Promoting Family-Centered Information Sharing Practices in Early Hearing Screening Contexts

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Overview

2 projects

- 1) Parent-Screener Interactions in a Universal Newborn Hearing Screening Program.

- 2) What's happening in BC? Developing a framework for promoting interdisciplinary collaboration, information sharing, and family-centered services within an early hearing detection and intervention environment?

Early Hearing Detection and Intervention (EHDI)

- All newborns screened for hearing loss before 1 month of age.
- Diagnostic audiologic evaluation before 3 months of age.
- Intervention by 6 months of age (Joint Committee on Infant Hearing, 2000).

Universal Newborn Hearing Screening

- Designed to identify infants who may have permanent, childhood hearing loss as well as those infants who require further audiological assessment to confirm hearing status.
- Programs differ in protocols and technology used.
- Average age of diagnosis of hearing loss with traditional model is typically over 3 years old.
- Late diagnosis of hearing loss is associated with delays in children's speech, language and social-emotional development.

Universal Newborn Hearing Screening Programs in Canada

- Approximately 10% of hospitals in Canada practiced high-risk screening with fewer programs implementing universal newborn hearing screening programs (Brown, Dort, & Sauve, 2001).

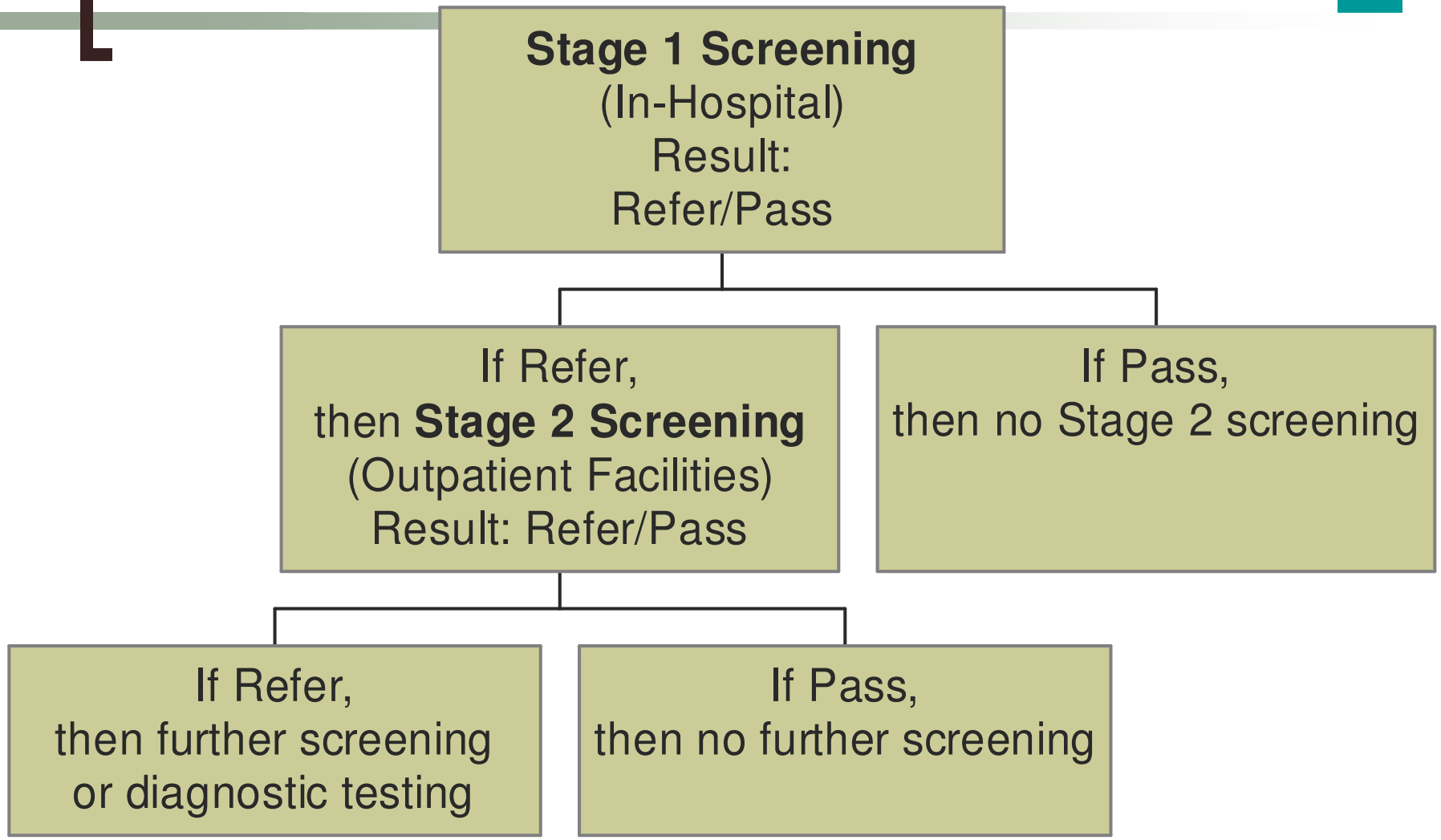
High-risk screening alone misses approximately 50% of children with permanent, congenital hearing loss (Mehl & Thomson, 1998).

How is newborn hearing screening possible?

Technology

- OAE: Oto-acoustic Emissions
- ABR: Auditory Brainstem Response

A Two-Stage Screening Protocol



Rationale for the Study

- Parents' reports of stress and anxiety following an initial stage of screening where a positive (refer) result was found
- Parent-professional interaction identified as a potential factor influencing parents' emotional reactions to screening
- Limited research available pertaining to communication of UNHS results, parent-professional interaction, and accounts of the results

Research Questions

- What is the discourse surrounding the disclosure of re-screen results in one UNHS program and how is this discourse constructed?
- What are potential social influences that shape these constructions?

Research Site

- A provincial universal newborn hearing screening project in Canada
- An outpatient facility where infants received a Stage Two screen in a two-stage screening protocol
- A room within an Audiology department of a Children's Hospital located in a metropolitan area

Recruitment of Participants

- Professionals at Stage 1 provided parents who fit criteria with information about the study
- If parents indicated interest, then I met parents on time and date of Stage 2 screening.
- Researcher contacts professionals at Outpatient facilities involved in Stage Two screening to provide screeners who fit criteria with an invitation to participate in the study

Participants

- 5 mothers
  - 5 mothers of infants who had received a “refer” result at Stage One
  - 4 of 5 mothers received “pass” results at Stage Two
  - 1 of 5 mothers received a “refer” result at Stage Two
- 1 screener who had communicated screen results at Stage Two to each of the parent participants: audiology assistant

Parent Participants

- Age: 20 to 26 years old
- Household income: $15,000-$25,000 to $45,000-$55,000
- 4 of 5 mothers part of a two-parent household
- 2 of 5 mothers first-time parents
- 1 mother of an infant who had been diagnosed with a hearing loss
- No prior knowledge of UNHS or involvement with the provincial project

Types of Interactions

Observation of Screening (Screener - Parent) →	4 of 5 mothers
Parent Interview (Researcher - Parent) →	All 5 mothers (1 mother retrospective)
Screener Interview (Researcher - Screener) →	1 screener

Sources of Data

14 interactions

- 4 videotaped screening interactions
- 5 follow-up interviews with parents
- 5 follow-up interviews with a screener
- Follow-up interview included a videotape review portion

A Discourse Analytic Approach

(see Potter & Wetherell, 1987)

- Repeated viewing and listening to the video- and audio-taped data
- Transcription of video- and audio-taped data using Jeffersonian transcription key (see Jefferson, 1985)
- Coding of transcripts
- Reading transcripts prior to analysis: “What feelings came across as I was reading the text?” “What aspects of the text are influencing me to read the text in this way?”

Transcription Symbols (from Jefferson, 1984, 1985)

Characteristics of Speech Delivery

- Sustained sounds are indicated with a colon (:)
- Falling intonation - down arrow (↓); Rising intonation – up arrow (↑)
- Emphasis on speech with underlined text
- Increased volume speech indicated by CAPITAL letters
- Markedly quieter speech with a degree sign at each end of utterance or passage (°)
- Greater than and less than symbols enclose speech delivered more rapidly (>text<) or more slowly (<text>) than usual for speaker
- Laughter and audible inhalations (.hhh) or audible exhalations (hhh)

Transcription Symbols (from Jefferson, 1984, 1985)

Gaps, Overlaps in Talk, and Transcriber's Notations
▪Brackets indicate the start and end points of overlapping speech [text] ▪A break and subsequent continuation of a single interrupted utterance is indicated with an equal sign (=) ▪Pauses/Silences: timed in tenths of a second and indicated in parentheses within and between turns (# of seconds) ▪Micropause: A brief pause is indicated with a period in parentheses (.) ▪Transcription doubts and difficulties – within parenthesis (text) or parentheses enclosing blank space ( ) ▪Transcriber's descriptive comments in double parentheses that include activity description or aspects of the interactional setting ((italic text))

Transcription: An Example…

Lori: [So do you - do you] know about the - the TEst? Do you know what we're doing or?

Kate: U::m:: not really, no.

Lori: Okay. So >you weren't with him in the hospital when they did the screen?<

Kate: I WA:s, but she didn't really te:ll=

Lori: Oh:

Kate: =me a whole lot.

Lori: [Oh okay alright]

Kate: >She kinda stuck something in his ear and told me to come back< s(hhh)o:

Analysis: Becoming aware of what the text was doing

- Searching for patterns of variation and consistency
- Developing hypotheses about functions of talk in interactions
- Examining the linguistic resources of discourse
- Writing: clarifying analysis; noting inconsistencies and tensions which led to new insights

Screener's Talk:

An Example

- Are you concerned?
- Are you?
- Is it…?
- In what way?
- To loud noises you mean or to your voice?
- And you remember your son doing that at a young age?
- Okay (repeated)
- Okay. Alright. Were you with her in the hospital when they checked her?
- And did they explain the test to you there or?

The Talk of the Interactions

Screener

- Took the lead (How?), goal-directed talk, requests, declarative statements, Yes-No questions; initiated topic shifts

Parents

- Followed the lead of the screener (How?); shorter conversational turns, acknowledgment tokens, few initiations, few questions

Another example…

Lori: What we're looking for. >We're gonna put some sounds in her ears< and we're looking for -- >it's called an emission but it's< like an ↑e:cho:=

Janice: Okay.

Lori: =>In response to that sound.< And it comes from her inner ear.

Janice: Okay.

Lori: And what we know about the inner ear is that when we hear that echo coming back out, it's healthy. It means that it's working properly and that she's hearing the sound.

Janice: Okay.

Lori: Okay. And we test at three different pitches or to:nes.

Janice: Okay.

Lori: Okay. And that's why we... you know, it is just a screening. We're not testing at <every (.) conceivable, audible sound.>

Janice: Okay.

Lori: But we're testing the important frequencies for speech perception. So. ↑Okay. And we need to do bo:th ↑ea:rs.

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How was the discourse constructed?

Screener Talk

- Factual accounting conveyed a sense of confidence and certainty; indicated lack of personal stake or interest in claims made; could remove self from her talk with parents; could build up facticity of accounts

Parents' Talk

- Put forth claims and supported them through various devices; indicated personal stake and interest in claims

Construction of the Wait Period

Screener's Version

- need to repeat the screen several times
- parent may not be anxious about the screen result but may just want to complete the screen

Parent's Version

- time to screen this ear is much longer than for the other ear
- concern that child may not be able to hear in one ear

Eye gaze - An example

Counter	Lori's Eye Gaze	Carol's Eye Gaze	Action
4:19	Screen device	Lori	Wait for result (L,C)
4:20	Screen device	Screen device	Wait for result (L,C)
4:21	Screen device	Thomas	Wait for result (L,C)
4:22	Screen device	Lori	Wait for result (L,C)
4:23	Screen device	Screen device	Wait for result (L,C)
4:25	Screen device	Thomas	Wait for result (L,C)

Videotape Review:
Screener Interview

Construction of a “Pass” Result

- Pass as an indication of physiologic response and biological functioning
- Pass as one of two options on the handheld screen device indicating detection of emission or echo
- Pass as ability for infant to hear sounds, such as the sounds of speech

Construction of a "Refer" Result

Parents' Versions

- Associated with infant's ability to hear and the possibility of a hearing loss
- Linked with the infant's observable behaviours in response to sounds

Screener's Versions

- A number of factors of the screening environment may have influenced the result
- Fluid or vernix in the ear
- Does not mean that the infant is deaf

Parent Interview: What does a “refer” result at Stage One mean to parents?

Variation in Discourse

- Accounts of screen results varied depending upon factors such as:
  - conversational partner
  - timing during interaction
  - nature of the conversational turn

Consistencies in Discourse

- Consistencies: screener's use of factual accounting
- Positive Connotation to word "pass" associated with terms such as "good," "fine," "normal," "healthy," "working properly," "hearing," "happy," and "relief"
- Use of the word "fail" vs. "refer."
- Parents' accounts of receiving limited amount of information at Stage One

Social Implications of the Interactions

- Competing versions (e.g., referral as a "double bind;" Chenail et al., 1990)
  - Lori: "I don't want to make it sound like it's nothing and frivolous but at the same time it's not necessarily the end of the world either."
  - "cautious but not alarming"
- Unvoiced concerns and unasked questions

Possible Social Influences on the Interactions

- Screening embedded within a biomedical framework; instrumental prioritized over interpersonal (Walker et al., 2001)
- Screening Framework - guidelines and recommendations; less focus on process and desired outcomes for the interaction

Future Implications

- May help to inform the development of family-focused services in newborn hearing screening programs:
  - Parent-centered screener talk (see Street, 1991; Street & Millay, 2001)
  - Inviting discussion of parents' unvoiced concerns
- May help to improve follow-up of parents and their infants to subsequent stages of screening and diagnostic testing

Future Implications (continued)

- May indicate the importance of attending to the *process* of screening in more depth rather than predominately on outcomes
- May contribute to theories of meaning construction through its emphasis on social contexts and their influence on screener-parent interaction and language use
- May inform theories of curriculum development for training screeners UNHS programs

Practical Implications

- Video as a powerful resource for training.
- Training: Scripts? Being attuned to the family's needs. Attention to discourse.
- Timing of the appointments: Giving families the time they need.
- Family-friendly screening environments. How can this be promoted?
- Screener: *Finding balance* – how to indicate the importance of follow-through yet not cause undue concern…

Limitations of the Study

- Lack of diversity in talk of participants who differed in age, ethnicity, and degree of hearing loss
- Lack of diversity of types of screening interactions observed (e.g., all Stage Two, similar types of screening procedure)
- Issues of reactivity

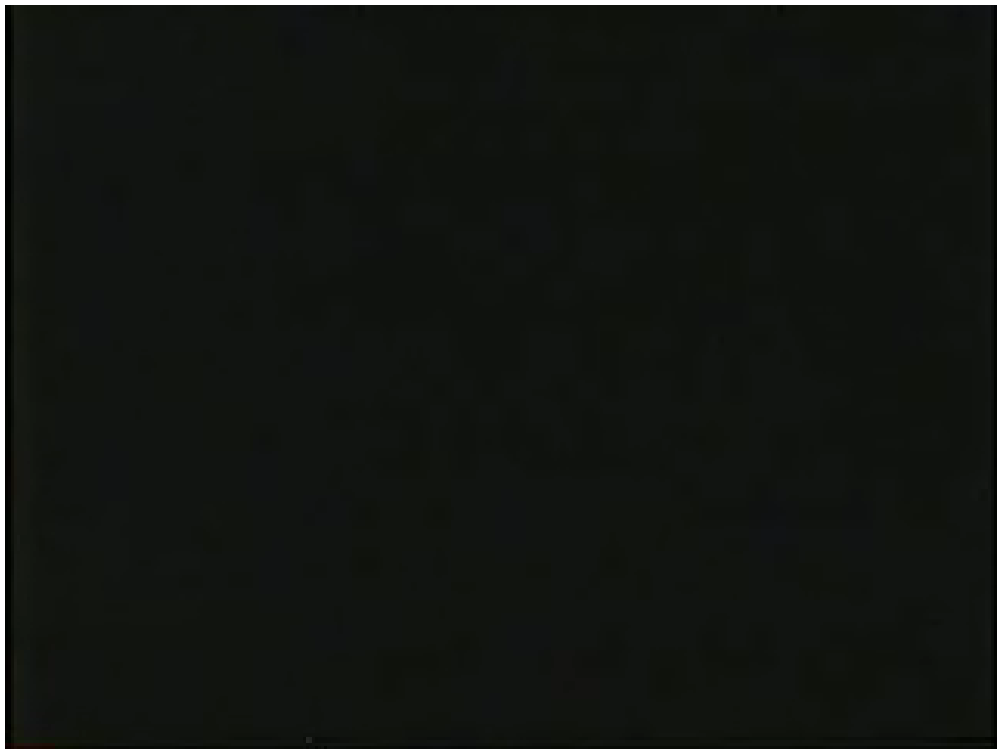
Early Hearing Detection and Intervention in BC

- In March, 2005, the provincial government in BC announced funding for the “Sound Start” Early Hearing Program.

- Early Hearing Program will be delivered and managed through the Provincial Health Services Authority and the regional health authorities.

In BC, the aim is to begin screening newborns in Well Baby Nurseries in fall, 2007.

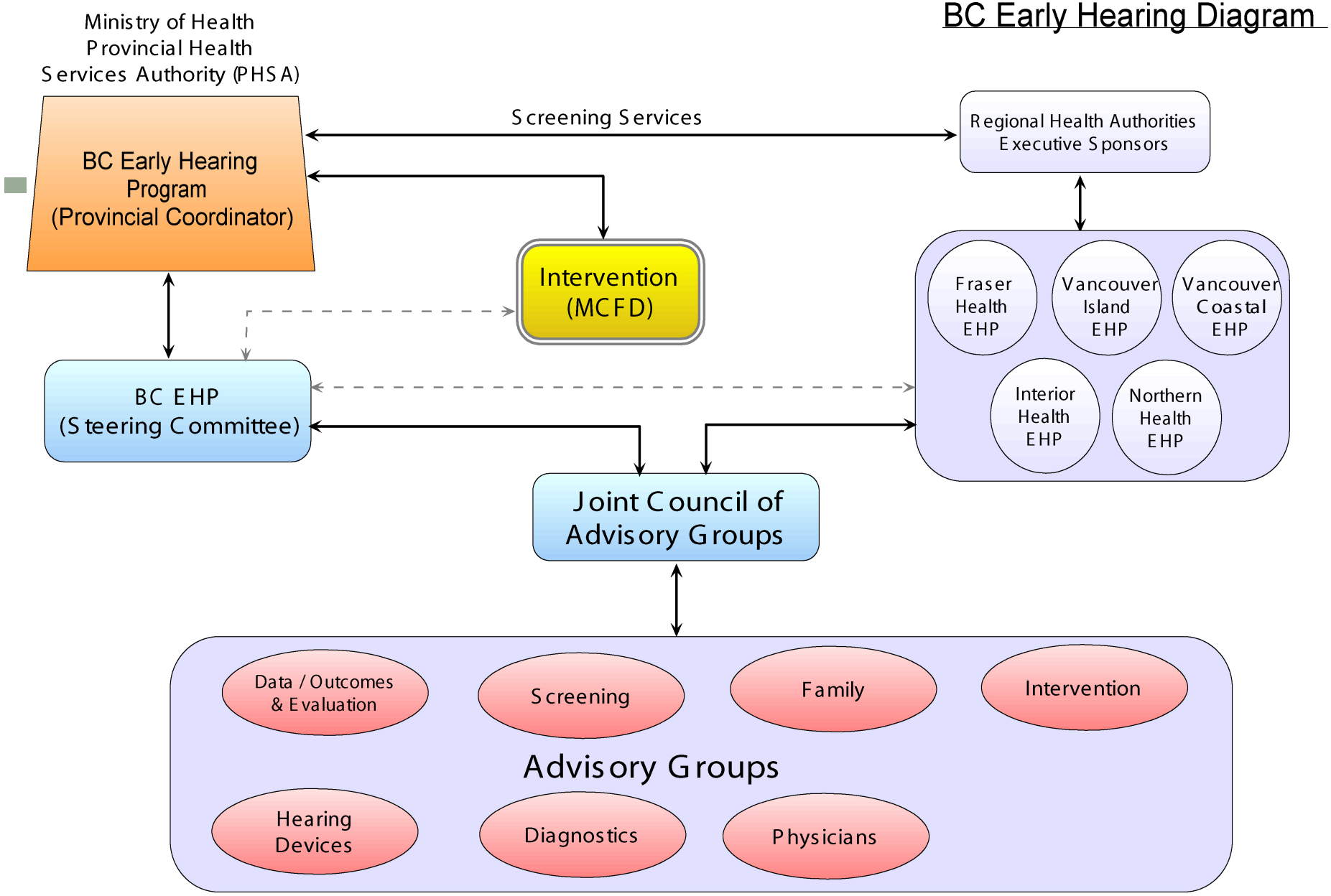
BC Early Hearing Program: Announcement



Organizational Structure of EHDI-BC

- **Steering Committee**
- **Advisory Groups**
- **Regional representation**
- **Provincial Coordinator**

BC Early Hearing Diagram



Our Advisory Group…

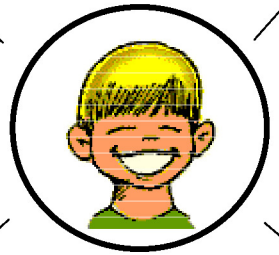
- **Purpose:**
  - **Develop a framework for program monitoring, evaluation, and reporting that incorporates outcomes and indicators for screening, assessment, and intervention components of the program.**
  - **Key questions: How will we know that early identification is making a difference? Is it improving children's outcomes?**

Review of Data Sources

- **Environmental Scan: Where are the data and how are data being collected and managed?**
- **Telephone and e-mail interviews**
- **Participants: audiologists, audiometric technicians, teachers of the deaf and hard of hearing, early intervention professionals.**

Data Sources for Deaf or Hard of Hearing Children

Universal newborn hearing screening data



Data Set:

Individual Education Plan (IEP)

Form 1701

Ministry of Education

Data Set:

Audiological assessment data

Other medical data

Ministry of Health

Data Set:

Infant Development Program data

Early intervention data

Ministry of Children and Family Development

Issues in Developing the Framework

Current system involves

- fragmented systems of data collection.
- several independent, stand-alone systems.
- inconsistencies in data collected.
- disjointed records for each child.
- potential for duplication in records.
- inability to fully support a universal newborn hearing screening program.

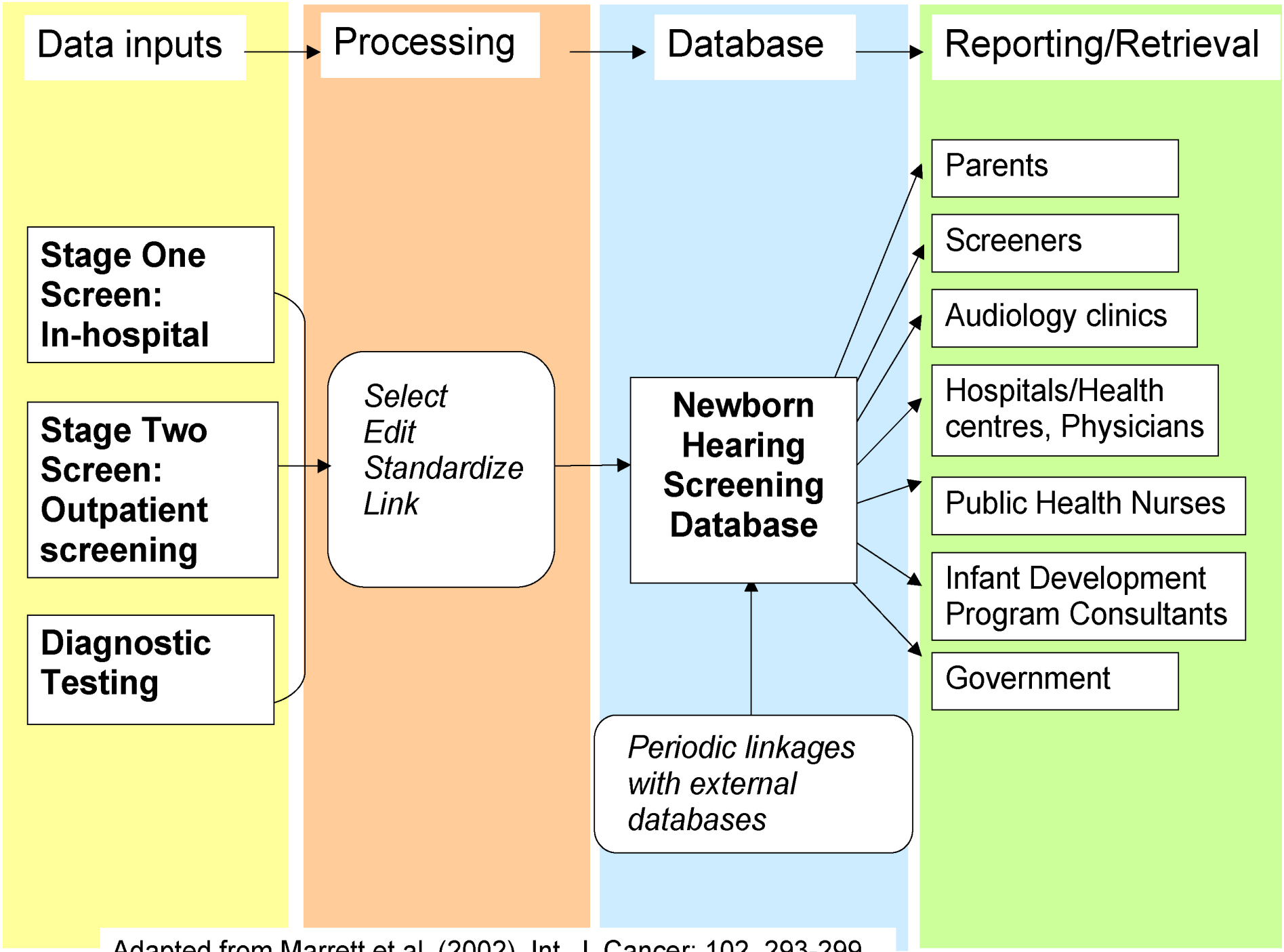
Continuum of Services

- **Infant screening for congenital, childhood hearing loss.**
- **Ongoing surveillance for later onset and progressive hearing loss.**
- **Medical and audiological assessment for confirmation of hearing status.**
- **Amplification for optimal use of available hearing.**
- **Educational programming to promote communication, language, and social-emotional development.**

What is needed?

1) Newborn Hearing Screening Database

2) BC Hearing Loss Registry



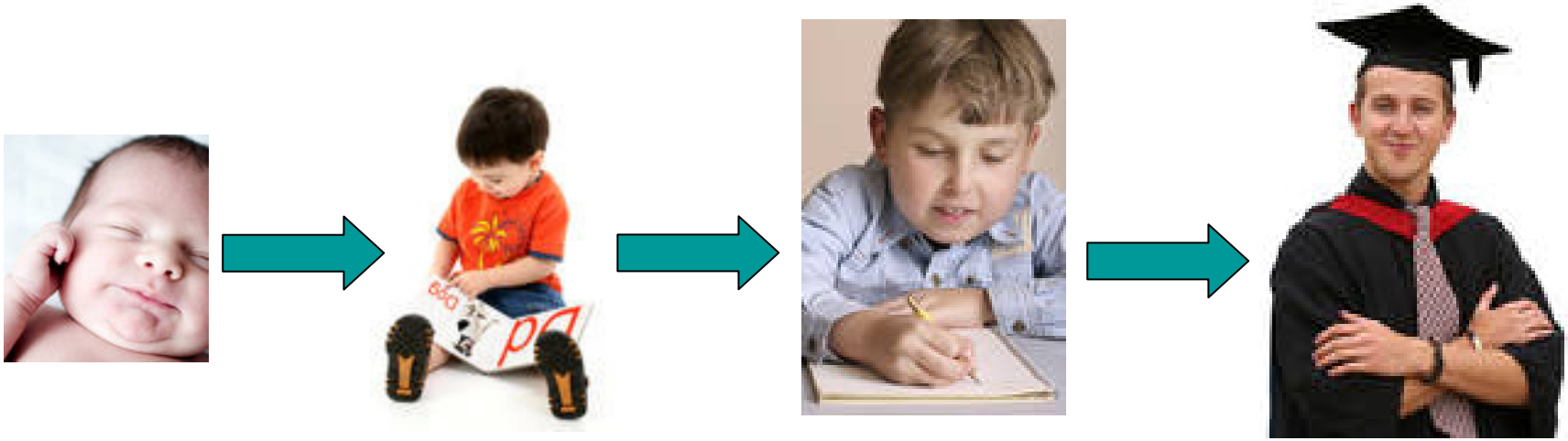
Adapted from Marrett et al. (2002). Int. J. Cancer: 102, 293-299.

BC Hearing Loss Registry: Objectives

- Collects data and generates statistics regarding trends and regional differences in incidence of hearing loss in BC and impact of hearing loss on children's developmental outcomes.

- Evaluate access to care and intervention and their short- and long-term impact on children's developmental outcomes.

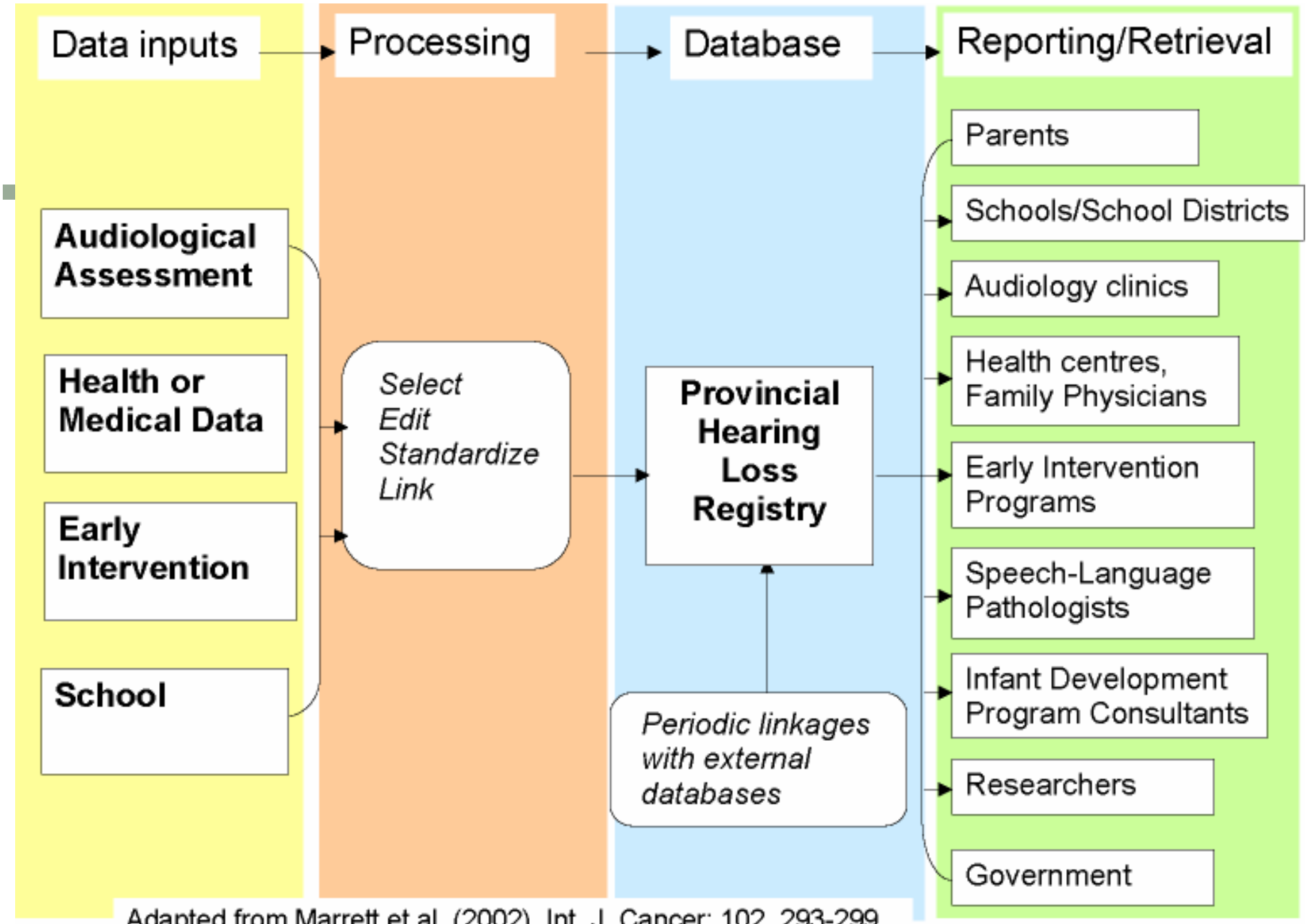
Monitoring Developmental Trajectories



Hearing Loss Registry

Aims to monitor:

- Type, severity, and laterality of hearing loss of each child over time.
- Type and severity of any additional disabilities.
- Speech, language, social-emotional, and educational outcomes of children with hearing loss over time.
- Interventions received by family and child and identify children who are behind in needed intervention services.



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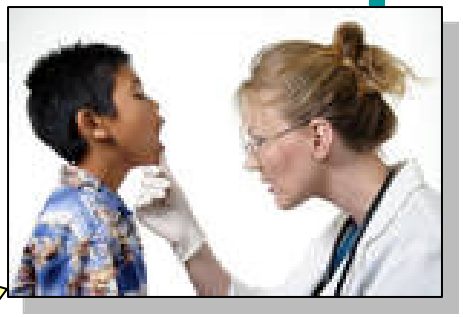
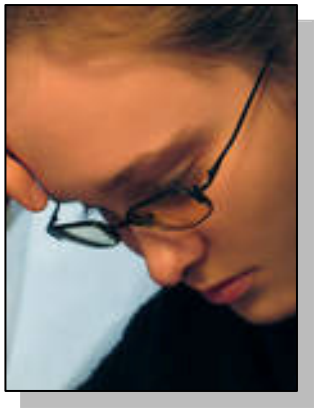
What can we share?

Specialists

Government:
Decision-Makers



Family Physicians



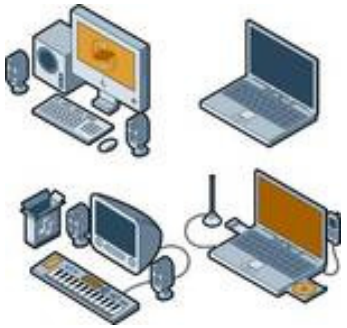
Researchers

Families

Educators

Life Cycle of Registry Development

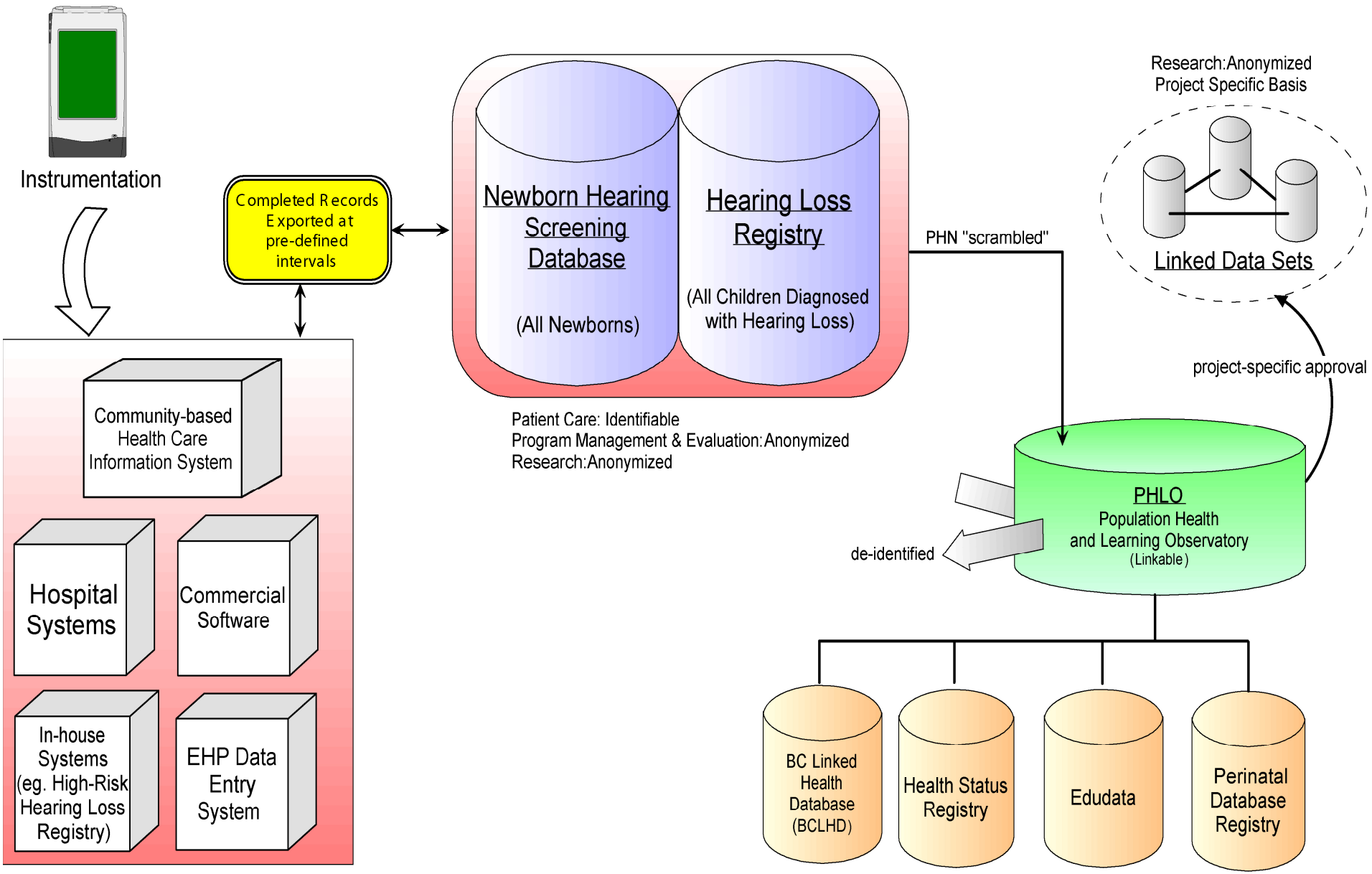
- Analysis
- Design
- Implementation
- Evaluation



Current and Future Directions: New Insights and Understandings…

- Develop requirements for the prospective part of the registry (ongoing).
- Pre- and post-screening comparison (2007-08): *How do the developmental trajectories of children who were identified with hearing losses before early hearing screening compare with those children who were identified early?*
- Investigate types of factors that may influence a deaf or hard of hearing child's outcomes over the life-course. *Beyond age of identification, what are other factors that may promote or hinder the developmental trajectories of children who are deaf or hard of hearing?*
    - Contributions from other health, developmental and educational data sets (e.g., school readiness, academic achievement).

BC Early Hearing Program Data Flow Diagram



Involving the Stakeholders

Interdisciplinary collaboration involving stakeholder representatives

- Discuss program goals, key outputs or measureables, and their fit with objectives.
- Discuss currently used methods for utilizing and analyzing data
- Identify gaps and needs.

BC Early Hearing Program's Hearing Loss Registry:

What we hope to achieve...

- **Family-centered program support.**
- **Program management and quality data and information.**
- **Research and evaluation.**
- **Program planning and development.**

Summary

Overview of 2 very different ways to support professionals and families within early hearing screening contexts.

- **Attentiveness to the *talk and interactional context* of the screen.**
- **Value of having a *shared, central resource* that can integrate various types of information from different sources.**

HELP's Vision

"To create, promote and apply new knowledge through leading interdisciplinary research to help children thrive."

Thank you!

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Please visit http://www.earlylearning.ubc.ca/