The Waisman Center

Len Abbeduto, PhD, Associate Director for Behavioral Sciences IDDRC & Director of UCEDD

September 16, 2010

Waisman Center Mission

To advance knowledge about human development, developmental disabilities, and neurodegenerative diseases throughout the lifespan

Four Major Activities

Research	• 75+ NIH-funded research projects in the biological, behavioral, and social sciences
Training	• undergraduates, graduate students, postdoctoral fellows, medical residents/fellows
Outreach	• behavioral treatment, community inclusion, and support programs
Service	• 10 specialty clinics • preschool with 90-100 children

Beginnings of the Waisman Center

- Orthopedic Children's Hospital circa 1932 (becomes Nutritional Sciences Building)

- 3rd floor addition dedicated in 1963 as the Joseph P. Kennedy, Jr. Memorial Labs.

CLASS OF SERVICE
This is a fast message unless its deferred character is indicated by the proper symbol.

WESTERN UNION
TELEGRAM
W. P. MARSHALL, PRESIDENT

SYMBOLS
DL = Day Letter
NL = Night Letter
LT = International Letter Telegram

The filing time shown in the date line on domestic telegrams is LOCAL TIME at point of origin. Time of receipt is LOCAL TIME at point of destination

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UNIVERSITY OF WISCONSIN
OFFICE OF THE PRESIDENT

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DR FRED HARRINGTON, PRESIDENT UNIVERSITY OF WISCONSIN=
MADISON WISC.

1963 NOV 20 AM 7 44

=IT IS A PLEASURE TO EXTEND MY BEST WISHES AND CONGRATULATIONS TO DR HARRY A WAISMAN AND HIS ASSOCIATES ON THE OCCASION OF THE DEDICATION OF THE JOSEPH P KENNEDY MEMORIAL LABORATORIES AT THE UNIVERSITY OF WISCONSIN MEDICAL SCHOOL. I AM PARTICULARLY PLEASED THAT YOU WILL BE JOINED FOR THIS EVENT BY SENATOR KENNEDY AND MR AND MRS SARGENT SHRIVER.

¶IT IS MY HOPE THAT THROUGH THE FACILITIES OF THIS AND OTHER SUCH LABORATORIES THROUGHOUT THE COUNTRY, MANY MORE OF THE CAUSES OF MENTAL RETARDATION NOW AFFLICTING MILLIONS OF AMERICANS WILL BE DISCOVERED AND THAT PREVENTATIVE MEASURES TO THIS MOST SERIOUS MEDICAL PROBLEM WILL BE DEVELOPED.

¶MY SPECIAL GOOD WISHES GO TO DR WAISMAN ON THE CULMINATION OF HIS DREAM AND TO THE MANY YOUNG PEOPLE WHO, THROUGH HIS EFFORTS AND THAT OF THE UNIVERSITY OF WISCONSIN, WILL NOW BE ABLE TO ENTER AND SOON CONQUER THE VAST FIELD OF MENTAL RETARDATION AND ITS ATTENDANT PROBLEMS.=

JOHN F KENNEDY.

THE COMPANY WILL APPRECIATE SUGGESTIONS FROM ITS PATRONS CONCERNING ITS SERVICE

Who was Harry Waisman?

- director of research at the Joseph P. Kennedy, Jr. Memorial Laboratories
- pediatrician, biochemist, pioneer in research on intellectual disabilities
- advocated for testing of all newborns for PKU

Construction of the Waisman Center

- 1961 Presidential Panel on Mental Retardation recommended creation of multidisciplinary centers focused on intellectual disabilities

- Waisman Center opens in 1973

Expansion Project

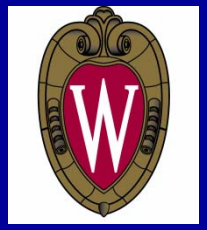
- Construction began in 1998; completed in 2001
- New research laboratories; space for outreach and training programs; remodeled Waisman Early Childhood Program
- Total of 38,720 assignable square feet at cost of $25 million

What is in the Waisman Center "Complex"?

- ***South Tower***
  - Ziemann Suite: 8th Floor
  - Research Floors: 7, 6, 5, 4, 3
  - Clinics and Clinical Programs: 3, 1
  - Support staff: 2nd floor

- ***North Tower***
  - Research Laboratories Floors: 6, 5, 4, 1
  - Administration, Conference Center: 2nd floor

- ***West Annex***
  - Auditorium
  - WECP (Preschool)
  - UCEDD
  - Outreach, Community Inclusion Programs



Chancellor, UW-Madison

Dean, Graduate School

Director, Waisman Center

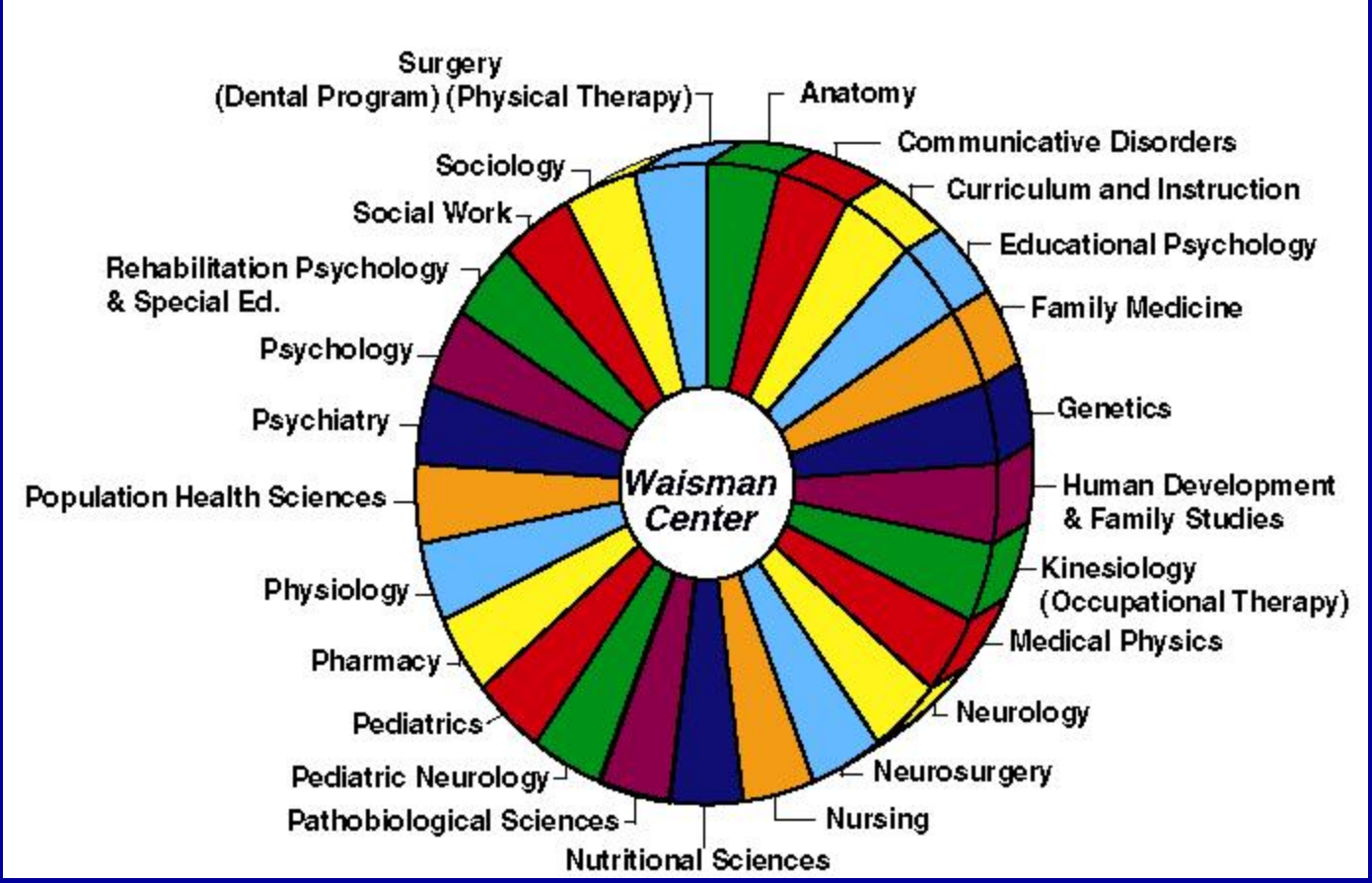
Intellectual and Developmental Disabilities Research Center (IDDRC)

- Communication and Cognitive Sciences Group
- Social & Affective Sciences Group
- Molecular & Genetic Sciences Group

University Center for Excellence in Developmental Disabilities (UCEDD)

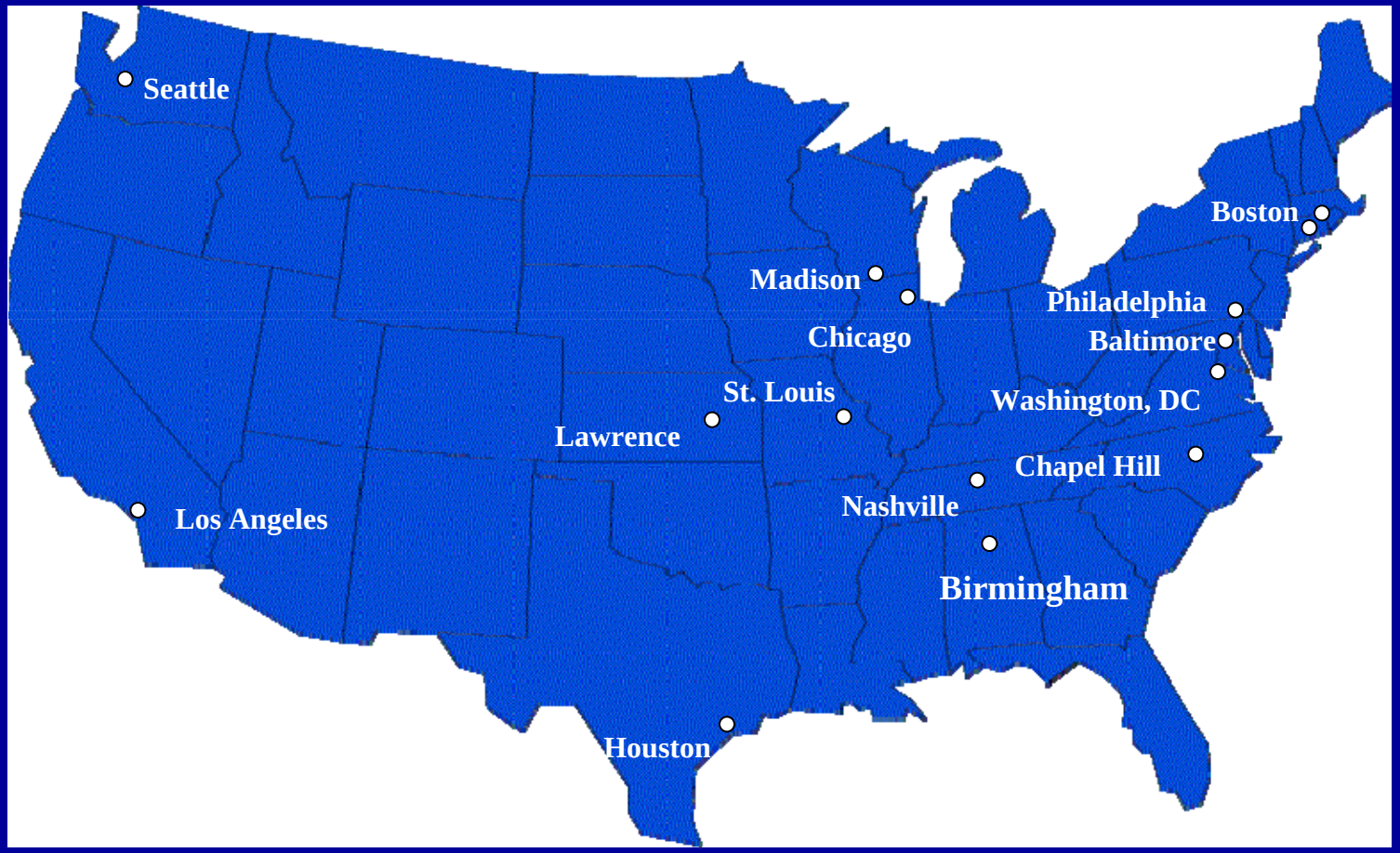
- Health Unit
- Community Inclusion Unit
- Early Childhood and Education Unit

A Multidisciplinary Environment

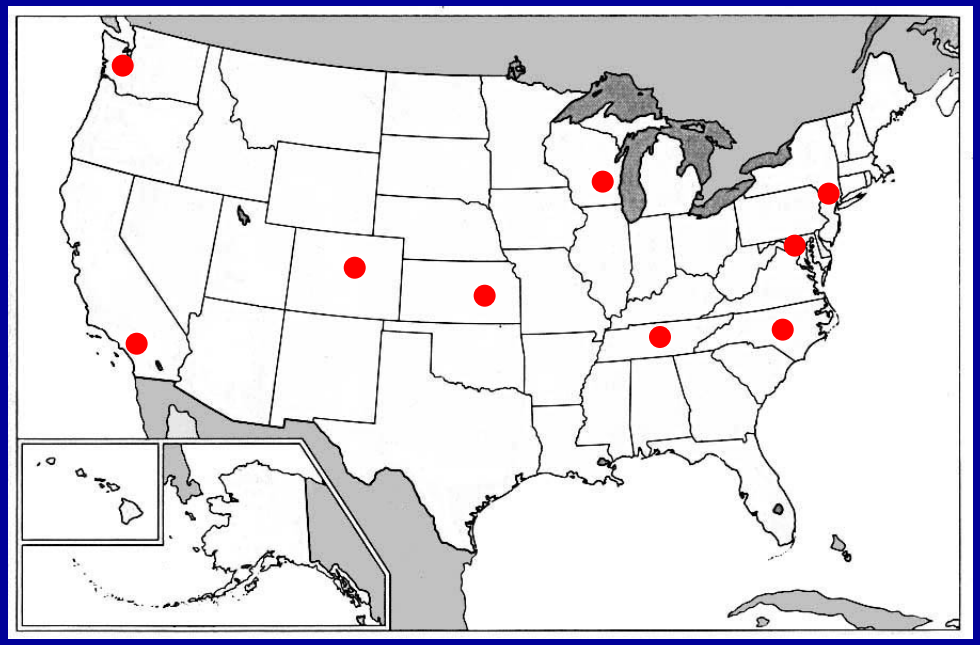


- ***25 affiliated UW departments***

NICHD Network of 15 IDDRCs



Only 9 have both an IDDRC and UCEDD



The Waisman Center houses <u>both</u> . . .

- ***IDDRC***
  —NICHD funding
- ***UCEDD***
  — ADD funding

Fragile X Syndrome

- “Discovered” in the 1970’s
- Leading inherited cause of intellectual disability
- X-linked
- Caused by a single gene (FMR1)
- Excessive lengthening of DNA
  - Normal: 5 – 54 CGG repeats
  - Premutation: 55-199 repeats
  - Fragile X syndrome: 200 or more repeats (full mutation)
- FMRP (protein absent in fragile X syndrome)

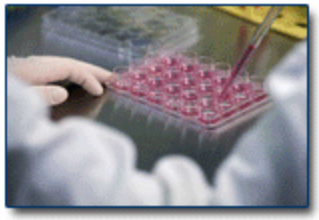
Waisman Activities on Fragile X Syndrome and Associated Disorders

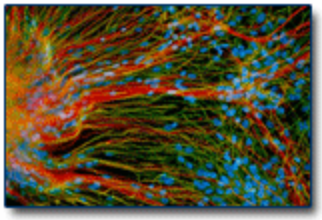
- Fragile X Syndrome Clinic (Greg Rice, MD, Medical Director)
- NICHD Fragile X Research Center on Families
- Individual investigator research projects
  - Biology (e.g., Bhattacharyya)
  - Behavioral Science (e.g., Turkstra)
  - Epidemiology (e.g., Seltzer)
  - Intervention (e.g., Abbeduto)

Waisman Center Clinics

- Biochemical Genetics Clinic
- Cerebral Palsy & Neuromotor Development Clinic
- Communication Aids & Systems Clinic (CASC)
- Developmental Disabilities & Child Development Clinic
- Early Autism and Communication Research Clinic
- Feeding Clinic
- Genetics Clinic
- Phonology Clinic
- Spasticity and Movement Disorders Clinic
- Fragile X Clinic

Stem Cell Research at The Waisman Center





University of Wisconsin - Madison

Anita Bhattacharyya, Ph.D.

Biological basis of neurodevelopmental disorders

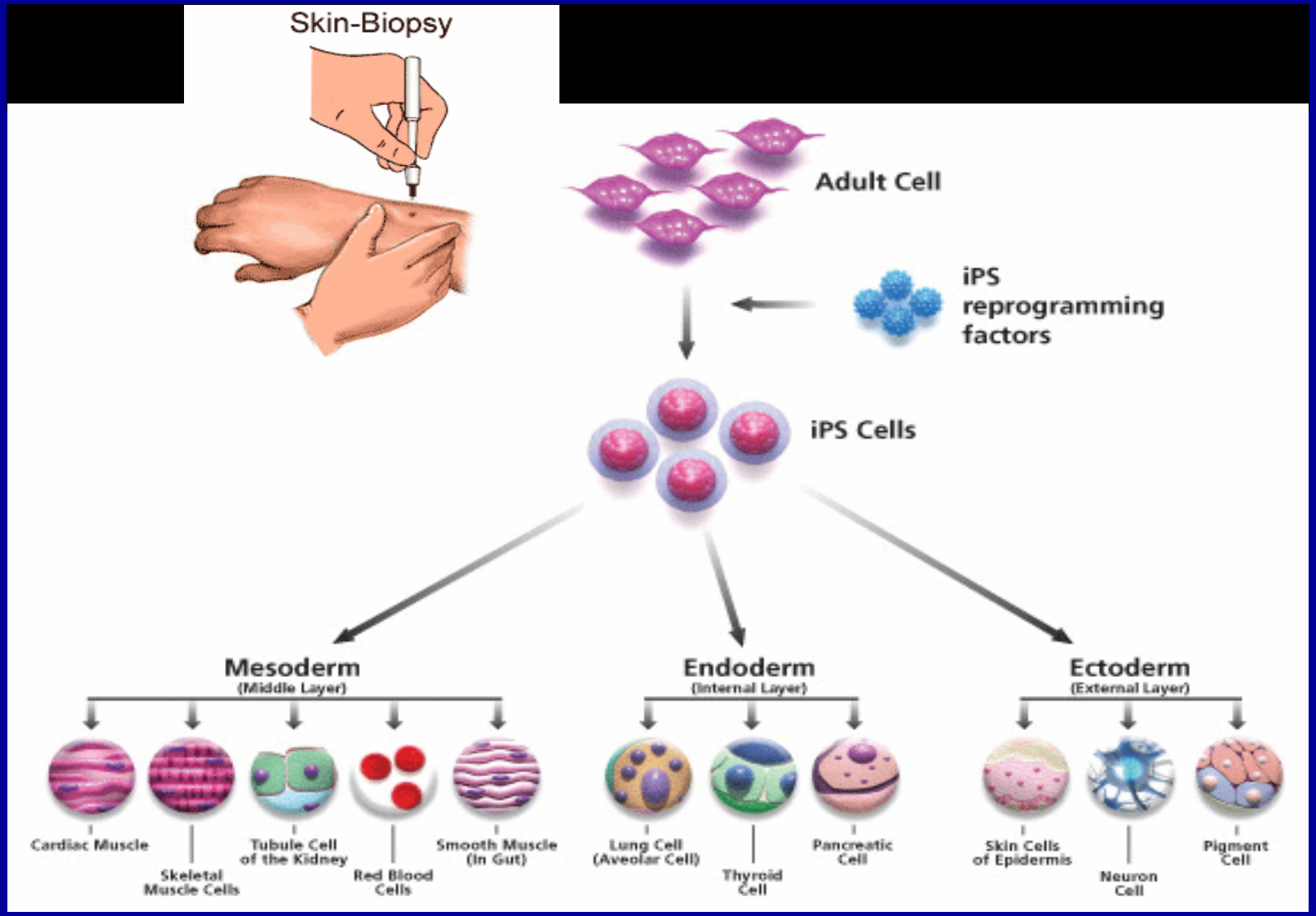
Neurodegenerative

- Parkinson's
- ALS
- SMA
- Huntington's
- Alzheimer's
- Stroke
- Retinal degeneration
- Prenatal brain injury
- Demyelinating disorders

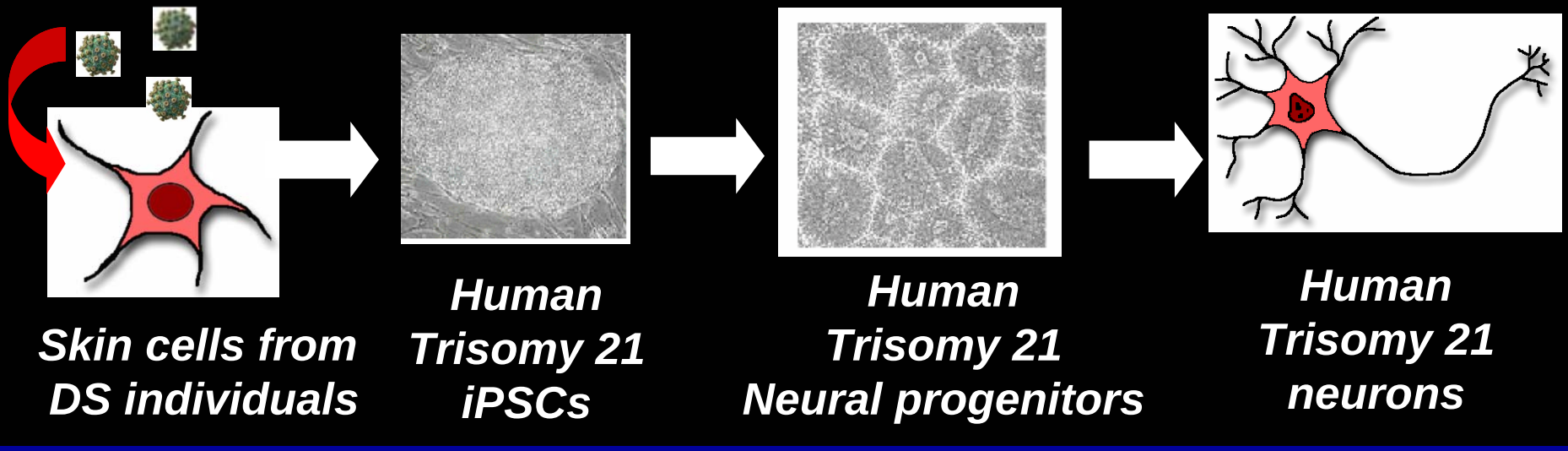
Neurodevelopmental

- Down syndrome
- Rett syndrome
- Fragile X syndrome
- Alexander's Disease
- Autism

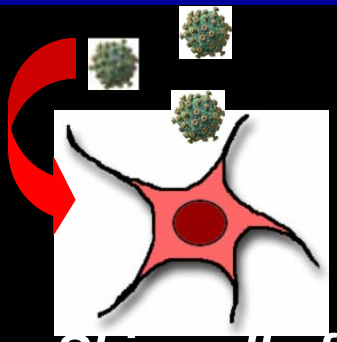
Induced Pluripotent Stem Cells (iPS cells)



Down syndrome (Trisomy 21)
iPS cells

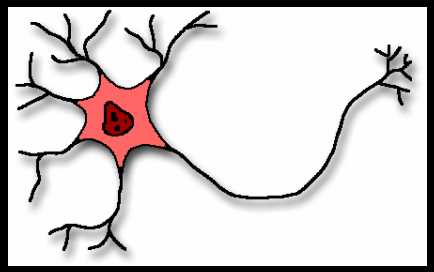


Fragile X and Autism iPS cells



Skin cells from individuals with Fragile X (FX)

FX iPSCs



Human FX neurons

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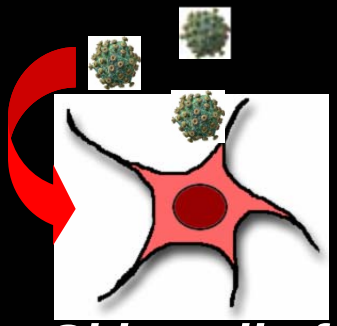
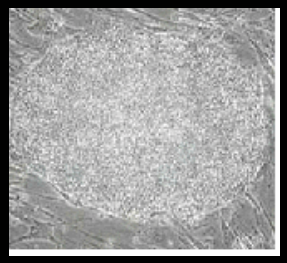
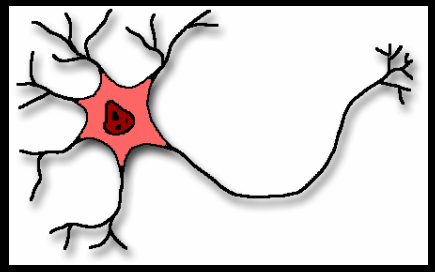


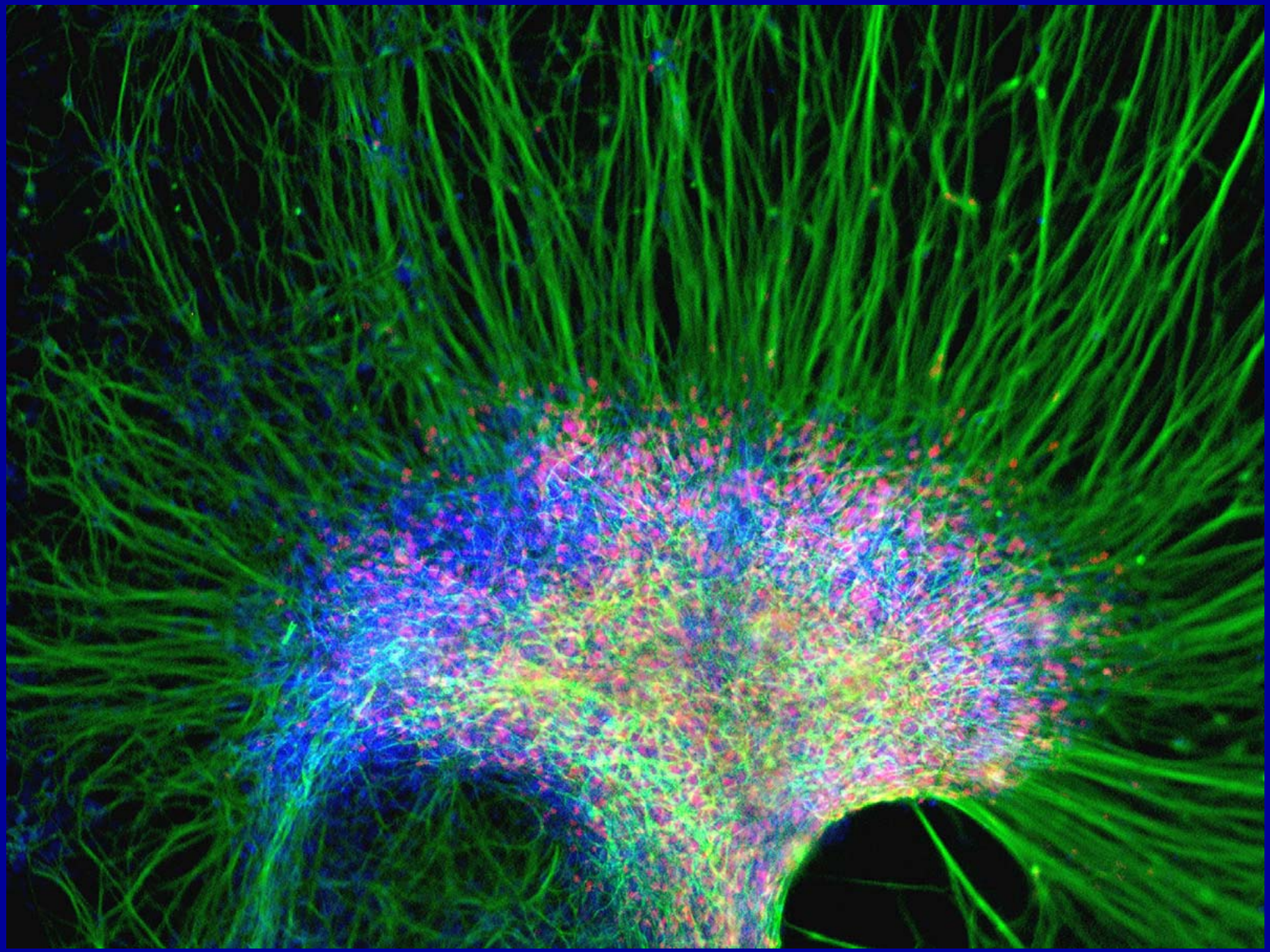
Skin cells from individuals with Fragile X (FX) AND autism



FX+autism iPSCs



Human FX+Autism neurons



Supporting Families of Teens with Autism during the Transition to Adulthood

Leann E. Smith, PhD

Why Do Families Need Supports?

- Parents of children with autism spectrum disorders (ASDs) report higher levels of stress than parents of children with other disabilities including
  - Down syndrome
  - Fragile X syndrome
  - Cerebral palsy
  - Undifferentiated developmental disability
- This pattern has been observed in families of preschoolers, school-age children, adolescents, and adults
- Challenging behaviors—lack of awareness and understanding in community

Why Do Families Need Supports?

- Stress has long-term effects parental well-being
  - Anxiety
  - Depression
  - Positive Affect

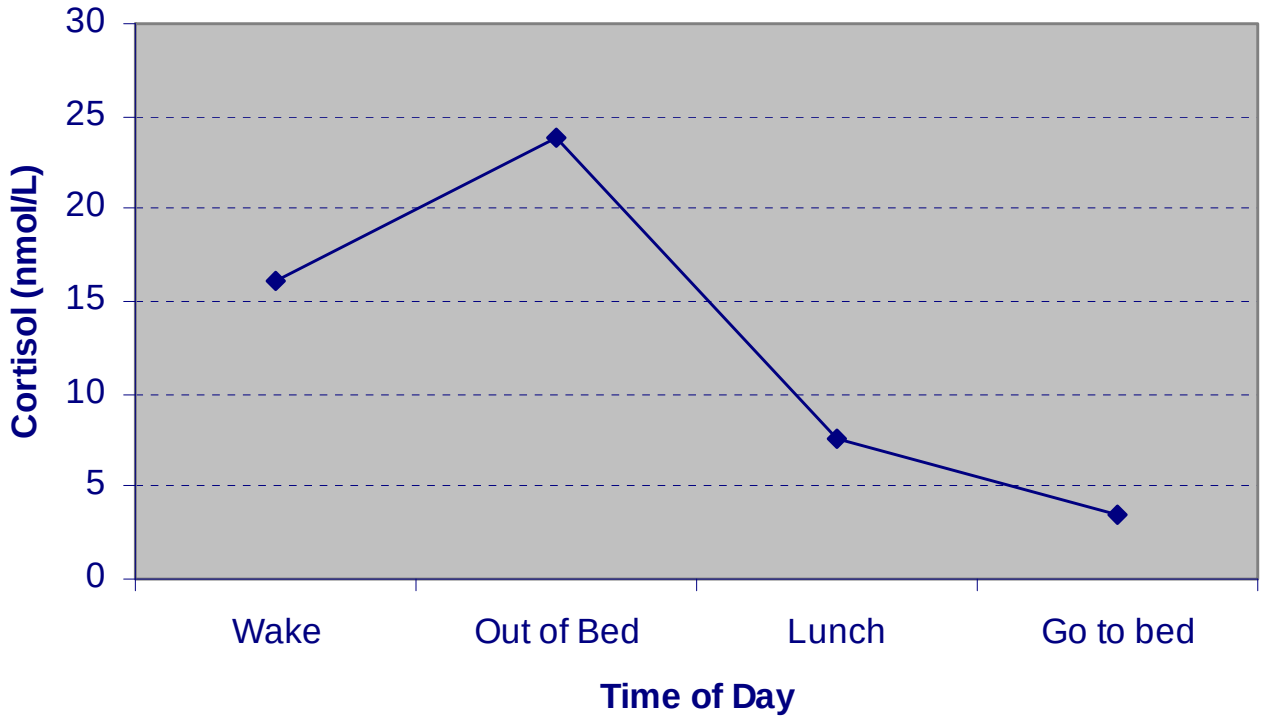
Why Do Families Need Supports?

- Stress has long-term effects on physical health
  - Impact on cortisol, a stress hormone

Normal Pattern of Cortisol Expression

- In healthy individuals, cortisol rises early in the day to help us “rev up” for the day’s challenges and declines thereafter.
- At the end of the day, cortisol is very low which allows us to get adequate rest.

Normal Pattern of Cortisol Expression



Interpretation of Dysregulation of Cortisol

- Dysregulation of cortisol has been linked to physical and mental health problems.
- Acute stress – hyperactivation
- Chronic stress – hypoactivation
  - Parents of children with cancer
  - PTSD
  - Burnout

Cortisol Expression by Groups

Why Do Families Need Supports?

- Stress has long-term effects on physical health
  - Impact of cortisol
  - More physical health problems and symptoms
- Need for Supports for Parents to Reduce Stress

Why Do Families Need Supports?

- Adolescence is an important time
  - Transitions
  - Exiting school system

- Need for community activities and supports for adolescents and adults with ASD
  - Fewer adult services
  - Fewer social activities

Why Do Families Need Supports?

- Research Indicates Services Should Provide:
  - Supports to the entire family as well as the individual with ASD
  - Supports at every point in the life course, not just during early childhood
- Increasingly fewer services for families as children grow into adolescence and adulthood
  - Transitioning Together Program seeks to address this gap

Transitioning Together

- Education and Support Program for Families of Adolescents
  - Individual Family Sessions
  - Multi-Family Group Sessions
  - Social Skills Group for Teens
  - Regular Referrals and Sharing of Resources

Transitioning Together

- 2 Individual Family Sessions
  - Discuss current community connections, supports, and needs
  - Discuss family hopes and develop goals for the program
- 8 Group Sessions
  - Provide information to families
  - Collaborate to find workable solutions to problems
  - Social skills group for adolescents

Transitioning Together: Topics for Group Sessions

- Autism in adulthood
- Transition planning
- Structuring the family environment
- Problem-solving
- Risks to independence
- Community involvement
- Risks to health and well-being
- Legal issues

Transitioning Together

- Overall goal to reduce the level of family distress and promote positive well-being and community involvement

Transitioning Together

- Preliminary Findings From Pilot Study
  - 11 families (mothers, fathers, and teens) participated in the pilot intervention
  - High levels of satisfaction
  - Improvements in parental empowerment
- Next Steps: Expand Program to Other Areas in Wisconsin

Acknowledgements

Collaborators

- Marsha Mailick Seltzer, PhD
- Jan S. Greenberg, PhD
- Larry Kaplan, MD
- Katherine Hamm
- Rebecca Shalev
- Renee Makuch

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- NICHD (P30 HD03352, T32 HD07489)
- UW ICTR-CAP through NIH (1 UL1 RR025011)
- Autism Society of Southeastern Wisconsin

UW Waisman Center
Parent and Child Emotion Study (PACES)

Emotion Regulation and Co-Regulation in Families of Children with Fetal Alcohol Spectrum Disorders (FASD).

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NICHD Postdoctoral Fellow

Rachel Fenning Baker, Ph.D.
Assistant Clinical Professor of Pediatrics

Funding Sources: Waisman Center, University of Wisconsin-Madison, Palmer funds (J. Baker & R. Fenning Baker, PIs) & NICHD T32 HD07489 (L. Abbeduto, PI)

PACES Team

- Investigators:
  - Jason K. Baker, Ph.D.
  - Rachel Fenning Baker, Ph.D.
- Research Assistants:
  - Christine Meng, M.A.
  - Sarah Frankfurt
- Key Personnel
  - Gregory Rice, M.D.
  - David Wargowski, M.D.
- Consultants
  - Marsha Mailick Seltzer, Ph.D.
  - Daniel S. Messinger, Ph.D (UMiami)
- Advisory Committee
  - Marsha Mailick Seltzer, Ph.D.
  - Len Abbeduto, Ph.D.
- Key Community Contact & Advisor:
  - Georgiana Wilton, Ph.D. (Family Empowerment Network)

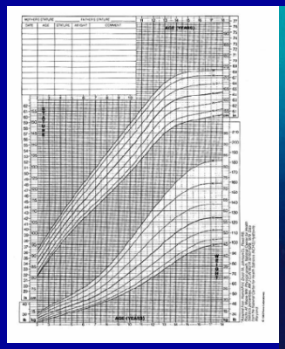
FASD

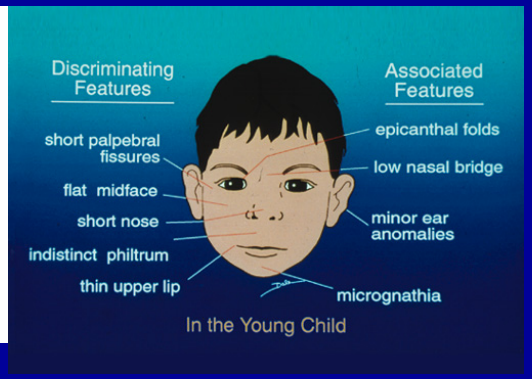
Growth Deficiency

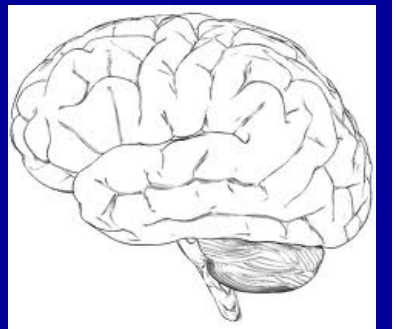
Facial Features

Brain Dysfunction

Gestational Alcohol







Includes: FAS, FAE, ARND, ARBD, etc.

FASD-Related Difficulties

- Social, behavioral, and emotional problems

  (Carmichael-Olsen et al. 1998; O'Connor, Shah, & Whaley, 2002; Streissguth, 2007).

- Executive functioning difficulties (impulsivity, inattention, processing problems; Schonfeld, Paley, Frankel, & O'Connor, 2006; Streissguth, 2007).
- Children's emotion regulation as a mechanism for risk-outcome associations.

Emotion Regulation

- *"The extrinsic and intrinsic processes responsible for monitoring, evaluating, and modifying emotional reactions, especially their intensive and temporal features, to accomplish one's goals"* (Thompson, 1994).

Emotion Regulation

- In otherwise typically-developing populations, dysregulation implicated in the development of:
  - Depression/anxiety, aggression, social skills, empathy, conduct disorder (Cole, Michel, & Teti, 1994; Rubin, Coplan, Fox, & Calkins, 1995).
- In children with early developmental delays (J. Baker, Fenning, Crnic, Baker, & Blacher, 2007) dysregulation at age 4:
  - predicted social skills at age 6.
  - was a stronger predictor than for TD children.

Contributors to Regulation

- Child Characteristics
  - Temperament
  - Psychopathology
  - Developmental background
- Parent/Family Characteristics
  - Family Climate
  - Emotion Socialization
  - Emotion Co-regulation

Parenting and Regulation

- Mother's ability to co-regulate their typically-developing children tied to a host of child outcomes

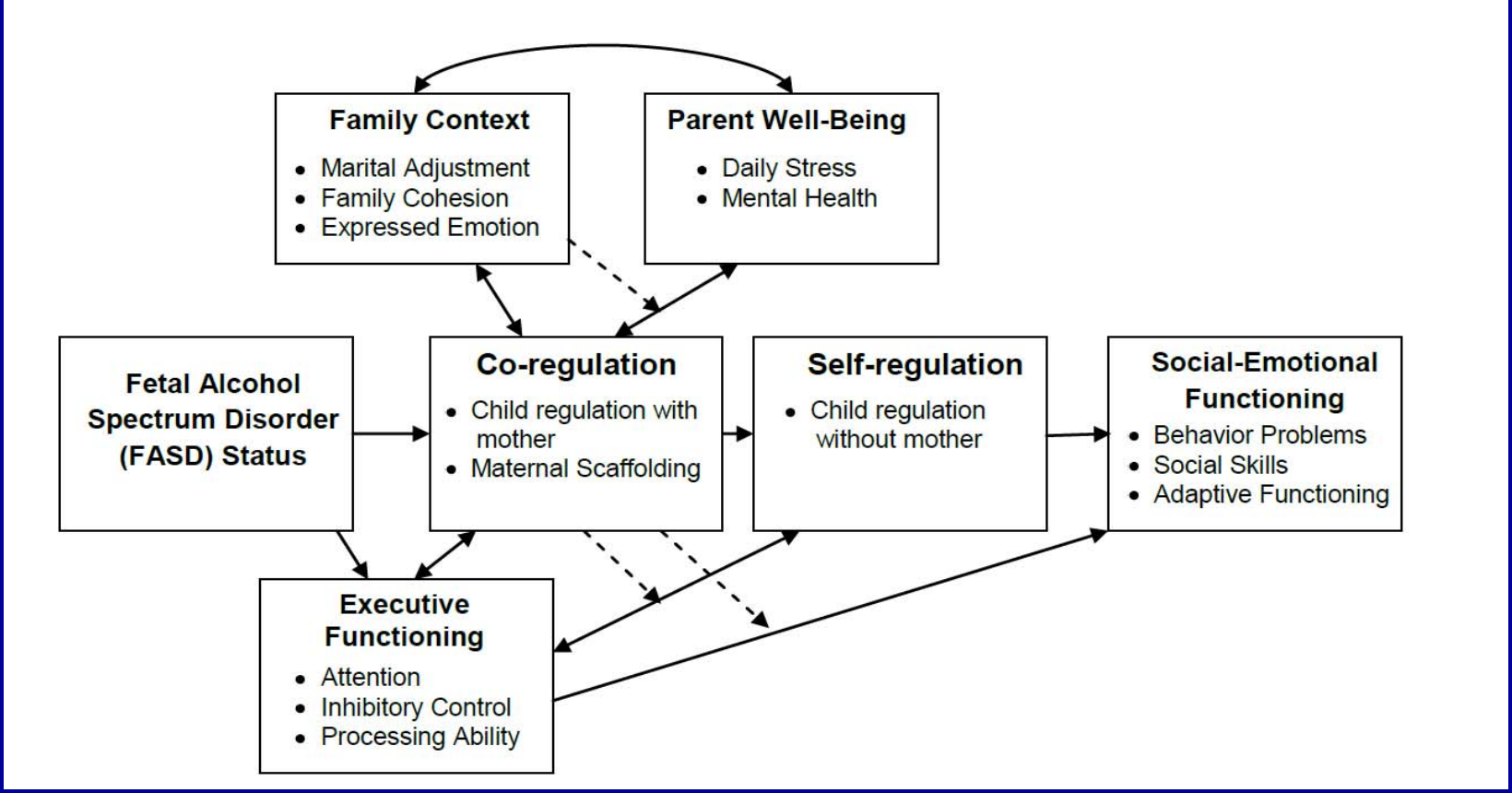
  (Baker, Fenning, & Crnic, in press; Eisenberg, Cumberland, & Spinrad, 1998; NICHD ECCRN, 1999).

- Mother co-regulation abilities in children with developmental delays (Baker et al., 2007):
  - Strongest predictor of later social skills.
  - Stronger relations than found in the TD group.

PACE Study Aims

1. To characterize the specific emotion regulation difficulties experienced by children with FASD.
2. To understand potential contributors (e.g., child executive functioning, family environment, parent co-regulation) and outcomes of regulation in this population.
3. To examine whether parent and/or family factors can promote resilience in children with FASD through their regulation abilities.
4. To understand the effect of FASD on families and to identify resilience factors for families.

Proposed Model



Procedures

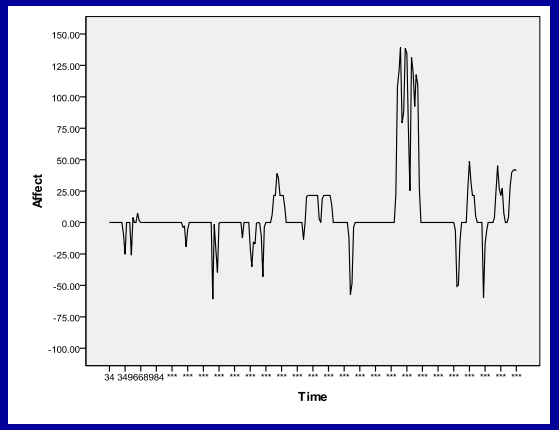
- Initial screening (10 min)
  - Risk / Previous FASD diagnosis
- Home/Lab Visit (1-2 hours)
  - FASD evaluation / confirmation
  - Child cognitive/EF assessment
  - Child regulation and parent-child co-regulation
- Completion of Questionnaires (30 min)
  - Child overall functioning
  - Family environment / parent functioning
- Follow-up (if desired)

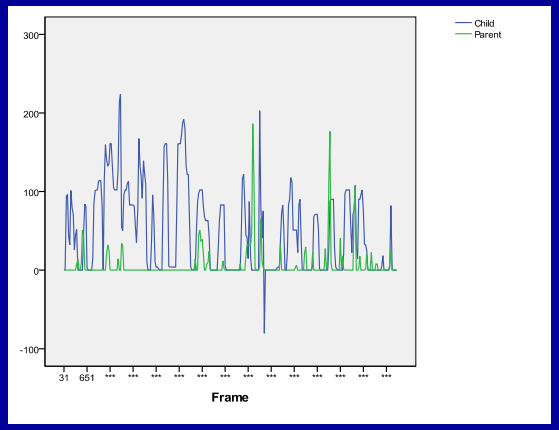
Visit: Observation Tasks

- Child Regulation
  - Delay of Gratification
  - Locked Box
- Parent-Child Co-regulation
  - Free Play
  - Clean-up
  - Problem Solving Tasks
- *Coded with global and time-based ratings*

Time-Based Analysis

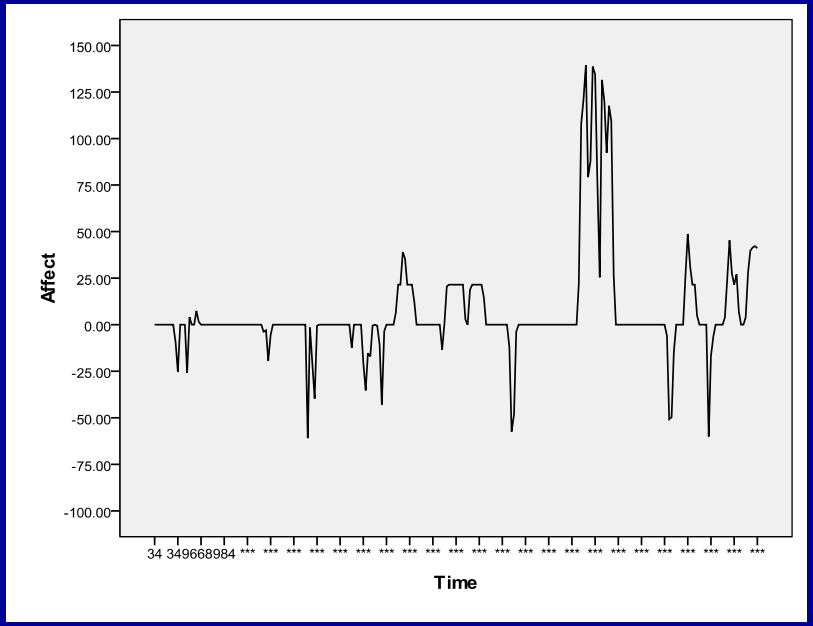
- Child Frustration Tasks
  - Affect/Regulation
    - Soothability, lability, intensity
  - Association with Behavior
    - ER strategies
- Parent-Child Interaction
  - Affect/Regulation
  - Parent-Child Synchrony
  - Parent-Child Causal Effects
    - Parent led vs. child led





Child Regulation: Frustration Task

Control



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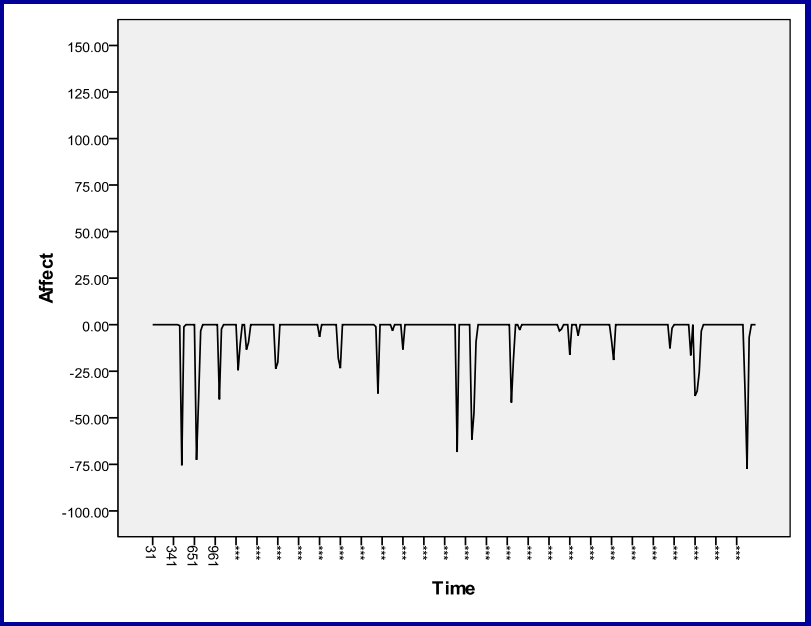
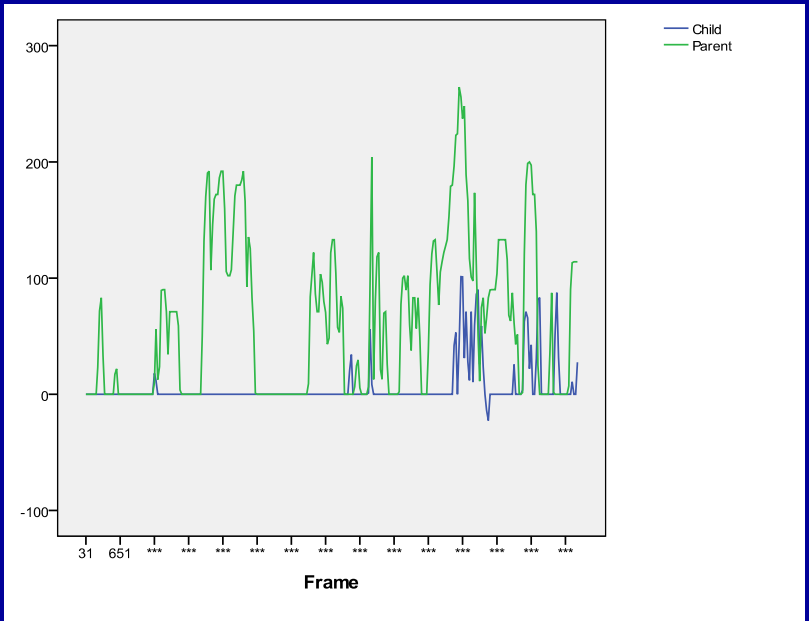


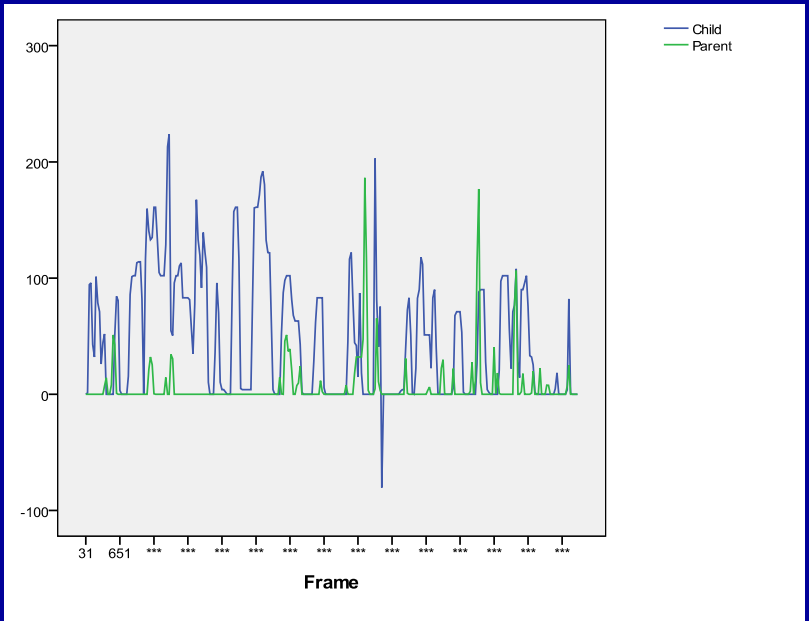
Parent-Child Free Play

Control



Cross Correlation = .29***

Target



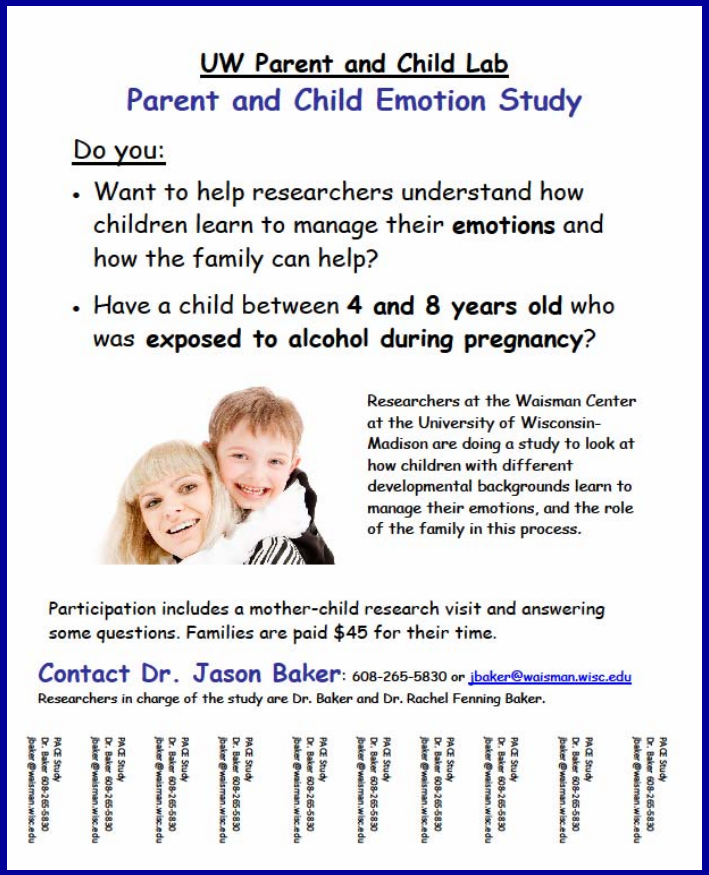
Cross Correlation = .00*ns*

Long-Term Goals of the Study

- Pilot data for larger grant
  - Physiological measures
  - Emotion socialization
  - Longitudinal follow-up
- Intervention
  - Emotion management
  - Co-regulation / Emotion socialization

FASD Recruitment

- 45 Children between 4:6 (3:6) and 8:11
- Diagnosis or <u>suspicion</u> of FASD
  - Exposure and/or associated symptoms
- Within a 6 hours drive from Madison, WI



UW Parent and Child Lab

Parent and Child Emotion Study

Do you:

- Want to help researchers understand how children learn to manage their **emotions** and how the family can help?
- Have a child between **4 and 8 years old** who was **exposed to alcohol during pregnancy**?

Researchers at the Waisman Center at the University of Wisconsin-Madison are doing a study to look at how children with different developmental backgrounds learn to manage their emotions, and the role of the family in this process.

Participation includes a mother-child research visit and answering some questions. Families are paid $45 for their time.

Contact Dr. Jason Baker: 608-265-5830 or jbaker@waisman.wisc.edu

Researchers in charge of the study are Dr. Baker and Dr. Rachel Fenning Baker.

PACE Study Dr. Baker 608-265-5830 jbaker@waisman.wisc.edu

FASD Recruitment: WI

- National: FASD = 1:100 (Sampson, Streissguth, Bookstein, et al., 1997).
- WI: 72,000 births/yr = 3,960 potential (5.5yrs)
- http://www.cdc.gov/ncbddd/fasd/data.html

Undiagnosed FASD

- Alcohol exposure noted, and symptoms similar to:
  - ADHD, especially:
    - Primarily inattentive type (O'Malley et al., 2002).
    - Atypical response to traditional medication (Doig et al., 2008; Osterheld et al., 1998; Snyder et al., 1997).
    - High sensitivity to side effects (Coe et al., 2001).
  - ASD
  - Borderline to mild intellectual disability
  - Reactive attachment disorder*

Thank you