The Waisman Center

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

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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.
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
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”?

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

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

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

- 25 affiliated UW departments
NICHD Network of 15 IDDRCs

- Seattle
- Madison
- Lawrence
- Los Angeles
- Chicago
- Nashville
- St. Louis
- Birmingham
- Houston
- Philadelphia
- Baltimore
- Washington, DC
- Chapel Hill
- Boston
- Madison
- Seattle
- Nashville
- St. Louis
- Baltimore
- Washington, DC
- Birmingham
- Houston
- Philadelphia
- Boston
- Madison
- Seattle
- Nashville
- St. Louis
- Baltimore
- Washington, DC
- Birmingham
- Houston
- Philadelphia
- Boston
Only 9 have both an IDDRC and UCEDD

The Waisman Center houses both . . .

- **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
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

Skin cells from DS individuals → Human Trisomy 21 iPSCs → Human Trisomy 21 Neural progenitors → Human Trisomy 21 neurons
Fragile X and Autism iPS cells

Skin cells from individuals with Fragile X (FX)

FX iPSCs

Human FX neurons

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 on 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

![Graph showing cortisol levels over the course of a day.](image-url)
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
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
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UW Waisman Center
Parent and Child Emotion Study (PACES)

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

Jason K. Baker, Ph.D.
NICHD Postdoctoral Fellow

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

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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.
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

Target
Parent-Child Free Play

Control  

Target

Cross Correlation = .29***  

Cross Correlation = .00ns
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 suspicion of FASD
  – Exposure and/or associated symptoms

• Within a 6 hours drive from Madison, WI
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