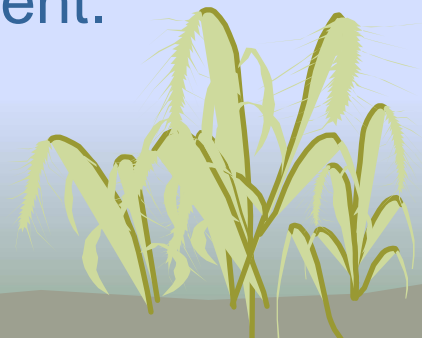
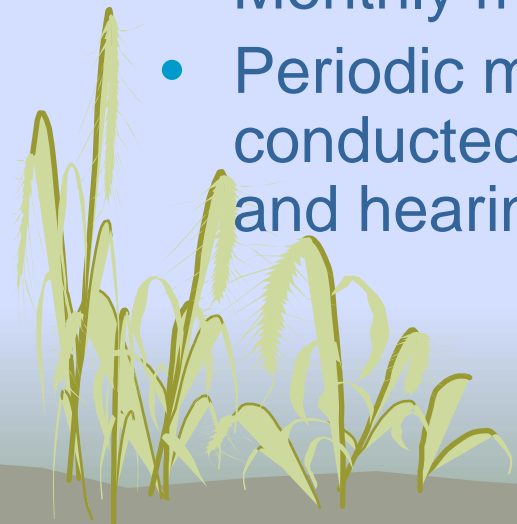


*IX. Monitoring and Evaluating
EHDI System*



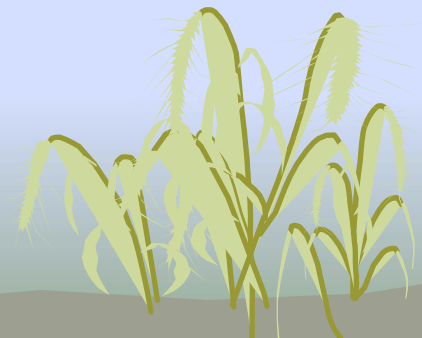
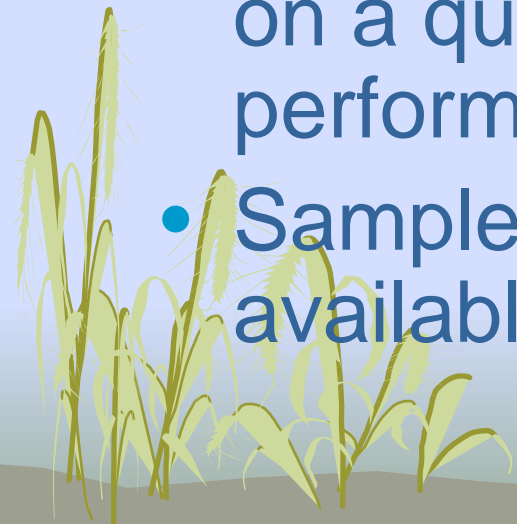
What types of activities are you currently doing to monitor/evaluate the EHDI systems?

- Quarterly reports to the Guam EHDI Advisory Council
- Under the MCHB Continuation Grant a logic model was developed to monitor and track infants loss to follow-up. Copy of the logic model is provided.
- Monthly meeting with GEIS
- Periodic meetings with the Clinical Audiologist is conducted regularly to ensure audiological follow-up and hearing aids assessment and management.



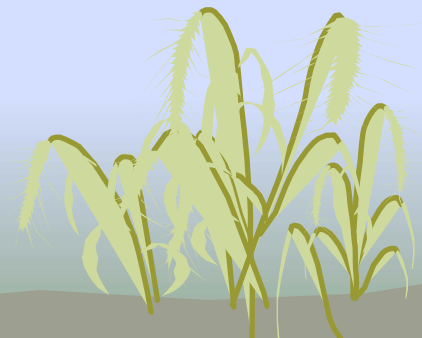
Does the Guam EHDI program monitor performance of individual hospital screening programs? If so, is feedback provided to the hospitals?

- Yes, screener referral rates are monitored carefully at each of the birthing sites.
- Feedback is given to nursing supervisor on a quarterly basis to monitor performance of individual screeners.
- Samples of feedback reports are available for review.



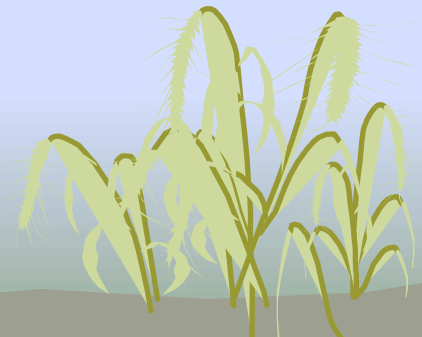
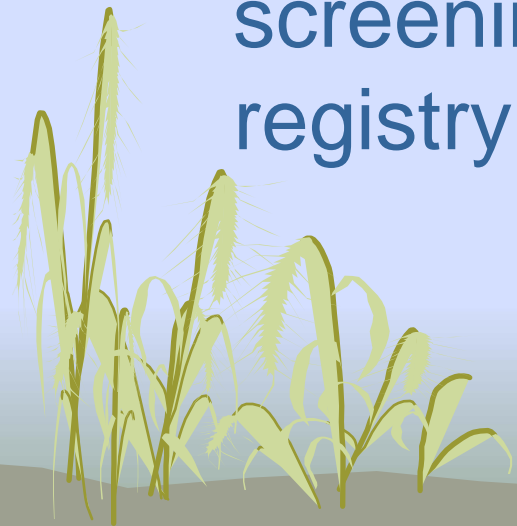
Is Guam using any surveys to obtain feedback from parents, physicians, EI programs, hospitals, audiologist?

- At the current time surveys are conducted with parents when training is provided.
- Surveys are also conducted with early intervention staff when training is provided.
- Surveys for physicians and audiologist are being planned.



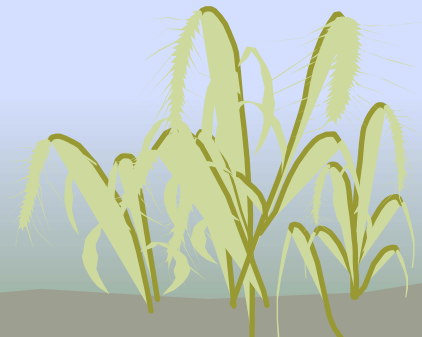
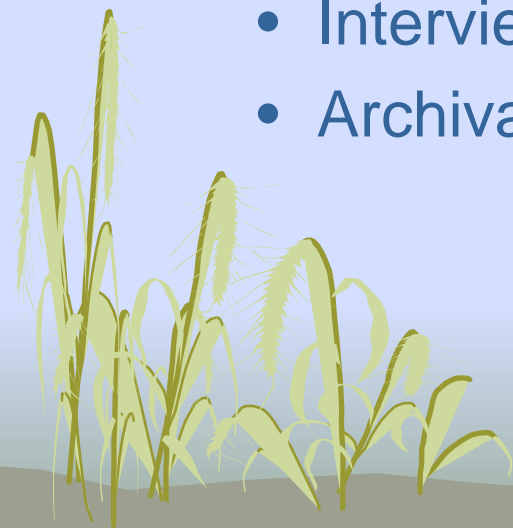
Are you matching data with any population-based reporting system? (such as metabolic/blood spot, vital records/birth certificates)

- Yes, the monthly birth rate at each birthing site is matched with the hearing screening results.
- There are plans to match hearing screening data with the birth certificate registry.

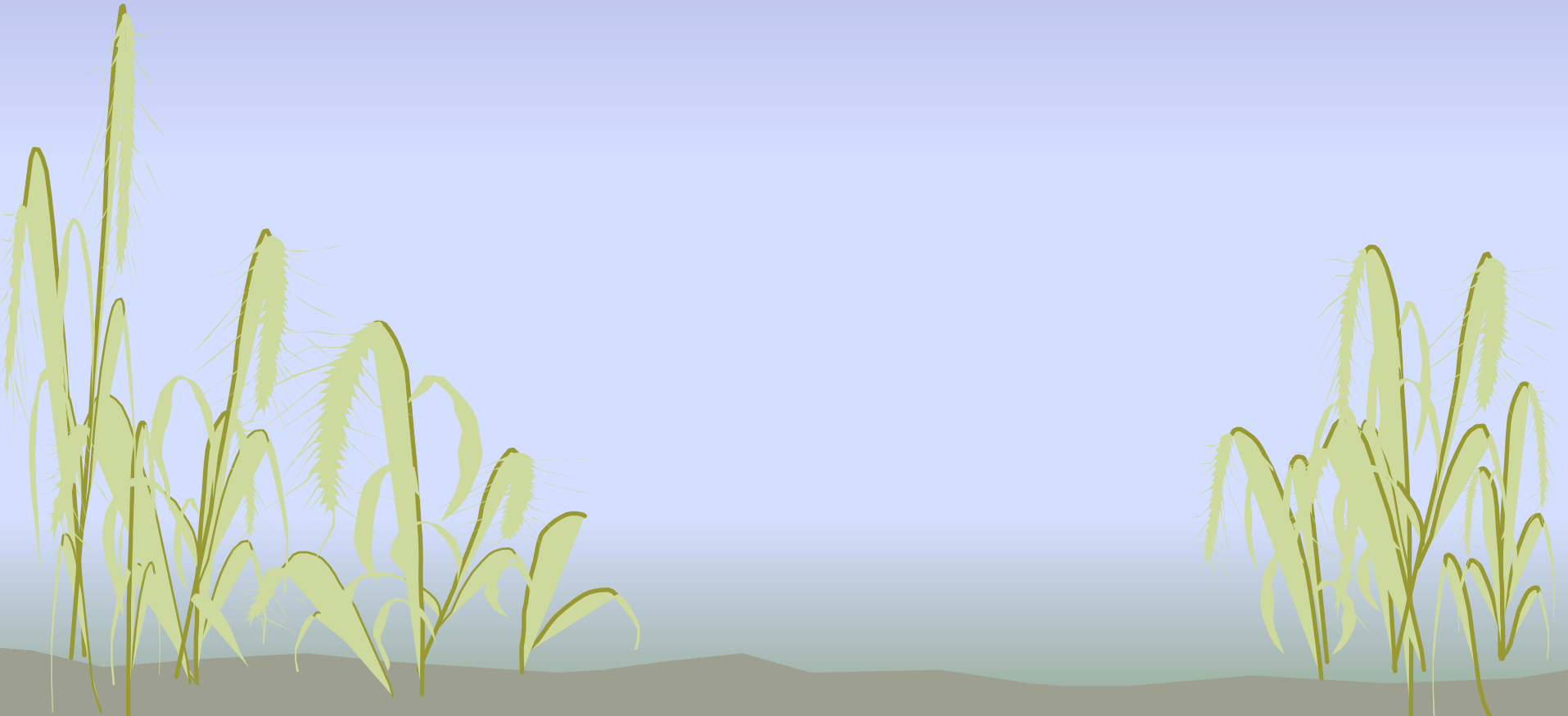


Does Guam have a written EHDI program evaluation plan?

- Yes, the program evaluation is described in both the MCHB and CDC grant applications.
- Evaluation procedures include:
 - Follow-up studies of identified children
 - Parent satisfaction surveys
 - Interviews with parents and stakeholders
 - Archival monitoring of early intervention program

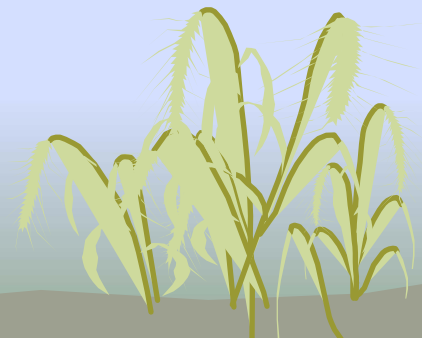


*X. Resource Materials, Training,
and Public Awareness*



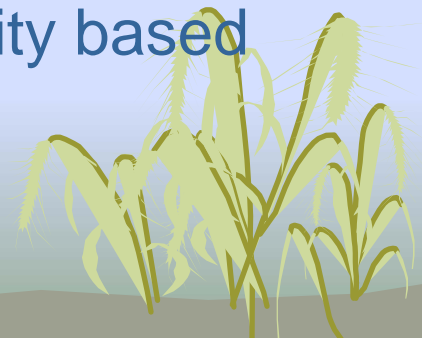
Do you provide a list of resources and contacts that discuss the various communication options to enable families to make informed decisions?

- Presentations are provided to parents using the SKI-HI Curriculum in Topic 7: Exploring Communication Options. SKI HI also includes electronic web-link resources for parents and service providers.
- Guam EHDI has recently completed a Directory of Services including electronic online resources for parents and service providers.



What educational materials do you provide to other stakeholders and the public?

- Guam EHDI Project recently completed a Directory Resources that include books, videos, tapes that families and providers may use.
- Other education materials developed include the following:
 - Brochures
 - Posters
 - Pamphlets
 - CD-ROMS
 - Public Service Announcements
- In addition, the Guam EHDI staff presents information at meetings, conference, and other community based venues.



What trainings/seminars/conferences are provided by the Guam EHDI program? For whom?

- Training/Seminar/Conferences
 - Hearing Screening Training
 - Nurses @ birthing sites (GMH, SM)
 - Nurses @ Public Health
 - GEIS Staff
 - School (Who?)
 - Awareness Presentations – Public/Professionals
 - Parents (Parent to Parent Support Groups)
 - General Hospital Staff (Grand Rounds)
 - Hospital Unit Managers
 - Public Health Nursing Staff
 - Mall Exhibits

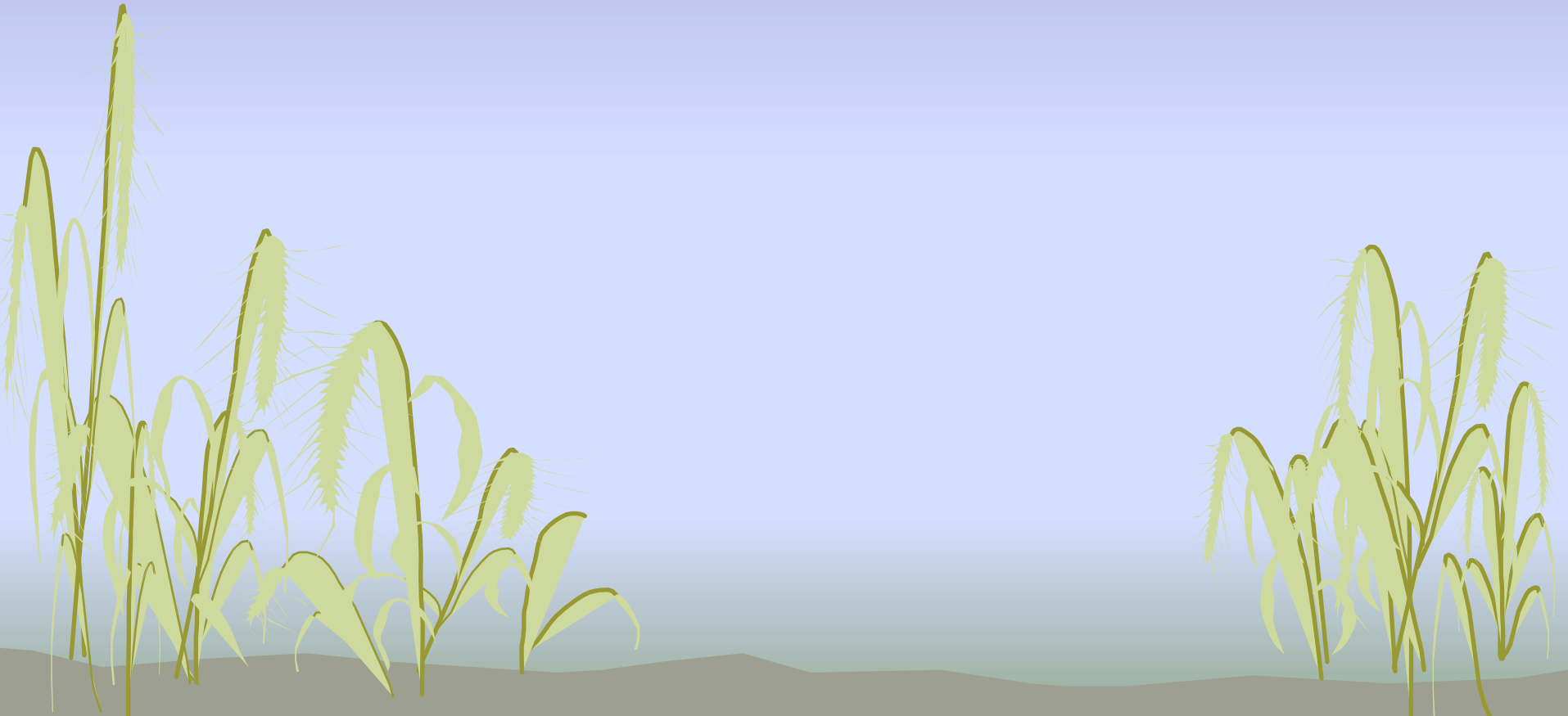


What challenges does your program face regarding increasing awareness about the Guam EHDI?

- Language barriers (ESL)
- Transportation issues
- Cultural beliefs/differences
- Denial/avoidance

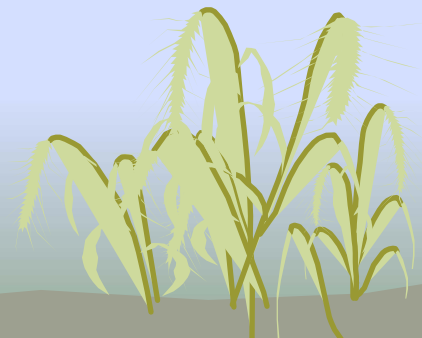
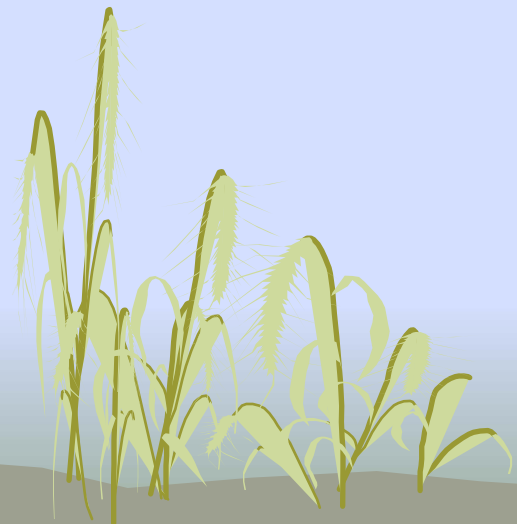


XI. Legislation



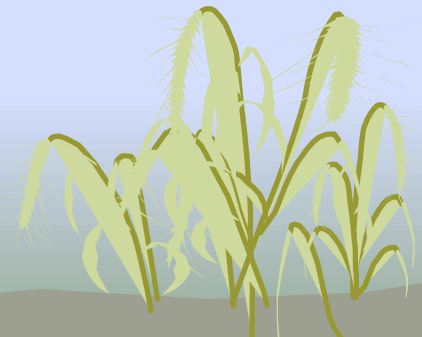
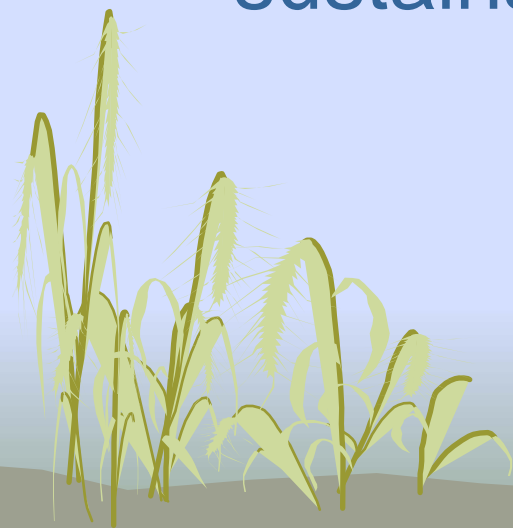
Does Guam have legislation related to EHDI? If yes, when?

- Yes, in December 22, 2004, Public Law 27-150 the Guam UNHS was passed into law. A complete copy of the law is provided.

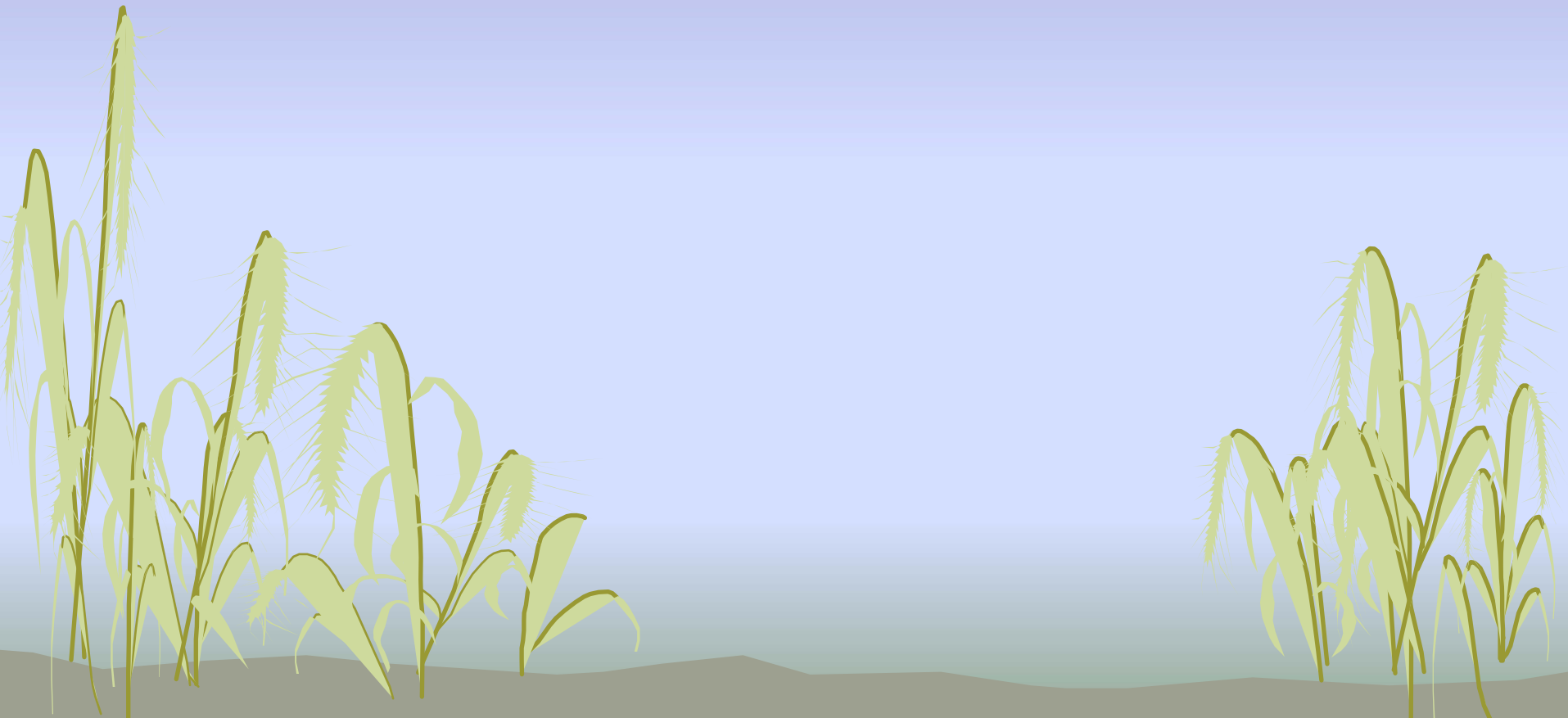


If you currently have EHDI legislation what does it mandate or encourage? Screening? Reporting – aggregate, individual? Education? Advisory committee? Other? Are there any plans to amend it in the future? If yes, when and why ?

- A complete copy of the public law is provided for review.
- There are plans to amend the law to include a revenue source for sustainability.



XII. EHDI International

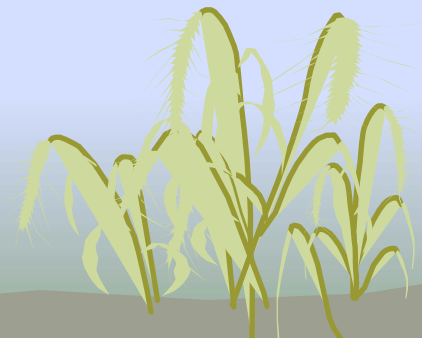


Do you have any experience working with families who travel to this country looking for help for their children with hearing loss? Are these children included in the Guam EHDI database?

- Yes, Guam EHDI provides assistance and support to the Federated States of Micronesia, Republic of Palau, Republic of the Marshall Islands, Japan, Korea, China, Indonesia, and other Asian countries.
- Only infants who are screened at birth on Guam are included in the data base.

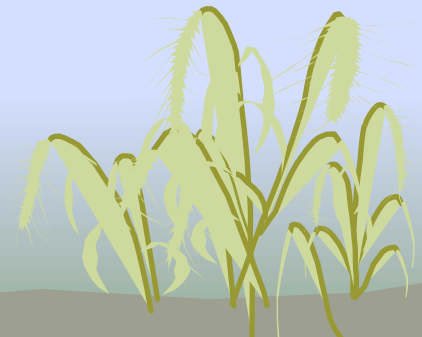
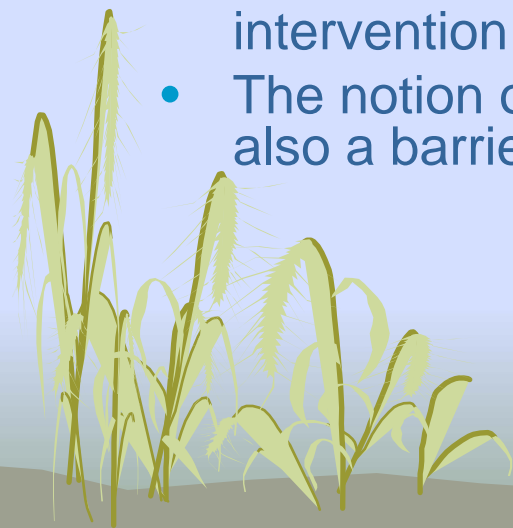
How do you work with non-English patients who have low proficiency in English? For e.g. how do you inform them about the Guam EHDI process (screening, evaluation and early intervention)? Do you have multilingual staff who are able to communicate with these patients and guide them through the Guam EHDI process?

- Guam EHDI provides both translated brochures and native speakers of Pacific languages who interpret information to multilingual families to ensure that families understand the Guam EHDI process. The Guam EHDI staff have Chamorro and English speakers only, however translators are available through various units on the UOG campus, such as the Micronesian Language Institute and the English Language Institute.

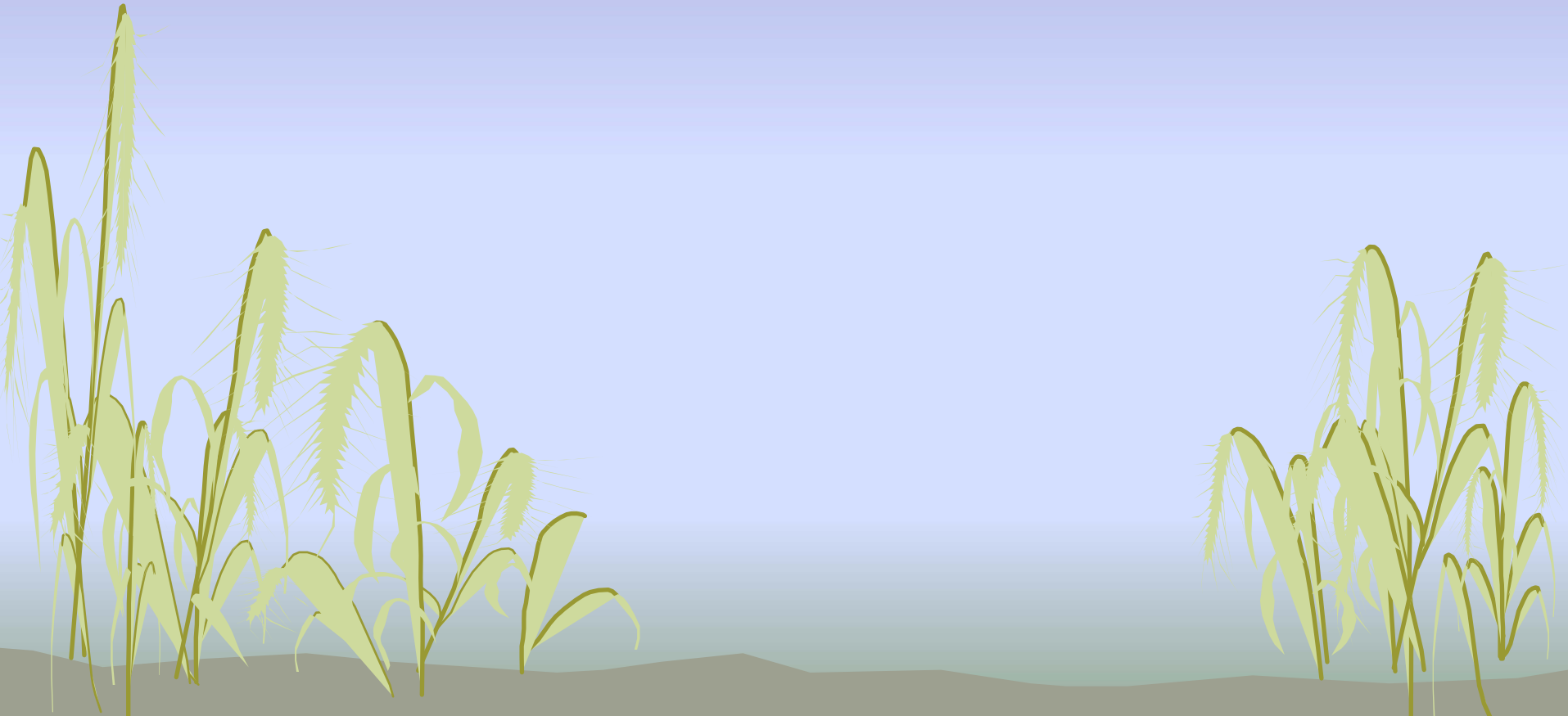


Could you please describe the language, cultural, or any other barriers your state has when attempting to reach minority populations with hearing loss?

- Language barriers are not as problematic as the cultural belief system that must be overcome, e.g. if an infant appears “normal” the tendency is not to follow up on appointments, because some cultures believe that Western society is trying to create a problem when one does not exist.
- Also, another belief is that newborn infants should not be taken out into a public place before they have been baptized or other ritual is performed to “protect” them
- Some cultures believe that an infant will outgrow a problem and intervention is intrusive and not necessary.
- The notion of “shame” or “denial” that a problem may exist is also a barrier to provision of early intervention services.

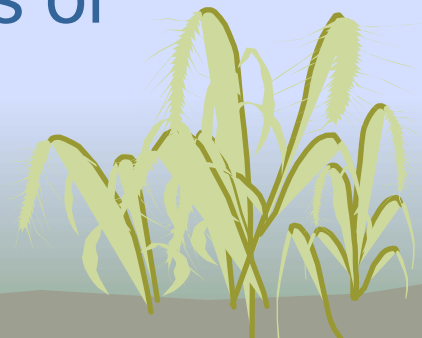


XIII. Other Issues



What funds are available for screening, audiological evaluations, Early Intervention, hearing aids, other assistive devices, and cochlear implants?

- At the present time, funding for audiological services and early intervention is also provided by the Guam PSS-Part C funds
- For hearing aids, assistive devices, and cochlear implants, funds are available only through private insurance coverage
- There are plans to look into other potential funding sources to support these types of services in 2007 and 2008.



Other issues:

- Collaboration with U.S. Naval Hospital Guam is still up in the air. Guam EHDI has stopped receiving data since May, 2005 when there was a change of command.
- Equipment maintenance in an island environment continues to be a challenge
- Access to technical support and equipment is frequently delayed and impedes progress
- Lack of a resource pool to draw on for audiological services, speech & language services, and other health care needs
- Lack of experts in the different communication methodologies which limits family's options.
- Funding for hearing aids and lack of a hearing aid loaner bank has been a challenge for families.

