

# Medically involved infants and toddlers in the Early Intervention Program: Implications for policy

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# Presenter Disclosures

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Roy Grant

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose



# The Early Intervention Program (EI)

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- Entitlement program established under Part C of the Individuals with Disabilities Education Act (“IDEA”)
- Intended to facilitate the earliest identification of developmental delays
- Major system for developmental evaluation and services to infants and toddlers with delays birth to 36 months
  - Health insurance coverage for developmental services is often very limited
  - Result has been cost-shifting from health care to EI system



# EI eligibility

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- The EI eligibility threshold (degree of developmental delay determined by multi-disciplinary evaluation) is set by each state and incorporated in regulation
- IDEA requires that each state's eligibility standards also include infants and toddlers diagnosed with a "condition with a high probability of developmental delay"

# Children with special health care needs (CSHCN) and EI

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- Medical conditions with high probability of delay include extreme prematurity, neurologic disorders, syndromes, etc.
- These conditions are consistent with the narrow definition of CSHCN
- These children also meet diagnostic eligibility criteria for federal social security benefits based on disability (SSI-D)
  - SSI-D also has means testing as part of eligibility determination



# CSHCN and the medical home

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- American Academy of Pediatrics developed the “medical home” model as the standard of care for CSHCN: Health care that is continuous, comprehensive, coordinated, family-centered and culturally sensitive
- The medical home model has since been extended as the “gold standard” of care for all children



# Pediatricians' role in EI

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- Under IDEA, pediatricians are “primary referral sources” who must refer to EI based on suspicion of delay
  - Except if parent objects
- EI provides the evaluation and services
- This often leads to fragmentation of developmental services from health care
  - Major quality of care problem for CSHCN
- Pediatricians also provide Rx for PT and OT services

# Medical involvement in an EI-referred population study: Purpose & setting

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- Purpose: To determine the extent to which infants and toddlers referred to EI are “medically involved” and require care as CSHCN
- Sample: 575 consecutively referred infants and toddlers receiving EI evaluation at a NYC tertiary care teaching hospital
  - Virtually all were patients of that hospital
- Comparison was made with a community sample of EI-referred infants and toddlers

# Medical involvement in EI-referred population study: Method

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- Retrospective chart review
- Evaluations were kept consistent to the extent feasible:
  - Exam by developmental pediatrician
  - Psychological testing (BSID)
  - Supplementary evaluations (PT, OT, Sp/L)
  - Social work interview
- Consultation with primary pediatrician

# Medical involvement in EI-referred population study: Method, cont'd

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- Medical diagnoses were categorized as:
  - **Prematurity & low birth weight** (most extremely premature: <1000 g,  $\leq$ 26 weeks gestation)
  - **Organ system anomalies** (e.g., tetralogy of fallot, biliary atresia)
  - **Genetic syndromes and inborn metabolic disorders** (e.g., Down, Soto, DiGeorge syndromes)
  - **Neurologic disorders** (e.g., seizure disorder, microcephaly, cerebral palsy)
  - **Infectious diseases** (e.g., CMV, congenital syphilis)
  - **None**

Excluded: asthma, otitis media, pneumonia, etc.



## Medical involvement in EI-referred population study: Population (n=575)

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- Mean age, 20 months on evaluation
  - Range, 2-35 months
    - Mean age at referral, ~18-19 months
- 62% male
- 66% living in households with incomes at or below FPL

# Medical involvement in EI-referred population study: Results (n=575)

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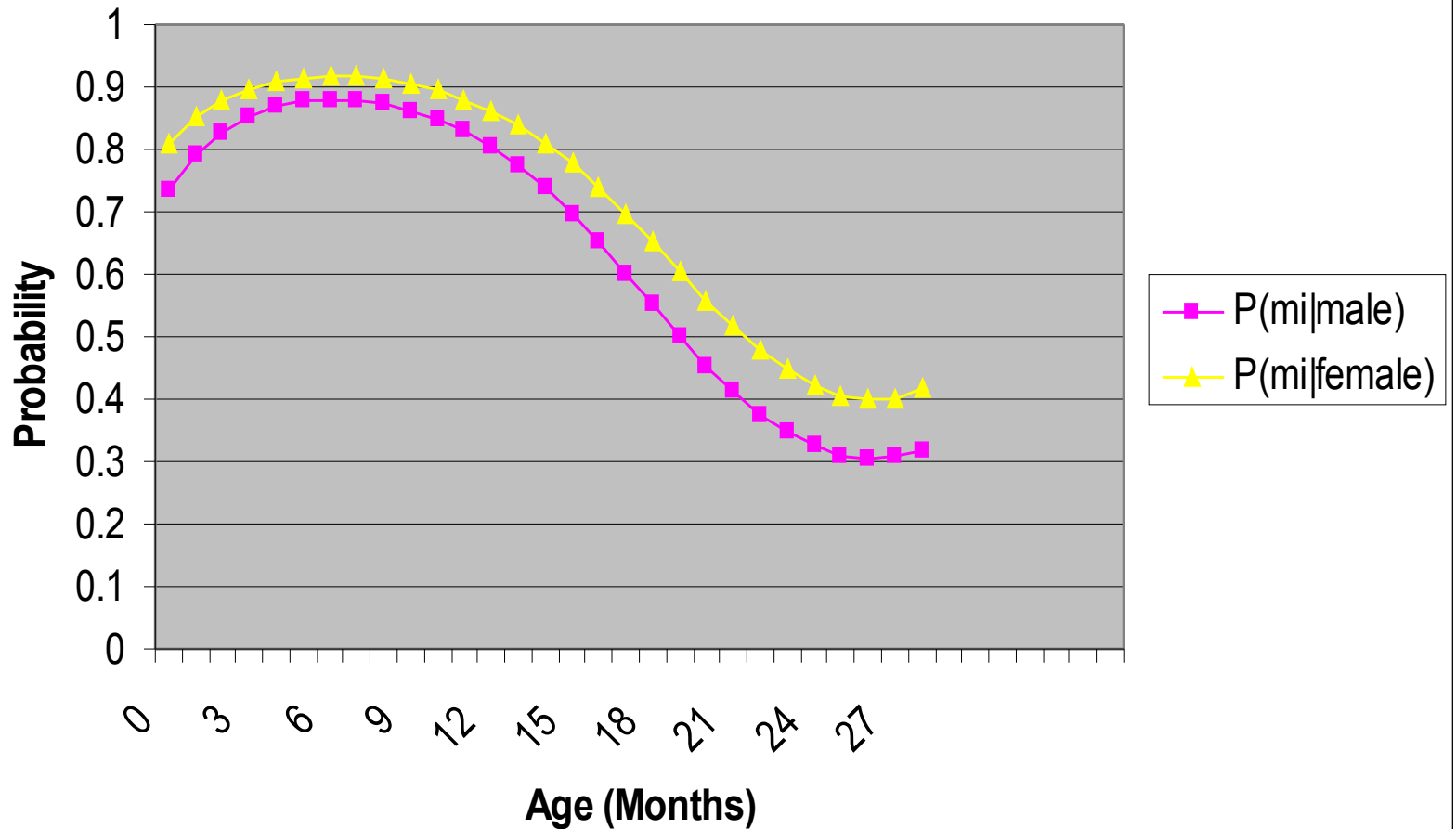
<b>Primary medical diagnosis by category</b>	<b>Percent</b>
Premature, low birth weight (typically ELBW with BPD, grade 3 or 4 IVH, ROP)	16%
Organ system anomaly	13%
Genetic syndrome, inborn metabolic disorder	11%
Neurologic disorder	16%
Infectious disease	2%
None	42%

# Medical involvement by age

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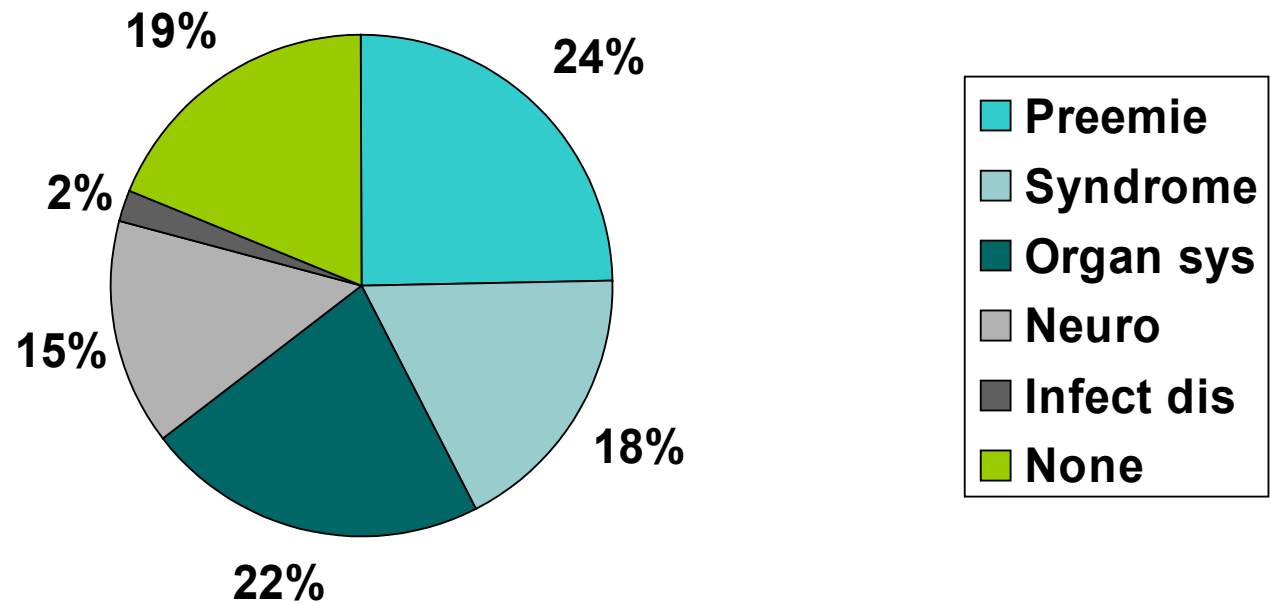
Age category	Percent medically involved
2 - 12 months (n=142)	89%
13 - 18 months (n=100)	71%
19 - 24 months (n=137)	42%
25 - 35 months (n=196)	36%

# Probability of being medically involved as a function of age and gender, birth to 30 months ( $p < 0.01$ )



# Medical involvement by category: 2-18 mos mean age: 11 months; (n=242)

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# Comparison with community hospital sample

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- The high prevalence of rarely occurring conditions in this tertiary care sample suggested bias based on this setting
  - Hospital was a regional pediatric transplant center
- Comparison was made for a subset of patients with infants and toddlers referred by local pediatricians and evaluated at a community hospital
  - Evaluation protocol for comparison group was consistent with that for tertiary care sample



# Results of comparison (n=221)

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- Medical involvement was significantly higher in the tertiary care hospital sample ( $p < 0.01$ )

HOWEVER

- There was no significant difference for infants through 12 months of age
- Predominant diagnosis among community hospital infants was prematurity and low birth weight

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# Conclusions

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- There is a significant likelihood that EI-referred infants will have a serious associated medical condition
- This medical diagnosis indicates that the baby should be considered an infant with special health care needs
- Health care and developmental services should be integrated in a medical home model



# Policy implications

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- Linkages between pediatric primary care providers and local EI programs should be developed to foster coordination of medical and developmental care
- EI programs should ensure that they have a workforce appropriately trained for medically involved infants
  - EI reimbursement should be adequate to encourage and sustain participation of health care providers
- States seeking to control EI costs should not take steps that negatively impact upon the quality and level of care for medically involved infants and toddlers
  - R Grant. State strategies to contain costs in the Early Intervention Program: Policy and evidence. *Topics in Early Childhood Special Education*. 2005;25(4):243–250



# For more information contact

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