

Using Part C of IDEA to Support Statewide EHDI Programs



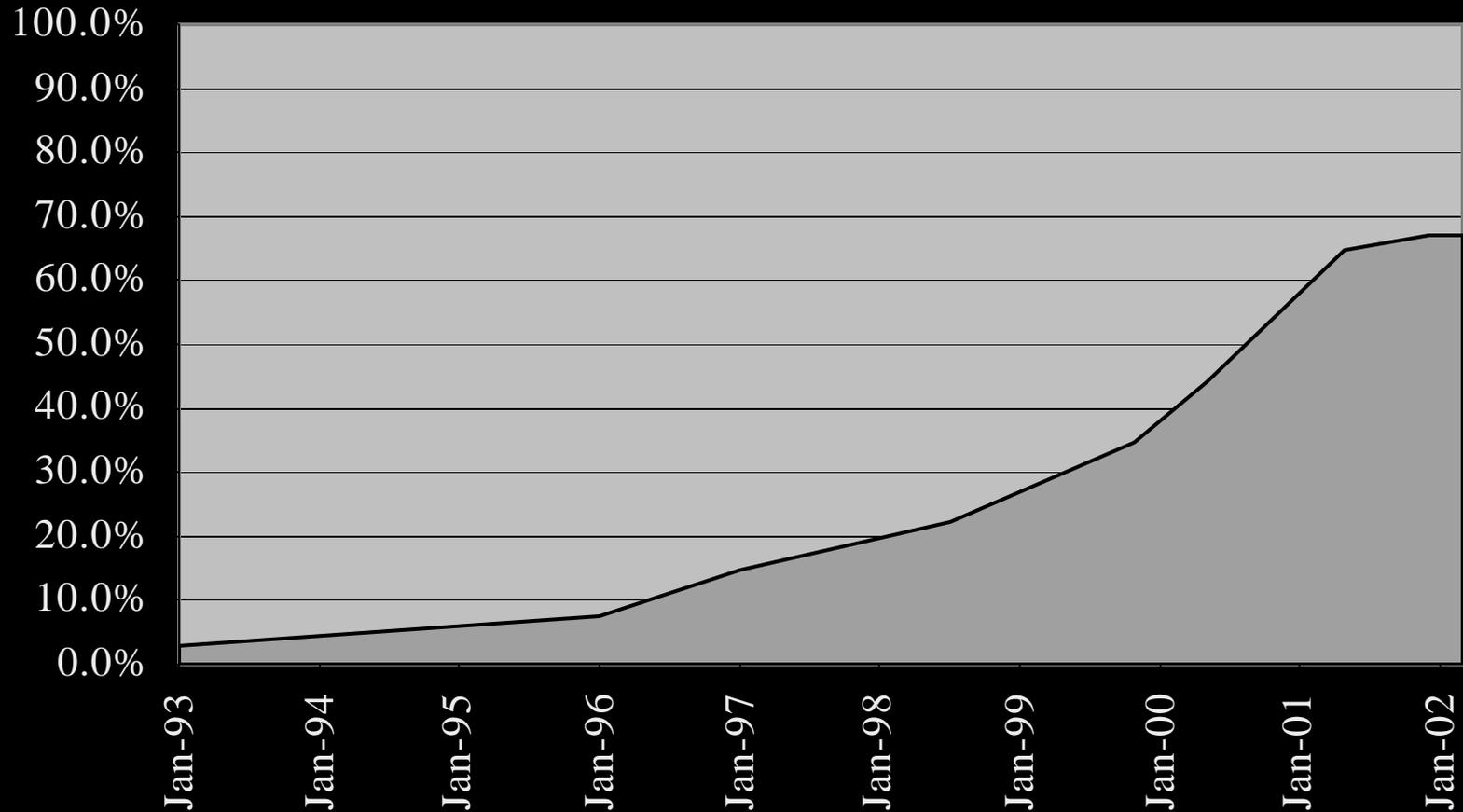
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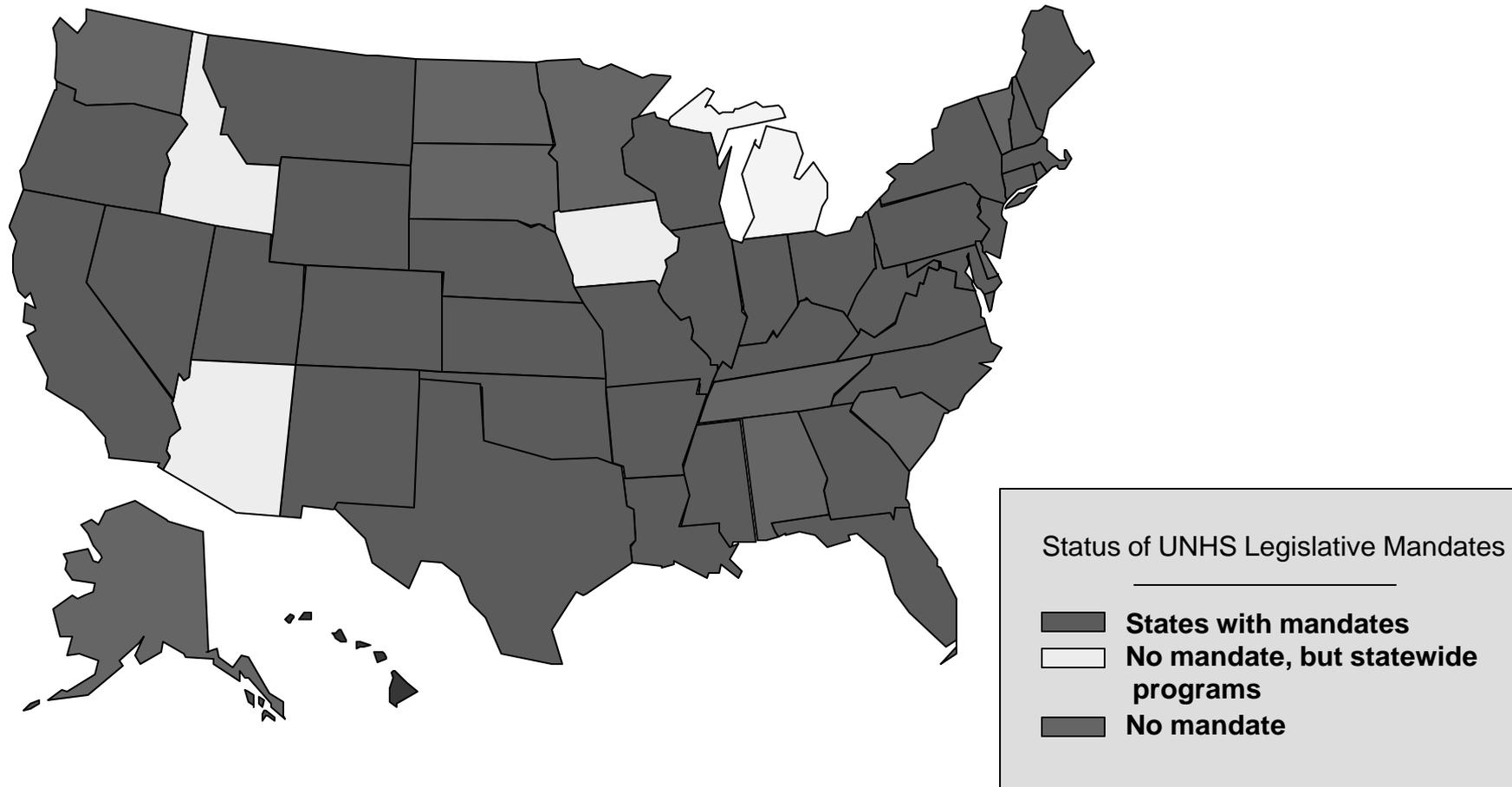
Utah State University

www.infanthearing.org

Percentage of Newborns Screened for Hearing Prior to Hospital Discharge



States with Legislative Mandates Related to Universal Newborn Hearing Screening



Part C of the Individuals with Disabilities Act (IDEA, 1997)

It is therefore the policy of the United States to provide financial assistance to States –

- 1) to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families**

Part C of the Individuals with Disabilities Act (IDEA, 1997)

In order to be eligible for a grant...a state shall demonstrate...

- 1) It has adopted a policy that appropriate early intervention services are available to all infants and toddlers with disabilities in the State and their families**

Part C of the Individuals with Disabilities Act (IDEA, 1997)

a)...A statewide system...shall include, at minimum, the following components

1. Definition of eligibility criteria

2. Statewide policy to ensure services to all infants and toddlers

3. Timely, comprehensive multidisciplinary evaluation

4. An individualized family service plan (IFSP) for all identified children

5. Comprehensive child find system

6. Public awareness program

7. Central information directory of services

8. Comprehensive system of personnel development

9. A lead agency

10 Procedural safeguards

11. State interagency coordinating council

Status of EHDI Programs in the US: Early Intervention



- **Current system designed to serve infants with bilateral severe/profound losses--- but, majority of those identified have mild, moderate, and unilateral losses**
- **State EHDI Coordinators estimate that:**
 - **Only 53% of infants with hearing loss are enrolled in EI programs before 6 months of age**
 - **Only 31% of states have adequate range of choices for EI programs**

Federal regulations for IDEA require all states to provide Part C services to any child who:

- (i) is experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the areas of cognitive development, physical development, communication development, social or emotional development, and adaptive development; or**
- (ii) has a diagnosed physical or mental condition which has a high probability of resulting in developmental delay.**

Are Children with Hearing Loss Eligible for Part C Service?

- **55 of 55 (100%)** indicated that services would be provided to a child who had a diagnosed physical or mental condition with a high probability of resulting in developmental delay.
- **38 of 55 (71%)** listed hearing loss, auditory impairment, deafness, or something similar as one of the specific conditions.
- **Only 7 of 55 (13%)** of the **State Plans** provided any kind of operational definition that could be used to determine if a specific child with hearing loss would be eligible.
- **Five other states (9%)** provided some type of operational definition for hearing loss in other documents.

www.infanthearing.org/earlyintervention/eligibility.pdf

Part C Early Intervention Eligibility for Infants and Toddlers with Hearing Loss

DRAFT: NOT FOR DISTRIBUTION

Part C State Coordinator as of November 13, 2002 as posted at www.nectac.org/contact/ptccoord.asp	As Defined by the State Plan, are infants and toddlers with <u>established risk conditions</u> eligible for Part C-funded services? ^{1a}	Are Specific Conditions Listed? ^{1b}	Is Hearing Loss Noted as a Specific Condition? ^{1c}	Is Hearing Loss Operationally Defined in the State Plan or in other official documents? If yes, what is the definition?
Alabama Elizabeth Prince, Part C Coordinator Early Intervention Program 2129 East South Boulevard PO Box 11586 Montgomery, AL 36111-0586 (334) 613-3543 Fax: (334) 613-3541 E-mail: bdprince@rehab.state.al.us http://www.rehab.state.al.us/intervention.html	Yes ... criteria applies to conditions with known etiologies... includes but is not limited to: <ul style="list-style-type: none"> • Chromosomal abnormalities • Genetic or congenital disorders • Severe sensory impairments (including hearing and vision) • Inborn error of metabolism • Disorders reflecting disturbances of the nervous system • Congenital infections • Disorders secondary to exposure to toxic substances (incl. fetal Alcohol Syndrome) • Severe attachment disorders 	Yes	Severe sensory impairments (including hearing and vision)	State Plan: No
Alaska Jane Atuk, Part C Coordinator Maternal and Child Health State Department of Health and Social Services 3601 C Street, Suite 934, PO Box 240249 Anchorage, AK 99524-0249 (907) 269-3419 Fax: (907) 269-3465 E-mail: jane_atuk@health.state.ak.us http://health.hss.state.ak.us/dph/mch/sus/default.htm	Yes Disabling condition means physical, mental, sensory or physical conditions which have a high probability of resulting in a 50% developmental delay... even though [it] may not be exhibited at the time. The team's decision shall be supported by a physician's report documenting the condition.	No	No	State Plan: No

¹ Notes:

- a) "Are infants and toddlers with established risk conditions eligible for Part C-funded services?" Based on State Plan, answered Yes or No as well as summarizing the relevant criteria and conditions under which child

Who is Eligible for Part C Services?

Which of the following children would be eligible for Part C funded early intervention services in your state? Assume that all of the children are six months old, none exhibit any developmental delays as measured by objective developmental measures, and all of them come from upper-middle class two-parent families.

- Child has a profound, permanent sensorineural hearing loss in both ears (PTA>100 dB)
- Child has a profound, permanent sensorineural hearing loss in one ear (PTA>100dB), but normal hearing in the other ear
- Child has a moderate, permanent sensorineural hearing loss in both ears (PTA=55dB)
- Child has a mild, permanent sensorineural hearing in both ears (PTA=35dB)
- Child has a mild, fluctuating conductive hearing loss (PTA=35dB) in both ears due to otitis media

Partial and Preliminary Results (n=18 states)

Child has a profound, permanent sensorineural hearing loss in both ears (PTA>100 dB)	Yes: 94%
Child has a profound, permanent sensorineural hearing loss in one ear (PTA>100dB), but normal hearing in the other ear	Yes: 61%
Child has a moderate, permanent sensorineural hearing loss in both ears (PTA=55dB)	Yes: 94%
Child has a mild, permanent sensorineural hearing in both ears (PTA=35dB)	Yes: 67%
Child has a mild, fluctuating conductive hearing loss (PTA=35dB) in both ears due to otitis media	Yes: 22%

Comprehensive Child Find System

34.C.F.R. Part 303.321

(b) Procedures. The Child Find System must include the policies and procedures that the state will follow to ensure that:

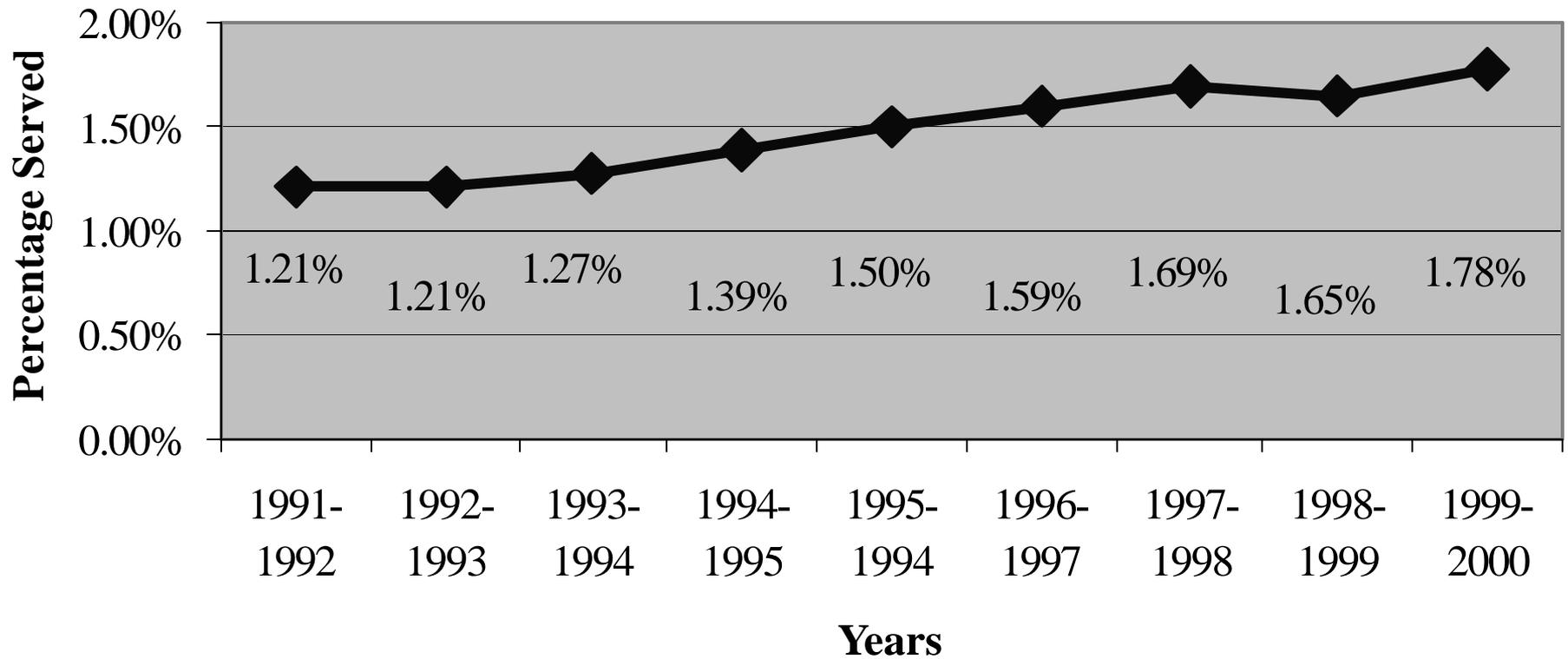
- 1) All infants and toddlers in the state who are eligible for services under this part are identified, located, and evaluated.... The procedures required in paragraph (b) (1) of this section must:**
- 2) (i) Provide for an effective method of making referrals by primary referral sources.**
 - (ii) Ensure that referrals are made no more than 2 working days after a child has been identified.**
 - (iii) Include procedures for determining the extent to which primary referral sources, especially hospitals and physicians, disseminate the information....prepared by the lead agency on the availability of early intervention services to parents of infants and toddlers with disabilities....**

Comprehensive Child Find System (continued)

(e) Timelines for public agencies to act on referrals.

- (1) Once the public agency receives a referral, it shall appoint a service coordinator as soon as possible.**
- (2) Within 45 days after it receives a referral, the public agency shall...**
 - (i) Complete the evaluation and assessment activities in Sec. 303.322, and**
 - (ii) Hold an IFSP meeting in accordance with Sec. 303.342**

Percentage of Infants & Toddlers Served in IDEA Part C Programs



Potential Impact of EHDI Programs on Part C Services

- 205,769 infants and toddlers currently served in Part C Programs
- 12,000 babies are born each year with congenital hearing loss
- At any given time there are 36,000 infants and toddlers with hearing loss that need to be served (12,000 per year X 3 years)
 - Assume 33% of these children are currently being served:
 - 67% of 36,000 = 24,000 new children to serve
 - 11.67% more children (same increase as from 1996/97 to 1999/2000)

Comprehensive Multidisciplinary Evaluation

- **Most infants and toddlers referred for Part C evaluations qualify for services---i.e., Part C is conducting evaluations for about 2 % of the population**
- **About 1% of all newborns screened for hearing loss are referred for diagnostic services**
- **EHDI programs could increase the Part C diagnostic evaluation workload by 50%**

Comprehensive Multidisciplinary Evaluation

Assume an infant or toddler has been referred to your Part C program from a hospital-based newborn hearing screening program as needing a diagnostic evaluation to make a definitive determination about whether a hearing loss is present. Further assume that the child is not eligible for Medicaid, and the family has no health insurance. Would your Part C Program....

Pay for the diagnostic evaluation procedures	84%
Not pay for the diagnostic evaluation procedures	6%
Other	10%

“Take Home” Messages

- Closer cooperation between EDHI and Part C would be mutually beneficial
- Part C is not the “pot of gold” at the end of the rainbow
- Collaboration is deceptively simple...the devil is in the details