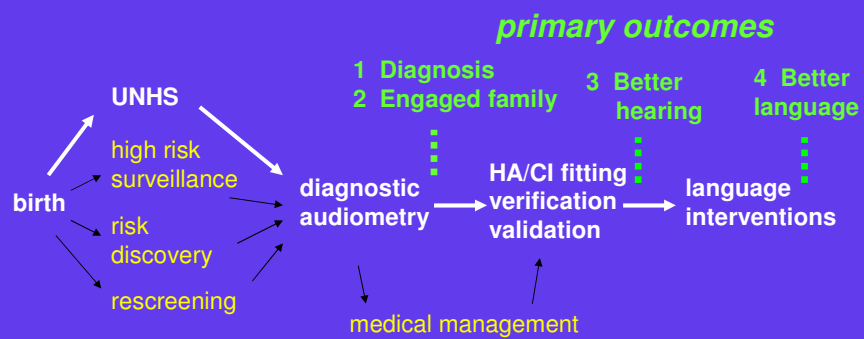


# Ontario Infant Hearing Program Service models & Family engagement

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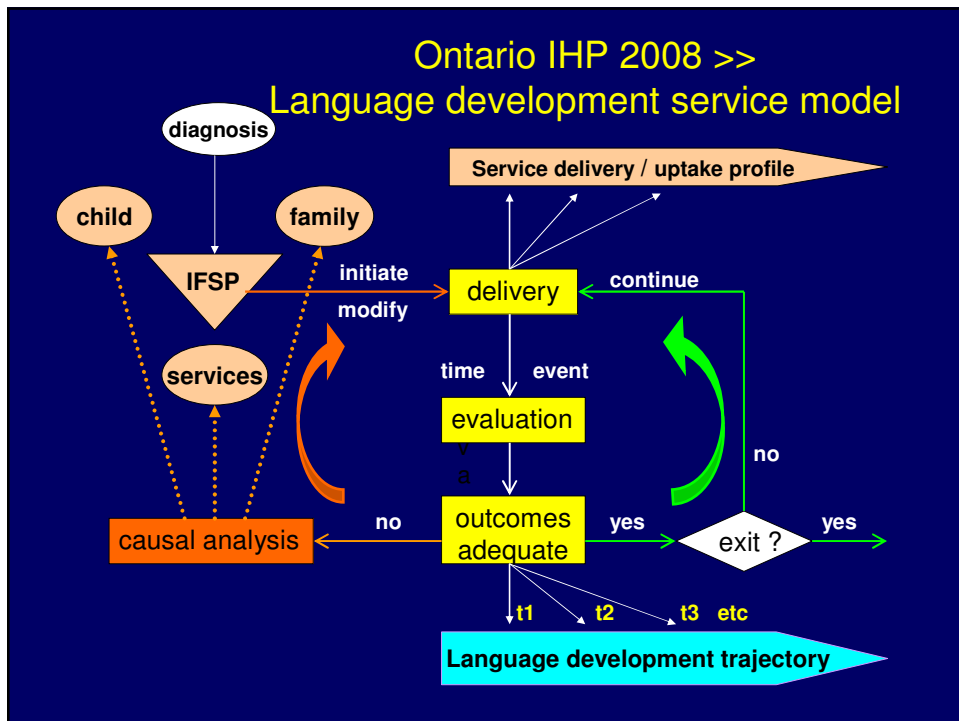
## Early Hearing Detection & Intervention (EHDI) model



[... program evaluation & quality improvement...]

# Language Development Example

IHP Service Model:  
Processes & Outcome measures



## Language-related measures

- Language development trajectory:  
Age-specific percentile rank scores on Preschool Language Scale (PLS-4)
- Service delivery / uptake profile:  
Provider, Quantity, Style, Transfer  
Style category on auditory-visual continuum  
A ... Av ... AV ... aV ... V

## Family Engagement

What is it?  
Why does it matter?  
How to measure it?  
How to facilitate it?

## What is family 'engagement' ?

- Understands what the diagnosis means
- Accepts the truth of the diagnosis
- Cares about child's communication development
- Constructively adapts worldview to the new reality
- Has the resources (cognitive, economic, etc) to respond to child's needs & intervention demands
- Can deal effectively with amplification, etc
- Can attend, participate effectively in & transfer language intervention service content
- Can cope with other personal / environmental stressors
- Has a supportive relationship structure

## Moeller Family Participation Scale

*Moeller MP Pediatrics 2000;106:e43*

- Explains more variation in language outcomes than anything else!
- Five-point rating by provider: 1 ~ 2 >> 3 >> 4 ~ 5
- 1 = 'Good adjustment, actively engaged, strong conversational partners', etc.
- 5 = 'limited understanding of deafness, participation sporadic or ineffective, very basic communication, significant interfering life stresses', etc.

## FPS limitations

- Scale points reflect combinations of many diverse variables
- Rationale for combinations is unclear
- Variables appear & disappear over points
- Some binary, some rank, some qualitative
- Subjectivity very high for some items
- Yet.....it worked

## Perhaps we can do better...

- Qualitative analysis of FPS: identify key dimensions & scale points
- Group dimensions into major domains
- Develop a rational, conceptual model
- Develop questionnaires (sets of items)
- Express all domain scores as profile
- Validate psychometrically

## Family Engagement Profile (FEP) domains

- Understanding
- Acceptance > Adjustment > Empowerment
- Attendance > Participation > Effectiveness
- Stressors (barriers) vs Resources (Facilitators)
- Capacity, Opportunity, Diversity

## Threats & known consequences

- Preceding misinformation (Understanding)
- Ignorance or misconception of disorder:  
nature, implications, options,... (Understanding)
- Disbelief, denial, devaluation (Acceptance)
- Anger, guilt, anxiety (vs concern) (Adjustment)
- Disempowerment (Adjustment)
- Paralysis, indecision, delay, loss to followup...  
undermine whole point of early identification

## How can the audiologist facilitate family engagement?

- The approach & style of information and support can have a major impact on successful adjustment & engagement
- Approach based on underlying conceptual 'model', evidence & experience
- Grief (Kubler-Ross), Stress & Coping, Family Systems, Social Construction models

## UK NHSP investigations: sharing news & family support

*(Gwen Carr, Alys Young)*

- Family experiences: NDCS database
- Family focus groups
- Deaf community's viewpoints
- Research programs
- Evidence reviews (across 'disabilities')
- Clinical trials
- Synthesis of all information sources

## UK findings (my wording)

- Traditional 'medical' model is inadequate
- Traditional Grief model rarely optimal
- 'Positive Support' Model
  - Collaborative engagement, moving forward together, much can be achieved, you are not alone*
  - What are the (positive) possibilities?
  - What are reasonable goals, expectations?
  - What you can do, what we can do, what do you need, who can help most, when and how...

## Important info delivery elements

- Expertise
- Honesty
- Empathy
- Professionalism
- Accessibility
- Continuity, integration, consistency  
(reasonable alternatives, not doctrinaire advocacy)



## 'Sharing the news' elements: Positive Support Model

- Privacy, space, comfort
- Time, timing (x2), pacing, accompaniment
- Respect for individuality, culture, values, beliefs
- Empathy, warmth, caring vs sympathy
- Invite feelings, views, questions, concerns
- Inquiry & exchange, not delivery, '3<sup>rd</sup> ear'
- Avoid jargon, verify understanding, use open Qs
- Provide review, take-home materials, activities, access, appointments