An Opportunity to Help Children

Early Cerebral Palsy Risk Detection and Intervention

Task Force Presentation for
NM LHHS Committee Meeting 10/11/18

Four of our 30 multidiscipinary task force members

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What is Cerebral Palsy?

- Disorder of Movement
  - Limits daily activity
    - Feeding
    - Using hands
    - Sitting, walking……
- Non-progressive brain disturbance
  - Many causes
  - Lifelong
- The cause happens early in life
  - Often before birth
  - Up to several years of age

International Consensus Definition (Rosenbaum et al 2005)

How Common is Cerebral Palsy?

Worldwide

- Most common physical disability in childhood
- 1 in 300 births
- 17 million worldwide

New Mexico

- 200 – 400 children 0-3 years old have CP
  - Total of 24,500 children this age
- Mild cases usually diagnosed after 2 years old

What Improves Outcome?

Early Diagnosis

Early Intervention (0-3 yrs)

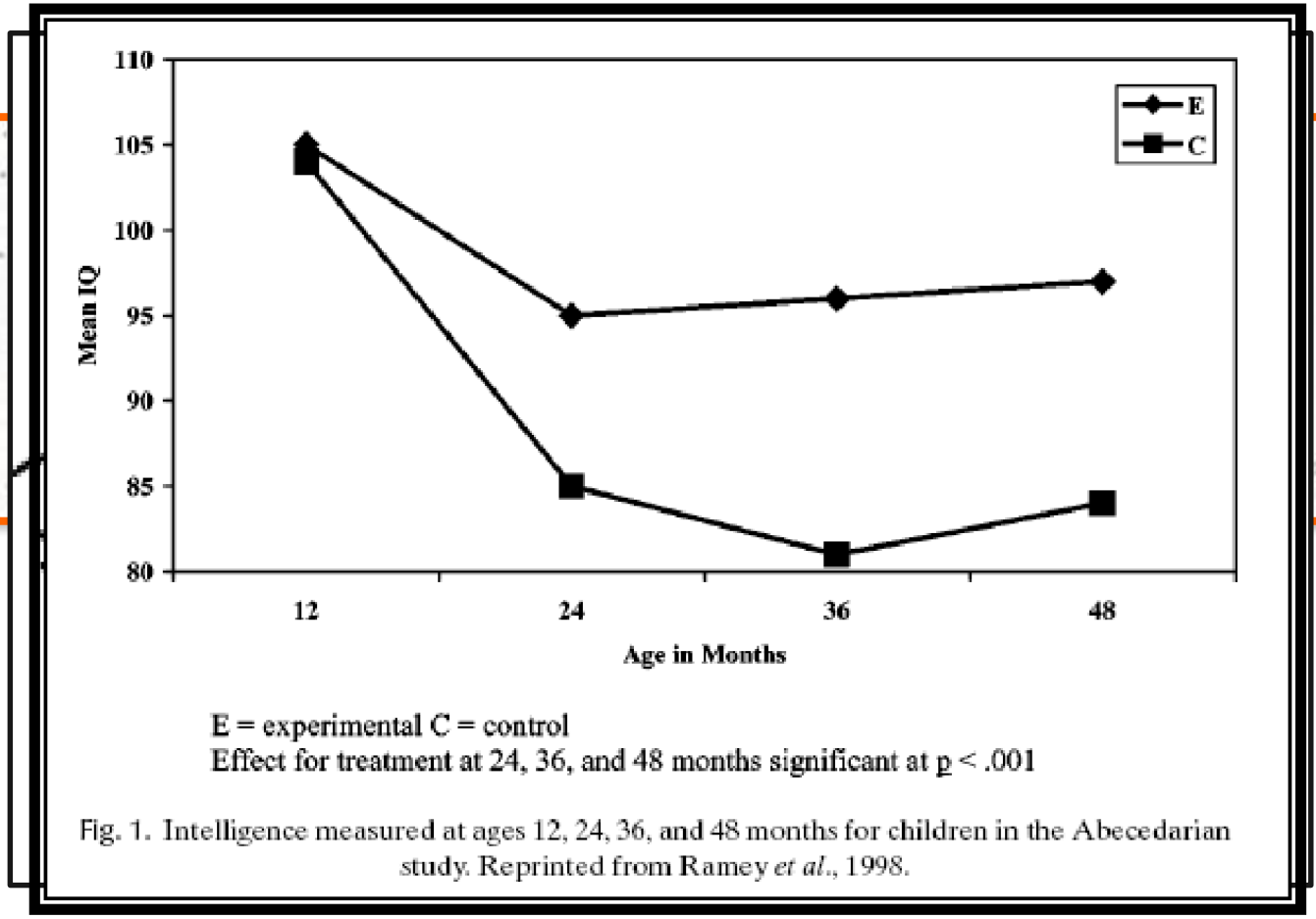
Improved Brain Development

Money Saved!

What Does Economics Tell Us About Early Childhood Policy?
Rand Corporation Research Brief, 2008
Presented at New Mexico Conference on Early Education 2009

Why Does Early Treatment Help?

Birth



E = experimental C = control
Effect for treatment at 24, 36, and 48 months significant at $p < .001$

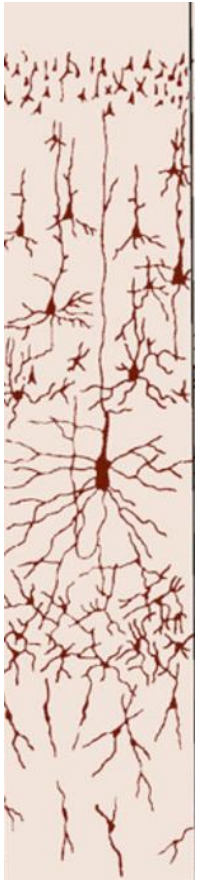
Fig. 1. Intelligence measured at ages 12, 24, 36, and 48 months for children in the Abecedarian study. Reprinted from Ramey *et al.*, 1998.

6 years

Leggio 2005
Conel
Ramey 1998

Brain Development Summary

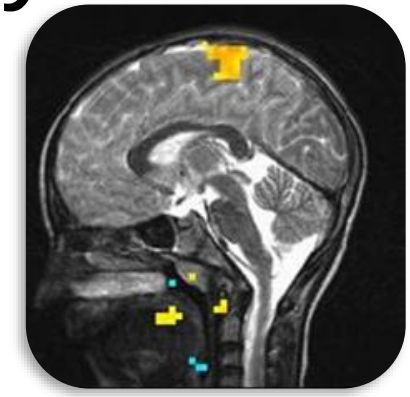
Early Individualized Therapy Data

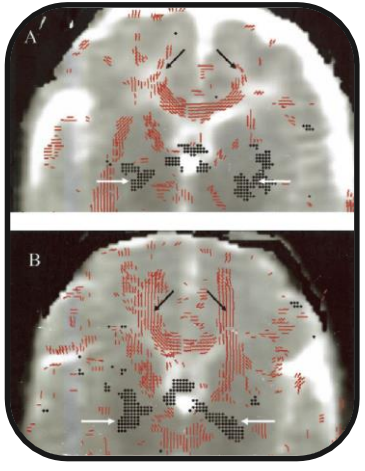


Neurons

Hubel, Weisel 1970

Individuals





Als, 1996

Populations

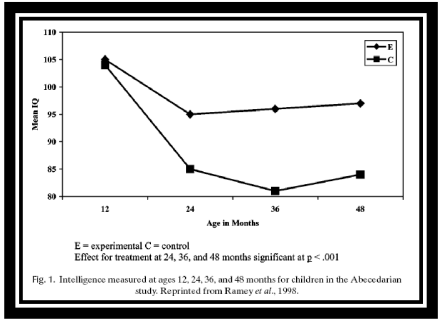


Fig. 1. Intelligence measured at ages 12, 24, 36, and 48 months for children in the Abecedarian study. Reprinted from Ramey *et al.*, 1998.

Ramey 1998

Early Detection and Diagnosis of Cerebral Palsy and "High-Risk of Cerebral Palsy"

INTERNATIONAL CLINICAL PRACTICE GUIDELINE

Novak I, Morgan C, Adde L, Brunstrom-Hernandez J, Blackman J, Boyd RN, Cioni G, Damiano D, Darrah J, de Vries LS, Eliasson AC, Einspieler C, Fahey M, Fehlings D, Ferriero DM, Fetters L, Fiori S, Forssberg H, Gordon AM, Greaves S, Guzzetta A, Harbourne R, Hadders-Algra M, Kakooza-Mwesige A, Karlsson P, Krumlinde-Sundholm L, Latal B, Loughran-Fowlds A, Maitre NL, McIntyre S, Noritz G, Pennington L, Romeo DM, Shepherd RB, Spittle AJ, Thornton M, Valentine J, Walker K, White R & Badawi N.

Journal of American Medical Association in Pediatrics, 2017

What Does the New Research Say?

1. Specific testing of children 0-6 months old can now identify children at risk for cerebral palsy
2. Referral for services early is now recommended as the standard of care
3. No longer should we “wait and see” because we often miss the critical window when early help can make the biggest difference due to rapid brain development in the first year

Signs Prompting Referral for Specialized Evaluation

Persistent fisting of the hands past 4 months of age

Persistent poor head control past 4 months of age

Stiffness or tightness in the legs at 6 months

Not putting weight on legs at 4 months

Meet Aaliyah

Compare her left hand function at her physical therapy evaluation

versus

1 month of physical therapy and training parents what to work on at home

THERE IS NO CURE, BUT EARLY TREATMENT CHANGES OUTCOMES

Early treatment by licensed professionals in the first year of life

Brain connections are developed with guided activity

Much better lifetime outcomes

INFANT TREATMENT IS EFFECTIVE

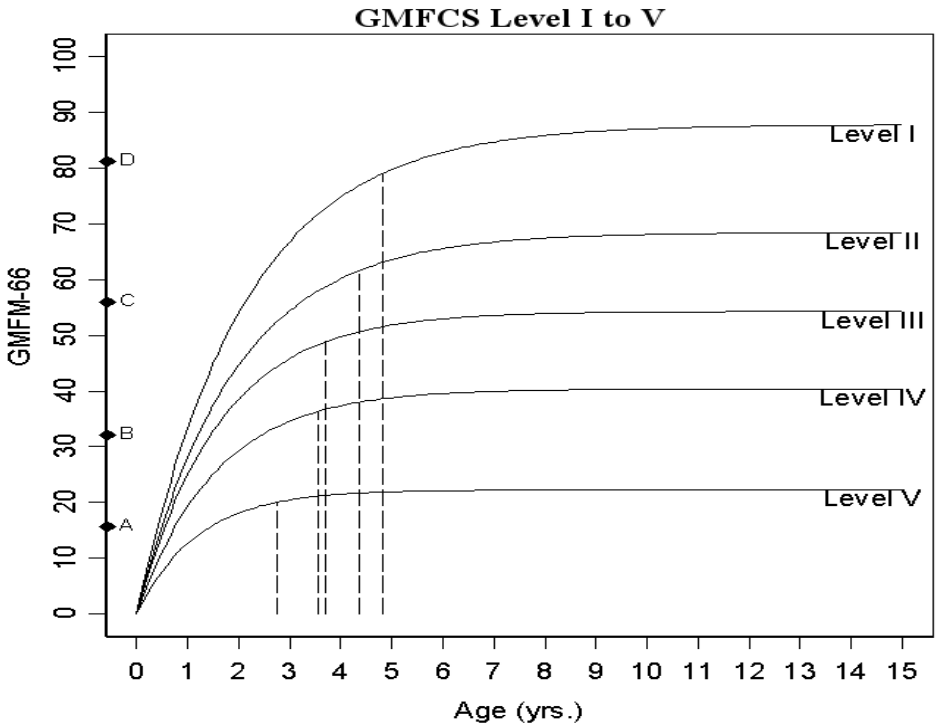
Some Children Require Specialized Equipment

Powered Mobility allows play with peers

The greatest potential is in the first 3 years of life

90% of motor potential is achieved

BY 3-5 YEARS OF AGE



This graph shows the observed and predicted GMFM-66 scores for children in GMFCS Levels I through V. The curved solid lines indicate average performance. The horizontal dotted lines on the right of the figures indicate the band expected to encompass 50% of children's limits of development. The solid vertical lines indicate the average age-90 (the age in years by which children are expected to reach 90% of their motor development potential). The dotted vertical lines indicate the bands expected to encompass 50% of age-90 values around the average. The absence of 50% bands in level IV and level V indicates low variation in age-90 values.

Family Story

Meet Vail and Matea

TRAINING DEVELOPMENT PLAN

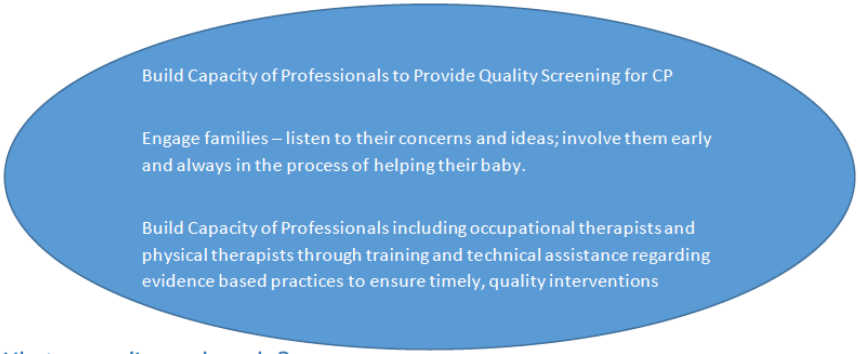
MEDICAL PROVIDERS NEED TO BE TRAINED STATEWIDE ON STANDARD FOR SCREENING, EVALUATION, AND REFERRAL

PHYSICAL AND OCCUPATIONAL THERAPISTS and EARLY INTERVENTION PROVIDERS NEED TO BE TRAINED ON SCREENING AND COLLABORATION WITH PRIMARY CARE PROVIDERS

TRAINING ON THE MOST EFFECTIVE TREATMENTS IS NEEDED

INVESTMENT IN WORKFORCE DEVELOPMENT

Solutions for New Mexico



What can policy makers do?

1. Invest in professional development of existing professionals to identify infants at high risk for Cerebral Palsy.

2. Support professional development of existing professionals to improve the quality of intervention using evidence based practices to ensure high quality supports and services for infants at high risk for CP and their families.

3. Invest in innovative service delivery such as telemedicine for families in remote and difficult to reach areas.

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