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 diagnostic 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 dizygotic (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 in 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
References


Foley, G: The loss-grief cycle: coming to terms with the birth of a child with disbability, in Mental Health in Early Intervention: Achieving Unity in Principles and Practice. Edited by Foley GM, Hochman JD. Baltimore, MD, Paul H. Brookes publishing. 2006 pg. 227-243


References


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

Gratitude is boundless.