

Dads and Autism

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NFAR Men's Group

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circlestretch

Help the child be...

- Calm enough to interact
- Truly connected to others
- In a continuous expanding balanced
back and forth flow of interaction

“Go for that gleam in the eye!”

<http://www.circlestretch.com>



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Pasadena, California October 2010- May 2011

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In Recognition of Veterans Day



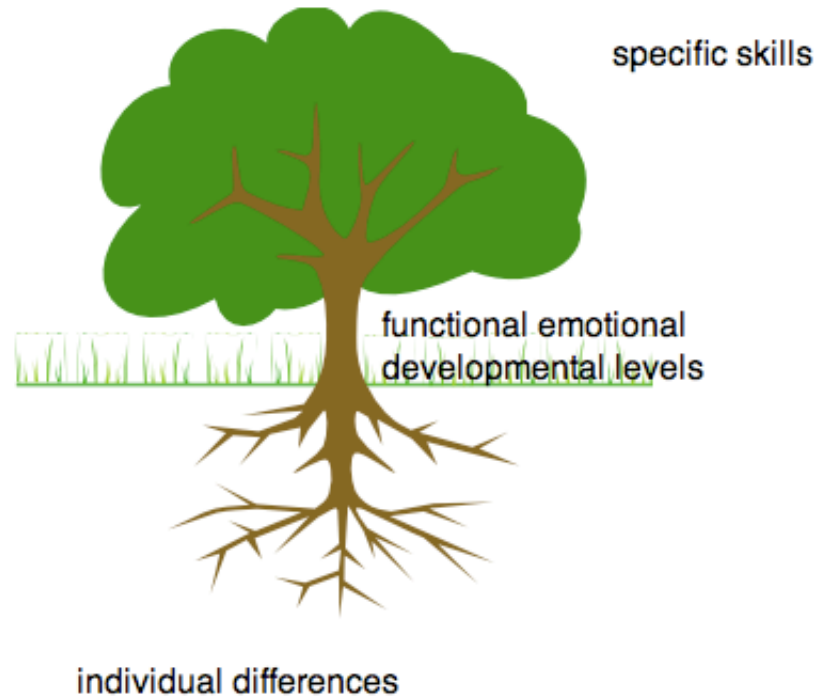
Disclosures

ICDL Faculty – minimal – ICDL grad school (psychopharmacology and biostatistics), review of clinical write ups, travel and room for meetings, token honorarium for co-writing and running Southern California Institute

NIMH/ Duke University – minimal – administrative time for pharmacogenetic research

NIH R21 grant/ San Diego BRIDGE Collaborative – minimal – token honorarium for ongoing consultation and participation

Not a lot to remember....



Take a card with you...



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back and forth flow of interaction

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Feder 411

- **Career** – biomedical engineering and math, Navy – some operational medicine, psychiatry at Balboa, child and adolescent at Tripler, Clinic at Pearl, Chief of Child at NNMC/ USUHS faculty, Greenspan & Wieder in DC, back to San Diego in '96, 'unejectible' in Solana Beach since 2001.
- **Research** – perfluorinated hydrocarbons, mathematical models of mind and cognition (ADHD), physician use of mammography, blood preservation, relationship based interventions, pharmacogenetics, early intervention, computer assisted analysis of play.
- **Disorders of Relating and Communicating, Development, & Autism Spectrum**
Disorders: 1980 Mass. Assn for the Blind (Congenital Rubella); 1982 teacher at school for autistic adults (Behavioral training); BUSM Pediatric Neurology 1985; Child Study Group – Tripler (Lee); Neurodev. Clinic NNMC 1993 - 1996; Greenspan, Wieder et al ICDL 1993-present; AACAP Autism Committee 1997-2000 & ad hoc (Volkmar, Cook); AACAP Autism Medication Panels (Volkmar); AACAP Autism in the schools training 2006 (Chenven, Akshoomoff, Feder).
- **Practice** – time 1/3 evaluation and case management, 1/3 therapy, 1/3 teaching and research; dx 1/2 developmental and learning disorders, 1/2 general psychiatric (ADHD, Bipolar, PTSD, Tourettes, Depression, OCD etc.); age range 1/3 infants and children, 1/3 older children and adolescents, 1/3 adults
- **Community work:** Rady Autism Research Workgroup, BRIDGE Collaborative, SDPS Ethics committee; ICDL: Institute, F2F and online courses, Grad School, Research Initiatives
- **Outside life** – reading, coaching science and engineering, running a dance company (ending), now an entertainment and production company, care of chronically ill house pets...

More to the point

- 1980 – BU: math and Mass Assn for the Blind
- 1990 – Hawaii: Bernie Lee
- 1992 – ‘Matt’ (The Autism File article)
- 1993 - DC: Greenspan, Wieder, et. al.
- 1996 – now: San Diego/ ICDL: clinical care, teaching, research & advocacy

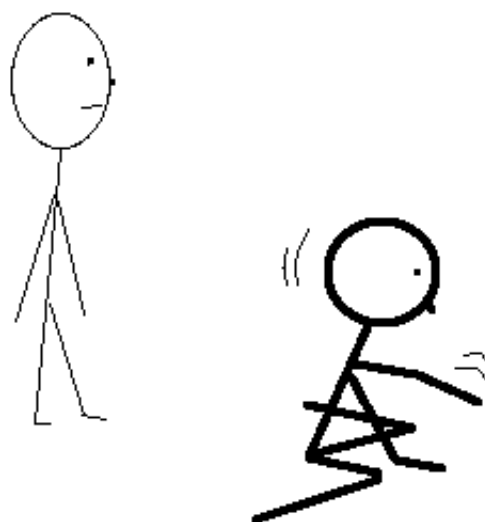
So who are we?

- Jocks and geeks?
- Engineers and Artists
- Regular neurotypical people?

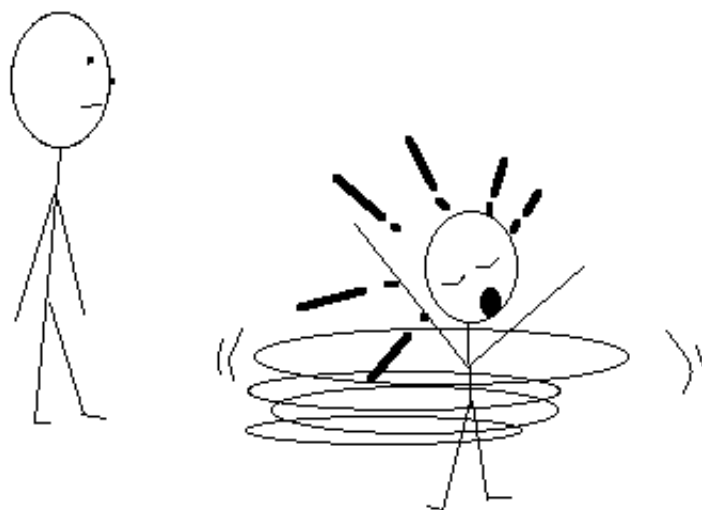
And what is going on?

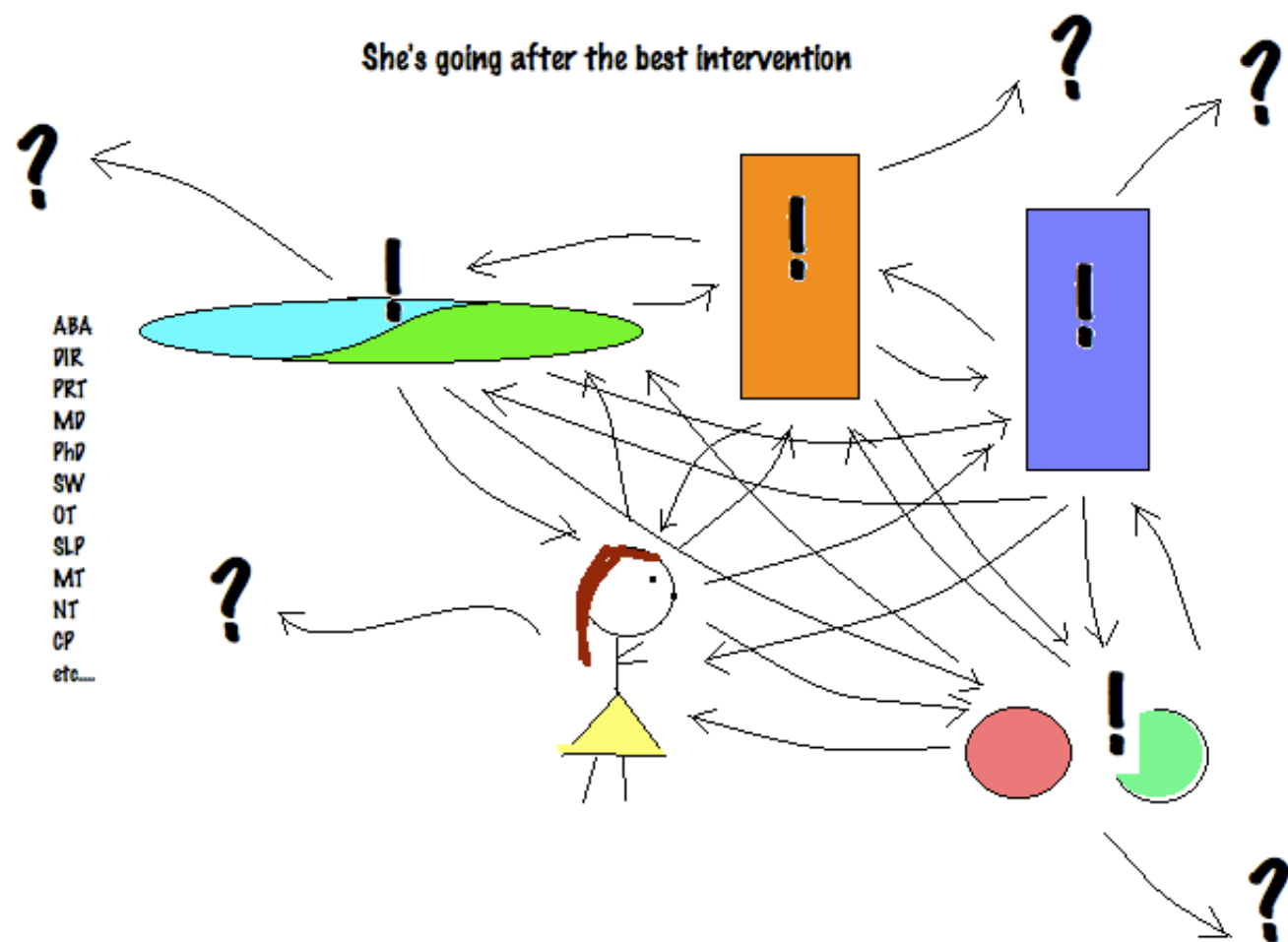
- Kid w/ autism
- Easy to say
- Incredibly complex

is there anything really wrong?

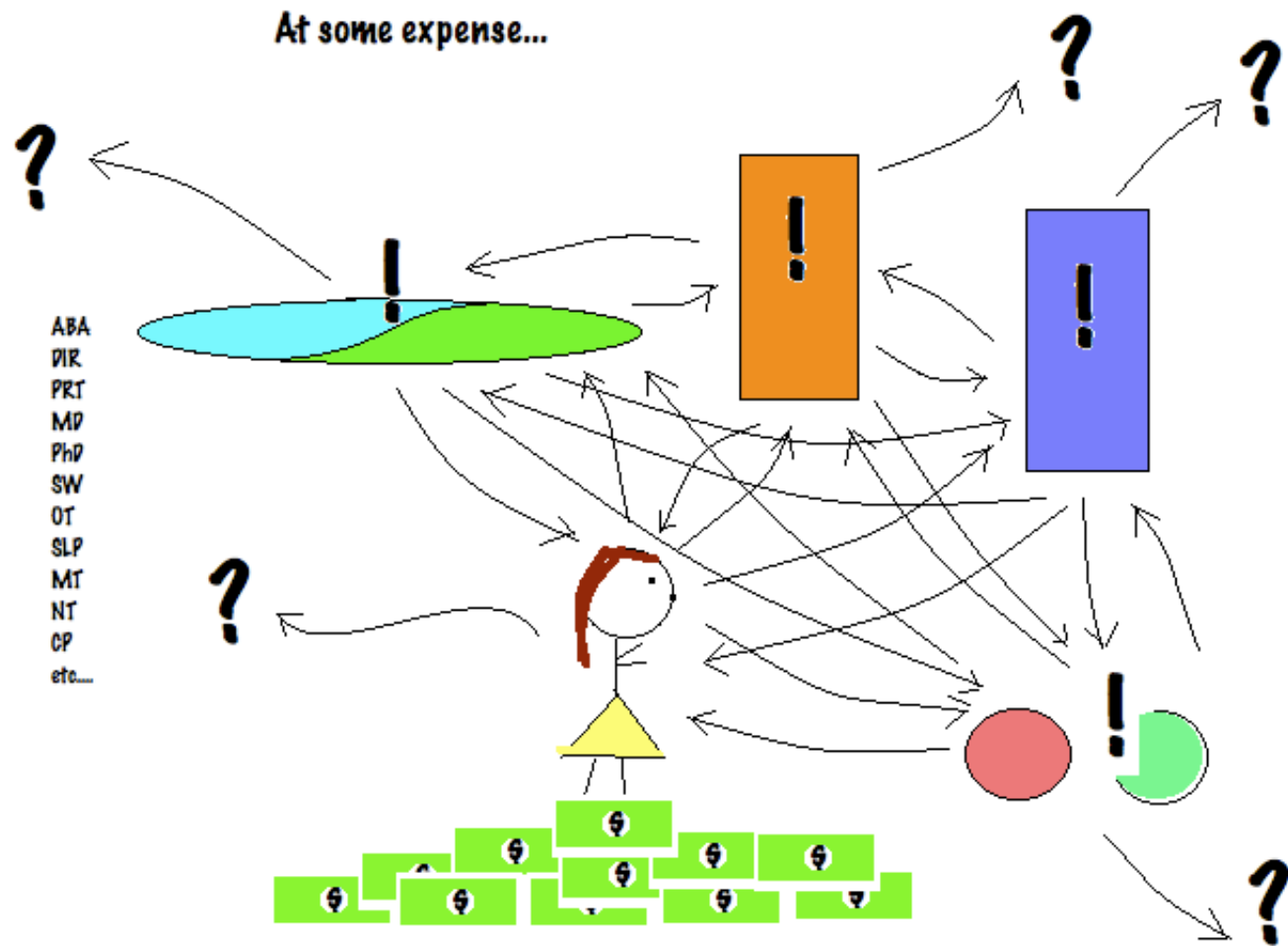


Maybe there's screaming...
maybe all night....

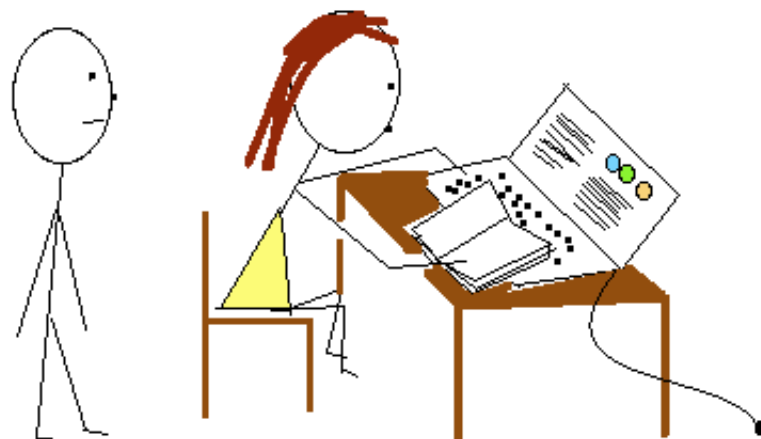




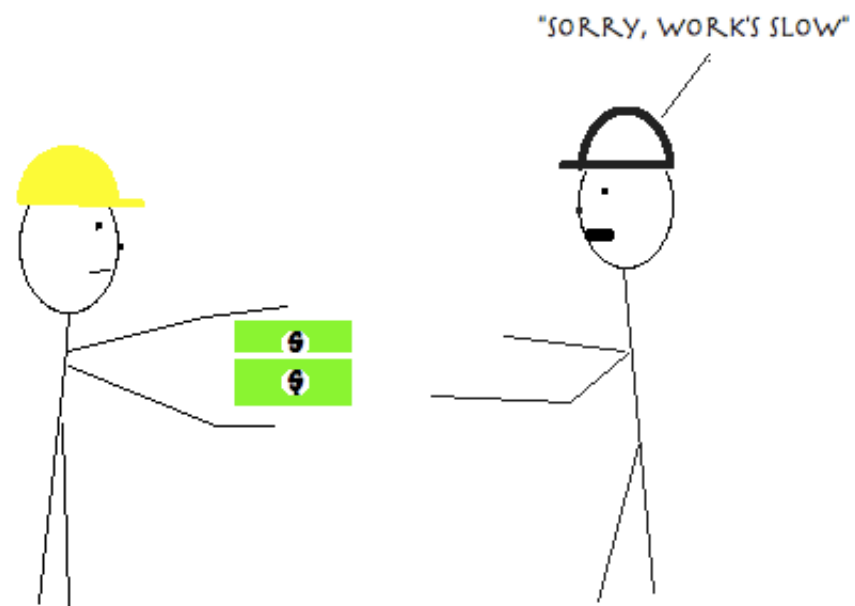
At some expense...



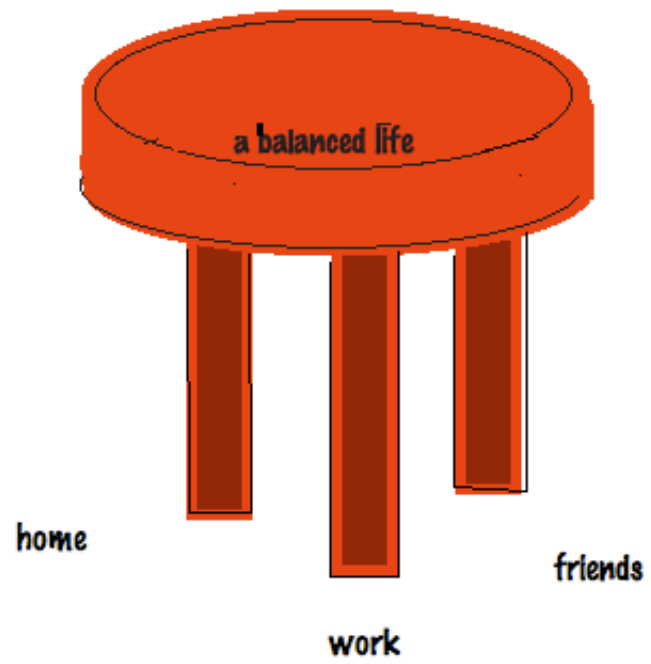
Day and Night....



Tough Times at Work



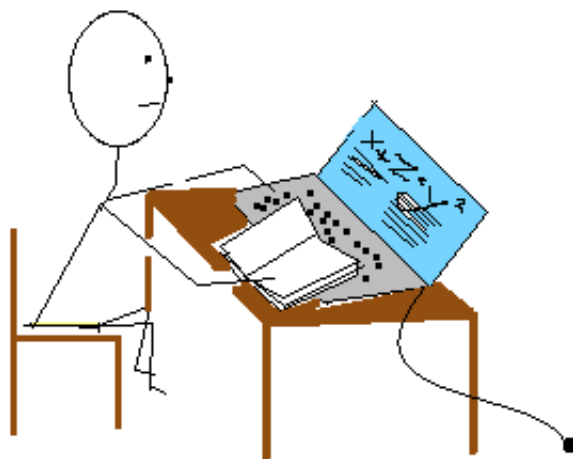
Three legs to the stool



Three sheets to the wind



Always busy with stuff



Three minutes of play



How do you engage a kid in interaction?

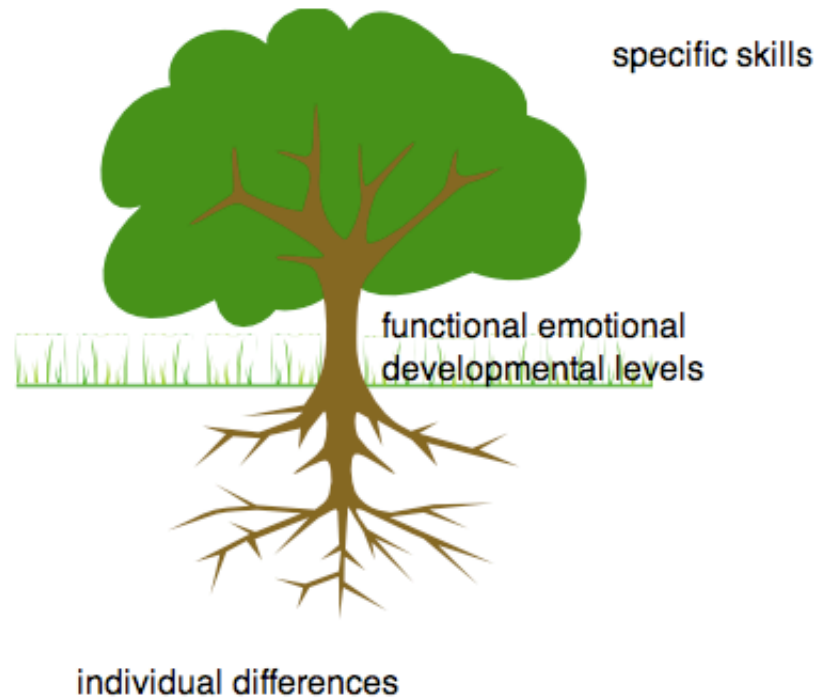
(and is it useful to do?)

- Help him be calm enough or active enough to do stuff with him
- Might mean understanding sensory, motor, other things.
- Give him an opportunity to interact and build on that with him (Improve: ‘yes, and’)
- Yes, it’s useful – helps him learn the world.

Cheat sheets

- A Tree to remember
- Things worth knowing about your child
- Tracking the quality of the interaction
- Tracking your own ability to improve the interaction

Kids (people) are like trees...



Things Worth Knowing about Your Child

(Individual Differences)

- Sensory sensitivities and processing
- Postural control and motor planning
- Receptive communication
- Expressive communication
- Visual-spatial communication
- Praxis: knowing how to do things to solve the social problem of the moment

INDIVIDUAL DIFFERENCES

Regulatory Capacities (reactivity)	Postural Control for Functions	Response to the Sounds, Gestures and Verbal Communication (in back and forth reciprocal interactions for communication)	Use of Vocalizations, Gestures, Words and Language for Communication (in back and forth reciprocal interactions for communication)	Response to Visual Environment	Praxis - Executive Function - Prefrontal cortex orchestrating information for function. Praxis is the moment from which one faces the future with the resources gained from the past experiences.
<p>Indicate +1 = hyper -1 = hypo ± = both responsivity in each sensory domain</p> <p>___ auditory ___ visual ___ tactile ___ vestibular ___ proprioceptive ___ tastes ___ odors</p> <p>Dominant Functional Profile (Describe):</p>	<p>Can sequence purposeful gestures and actions, to obtain desires, to -</p> <ol style="list-style-type: none"> Simple physical actions to indicate desires (gaze, reach) Physically mirror gestures Physically imitate gesture Imitate physical actions with purpose. Obtain desires Problem solve steps with body to move in space to interact with people & objects in environment for exploration. for function and purposeful use of toys for self help for back and forth interactions with family and peers. <p>(# ___ steps recorded)</p>	<p>Observations of the child's ability to attune and orient to the auditory environment, to affect and gestures and to comprehend words (w) (with benefit of signs/gestures (s) and/or visual (v) strategies.</p> <ol style="list-style-type: none"> Orient to the auditory source in the environment (auditory figure ground). Attune to key tones in another's vocalizations. Respond to key gestures in another interaction. Respond to key words in another interaction. Switch auditory attention back and forth between self and others (self monitor, other monitor & integration) Follow directions (record # ___). Understand questions (how, who, what, where, when, what if, if then). Engage in conversations with abstract ideas. 	<p>The child uses -</p> <ol style="list-style-type: none"> Mirror vocalizations with the intention to communicate Mirroring gestures with intention to communicate. Intentional use of unique non-verbal gestures to convey intentions. Intentional use of affective tones and sounds to convey intentions. Uses single meaningful words to convey intentions, actions and desires. Uses two word phrases meaningfully. Uses sentences meaningfully. Uses phrases and sentences in back and forth exchanges with a logical flow. 	<p>The child uses visual spatial strategies systematically to explore and discriminate desired objects. The child can -</p> <ol style="list-style-type: none"> Observe and focus on desired object Alternate gaze (initiate joint attention visually) Follow another's gaze to determine the object of their attention and their intent. (respond visually) Switch visual attention back and forth between self and other (self monitor, other monitor & integration) Differentiate salient visual stimuli from background stimuli (visual figure ground) Actively search for object she sees hidden Can explore two areas of room and search for desired object Can explore more than two areas with active visual assessment of space, shape and materials. 	<p>Praxis encompasses all of these individual processing differences as it depends on the child's -</p> <ul style="list-style-type: none"> Ideation Planning Sequencing Execution Adaptation <ol style="list-style-type: none"> Initiates ideas in play with clear goals and purpose. Is able to associate sensory perceptions from the body, visual system, auditory system to develop a plan. Develop the steps of the sequence (# steps - 1, 2, 3, 4) Execute the steps and persist. Adapt plan if it does not work or is interfered with by another's action.

Instructions: Identify child's functional capacities based on observations (o) and parent reports using operational criteria. Match operational criteria with "algorithms" for each NDRC subtype I-IV. (validate with FEAS)

Individual Differences – Charlie – **Preschool 5/05 & Kindergarten 9/05**

<i>Sensory</i>	<i>Postural</i>	<i>Response to Communication</i>	<i>Intent to Communicate</i>	<i>Visual Exploration</i>	<i>Praxis -</i>
Sensory seeking, distractible ... Auditory Visual Tactile Vestibular Proprio-ceptive Taste Odor	Low tone; A bit clumsy - impedes rapid reciprocity in the moment 1 indicate desires 2. mirror gestures 3. imitate gesture ---- 05/05---- 4. Imitate with purpose. 5. Obtain desires 6. interact: - exploration - purposeful -self help -interactions	Trouble managing more than one thing at a time 1. Orient 2. key tones 3. key gestures 4. key words ---- 05/05---- 5. Switch auditory attention back and forth 6. Follow directions 7. Understand W ?'s 8.abstract conversation.	Dysarthric – Logical discourse is Difficult 1. Mirror vocalizations 2.. Mirror gestures 3. gestures 4. sounds 5.Words ---- 05/05--- 6. two –word 7. Sentences 8. logical flow.	Distractible. 1. focus on object ---- 05/05---- 2. Alternate gaze 3. Follow another's gaze to determine intent. 3. Switch visual attention 4. visual figure ground 5. search for object 6. search two areas of room 7. assess space, shape and materials. -	Easily frustrated Ideation -- 05/05--- Planning (including sensory knowledge to do this) Sequencing Execution Adaptation

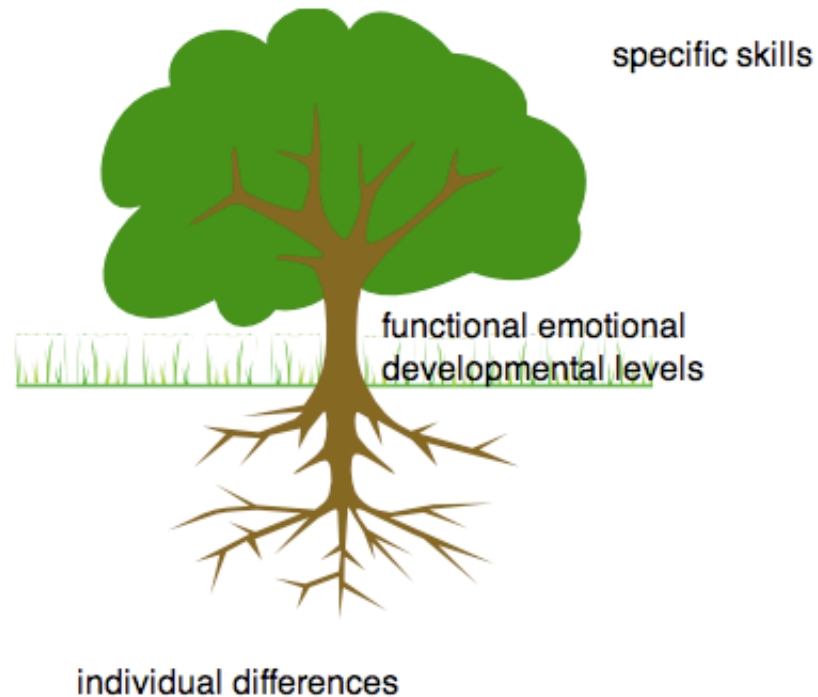
Individual Differences – Charley – First Grade

<i>Sensory</i>	<i>Postural</i>	<i>Response to Communication</i>	<i>Intent to Communicate</i>	<i>Visual Exploration</i>	<i>Praxis -</i>
<p>Sensory seeking, distractible ...</p> <p>Auditory</p> <p>Visual</p> <p>Tactile</p> <p>Vestibular</p> <p>Proprioceptive</p> <p>Taste</p> <p>Odor</p> <p>Taste and odor are better</p>	<p>Low tone; A bit clumsy - impedes rapid reciprocity in the moment</p> <p>1 indicate desires</p> <p>2. mirror gestures</p> <p>3. imitate gesture</p> <p>4. Imitate with purpose.</p> <p>----3/07----</p> <p>5. Obtain desires</p> <p>6. interact:</p> <p>- exploration</p> <p>- purposeful</p> <p>-self help</p> <p>-interactions</p> <p>Much better postural control – not flopping on floor</p>	<p>Trouble managing more than one thing at a time</p> <p>1. Orient</p> <p>2. key tones</p> <p>3. key gestures</p> <p>4. key words</p> <p>----3/07----</p> <p>5. Switch auditory attention back and forth</p> <p>6. Follow directions</p> <p>7. Understand W ?'s</p> <p>8.abstract conversation.</p> <p>Stronger foundation</p>	<p>Dysarthric –</p> <p>Logical discourse is Difficult</p> <p>1. Mirror vocalizations</p> <p>2.. Mirror gestures</p> <p>3. gestures</p> <p>4. sounds</p> <p>5.words</p> <p>----3/07----</p> <p>6. two –word</p> <p>7. Sentences</p> <p>8. logical flow.</p> <p>NOT CHANGED</p>	<p>Distractible.</p> <p>1. focus on object</p> <p>2. ----3/07----</p> <p>2. Alternate gaze</p> <p>3. Follow another's gaze to determine intent.</p> <p>3. Switch visual attention</p> <p>4. visual figure ground</p> <p>5. search for object</p> <p>6. search two areas of room</p> <p>7. assess space, shape and materials.</p> <p>Can focus pretty well on an object now</p>	<p>Easily frustrated</p> <p>Ideation</p> <p>Planning (including sensory knowledge to do this)</p> <p>----3/07----</p> <p>Sequencing</p> <p>Execution</p> <p>Adaptation</p> <p>A step forward..</p>

Tracking the Quality of the Interaction

- Regulated?
- Engaged (emotionally, not just actions)
- Flow of interaction?
- Complexity?
- (this is different from teaching play, teaching language, or teaching compliance)

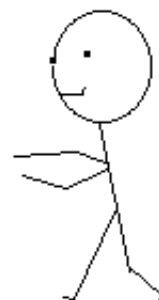
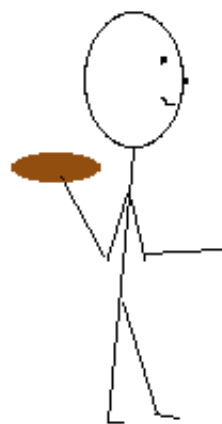
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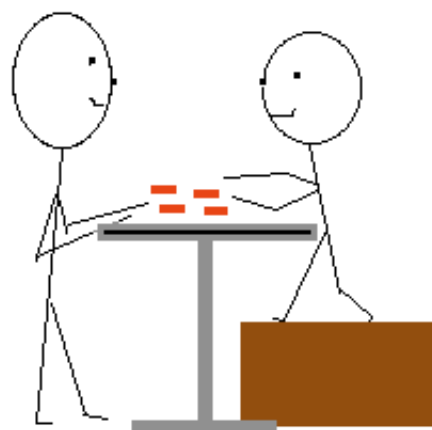
Three minutes of play



all kinds of three minutes



all kinds of three minutes



NDRC – NEURO-DEVELOPMENTAL DISORDERS OF RELATING & COMMUNICATION - FUNCTIONAL EMOTIONAL DEVELOPMENTAL LEVELS

Child:	Caregiver:		Examiner:		Date:	Diagnosis:	
	1	2	3	4	5	6	7
Draw line through To highest level (1-6) child has reached The more robust and qualitative, the higher the rating.	Not reached	Barely even with support-very intermittent (very in and out)	With persistent and/or predictable support has islands of this capacity	With structure and scaffolding, given high affect, gestural, language, sensorimotor support can expand	Not at age-expected level, immature-fragmented; may be cyclical but comes back for more	Age-appropriate level but vulnerable to stress and/or with constricted range of affects	Age-appropriate level with full range of affect states.
Functional Capacities							
I. Self-Regulation And Attention Take in sights and sounds and maintain shared attention							
II. Engagement And Relating Woo another or be wooed, stay engaged through emotions							
III. Use Affect to Convey Intent - Two Way Communication For requests, emerging back and forth interactions							
IV. Behavioral Organization Problem Solving Continuous flow of affective interactions with people for shared social problem solving							
V. Creates and Elaborates With Symbols .Represents ideas and emotional themes .							
VI. Emotional Thinking Logical –Abstract Bridges ideas, elaborates and can reflect on actions, motives, aware of time and space							

1-> 4: Child requires caregiver support; 5-> 6: Child attains developmental level independently but constricted; 7: Age appropriate

Likert Scale for Each Level

1. Not doing it
2. Barely able to do it
3. Islands of time where the child can do it
4. Can expand those islands with our help
5. Comes back for more with little or no support
6. Pretty normal unless under stress
7. Age appropriate

Sample Full FEDL (Charlie)

	Not there	Barely	Islands	Expands	Comes back	Ok if not stressed	Ok for age
Co-regulate		3/06	3/07	3/08	3/09		
Engage		3/06	3/07	3/08	3/09		
Circles		3/06, 3/07	3/08	3/09			
Flow	3/06	3/07	3/08, 3/09				
Symbolic	3/06	3/07, 3/08	3/09				
Logical	3/06	3/07, 3/08	3/09				
Multicausal	3/06, 3/07	3/08	3/09				
Grey area	3/06, 3/07,	3/08, 3/09					
Reflective	3/06, 3/07	3/08, 3/09					

Data Tracking Sheet

	In Class am Time: _____	Recess Time: _____	In Class Time: _____	Lunch Time: _____	Afternoon Time: _____
<u>Co-Regulation</u> Is he calm enough and settled to attend to an interaction? Are you 'tuning in' to near where he is emotionally to help him join in? Examples of not regulated: stretching, distracted, staring off, eyes not on the group/activity, over/underactive for the situation					
<u>Engagement</u> Gleam in the eye? Is he "on the same page", paying attention to the same thing the "group" is? -eye gaze to peers and eye gaze to activity/items that the group is interacting with... visually and/or verbally referencing peers					
<u>Social Reciprocity</u> <u>(Circles, Flow)</u> True Back and Forth in speaking and listening interactions -opening (initiating) and closing (ending) circles of communication verbally or nonverbally					

School Data Tracking Sheet

instructions and comments

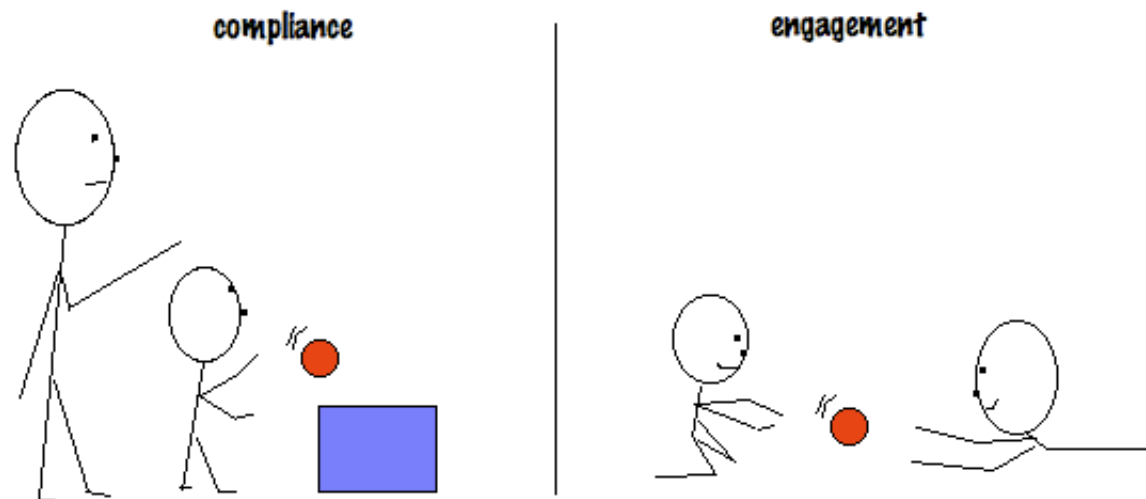
Fill in #minutes/15 minute sample for tracking **co-regulation and **engagement**

Use hash marks to count number of times the child initiates or responds appropriately for **social reciprocity

**Complete one data sheet per week during all kinds of activities including class time, free choice, recess, and lunchtime

Comments: _____

This is about engagement, not compliance



Compliance vs. Engagement

Compliance	Engagement
Do/think what I want you to do/think	Think for yourself and with me
Drills will create skills	Shared emotional signaling creates a relationship that inspires learning and problem solving
Schemes to cover new situations	Relationships, available and internalized, give self-assurance to respond to new situations
Limited sense of competence, self-esteem: “I can do it. I learned how.”	More full sense of competence, self-esteem: “I can figure it out.”

A Complementary Relationship

Behavioral based contributes...	Relationship-based expands...
Imitation	Autonomous thinking
Limits	Negotiation
Facts	Exploration

Tracking your ability to support your child's interaction

- You want to help your child
- Reading cues
- Responding to cues
- Getting new ideas: bounce it off of other people - get their ideas and figure out what works for *you*.

Relationships - Caregiver Profiles:

	Not yet able to support	Just starting to support	Islands of support	Moderately effective in supporting '50%'	Becoming consistent in ability to support	Effective except when stressed	Very Effective in supporting
Comforting the child							
Finding appropriate level of stimulation							
Pleasurably engages the child							
Reads child's emotional signals							
Responds to child's emotional signals							
Tends to encourage the child]					

Relationships - Caregiver Profiles: first grade teacher, aide

	Not yet able to support	Just starting to support	Islands of support	Moderately effective in supporting '50%'	Becoming consistent in ability to support	Effective except when stressed	Very Effective in supporting
Comforting the child			Not fuzzy, but not reactive		melroe		
Finding appropriate level of stimulation			directive	unflappable			
Pleasantly engages the child		directive		Persistent attempts to engage him			
Reads child's emotional signals		Sees when he is upset	Can predict when he will become upset				
Responds to child's emotional signals	Unsure what to do	Interested in the flow of activity, not interaction					
Tends to encourage the child		directive	Wants him regulated so he can learn (not interact per se)				

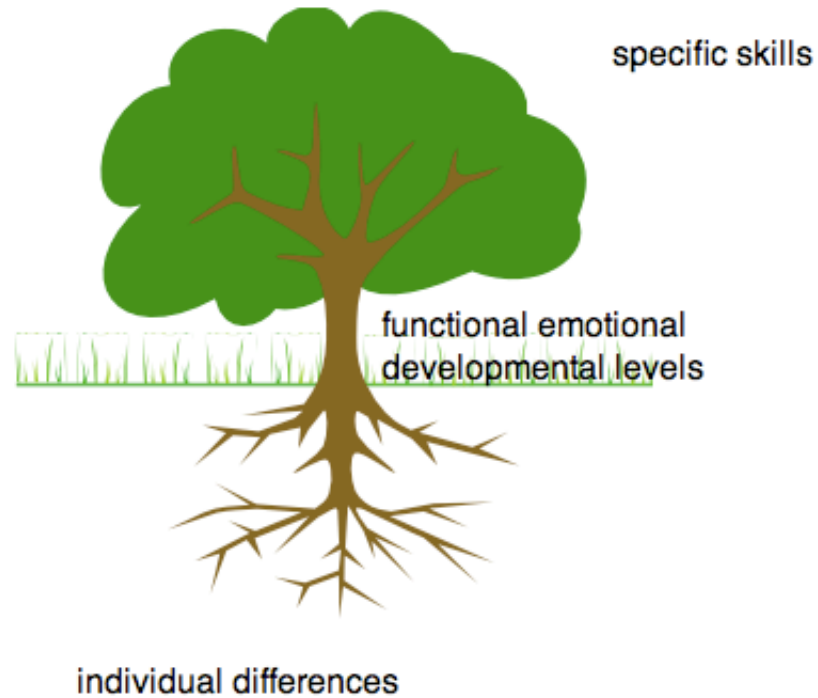
Relationships - Caregiver Profiles: **second grade teacher,** **resource teacher, aide**

	Not yet able to support	Just starting to support	Islands of support	Moderately effective in supporting '50%'	Becoming consistent in ability to support	Effective except when stressed	Very Effective in supporting
Comforting the child					Kind and clear melloe	Really there for him, can help him settle	
Finding appropriate level of stimulation			directive	Pretty good with him		Calm and positive, able to flexibly shift level of stimulation	
Pleasurably engages the child		directive		Learning to engage	Some nice non-verbal flow		
Reads child's emotional signals			Predict when he is upset	Tries hard to do this in the moment		Naturally reads his cues	
Responds to child's emotional signals		Still unsure what to do		Interested in the flow of interaction		Naturally responds	
Tends to encourage the child		Still directive			Strong desire to see him regulated and engaged	Regulated for interaction; coaches aides, staff	

Yes it helps

- Clinical experience shows tremendous gains when you do this stuff
- Research is showing tremendous gains with corresponding changes in structural and functional brain imaging
- Makes explicit what happens in typical interactions that are necessary for development but aren't happening for a lot of our kids.
- And it's free.

Not a lot to remember....



Take a card with you...



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