

# The Laws that Every State Should Have and How to Get Them Passed

After You Have An EHDI  
mandate in place

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# Why Legislation?

- ◆ We need to institutionalize what we know works- we drew from from the JCIH and the National Goals, Program Objectives and Performance Measures for the EHDI Tracking and Surveillance System
- ◆ It requires thoughtful planning that brings diverse stakeholders together for a common purpose- trust is developed through the relationships that are forged.
- ◆ It's much more productive than complaining.

# Overview of what we will cover

- ◆ Key pieces of legislation that should be part of your states EDHI infrastructure.
- ◆ How to develop a coalition to get laws passed.
- ◆ How to make your case to legislators.

# Where Families Find Support

- Formal Parent Support Groups
  - △ Deaf Specific
  - △ General Disability
- Informal Parent Support

## Parent-to-Parent

- Mentor
- Role Model

## Adults Who Are Deaf/ Hard of Hearing

# family

## Information

- Internet Websites
- Brochures
- Books
- CDs/DVDs/Videos
- Resource Guides
- Curricula

## Professionals

- Service Coordinator
- Parent Educator
- Early Interventionist
- Audiologist
- Medical Home/ Physician
- Speech/Language Pathologists
- Teacher
- Hospital Staff
- Communication Instructor/Specialist

## Existing Communities

- Family
- Friends
- Neighborhood
- Places of Worship/Spiritual

# MANDATE NEWBORN HEARING SCREENING AND PROVIDE EVIDENCE BASED SUPPORTS: BUILD A SYSTEM THAT PROMOTES TYPICAL DEVELOPMENT

## Parent -to-Parent Guides

- Parents trained using a national curriculum provide unbiased information and support to families that lead to making informed choices that lead to successful outcomes.

## Early Hearing Detection and Intervention (1:3:6)

The bills listed on the this page come from evidence based practices that lead to babies identified at birth for hearing loss and getting the intervention they need for normal language acquisition and development.

- 1 = Screen by one month**
- 3 = Diagnose by three months**
- 6 = Intervention by six months**

## Deaf Mentors

Introduce successful adult role models so families make decisions out of confidence, not fear.

Provide Families with immediate exposure to sign language by providing in home instruction. Increase self-esteem and positive social skills.

## EHDI Part C Coordinator

Liaison between MDH and MDE- develop seamless system between identification and educational intervention

- Coordinate resources, services and train providers.
- Works as part of Part C
- Promote use of evidence based practice and uniform assessment for data tracking, accountability, improve outcomes
- Responsible for collecting and providing individual and aggregate data

## Newborn Hearing Screening Mandate

==>Minnesota is one of 5 states with an unsatisfactory rating from the CDC for underreporting to the Department of Health- Minnesota needs a mandate.  
==> Identification with intervention leads to typical language development and social, emotional, cognitive growth

## EHDI Advisory Committee

- Has representatives from stakeholder groups
- Develop guidelines for screening, reporting, and follow up, medical and educational intervention for uniform reporting, referral and implementation of evidence-based practice

## Hearing Aid Loaner Bank Program

Provides immediate amplification for families.  
Financial Commitment from the Lions Club has been exceeded  
Provides interim hearing aids until funds come through from insurance or parents  
Leverages hundreds of thousands of dollars in equipment donations from hearing aid manufactures and organizations.

With the passage of EHDI and supports how do we know if babies and toddlers in the state are progressing? How do we know if we are making a difference?

# In a Way, We are Detectives

- ◆ The babies have been identified as deaf or hard of hearing
- ◆ What's next? Solving the case:  
How best to educate deaf and hard of hearing children when every child and family is so different

*“ The temptation to form premature theories upon insufficient **data** is the bane of our profession. ”*



◆ *Sherlock Holmes*



# We need data, we need evidence

- ◆ data- a collection of facts from which conclusions may be drawn (Webster)
- ◆ evidence- something that furnishes proof

# I don't believe we can achieve these outcomes without state mandates

1) "Number and percent of children using each mode of communication, sign language, oral, cued speech at 6 month intervals."

2) "Number and percent of infants and children achieving communication and social skills scores commensurate with their cognitive abilities at age 1,3,5, and 7 years of age."

# Questions

- ◆ How is the EHDI system currently evaluated?
- ◆ Does this information help us know if the education system is helping children who are deaf and hard of hearing to succeed?
- ◆ What data do we need to evaluate the system in our state.

# Aggregate Data that The Feds Require

- ◆ IDEA requires that aggregate progress be measured and reported in 14 Indicators for infants and toddlers for each state.
- ◆ Office of Special Education Policy reviews State Performance Plans to see if the state is in compliance
- ◆ Can't extrapolate deaf and hard of hearing data

# Individual Assessment and Evaluation is Required By IDEA

## Part C

- ◆ In IDEA, a required part of the IFSP is to provide a statement of measurable outcomes expected to be achieved, timelines and progress made and recommended modification.  
Evaluation once a year and progress report six months later
- ◆ Provided to parents, can't measure the system with the data.

# An idea for IDEA

- ◆ IDEA requires that the states track the 14 disability categories
- ◆ IDEA has 14 indicators they evaluate (what's up with 14?)
- ◆ Why not disaggregate the data that they have and use it to develop intervention strategies that target specific populations.

# We decided aggregate data wasn't enough

- ◆ We needed to require the state to gather and report data

# Minnesota Statutes

- ◆ **Minnesota 2007125.163 (b)** The Department of Education must provide aggregate data regarding outcomes of deaf and hard-of-hearing children who receive early intervention services within the state in accordance with the state performance plan.



# 2009 Law for Part C and B

- ◆ MS125A.63
- ◆ *(1) identify and report the aggregate, data-based education outcomes for children with the primary disability classification of deaf and hard of hearing, consistent with the commissioner's child count reporting practices, the commissioner's state and local outcome data reporting system by district and region, and the school performance report cards under section 120B.36, subdivision 1;*

## 2009 Law

- ◆ *(2) describe the implementation of a data-based plan for improving the education outcomes of deaf and hard of hearing children that is premised on evidence-based best practices, and provide a cost estimate for ongoing implementation of the plan.*

# Accountability Built In

- ◆ Can't put the plan on the back burner
- ◆ Require that the data and report be made to the chairs and minority leaders of the finance and policy Education Committees in the House and Senate
- ◆ Must be sent to MCDHH

# With Data We Can Assess the System!

- ◆ What evidence is there that this program works?
- ◆ Program evaluation research
  - Often not in peer-reviewed journals
  - Often schools do not monitor their own success
- ◆ How do all the children do
  - Not just the program stars

# How to Use Data: Thinking Through Improvement

- ◆ Deaf Education Leaders Summit 2009 theme was data collection
- ◆ *Thinking Through Improvement* teaches a process that will allow participants to develop skills for analyzing and using data to make good decisions and improvements to existing programs.

# Status




**Pilot Project--Early Intervention**  
**Communication Progress Monitoring /**  
**Outcome Reporting Process for infants and**  
**toddlers who are**  
**Deaf or Hard of Hearing:**

- ◆ Pilot reporting is *in addition to* what is currently reported by early intervention providers and local school districts
- ◆ Selected assessments are reported every 6 months at the time of the annual IFSP or Review.
- ◆ Includes developmental scales, MacArthur Bates CDIs, SKI HI Language Development Scale, LittleEars Auditory Development Questionnaire, selected
- ◆ Strands from the CASLLS, ASL checklists as appropriate.

# Organizing 101

Influencing Opinion  
Makers and Advocating  
for Change  
in Public Policy

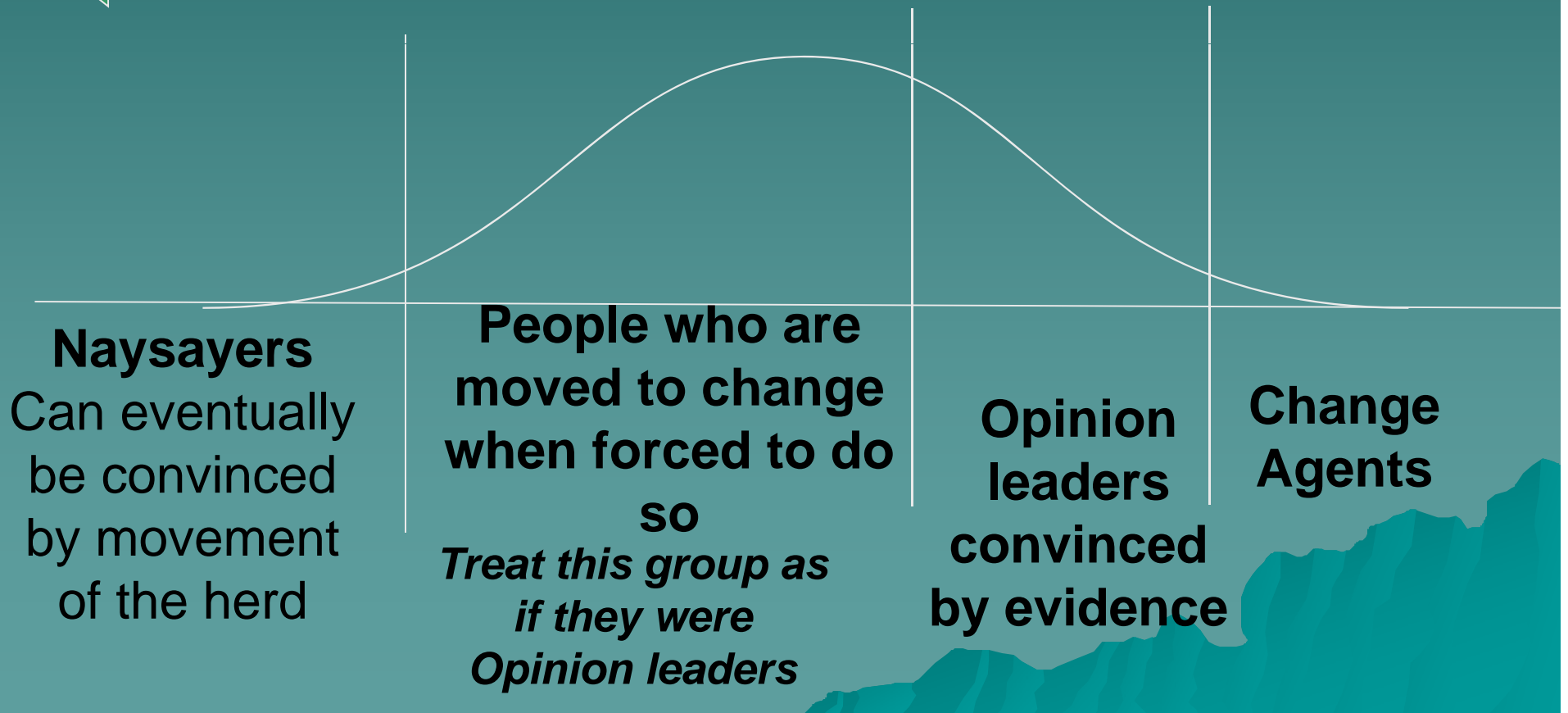
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# Commission of Deaf, DeafBlind and Hard of Hearing Minnesotans

- ◆ Advocate for improved outcomes in education, employment and increased public access
- ◆ Have a five year strategic plan with public policy goals
- ◆ Do our work through issue education, civic engagement, and advocacy training and grassroots organizing.

# The Bell Curve of Change



# Successful Change Agents

## (Lobbyists) Have:

- ◆ Vision- a clear goal and message that inspires
- ◆ A plan-
- ◆ Evidence- that is strong that supports their position and a team of experts and researchers for information as the game changes..
- ◆ Capacity- systems, staff, and citizen advocates, coalitions who use their power and influence on legislators and the governor's office.

# Find Supportive Opinion Leaders

- ◆ Identify legislators who have deaf or hard of hearing people in their families who serve on education committees
- ◆ Cultivate a relationship with your legislator.
- ◆ Work with research staff to make sure that your laws conform with state report requirements.

# Providing Evidence to Influence Opinion Leaders

- ◆ It's all about relationships.
- ◆ They need to trust what you tell them.
- ◆ You need to be sure what you are telling them is accurate.
- ◆ They are advancing your cause and using the evidence that you give them.
- ◆ It's their reputation and yours.

# Our Message to Legislators

- ◆ 2800 deaf and hard of hearing kids in Minnesota
- ◆ \$30 million a year is spent on their education.
- ◆ We don't know how they are doing.
- ◆ Only national data that we have is the Gallaudet study that says the mean reading level of students is 3rd grade 8 months
- ◆ Students have only gained one year's growth in reading in 35 years (Marc Marschark, Raising and Educating a Deaf Child since 94-142 was passed. Passage of EHDI)

# Mobilize Stakeholders

- ◆ Parents
- ◆ Deaf Community
- ◆ AG Bell
- ◆ Students
- ◆ Members of EHDI Team- physicians, audiologists, SLPs

# Celebrate Success

- ◆ Legislators see you as a trusted source
- ◆ They want to help their constituents
- ◆ Continue to look for opportunities to help make the community stronger and help legislators do their jobs.



# Your assignment from Mary

- ◆ What public policies do you think need to be changed for children who are deaf and hard of hearing to achieve at a level that is on par with their hearing peers?
- ◆ Who do you need to team with to make it happen?
- ◆ What evidence do you need to influence opinion makers?

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