

Newborn Hearing Screening on the Pacific Island of GUAM

”Hafa Adai!” from the People of Guam
“BUON GIORNO”





The Guam EHDI Tracking and Surveillance System: Using Data Trends to Improve Hearing Screening Outcomes

by

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Guam EHDI Tracking & Surveillance

June 3, 2006 @ 9:15-9:30AM Room E

Congress Center

Lake Como, Milan, Italy



This presentation was made possible
by....

UNIVERSITY OF GUAM (UOG)

GUAM

*C*enter of
*E*xcellence in
*D*evelopmental
*D*isabilities:
*E*ducation,
*R*esearch, and
*S*ervice
(Guam **CEDDERS**)



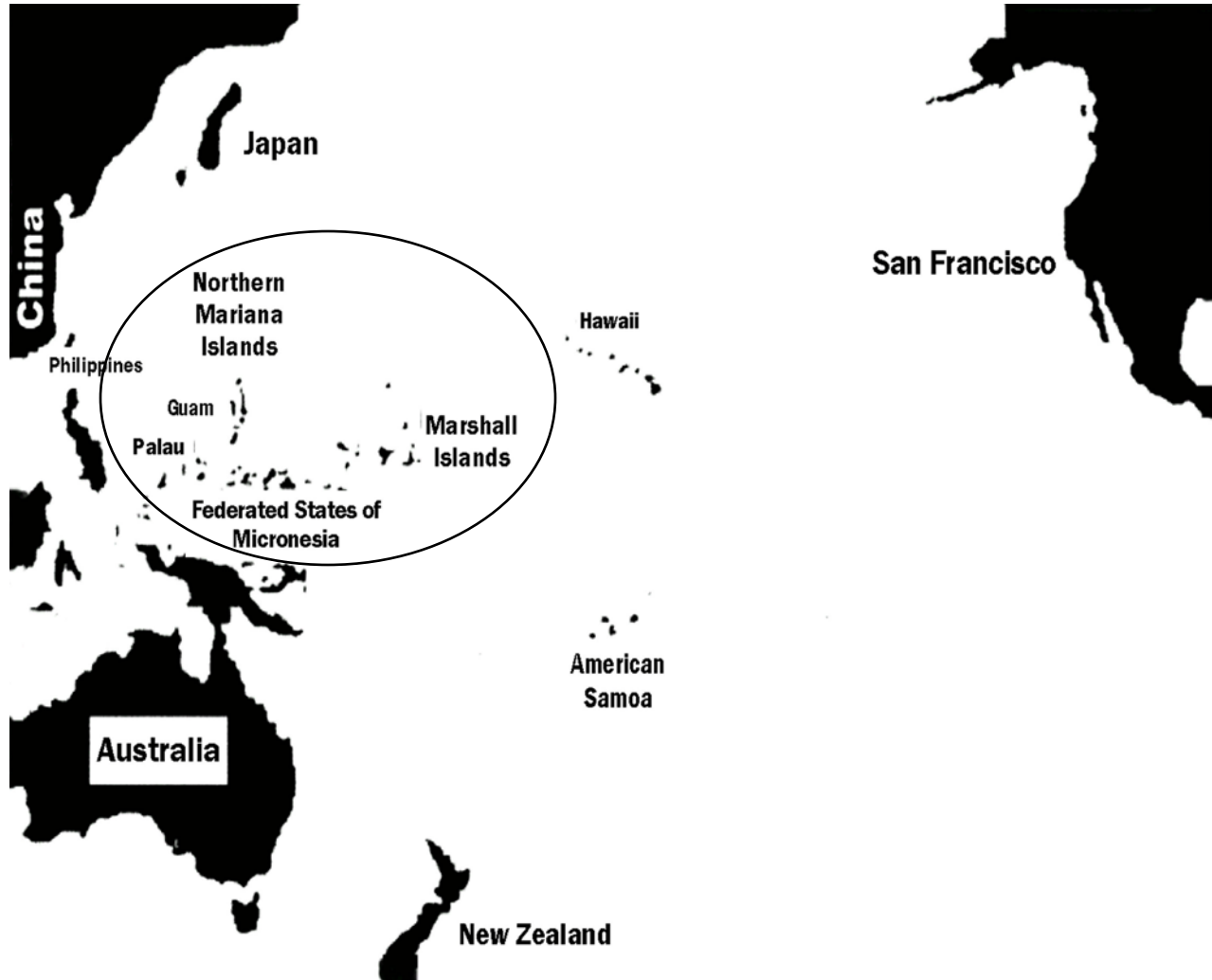
Guam is a U.S. Territory located in Micronesia

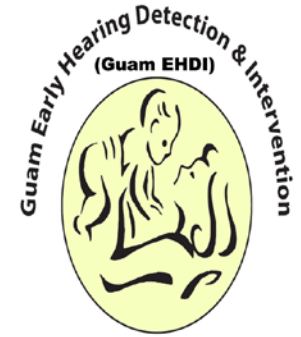
“Where America’s day begins”



- Population is approximately 160,000
- Birth rate: Approximately 3,500 births per year
- 3 Birthing Sites: 1 private, 1 public, and 1 military
- US Naval Hospital-Guam, reported in 2002 and 2003 but, discontinued reporting to Guam EHDI after 2004.
- High birth rate among single mothers
- High rate of teen pregnancies
- Academic achievement of school aged children is at the 15-20th percentile

**Guam is located 13° N Latitude, 144° E Longitude
Lying in the Southern End of the
Northern Marianas Islands**



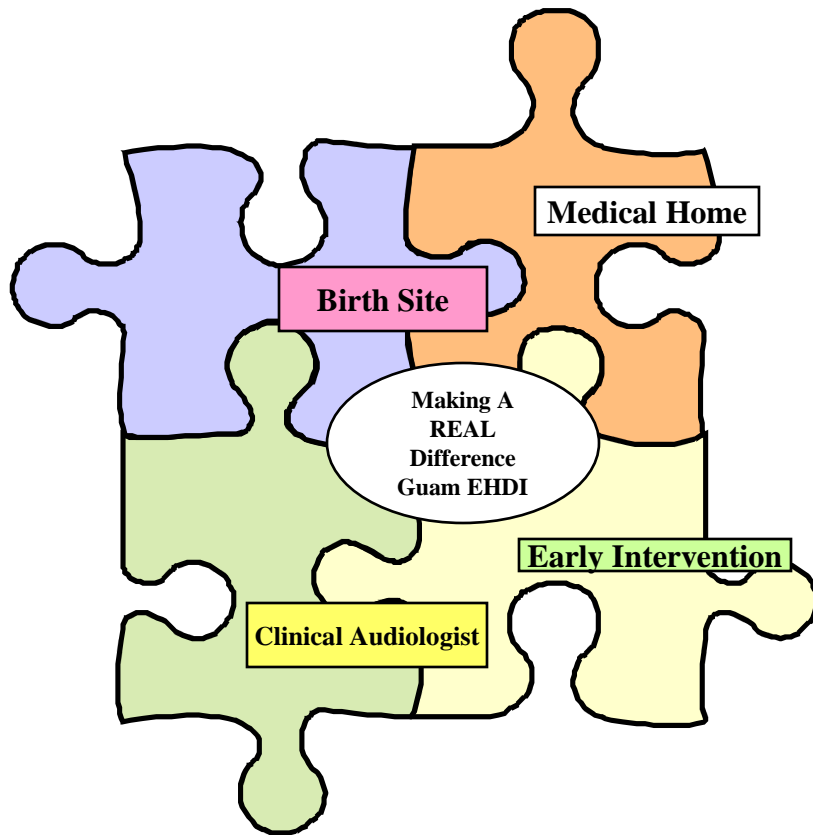


OUR STUDY

**Using Data Trends to Improve Hearing
Screening Outcomes**

The Guam EHD Tracking and Surveillance System

Purpose of the Study: *To demonstrate how programs can use the NHS database system to observe both quantitative and qualitative trends that can improve hearing screening outcomes*



Research Questions:

1. What is the status of newborn hearing screening on Guam?
2. How well are infants with hearing loss being identified and served?
3. What data manipulations can be used to reveal information that can improve services for infants with hearing loss?
4. How can data trends improve services?
5. How can case studies assist in improving services? What can this type of data reveal?

Research Methods

- **Descriptive statistics used to answer research questions 1 to 4.**
 1. What is the status of newborn hearing screening on Guam?
 2. How well are infants with hearing loss being identified and served?
 3. What data manipulations can be used to reveal information that can improve services for infants with hearing loss?
 4. How can data trends improve services?
- **Qualitative methods used to answer research question 5, specifically the use of Case Studies.**
 5. How can case studies assist in improving services? What can this type of data reveal?



Findings



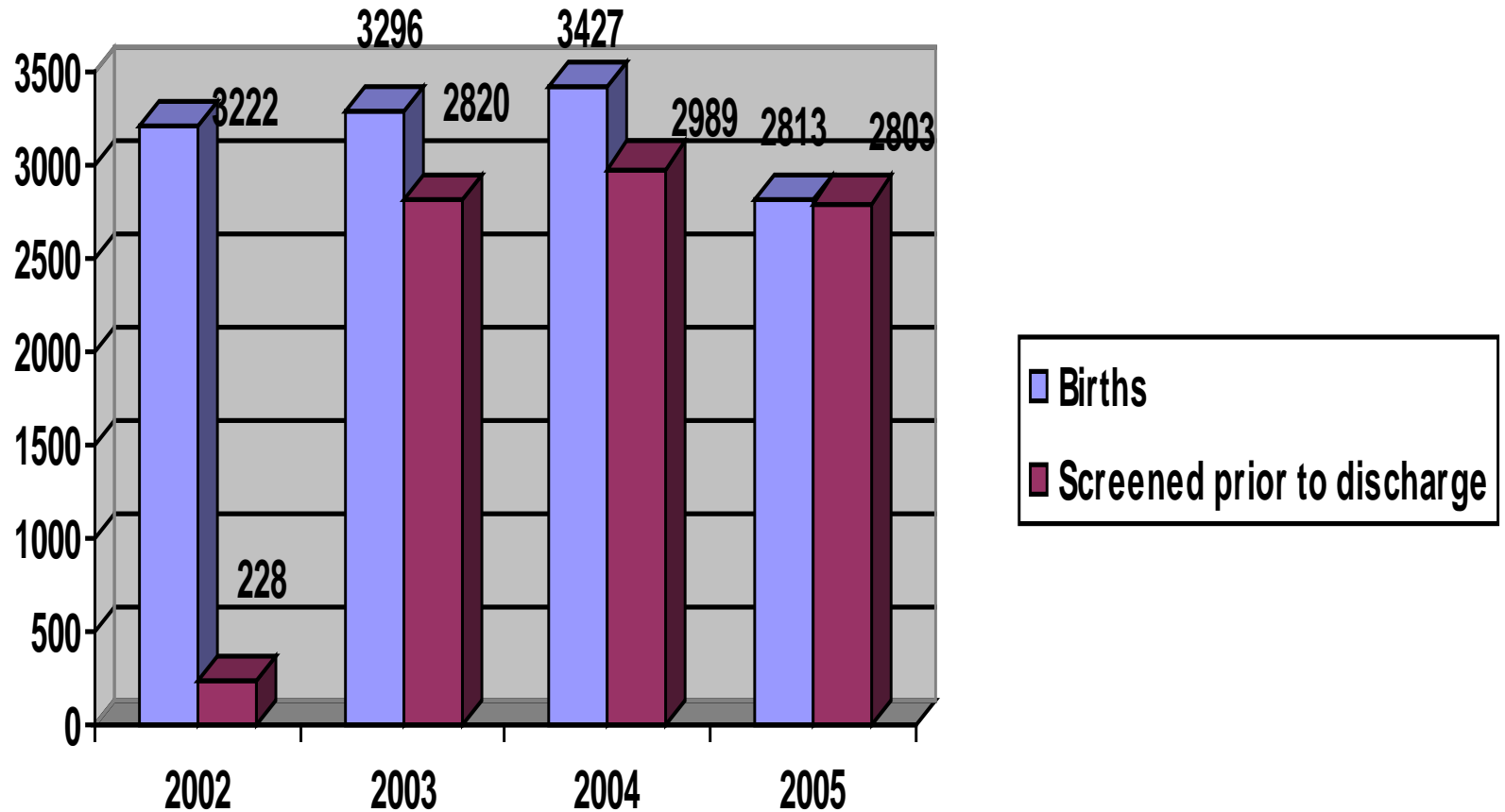
- 1) Finding from descriptive statistics
- 2) New Directions in Using NHS Database
- 3) Preliminary results from Case Studies

1) Descriptive Statistics

What is the status of newborn hearing screening on Guam?

How well are infants with hearing loss being identified and served?

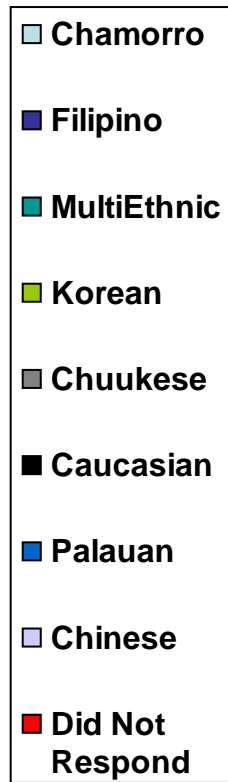
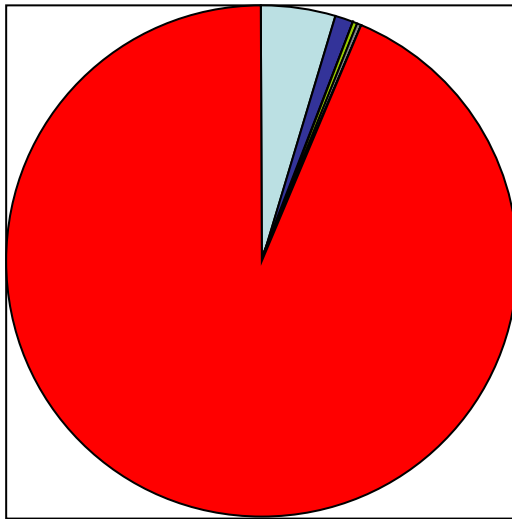
Guam's Statistics in Newborn Hearing Screening 2002-2005



Ethnic Distribution of Infants Screened

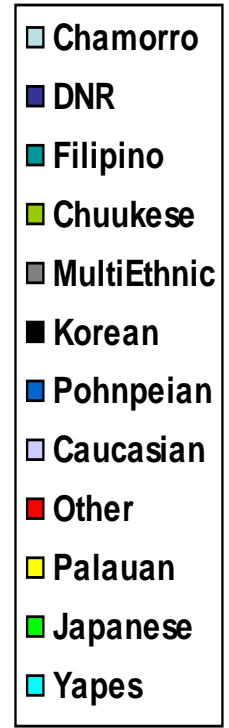
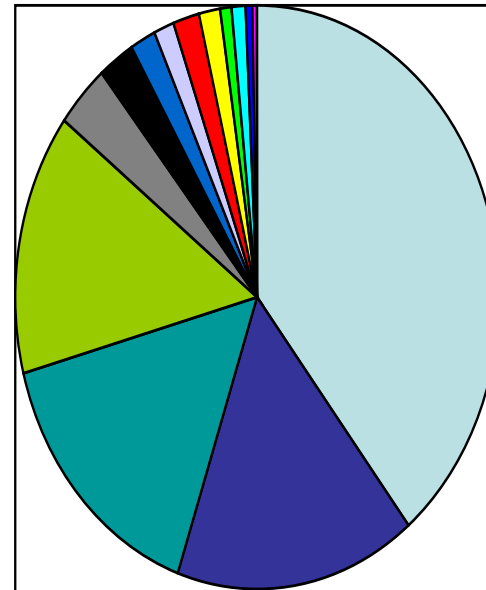
2003

N=2,820



2004

N=2,751



How many infants with hearing loss were identified from 2002 to 2004?



- A total of **19** infants were identified with hearing loss, 7 in 2003 and 12 in 2004.
- The results for 2005 are still in process
- The high risk group for 2003 to 2004 totaled 639

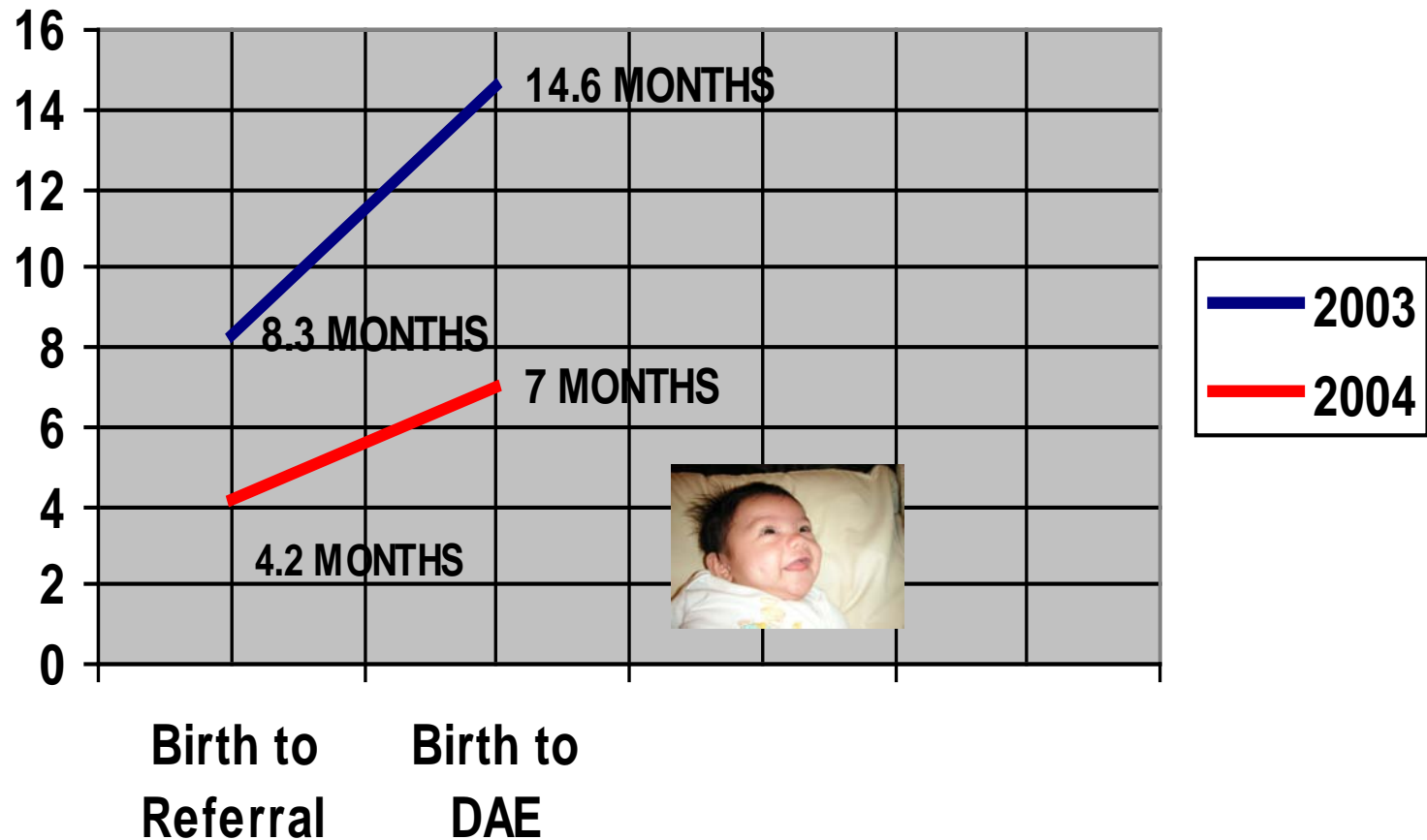
Statistics on Guam Infants Identified with Hearing Loss in 2003

2003 Infants	DOB	Referral Date	Total Months DOB to Referral	Date of Full Diagnostic Assessment DAE	Total Months from DOB to DAE
IB	6-03	10-04	17 mos.	3-05	21 mos
TC	9-03	11-03	2 mos.	1-05	16 mos.
SG	2-03	6-03	4 mos.	8-03	6 mos.
MG	11-03	12-03	1 mon.	3-04	4 mos.
IP	2-03	2-05	24 mos.	5-05	27 mos.
MS	7-03	2-04	7 mos	1-05	18 mos.
JT	12-02	3-03	3 mos.	10-03	10 mos.
2003 N=7	Range: 4 months to 27 months Average months from BIRTH to REFERRAL: 8.3 months			Range: 4 months to 27 months Average months from BIRTH to FULL ASSESSMENT-DAE: 14.6 months	

Statistics on Guam Infants Identified with Hearing Loss in 2004

2004 Infants	DOB	Referral Date	Total Months DOB to Referral	Date of Full Diagnostic Assessment DAE	Total Months from DOB to Assessment DAE
SA	9-04	10-04	1 month	12/04	3 mos.
KB	10-04	11-04	1 month	2/05	4 mos.
SE (twin1)	7-04	1-05	6 months	3/05	8 mos
SE (twin2)	7-04	1-05	6 months	3/05	8 mos.
AE	5-04	1-05	8 months	2/05	9 mos.
RL	8-04	9-04	1 month	2/05	6 mos.
ALG (twin1)	1-04	5-04	4 months	NDA*	-----
ALG (twin2)	1-04	5-04	4 months	10/04	9 mos
CJM	7-04	8-04	1 month	3/05	8 mos.
VS	4-04	3-05	11 months	LFU**	-----
CS	7-04	12-04	5 months	3/05	8 mos.
TW	2-04	4-04	2 months	9/04	7 mos
2004 N=12	Range: 3 months to 9 months Average no.of months from BIRTH to REFERRAL: 4.2 months			Range: 3 mos. To 9 months Average no. of months from BIRTH to FULL ASSESSMENT-DAE: 7 months	

Comparisons: Birth to Referral & Birth to DAE (2003-2004)



And...how is Guam doing in getting infants with hearing loss into early intervention services?

Time Lag Between DOB to IFSP for Identified Infants 2003

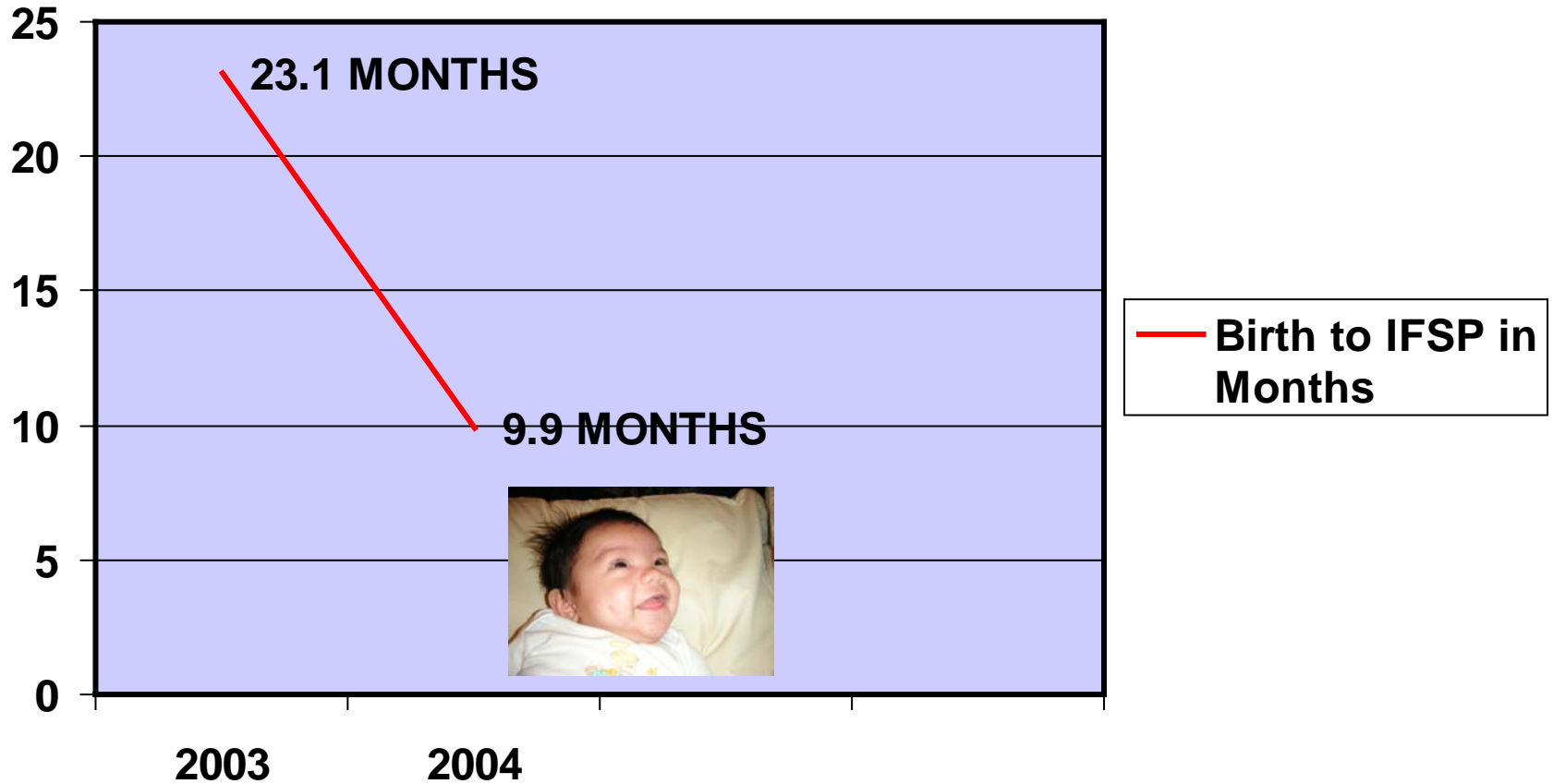
2003 Infants N=7	DOB	Date of IFSP	Total Months from DOB to IFSP
IB	6-03	4-05	23 months
TC	9-03	3-05	18 months
SG	2-03	6-05	28 months
MG	11-03	2-05	15 months
IP	2-03	6-05	28 months
MS	7-03	6-05	23 months
JT	12-02	3-05	27 months
Range: 15 months to 28 months Average Months from DOB to IFSP in 2003: 23.1 Months			

And...how is Guam doing in getting infants with hearing loss into early intervention services?

Time Lag Between DOB to IFSP for Identified Infants 2004

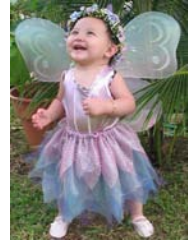
2004 Infants N=12	DOB	Date of IFSP	Total Months from DOB to IFSP
SA	9-04	2/05	11 months
KB	10-04	5/05	18 months
SE	7-04	9/05	10 months
SE	7-04	9/05	10 months
AE	5-04	4/05	13 months
RL	8-04	6/05	10 months
ALG	1-04	5/04	4 months
ALG	1-04	5/04	4 months
CJM	7-04	4/05	8 month
VS	4-04	7/04	3 months
CS	7-04	4/05	12 months
TW	2-04	6/05	16 months
Range: 3 months to 18 months Average Months from DOB to IFSP in 2004: 9.9 Months			

Comparisons: Birth to IFSP (2003-2004)





What made the difference?

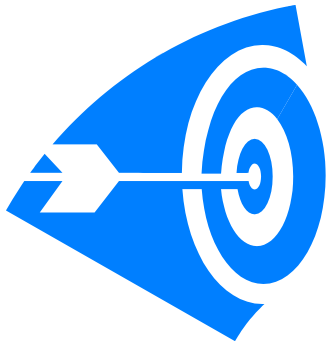


1. **Funding** from HRSA and CDC, including site visits, conferences, and electronic contact
2. **Public awareness** at all levels-educating everyone on the importance of infant hearing screening
3. **Aggressive effort** to obtain equipment, train qualified personnel, and provide technical support
4. Establishment of a **Community Advisory group** that included professionals and parents
5. Developing a collaborative partnership and **positive relationship** with birthing site personnel and early intervention
6. **Engaging parents** through parent support groups
7. Working toward the **Passage of Public Law 27-150**



BUT...While these were significant improvements, they still do not hit the target GOAL:

Identify and provide comprehensive services to infants with hearing loss by 6 months of age



AND some data findings were encouraging, but we need to do MORE....



Status of Guam's High Risk Infants



How is Guam doing with FOLLOW UP for Infants with High Risk factors?

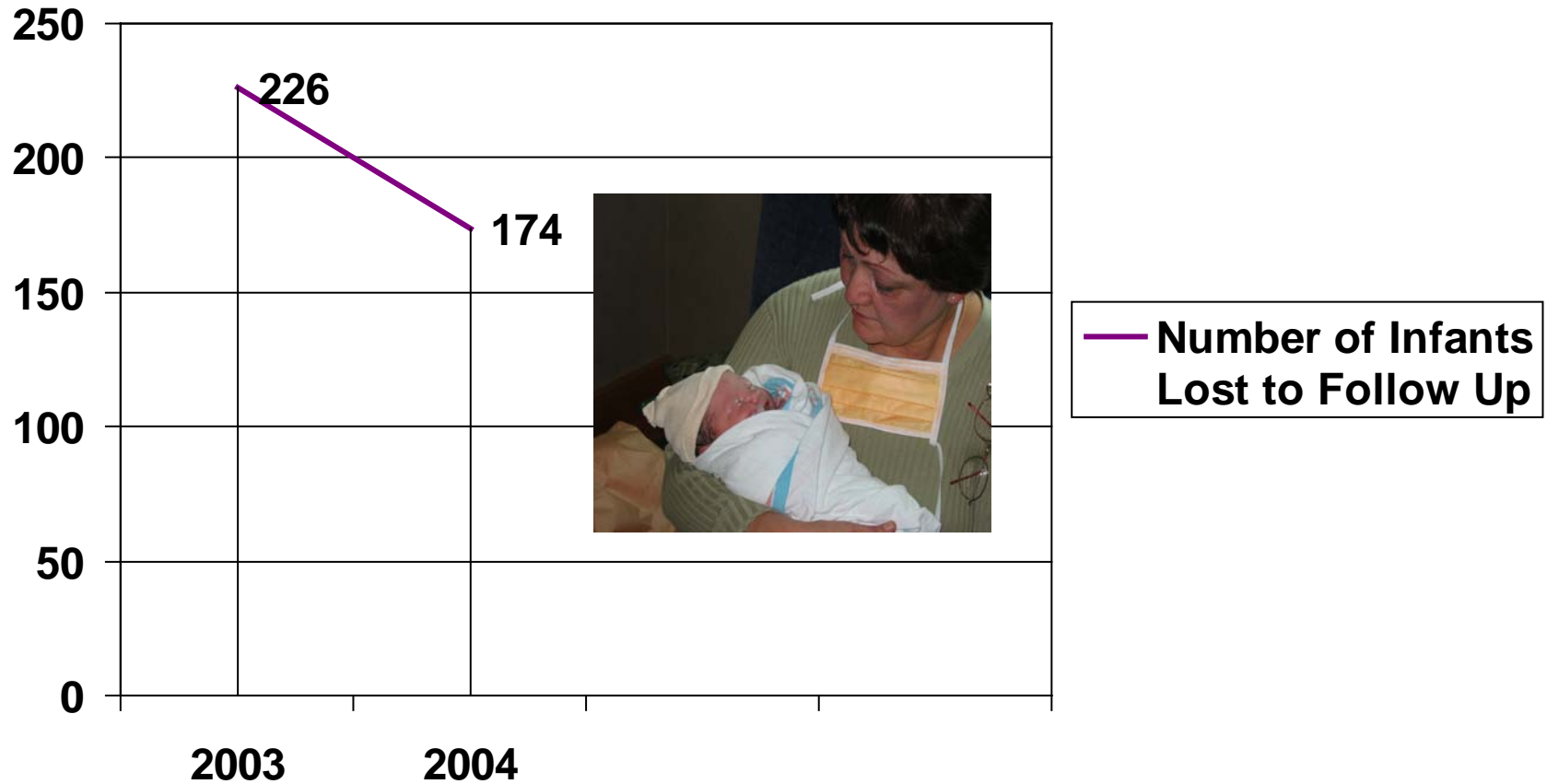
2003 MONTH	Number of HIGH RISK INFANTS	PASSED	REFERRED	INCOMPLETE Hearing Screening	Number Lost to Follow Up	% of High Risk Infants <u>Lost to Follow up</u>
January	25	9	1	0	15	60%
February	28	8	0	0	20	71%
March	23	8	0	0	15	65%
April	16	0	0	0	16	100%
May	38	4	0	0	34	90%
June	34	6	0	0	28	82%
July	37	7	0	2	28	76%
August	19	5	2	2	10	53%
September	17	5	0	2	10	59%
October	26	3	0	0	23	89%
November	21	5	0	0	16	76%
December	17	6	0	0	11	65%
TOTAL	301	66	3	6	226	75%

How is Guam doing with FOLLOW UP for Infants with High Risk factors?

2004 Infants with High Risk Factors Receiving Follow Up Services

2004 MONTH	Number of HIGH RISK INFANTS	PASSED	REFERRED	INCOMPLETE Hearing Screening	Number Lost to Follow Up	% of High Risk Infants <u>Lost to Follow up</u>
January	42	15	2	1	24	57%
February	12	4	1	0	7	58%
March	27	9	2	0	16	59%
April	32	19	1	0	12	38%
May	28	12	1	1	14	50%
June	22	9	0	1	12	55%
July	27	12	3	3	9	33%
August	29	11	0	3	15	52%
September	31	13	0	0	18	58%
October	36	17	0	1	18	50%
November	33	11	0	1	21	64%
December	15	6	1	0	8	53%
TOTAL	334	138	11	11	174	52%

Comparisons: Number of High Risk Infants Lost to Follow-Up (2003-2004)



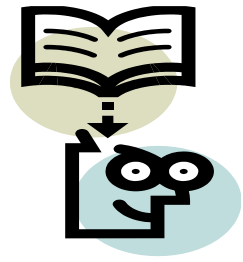
What did we do with this information?



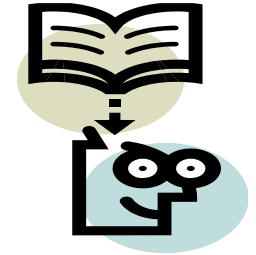
- We had **feedback sessions** with parents, advisory boards, birthing site staff, etc. where data findings were presented. There was a great sense of satisfaction and accomplishment on the data findings
- There was a lot of **brainstorming of possible solutions** on how to continue improvement, especially Lost To Follow Up issue

2) New Directions in Using NHS Database

What data manipulations can be used to
reveal information that can improve
services for infants with hearing loss?
How can data trends improve services?



New Directions



How could we use the database to assist us in decreasing the number of infants lost to follow up?

Guam ChildLink could generate a list of infants who did not show for follow up audiological appointments and other data fields

We wanted to know which ethnic group had the highest incidence of NO SHOW appointments (so we could investigate reasons for “lost to follow up” and we could begin to address the problem, i.e. development of culturally appropriate parent information materials)

We did a simple CROSSTABULATION of

Infants in need of re-screening or follow up and not returning
for appointments

with
ETHNICITY

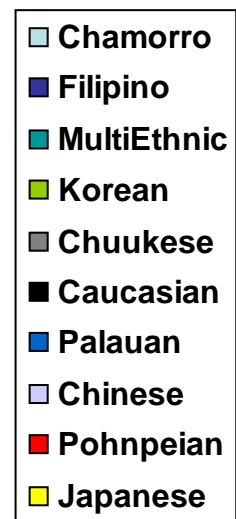
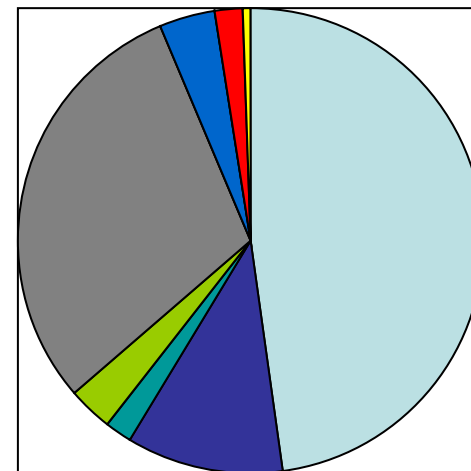
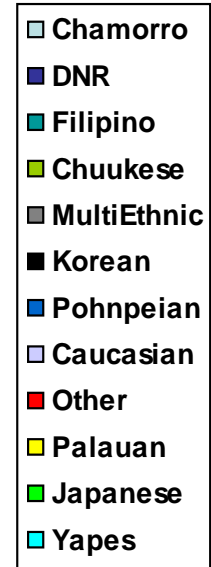
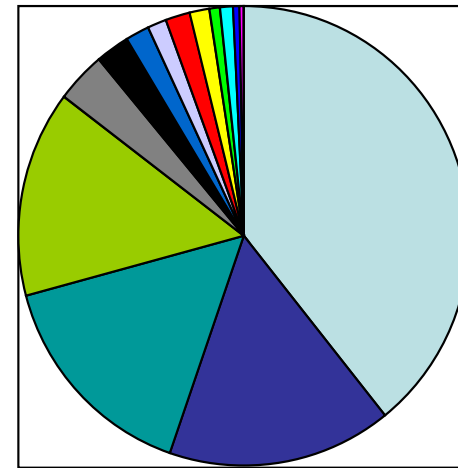


What we found....



The smaller culture group had the 2nd highest incidence of failed return appointments

- Top chart shows ethnic distribution of all 2004 infants screened [Colors are not always consistent across the 2 pie charts]
- Bottom chart shows ethnic distribution of infants who are NO SHOWS for follow up appointments



We investigated through brief informal interviews and determined that they were not returning for appointments because.....

- **They believed that the program was trying to create a problem with their infant, when a problem did not exist (infant responded to loud noises)**
- **They often lacked transportation and the ability to speak English**
- **They do not think a hearing problem is important, particularly in relation to other challenges they face such as housing, food, and health care when living on Guam.**
- **They often give birth on Guam and return to their home island**

**SO WE ARE NOW USING THIS DATA TO DRIVE
DECISION MAKING AND SET PRIORITIES**

3) Preliminary Results From Case Studies

How can case studies assist in improving services? What can this type of data reveal?

Then, we selected 5 files from the 19 infants identified with hearing loss and started

CASE STUDY

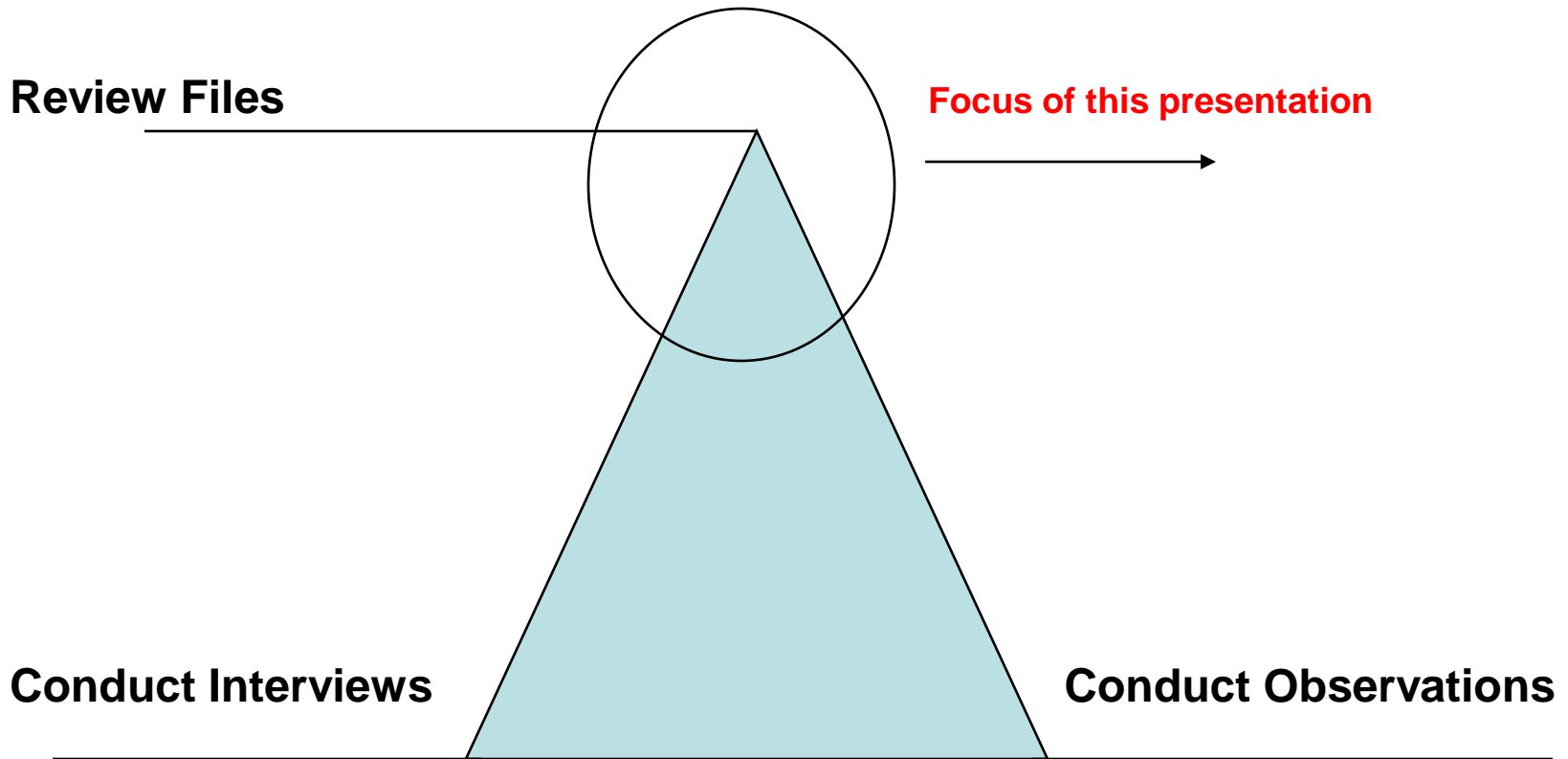
analyses to answer the following research question:

What variables were contributing to delays in getting the infant from initial hearing screening to the development of an IFSP?

Purposeful Sampling of Cases

- Purposeful sampling is a qualitative method where subjects/cases are selected in a specific way, as opposed to random selection
 - Sampling strategy used: **CRITERIA SAMPLING**
 - **CRITERIA** used for Subject selection: The infant had to:
 - have a significant hearing loss
 - been Identified between 2003 or 2004
 - have Informed Consent form on file
- Using this criteria, the 19 files were reviewed and 5 selected to be included in the case study.

Triangulating to Validate Findings



Brief Profile of the Cases

CASE #1-"Teacup"

CASE #2-"Wussy"

Brief Profile of the Cases

CASE #3-"Star 1"

CASE #4-"Star 2"

Brief Profile of Cases

- CASE #5 “Ditty”

General Observations
of all Cases:

Our PRELIMINARY Findings

resulted in the following.....

Early Intervention Services

- Were delaying the development of an IFSP in order to screen the infant 2, 3, or even 4 times to insure that the infant needed a full DAE. They were well intentioned as they wanted to be sure the infant had a potential hearing loss
- Delayed making immediate contact and follow up on infants referred due to scheduling problems. There was a paper processing issue.
- Valuable time was lost due to these delays.

The program has already made policy and procedural changes to address these issues

Parents of Infants with Hearing Loss

- In 3 of the 4 cases, parents showed a consistent pattern of no-show for follow up audiological appointments. In 2 cases they refused services altogether
- One case documented a parent who kept insisting that “the baby was making sounds” until services were discontinued
- BUT.....in one case everything was completed in a timely manner and significant improvements have already been observed.

Wussy

- Born Feb. 26, 2004 and had all rescreening and DAE completed by 6.1 months of age. IFSP on file by 8 months.
- At the annual evaluation on Nov. 9, 2005

	11/3/04	11/9/05	
	<u>8 mos</u>	<u>20 mos</u>	
Receptive Language Skills	8	24	REEL
Expressive Language Skills	3	22	SKI-HI
	2-4	22	HELP
	5	21	REEL

Wussy continues receiving early intervention services and audiological follow up.

Interpretation & Recommendations

- There is great value in using the NHS database for more than just reporting numbers. Simple manipulations can reveal information that can be used to improve services
- Strongly consider integrating both quantitative and qualitative methods when conducting studies or evaluating the program
- Cultural differences that are subtle and may go undetected can be addressed if data is manipulated in other ways
- Keep communication lines open among all stakeholders. The data findings should always be used to improve services and help families, NEVER for casting blame or making arbitrary changes
- Success in programs require a collaborative approach and willingness to cooperate to improve outcomes for infants
- These are preliminary findings and as our research continues we hope to discover new directions for improving services and in developing research directions that will assist families and professionals.



Post-Test

- Did you learn a little about the U.S Territory of GUAM?
- Do you have an understanding of the current status of newborn hearing screening efforts in GUAM
- Did you learn how Guam used the NHS database system to assist in improving hearing screening outcomes through various simple data manipulations?
- Did you understand how data feedback to key personnel regarding data trends can improve outcomes?
- Did you learn how qualitative research options, such as case studies, can offer new insights and directions in the research to improve outcomes for infants with hearing loss?

Did you get some ideas that you can try for your own home Country?

Si Yu'os Ma'ase
Grazie
Thank you

