A Parent-Centered Approach to Autism Diagnosis in Toddlerhood

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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
What we do in the Child Development Clinic

– Children ages birth to 3 ½ years of age

– Psychologists (clinical/developmental)

– Developmental testing (some therapy)
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)
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

<table>
<thead>
<tr>
<th>Dev. Clinic</th>
<th>Dev. Peds</th>
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<tbody>
<tr>
<td>-Psychologists</td>
<td>-MDs, NPs</td>
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<tr>
<td>-Birth to 3 ½</td>
<td>-Birth through young adult</td>
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<tr>
<td>-Psychosocial approach</td>
<td>-Medical perspective (incl. prescribing meds)</td>
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</table>
Developmental Clinic vs. Center for Autism Spectrum Disorders

**Dev. Clinic**
- Psychologists specializing in early childhood dev.
- Birth to 3½
- Broader developmental concerns

**CASD**
- Multidisciplinary (neuropsych, MD, SLP, etc.)
- 15m through young adult
- ASD-specific testing & programming

June 20, 2019
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
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)
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
The importance of cognitive testing

• Cognitive testing as the first step
  – Cognitive functioning provides context for the diagnosis

• Autism: social functioning as a \textit{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
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

June 20, 2019
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

June 20, 2019
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

<table>
<thead>
<tr>
<th>CONTENT</th>
<th>PROCESS</th>
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<tbody>
<tr>
<td>Focus on item admin.,</td>
<td>Adjusting the process according the parents’ needs</td>
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<tr>
<td>scoring, etc.</td>
<td></td>
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<tr>
<td>Following the protocol,</td>
<td>Talking through items ‘in real time’</td>
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<tr>
<td>taking careful notes/scoring</td>
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<tr>
<td>Interviewing after/before</td>
<td>Integrating interview into testing (to instantiate)</td>
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<td>floor-based testing</td>
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Focusing on the process during the interview

**CONTENT**

- Getting data from parents
- Asking directly about ASD
- Comparing parent report to observation during assessment

**PROCESS**

- Providing the parents with the opportunity to be heard; incorporating information into our perspective
- Assess for defensiveness, emotional receptivity & readiness
- Reconciling differences between parent report & observation
Focusing on the process during feedback

<table>
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<tr>
<td>&quot;Giving the diagnosis&quot;</td>
<td>Walking parents thru the diagnosis; helping parents understand the diagnosis</td>
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<td>Communicating criteria as they pertain to the child, parents’ concerns/report</td>
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<td>Easing into the diagnosis</td>
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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.)

<table>
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<tr>
<td>―“Your child has autism”</td>
<td>- Reflecting their concerns</td>
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<td></td>
<td>- Modify/amplify concerns</td>
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<td>- Framing concerns as ASD</td>
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<td></td>
<td>- Addressing defensiveness/skepticism as it arises and in respect to specific questions</td>
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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

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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 mode of 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