# AUTISM SPECTRUM DISORDERS:
# The Importance of Parent Child Relationships

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# Sensitive Responsive Caregiving:

- is essential to optimal child development &
- infant-caregiver attunement is at the heart of such caregiving.

# Emotional Signals

- primary means of communicating inner experience
- sharing affective states
- emotional exchanges are “transactional”

Tronic 1989

# Repeated “Conversations” Overtime:

- become the organizing substrate for the developing relationship as well as for the
- experience dependent development of the brain.

# Infants & Children with ASD

- present a particular *CHALLENGE* to infant-caregiver attunement
- to sharing affective connectivness
- have difficulty in co-orientation: perceiving, processing and responding to social experience
- develop unusual behaviors, interests, reactions
- interfere with communication skills, social and emotional development

# Parents Living with ASD

- need help finding ways to join their child at an emotional level
- need help learning to build many and varied experiences
- develop self-awareness and sense of self in their child

Family-focused transdisciplinary approaches maintain a well-integrated, coherent program of care and promotes progress and change.

# “Secure-Base” Professional

- is a person on whom the family can rely
- provides support, continuity, guidance
- sustains growth over time
- is aware of and encouraging of intervention fitted to the child and family

ASD refers to an etiologically & clinically heterogeneous group of neurodevelopmental disorders with difficulty in social relatedness & reciprocal communication.

Underlying neurobiology affects the way brain processes, responds to, and organizes experience, leading to atypical trajectories.

# Epidemiology

- The prevalence of ASD is rising:

  1/88 in USA (CDC 2012)
- Most pervasive pediatric epidemic
- Possible reasons for rise? Expansion of dxic criteria to a spectrum disorder; improved screening/dxic tools; improved access to services; greater clinician/public awareness; genuine rise in incidence

Rutter2005

# Etiology

- Idiopathic & result of unknown environmental exposures within the context of genetic vulnerability Muhle et al 2004
- Affects males disproportionately in 4:1 ratio
- Monozygotic(MZ) twins more likely than dizgotic (DZ)twins--36-95% vs. 0-31%, respectively (CDC 2012)
- Concordance for sub-threshold levels of social/communication difficulty (BAP), more common in MZ than DZ twins (Bailey et al 1995)

# Etiology

- Autism is highly genetic
- More than one gene is involved in idiopathic autism
- Epigenetic processes & environmental modifiers contribute to variable expression of ASD phenotype

(Muhle et al 2004)

# Etiology

- Recurrence risk:
  in simplex families (one child has ASD already) is 13.5% in multiplex families (more than one child has ASD) is 32.3% (Ozonoff et al 2011)
- If male: 25.9%  If female: 9.6% (Ozonoff et al 2011)
- ASD occurs (10-20%) in fragile X, Tuberous Sclerosis, 15q deletion, 22q deletion

(Hansen & Hagerman 2003)

# Etiology

- Copy number variants & *de novo* nucleotide mutations are increasingly implicated

  (Abrahams & Geschwind 2008)

- Abnormalities have been found on every chromosome. More than 100 candidate genes/susceptible loci identified (neurotransmitter fx/synaptic binding neuroligins) (Dawson 2008)

- Thalidomide & valproate: teratogenic for ASD

  (Hansen & Hagerman 2003)

# Neurobiology

- Many of studies involve older adults so may be result of ASD rather than cause
- Abnormal white matter found in 6-24 month infants suggesting abnormal connectivity before behavioral signs are noted

(Wolff et al 2012)

# Neurobiology

- Abnormalities in the timing/growth organizational patterns in both grey/white matter. White matter under-connectivity between distant temporal, parietal & associated cortical regions has been found, with over connectivity between cortical/sub-cortical regions & w/in primary sensory cortices

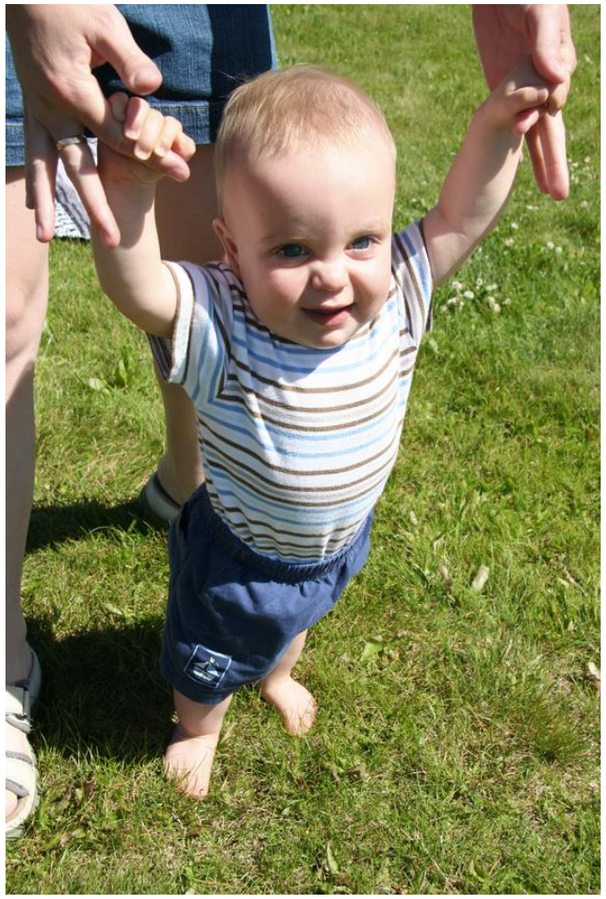
(Anagnostou & Taylor 2011)

# How Infants Relate and Learn

- Essential role of early parent-child relationships in the development of social brain circuitry & cortical specialization for language and social learning

(Dawson 2008)

- Interpersonal engagement is key!!



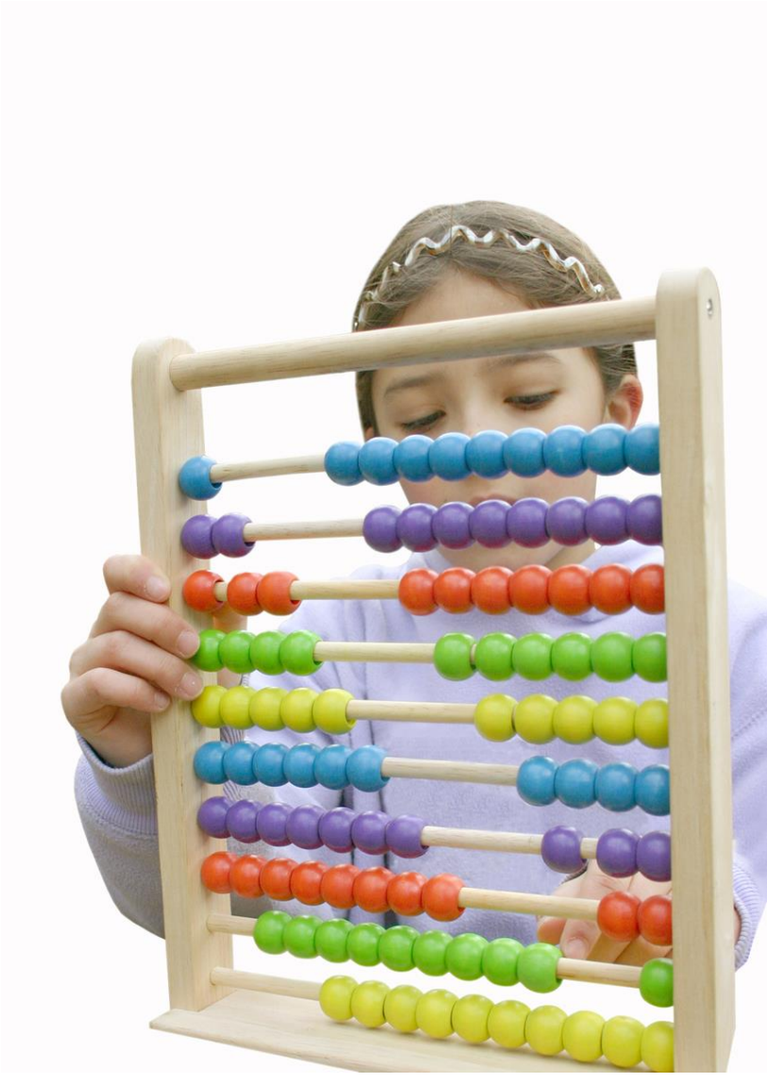
# How Infants Relate and Learn

- In social interactions, infants use statistical learning to perceive consistencies in their sensory social experiences
- They orient to faces, voices, social behaviors to discern patterns, make predictions and then generalize (Rogers & Dawson 2009)

# How ASD Affects Relating and Learning

- Decreased initiation of and responsiveness to social interaction by 8-10 months
- Decreased eye contact, directed facial expressions and vocalizations, response to name, repetitive behaviors by 12 months (Ozonoff et al 2010)
- Atypical development & maturation lead to inefficient/ineffective processing of socially relevant information

# How ASD Affects Relating and Learning



- Social brain development is further compromised as cycles of under-responsiveness result in fewer sustained interactions with caregivers
- Considering the role neuroplasticity plays in organizing experience, early identification is essential

# How ASD Affects Relating and Learning

- Because ASD infants are less social, less initiating, more fixated, limited in play--reciprocal human interactions must be promoted
- Parents must expand experiences despite child’s disregulation to foster flexibility, social experiences and communication
- Developmental integration through human experiences are essential

# Early Signs and Onset Patterns

- At 6 months, no noted differences in socially directed behaviors
- At 6-12 months, gradual loss of social communication skills and continuing through 36 months (Ozonoff et al 2009)
- Unrecognized gradual regression in many, rather than lack of social skills development from the onset or regression at 18-24 months
- It is possible to ID children at young ages!

# ASD Children and Families

- Need early awareness and family-focused evaluations with the development of individualized care
- Professionals need to be well trained in ASD
- We need to develop ASD Medical Houses

# Diagnosis and Assessment

- Standardized evaluations are limiting
- M-CHAT at 18,24,30 months (Robins et al 2001),
  ADOS-G (Lord et al 2000),
  ADI-R (Lord, Rutter &LeCouteur 1994) Others?
- Sustained evaluations over time with caregivers
- Multi-disciplinary, the only way to go!
- DSM-IV to DSM-V

# Family-Focused Assessment

- Parents need to participate by telling their stories, by playing with their child.
- Parents need to share their experiences of their child: strengths and areas of challenge
- Developmental patterns need to be identified as part of Diagnosis
- Diagnosis is a time of disequilibrium for the family

# Family-Focused Assessment

- Threshold into the world of ASD is the “Secure Base” of the assessment
- Family and child are joined in establishing a safe, informative process which will strengthen their confidence, help in understanding everyone’s needs and build communication

# Family-Focused Assessment

- A transdisciplinary assessment enables evaluators, parents, & child to learn about child and themselves
- Goal: establish a comprehensive constitutional profile of the child & a compatible intervention plan for all

# Family-Focused Assessment

- Paradigm shift: from viewing only behaviors/symptoms as core deficits to interactional & behavioral symptoms as indicators of deeper, more complex developmental patterns
- This shift sets the stage for a strong working alliance with the family

# Family-Focused Assessment

- There are steps involved is the assessment process which are general and broad as well as specific to the professional setting
- Affecting the opportunity of this sensitive and respectful process sets the foundation for the family and their journey

# Family-Focused Assessment

- The framework offered in DIR®: Developmental, Individual-Difference, Relationship-Based model (Greenspan & Wieder 1998) is a reasonable construct for organizing an understanding of how the child can become a developmentally integrated, functional person.
- Parents need to actively participate in the assessment process to share experiences & observations, thus forming the Parent-Professional partnership.

# Intervention and Treatment

- Current best practice guidelines call for INTENSIVE INDIVIDUALIZED INTERVENTION of at least 25 hours per week

  (Lord and McGee 2001;National Autism Center 2009)

- Focus is on developing critical thinking, promoting social skills, functional communication, and developmentally integrated learning and relating

- Central role of the FAMILY is stressed

# Intervention and Treatment Options

- Discrete trial training
- Developmental Skill building
- Developmental-relational interventions
- Speech and Language: pragmatic language development
- Occupational Therapy: attention and processing, motor planning, sequencing and sensory modulation

# Intervention and Treatment Options

- Social groups and curriculum-based social skills programs
- Education
- Medical care and interventions
- Structured activities such as sports and after-school activities
- Family play, outings and vacations

# Family Relationship-Focused Intervention

- Relationships as the foundation of meaningful learning allows intensive practice of concepts in naturalized relational interactions
- Skills are built by using shared AFFECT as the central organizer of experience
- Experiences are integrated across developmental domains (motor, cognition, communication, social, emotional)

# Family-Relational-Focused Intervention

- GOAL: to provide guidance and continuity as parents/family learn how to best be together
- GOAL: to facilitate the parents/family to enable their child to be even more present in the world

# Processing The Diagnosis

- The Loss-Grief Cycle (Foley 2006): Disorientation and Disequilibrium; Searching; Acknowledgement; Recovery; Maintenance
- Importance of Active Family involvement: take seriously the family perspectives

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Our best teachers are the children and their families, along with their professional teams.

Gratitude is boundless.