Early Hearing Detection & Intervention (EHDI)
Status, Challenges, Directions

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Program Goal

- Every child with significantly impaired hearing
- shall have full and equal access to
- prompt and effective services to optimize
- their development of communication skills

What the words really mean

- Every: no child shall be missed
- Full: all barriers to access minimized
- Equal: no child has limited access
- Prompt: as soon as the impairment occurs
- Effective: evidence-based, highest quality, appropriate to individual needs/characteristics
- Development: no quick fix, complex, lengthy
- Communication skills: language development, early literacy, cognitive & social development, readiness for school…..

Why a program for early hearing?

- Hearing underpins oral language development
- Family knowledge underpins ANY language dev.
- Language underpins literacy, school readiness

- Brain development underlying auditory perception & early language is EXPLOSIVE during infancy

  Use it or lose it (or never fully develop it…)

- Universal family right to know?
- Universal child right to communicate, to hear?

Why NEWBORN SCREENING ?

- Early enhancement of H and CD are crucial
- Early enhancement requires *earlier* diagnosis
- Earlier diagnosis requires *even earlier* detection

BUT

- Most hearing impairment invisible in young infants
- CANNOT be reliably detected behaviourally!
- Modern physiological tests can detect it at birth
- Access to babies easiest during birth admission

Why UNIVERSAL screening?

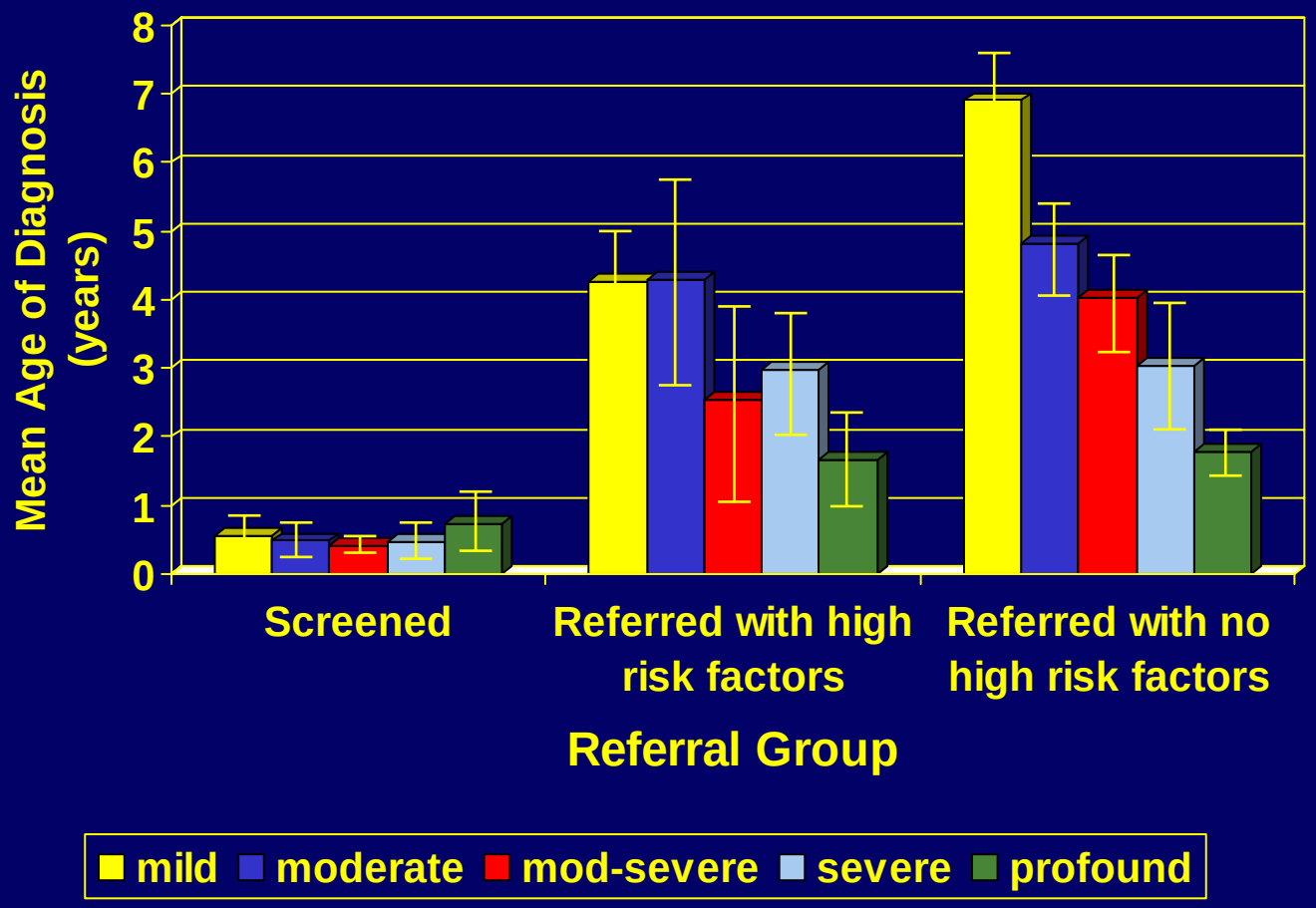
- Hearing impairment more common (~2/1000) than any other disorder for which newborns are screened
- Only about half of all newborns with impaired hearing have observable risk indicators (5-10% are at risk)
- Targeted high-risk hearing screening violates the equal access and universal rights principles
- Universal screening IS practicable and IS NOT costly, given the ensuing benefits to child, family, society

What happened before EHDI?

- Medical referral was hopelessly ineffective
- Public & professional awareness was minimal
- AVERAGE age at detection was 2-3 years
- Many children not diagnosed until school age

Age at diagnosis, by severity and route to diagnosis, N=613 with HAs (Ontario)

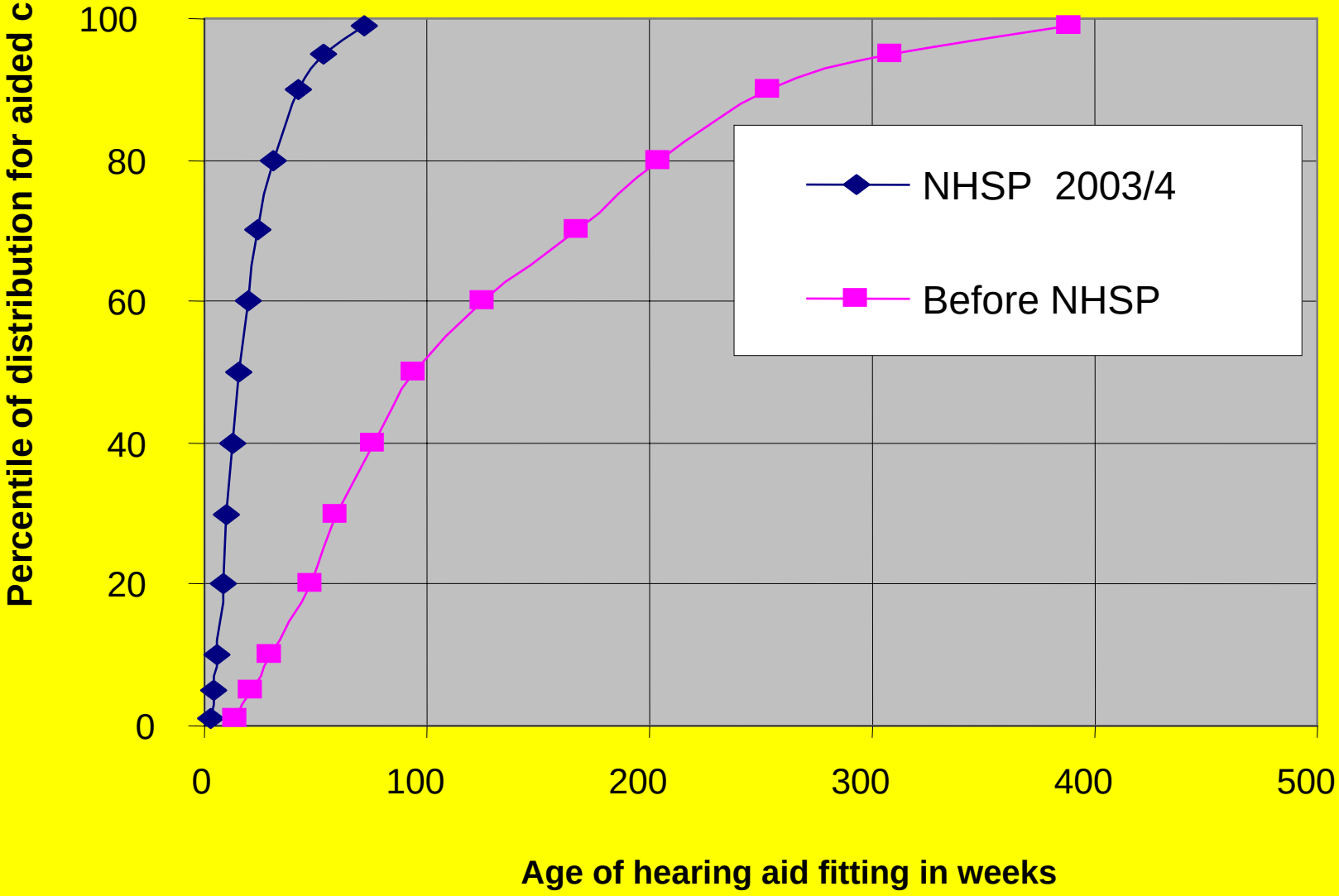
Durieux-Smith & Whittingham, J Sp Lang Pathol Audiol, 2000



EHDI IS EFFECTIVE!

- Better early hearing (HAs, ADs, CIs)
- Better language development outcomes
- Better family communication strategies
- More informed family decision-making
- Medical benefits (management, etiology, syndrome detection, surveillance, genetic counselling, etc)

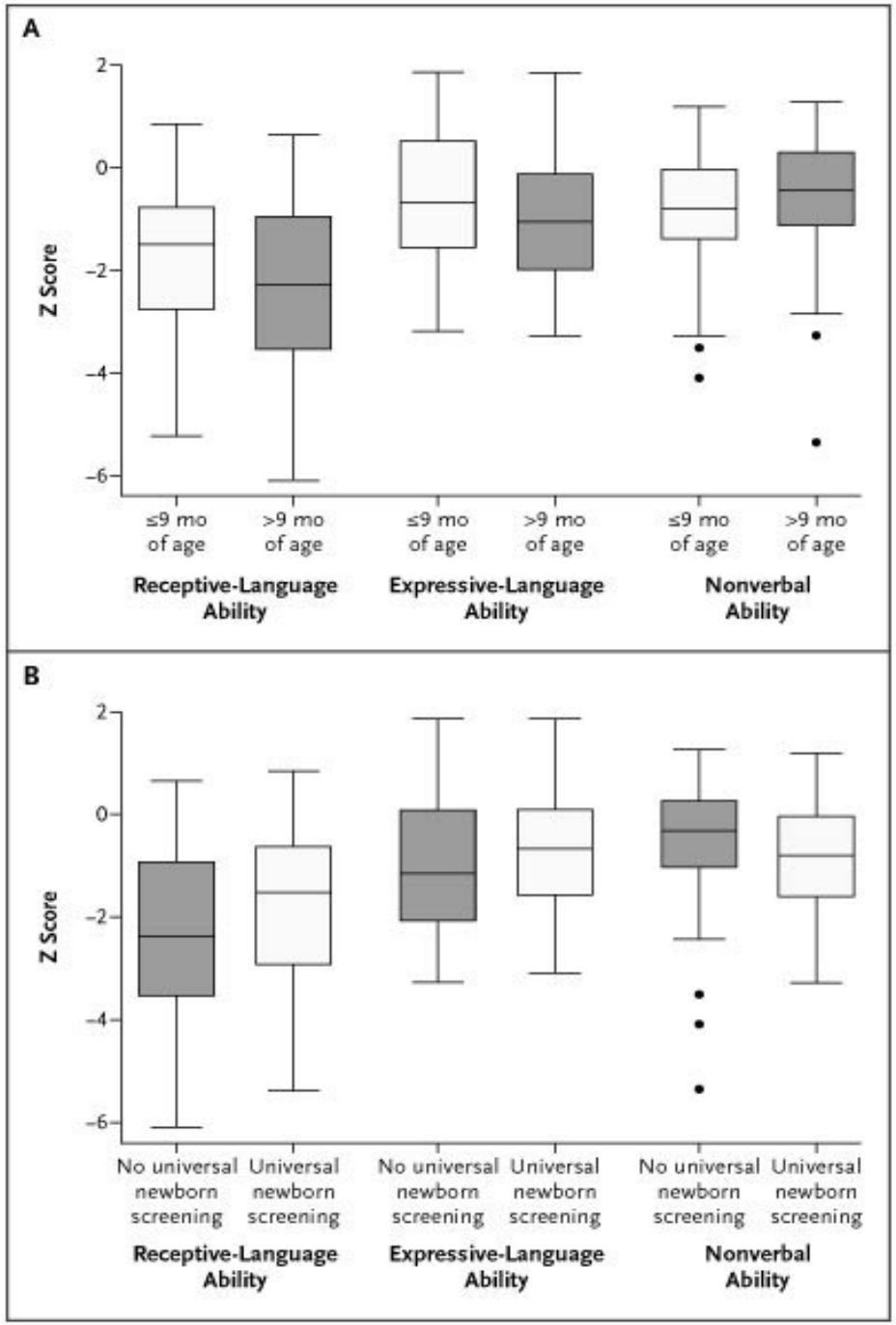
Distribution of age at hearing aid fitting for hearing impaired newborns before and after NHSP introduced



(NHSP eSP data Feb 2005, n=228; Davis et al 1997 n=495)

Kennedy C et al

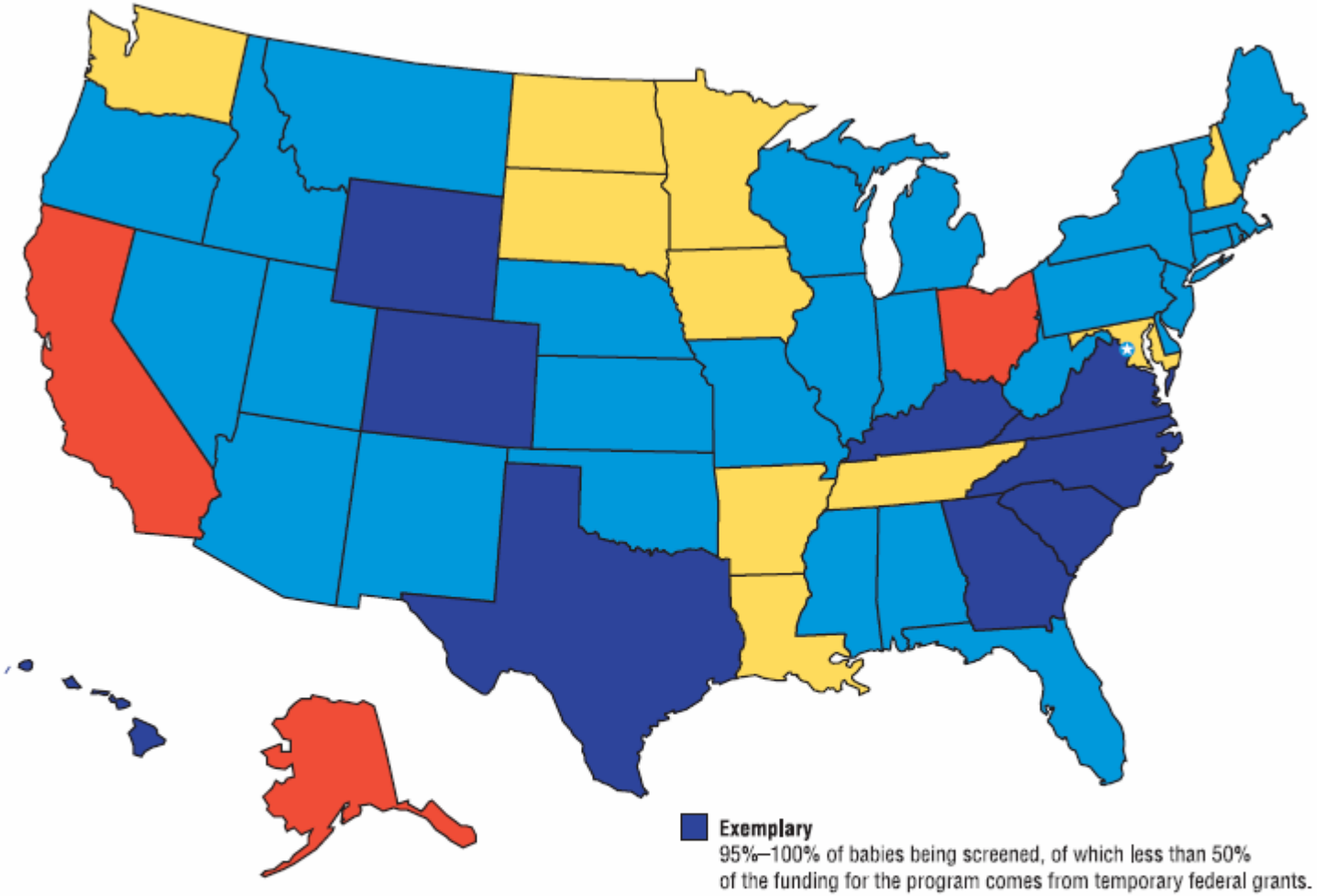
NEJM 2006, 354;20:2131-41



UNHS status in Canada

- NB, ON, PEI, YK — implemented
- BC, NS — announced 2005
- QB — draft PH proposal
- AB, MN, NF, SK — partial or NICU-only

The State of Infant Hearing Screening in America



Exemplary
95%–100% of babies being screened, of which less than 50% of the funding for the program comes from temporary federal grants.

Excellent
94%–100% of babies being screened, of which most of the funding for the program comes from temporary federal grants.

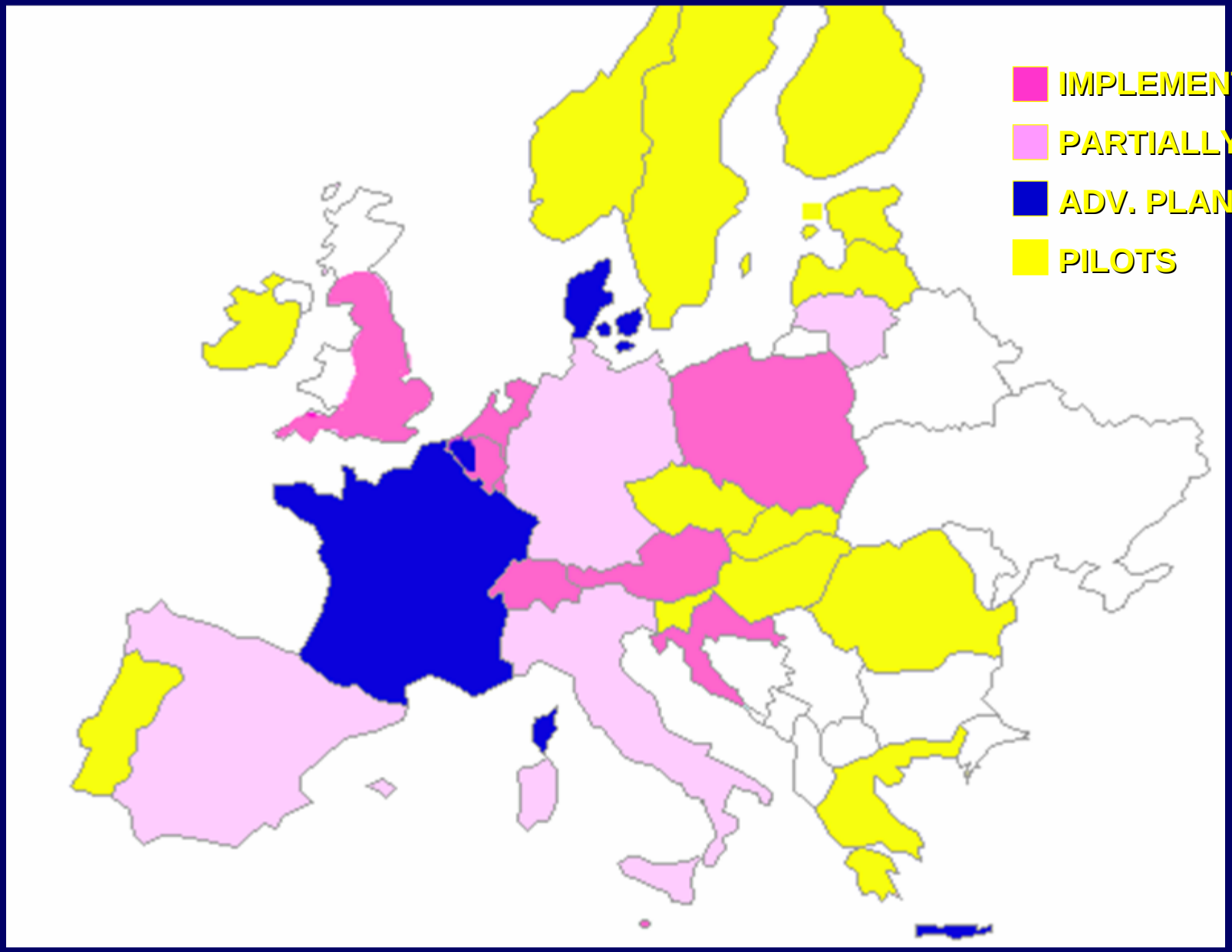
Good
80% to 94% of babies being screened.

Unsatisfactory
80% or less of babies being screened.

As of May 2004—Data collected by NCHAM

WORLD COUNCIL ON HEARING HEALTH
DEAFNESS RESEARCH FOUNDATION

EHDI SYSTEMS IN THE EUROPEAN AREA



Why is the IHP admired worldwide?

- Government recognition and support
- Quality and dedication of personnel

- Evidence-based, family-centered
- Completeness
- Centralized design, evaluation, development
- Regional implementation & adaptation
- Strong protocols & standardization

Standard protocols are CRUCIAL

- Driven by evidence: only one best approach
- Every child/family entitled to standard of care
- Diverse practices undermine program evaluation and contribution to knowledge
- Deviations must be known, justified, approved and accounted for in program reporting/QM

The domino effect problem

• Initial screening coverage	95%
• Compliance to re-screening	95%
• Test sensitivity	95%
• Compliance to diagnostics	95%
• Follow-up service uptake	90%
• NET PROGRAM PERFORMANCE	73%

- Continuous quality improvement CRITICAL!

IHP screening tests & protocol

- Automated Distortion Product Otoacoustic Emissions (ADPOAE, ‘AuDX’)

- Automated Auditory Brainstem Response (AABR, ‘ABaer’)

- No risk: AuDX > ABaer > ABaer > Dx
- At-risk: ABaer > Dx

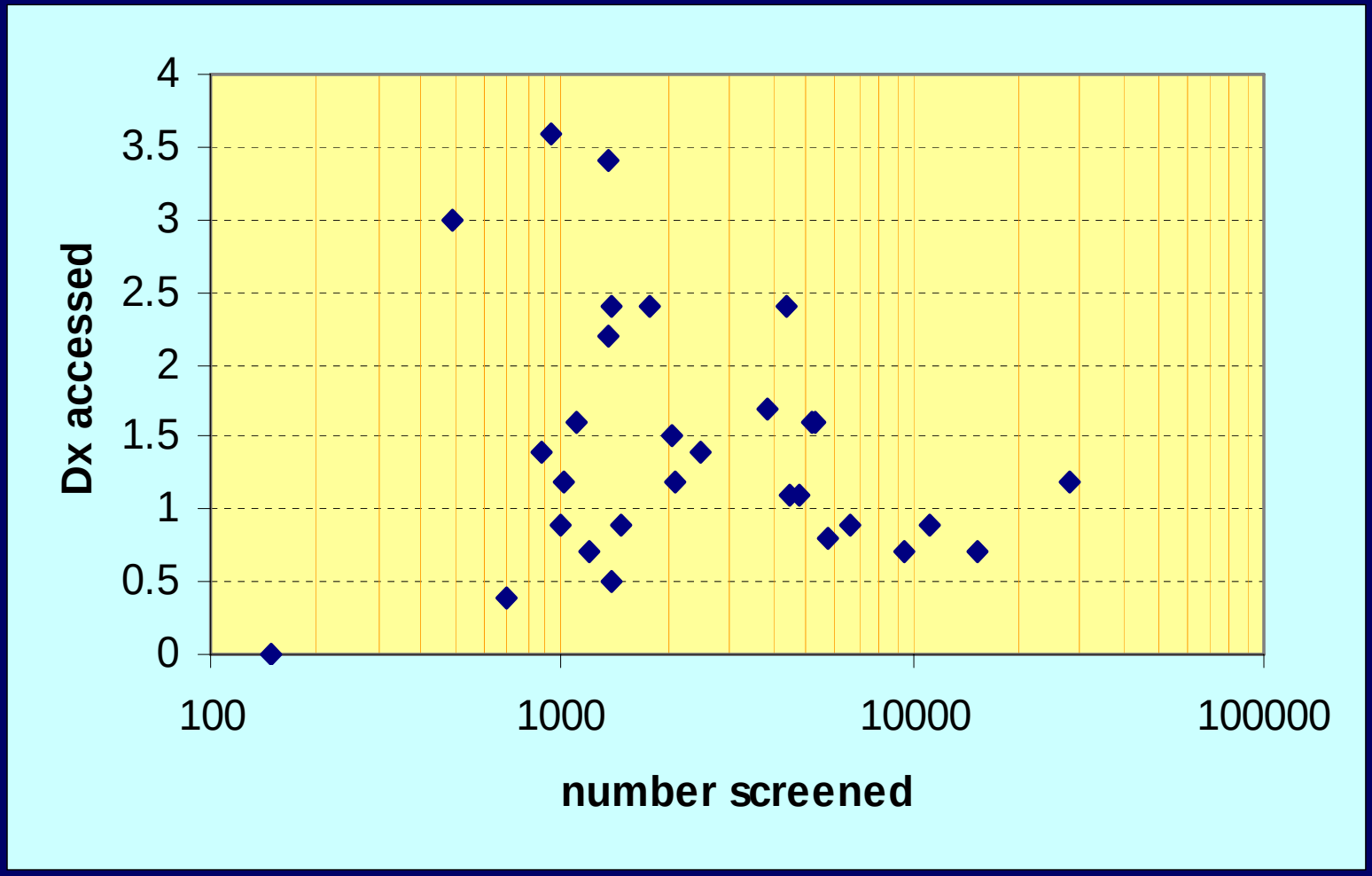
Screening

- Protocols are strong and evidence-based
- Newborn coverage is very good (>98%)
- Overall net refer rates to Dx are good (<2%)

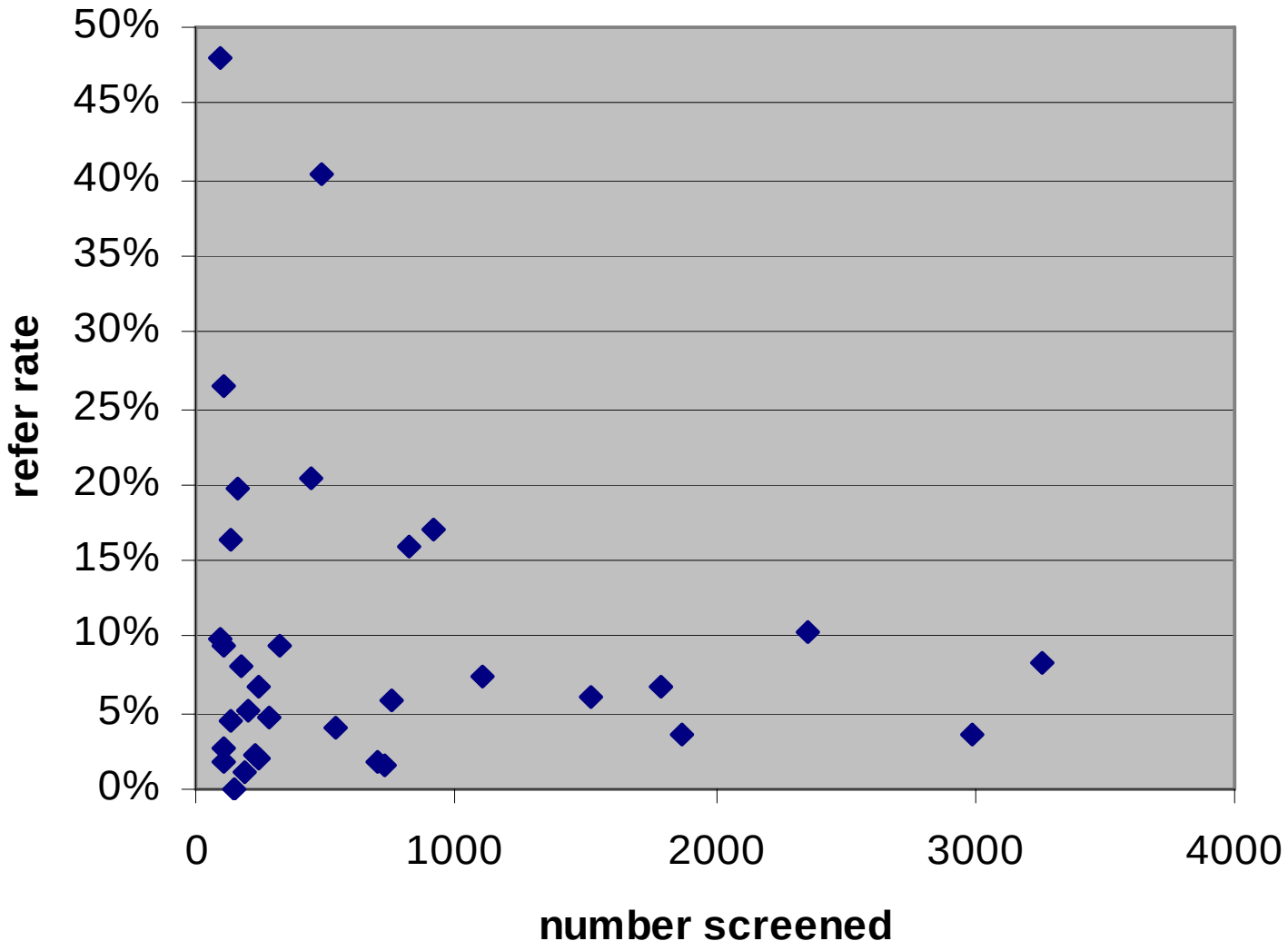
BUT

- World best practice targets now 99% & <1%
- High refer rate variability – why?
- Follow-up compliance probably ~ 85% - why?

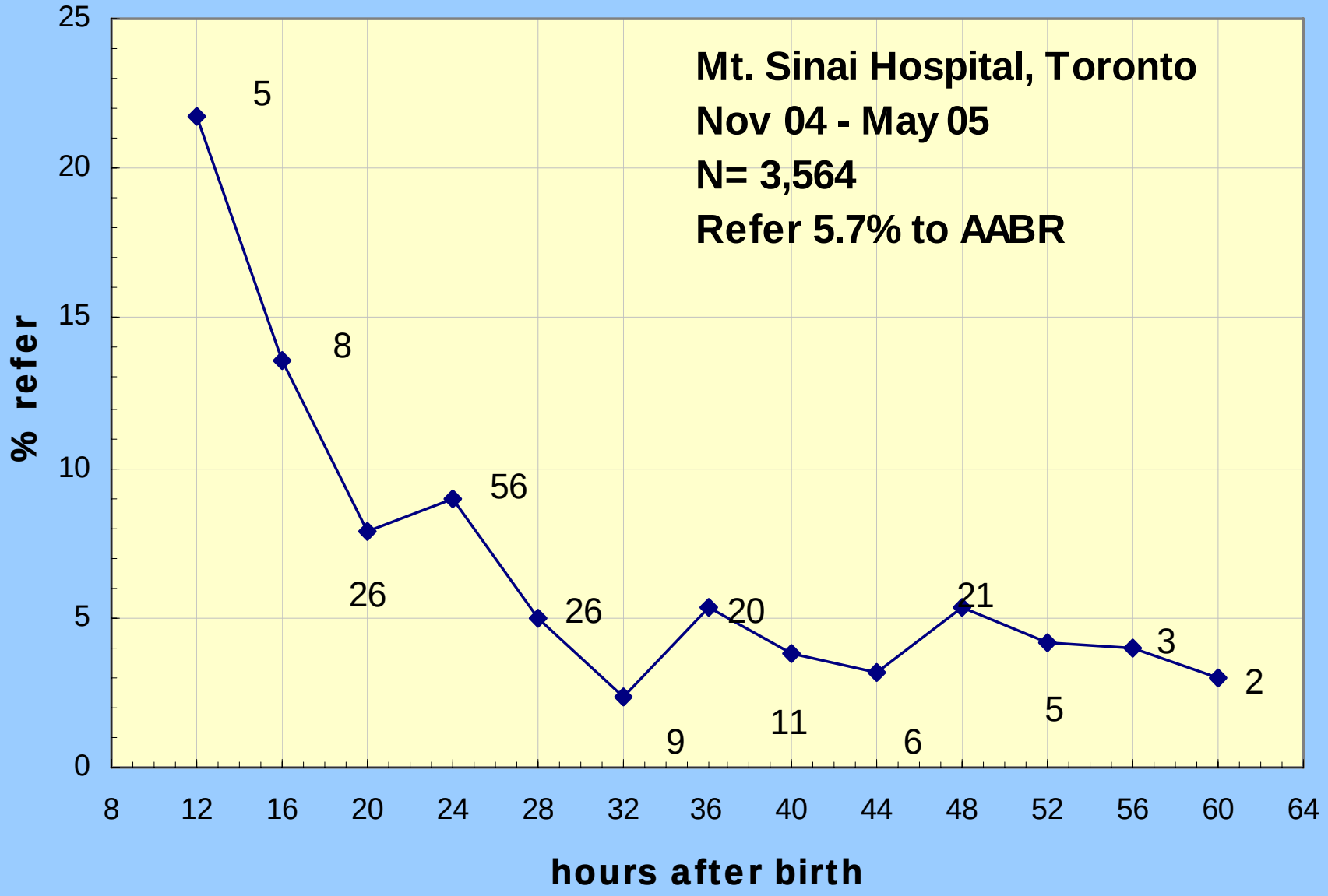
Variable referral to diagnostics from 32 IHP regions in 2006

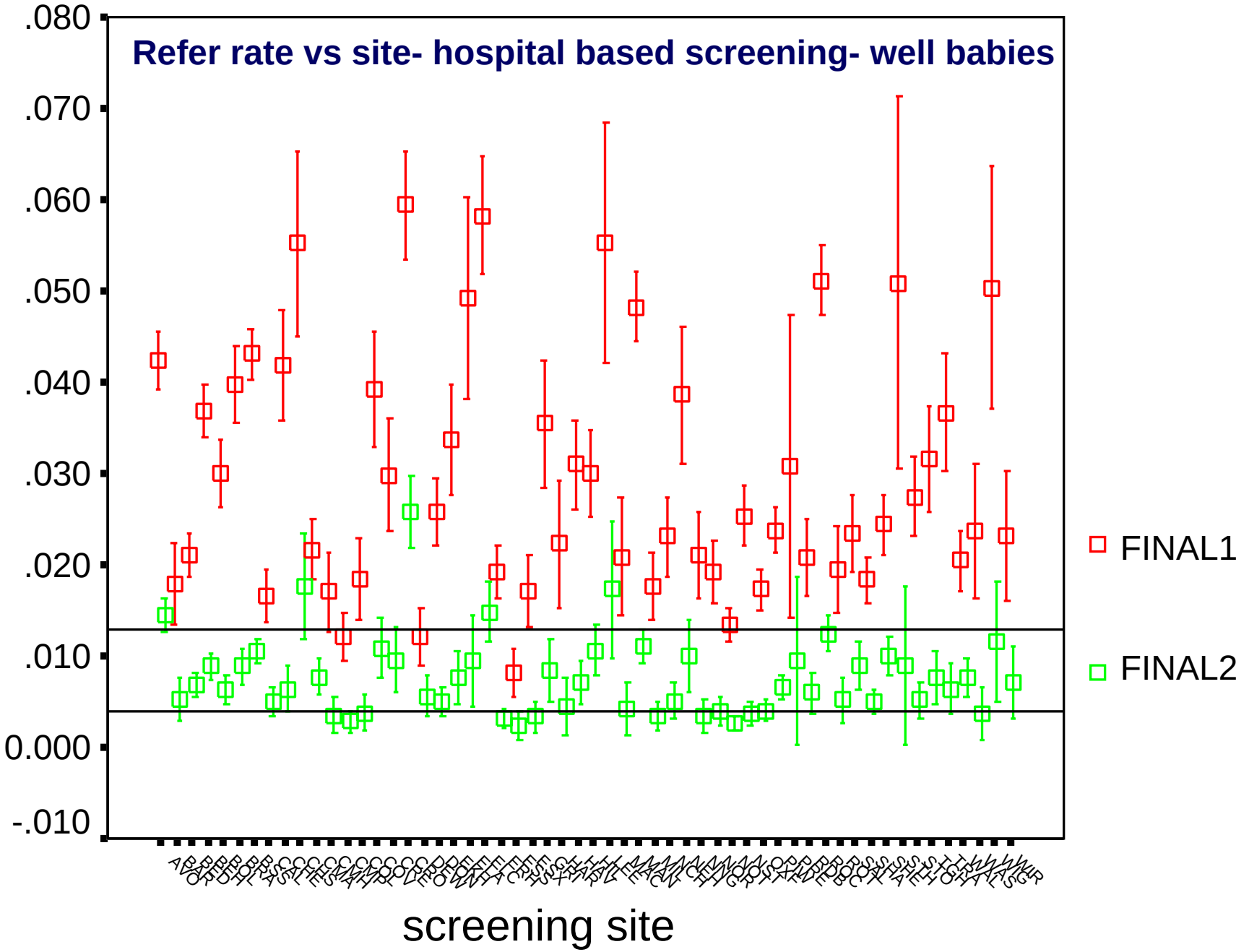


No-risk DPOAE refer % by screener caseload



WBN DPOAE % refer vs age




Refer rate vs site- hospital based screening- well babies
.080
.070
.060
.050
.040
.030
.020
.010
0.000
-.010
FINAL1
FINAL2
screening site

Improving screening

- Understanding best performance & practices
- Stronger quality management
- Standard province-wide training
- Better guidelines/support materials (web etc)
- More experience sharing/problem solving

- Improving critical messaging to families:

Confidence, acceptance, concern vs compliance

High-risk surveillance

- Very comprehensive protocol

- Better definition of risk indicators & priorities
- Better surveillance testing protocols
- Better information about yield vs risk
- Better family access & compliance strategies

Confirmation & diagnostic tests

- Rigorous, definitive assessment protocol
- Strong audiologist training & decision support

- Technical/procedural optimization
- Data management & new evidence pooling
- Information & messaging to families
- Linkages & synergy with other service providers, eg medical, family support, etc

Medical links & actions

- Etiologic investigation, HA ADP process, IHP compliance promotion, new risk discovery and prompt IHP referral

- No standard medical protocol in Ontario
- No standard fast-track / info exchange – ad hoc local arrangements
- Complicated interface with OHIP services
- Stronger physician support & engagement

Family Support

- Psychological support
- Information about CD options and services
- Empowerment of families

- Clarity & consistency of role, best practices
- Better training, decision support, QM
- Family needs, cultural adaptations, timely and understandable messages, appropriate & unbiased info, linkages & synergy, consistency

Hearing Aids

- World-leading protocols
- Strong training, decision support, QM

- Limited funding
- Cumbersome ADP-linked process
- Better program models conceivable

Communication Development

- Strengthened services for auditory-oral, auditory-verbal, ASL and dual programs
- Strong links with pre-school speech-language services
- Evolving synergies in Early Years Programs

- Limited evidence base for optimization, option selection, inter-option transition, maximization of family engagement and early literacy dev.

On the horizon

- Major advances in genetics
  Screening, diagnostics, prognostics, treatment
- Better cytomegalovirus (CMV) prevention
- Improvements in screening, diagnostic and assistive device technologies
- Improvements in language development procedures and strategies