A Parent-Centered Approach to Autism Diagnosis in Toddlerhood

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June 20, 2019

Disclosures

- None

Overview

- The Child Development Clinic
  - Who we are & what we do
- Differentiating among CNHS ASD testing providers
- Emphasis of developmental testing in our clinic
- Our clinic's process of diagnosing ASD in toddlers
  - The **parent-centered** approach

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What we do in the Child Development Clinic

- Children ages birth to 3 ½ years of age
- Psychologists (clinical/developmental)
- Developmental testing (some therapy)

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Developmental Clinic Assessment Measures

- Comprehensive developmental evaluation
  - Bayley Scales of Infant&Toddler Development
  - Vineland Adaptive Behavior Scales (Vineland-2)
  - Child Behavior Checklist (CBCL)
  - Social Responsiveness Scale (SRS-2)
  - Sensory Profile 2
  - Autism Diagnostic Observation Schedule (ADOS-2)

- Comprehensive clinical interview/parent report
  - Diagnostic (i.e. autism-specific) interview (ADI)

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Our population

- Infants & toddlers who are at-risk of developmental challenges
  - Medically complex: preemies, CHD, TBI, neurologic and/or chromosomal anomalies
  - Developmental delay; not meeting milestones
  - Screening measures (i.e. M-CHAT; ASQ)
  - "Speech delay"
  - Family history of autism

Developmental Clinic vs. Developmental Pediatrics

Dev. Clinic	Dev. Peds
-Psychologists	-MDs, NPs
-Birth to 3 ½	-Birth through young adult
-Psychosocial approach	-Medical perspective (incl. prescribing meds)

Developmental Clinic vs. Center for Autism Spectrum Disorders

Dev. Clinic	CASD
-Psychologists specializing in early childhood dev.	-Multidisciplinary (neuropsych, MD, SLP, etc.)
-Birth to 3 ½	-15m through young adult
-Broader developmental concerns	-ASD-specific testing & programming

Goals of assessment

- To gain a better understanding of a child's strengths & weaknesses
  - Delayed versus 'atypical development'

- To try to understand how s/he perceives the world, how s/he relates to the environment
  - To *see* the world through the child's eyes

Differentiating between domains

- Gross motor development as '*the most visible delay*'
  - Example: 15-month-old who doesn't walk
- Speech/language as main concern for toddlers
  - Example: 24-month-old who doesn't talk

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Differentiating between domains (cont.)

- Parents' concerns: walking & talking

- Our emphasis:
  - Broader cognitive functioning (nonverbal problem-solving & play)
  - Receptive language (what the child understands)
  - Social communication (how they use their social skills to request/engage/relate)

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Before assessing social development

- How is the child doing in terms of other domains of development?
  - Motor skills
  - Nonverbal problem-solving skills
  - Language (receptive & expressive) skills
  - Play skills

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The importance of cognitive testing

- Cognitive testing as the first step
  - Cognitive functioning provides context for the diagnosis
- Autism: social functioning as a relative deficit
  - Differentiating between cognitive impairments/developmental delay versus ASD
- Social skills in comparison to cognitive functioning

Cognitive development vs. social development

- We cannot expect a child with significant cognitive delays to meet social/social communication milestones above their cognitive level

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Assessing social functioning at the table

- Eye contact/social watchfulness
- Imitation
- Back-and-forth/turn-taking/reciprocal exchange
- Seeking praise/referencing parents
- Seeking assistance/gesture use
- Object-oriented vs. person-oriented

Assessing social functioning during play-based testing (i.e. ADOS)

- Eye contact
- Requesting/getting needs met (gesture use)
- Responding to playful obstruction/blocking
- Responding to name
- Pointing/following a point
- Anticipating social routines (bubbles; peekaboo)
- Back-and-forth play (ball)
- Sharing enjoyment
- Referencing parents/bidding for their attention
- Sharing & showing

Assessing social development in the clinical interview

- What are your primary concerns?
- Open-ended questions
  - Broad questions → increasingly specific
  - 'How does he get his needs met?'
  - 'Does he point to request?'
  - 'Does he coordinate EC while pointing?'
- Preparing for feedback: examples from the evaluation (observed) & home (parent report)

Assessing social development in the clinical interview (cont.)

- Relationships
  - Caregivers: Attachment, "rely on as secure base"
    - Bidding for attention, seeking praise, showing/sharing, separation/reunion, seeking when hurt
  - Siblings, peers
    - Reciprocating interactions, initiating interactions, parallel play, chasing games, back-and-forth play

- Environmental role in social development
  - Appropriate stimulation (versus screentime)

Focus of Developmental Evaluation

- Child-centered:
  - connecting with the child
    - adjusting approach depending on response
  - how does the child perceive/relate to the environment
  - strengths & weaknesses
  - answering the diagnostic question

- Parent-centered: their concerns; their perspective of underlying problem/diagnostic awareness

Focus of Developmental Evaluation (cont.)

- Child-centered:
  - Getting the best out of the child
  - Outcome-oriented (i.e. content/data)

- Parent-centered:
  - understanding parents' perspective, concerns
  - parents as active participants in evaluation
  - teaching through showing/doing
  - assessing parents' readiness, openness, etc.
  - *process-oriented*

Focus of Developmental Evaluation (cont.)

- As the diagnosis becomes clearer

  Child-centered→ Parent-centered

- Particularly for clear-cut ASD

Focus of Developmental Evaluation (cont.)

- The clearer the diagnosis, the more the clinician can focus on the parents

- Borderline ASD cases = more child-focused
  - Reliance on scoring, interpretation of assessment measures (ADOS, SRS, etc)

Focusing on the process during testing

CONTENT	PROCESS
-Focus on item admin., scoring, etc.	-Adjusting the process according the parents' needs
-Following the protocol, taking careful notes/scoring	-Talking through items 'in real time'
-Interviewing after/before floor-based testing	- Integrating interview into testing (to instantiate)

Focusing on the process during the interview

CONTENT	PROCESS
- Getting data from parents	-Providing the parents with the opportunity to be heard; incorporating information into our perspective
-Asking directly about ASD	-Assess for defensiveness, emotional receptivity & readiness
-Comparing parent report to observation during assessment	-Reconciling differences between parent report & observation

Focusing on the process during feedback

CONTENT	PROCESS
-"Giving the diagnosis"	-Walking parents thru the diagnosis; helping parents understand the diagnosis -Communicating criteria as they pertain to the child, parents' concerns/report - Easing into the diagnosis

Focusing on the process during feedback (cont.)

- Easing into the diagnosis
  - Goal of developmental testing
  - When social/social communication skills are lagging behind…
  - Have you heard about autism? What is your understanding of autism?
  - Have you thought about autism as it pertains to your child?

Focusing on the process during feedback (cont.)

CONTENT	PROCESS
-"Your child has autism"	-Reflecting their concerns -Modify/amplify concerns -Framing concerns as ASD -Addressing defensiveness/ skepticism as it arises and in respect to specific questions

Focusing on the process during feedback (cont.)

- Considering the parents' perspective:
  - Months of concern
  - Conflicting messages (family, friends, therapists, pediatrician, other specialists)
  - "Dr. Google"; ASD videos online; Parent forums
  - Lost sleep, rumination
  - Some ASD behaviors; other behaviors not observed

- Lack of a baseline
  - First child; Unfamiliar with young children
  - Cultural differences, expectations

Focusing on the process during feedback (cont.)

- Strengths…challenges
  - He makes eye contact…but not at expected moments
- Reassuring the parents that you see what they see
- Emphasis on strengths, while clarifying the inconsistencies (i.e. reduced, inconsistent…)
  - Relies on parents as a secure base…but not bidding for attn
- Directly confronting skepticism, as appropriate
  - If it were just 'sensory issues'…gestures, social fx, etc.

Goals of feedback

- Detailing ASD criteria
- How do these criteria pertain to your child?
- Taking time 'check in' with the parents
- Trying to reconcile parent report with clinical experience
- Goal of working towards a common understanding
  - Even if there is a vast divide between clinician/parents' perspectives

Goals of feedback (cont.)

- Providing diagnosis with a balance of:
  - confidence & humility
  - strength & empathy
  - 'telling it like it is' vs. being 'alarmist'
  - realistic & hopeful

Goals of feedback (cont.)

- Getting parents 'on-board' with the diagnosis
- Treatment-planning
  - Motivating & mobilizing
- Providing families with home-based recommendations (i.e. services are often not the most important modeof intervention)

Common questions during feedback

- The Future:
  - Verbal vs. nonverbal
  - General education vs. special education
  - College
  - Living independently
  - Relationships
- Severity level
  - Where are they 'on the spectrum'

Common questions during feedback (cont.)

- Stigma
  - vs. benefits of therapy
- "Losing the diagnosis"
  - Long-term benefit of having been diagnosed

Benefits of Process-Oriented/Parent-focused

- Adjusting feedback depending on parents' perspective, emotional state, etc.
- Assuring that the parents feel heard
  - Goal of addressing their specific concerns versus just telling them what's wrong
- Receiving ASD diagnosis associated with PTSD symptoms

Benefits of Process-Oriented/Parent-focused (cont.)

- Providing parents with a positive, supportive experience
  - First of many evaluations

- Helping them feel that we are "on their team"

What 'parent-centered' does NOT mean

- Not thoroughly assessing the child
- Letting parents make/not make the diagnosis
  - Reconciling their report with what we see
- Telling parents what they want to hear

Why it matters

- Providing parents with a "positive experience" (in process if not in content)
- Serving our families versus "telling parents what's wrong with their kid"
- Empowering families
  - Need 'buy-in' from the parents
  - Helping parents become advocates