Emergence, Early Intervention, and Prevention of Self-Injury Exhibited by Young Children with Moderate to Profound Disabilities

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Timeline/Advanced Organizer

Step 1: Naive
- 2001
- Straight to PREVENTION

Step 2: Confusion-to-Clarity
- 2003
- Early intervention

Step 3: Getting there
- 2008

Step 4: "One step back"
- 2010
- Risk factors

Step 5: TBD
Maintenance vs. Emergence

- Maintenance
  - Guides treatment recommendations
  - Functional analysis methodology (Iwata et al., 1982; Northup et al., 1991)
  - 8-year-old girl, borderline to mild MR, Brachial Plexus (L arm), foster care, history of self-mutilation and finger-biting.

- Ontogeny and early development (Berkson et al., 2001)
  - Necessary for prevention studies
    - Risk factors for emergence
    - Variables that affect how topographies (and functions) evolve over time
Berkson et al., 2001
Longitudinal Study on Emerging SIB

- SIB incidence study in a birth-to-three “Part C” program in Chicago
  - 4.6% of 457 birth-to-three children with DD (mild to profound) exhibited SIB or proto-SIB
  - Relation between age and more advanced adaptive behavior skills and SIB
    - but some children continued to engage in SIB after substantial developmental gains and age 3
- Anecdotally noted at least 2 types of SIB
  - Social
  - Nonsocial
Murphy et al., 2001  
Longitudinal Assessment

- 16 children identified as showing emerging SIB
- Descriptive naturalistic classroom observations
  - 3-4 hrs. observation time
  - 6 observation periods (repeated every 3 months for 18 months)
  - Recorded stereotypies and emerging SIBs and student-teacher interactions
- 4/16 children developed SIB – all correlated with low levels social contact with the student
- Correlation changed from low social contact to contingent attention for one of four children that developed SIB
Do **some** forms of SIB evolve from stereotypy?

- Emergence and Maintenance of Stereotypy and Self-Injury (Guess & Carr, 1991)
- Behavior-Environment Mechanisms Influencing the Evolution of Stereotypy into SIB (Kennedy, 2002)
- Early Intervention and Prevention of Self-Injurious Behavior Exhibited by Young Children with Severe Developmental Delays (Richman, 2008)
- Certainly not all cases – see Kurtz, Chin, Huete, & Cataldo, 2012
Emerging Stereotypy

• Stereotypies commonly occur in infants (MacLean, Ellis, Galbreath, Halpren, & Baumeister, 1991; Thelen, 1979)
  • Biological predisposition to engage in repetitive movements
  • Practice coordinating motor movements
  • Sensory stimulation

• Infants with severe DD spend a substantial proportion of waking hours engaged in stereotypy (Guess, Roberts, Rues, 2002)
  – Increases probability of contacting social consequences
Transition to SIB and Sensitivity to Social Reinforcers

• Selectively providing social consequences for more severe topographies of behavior (Lalli et al., 1995; Richman et al., 1999; Sprague & Horner, 1992)
  • e.g., hand mouthing vs. hand biting

• Descriptive analysis of common caregiver reactions to SIB (Thompson & Iwata, 2001)
  • Provide attention
  • Access to different activities
  • Stop making requests
Do some forms of SIB evolve from early chronic motor stereotypies?

- Video clip example of change in topography but no change in function.
Phase II: Longitudinal Assessment
Part I: Purpose

1. Document changes in topographies during 2nd and 3rd year of life

2. What are common functions of early childhood stereotypies, proto-SIB, and SIB for kids with severe disabilities?

Purely a direct observation assessment study – no intervention other than community based birth-to-three Part C services.

- No fun at all!

Participants

- 12 children, 14 to 32 months CA
- Mean CA at entry to study = 20 months
- Moderate to profound cognitive and communication delays
  - Standardized scores <50
- Currently engaging in stereotypic motor movements, proto-SIB, or SIB
- If SIB occurred, we consulted with caregivers and referred the child for treatment services
Syndromes and Disorders

- Recruited infants with genetic disorders and syndromes that are associated with abnormally high levels of stereotypy or presence of self-injury
- Participant diagnoses:
  - Angelman Syndrome
  - Cri-du-Chat Syndrome
  - Lissencephaly
  - Smith-Magenis Syndrome
  - Trisomy 13
  - Williams Syndrome
  - Cerebral Palsy
  - hypoxia during birth
Monthly Assessment Probes

- Repetitive Behavior Scales (Bodfish et al., 1999)
  - Changes in parent report (free recall) of topographies
  - Interview regarding severity of topographies
    - How often?
    - How much do they interfere with teaching/daily life?
    - How often necessary to stop it?
    - Reaction when blocked?

- Emerging Topographies Checklist (developed by Paige McKerchar for this study)
  - List of topographies – parent recognition of topographies rather than free recall

- Both used for operational definitions during direct observations
Functional Analysis

• Analogue conditions – varied antecedents and consequences for stereotypy, proto-SIB, and SIB
  • Toy Play (control condition)
  • Attention – test for Sr+, social attention
  • Tangible – test for Sr+, materials
  • Demand – test for Sr-, escape
  • Alone/ignore – test for automatic
    • Really hard to conduct Alone sessions in home with toddlers
    • Angry Moms' Club

• One 10 min session per condition was conducted per month by child’s primary caregiver in their home
  • Multielement design – each topography graphed separately
  • 10 sec partial interval recording system
  • Carefully documented new topographies observed during each monthly home visit
Functional Characteristics

- All 52 Topographies of stereotypy, proto-SIB and SIB appeared to be nonsocially mediated at study entry
  - Undifferentiated across FA conditions (73% of topographies)
  - Higher levels in low stimulation conditions

**Percent Intervals of Stereotypy, Proto-SIB and SIB Averaged Across all Participants**
Hand Mouthing

% Intervals Handmouthing

Sessions

0% 25% 50% 75% 100%

Attention

Alone/Ignore

Tangible

Demand

Toy Play

G. B.
Results Across Topographies

SIB body sites for
Prader-Willi Syndrome vs. IDD

Reprinted from Symons and Thompson, 1997.
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<table>
<thead>
<tr>
<th>Stereo</th>
<th>Proto-SIB</th>
<th>SIB</th>
<th>Tissue Dam.</th>
</tr>
</thead>
<tbody>
<tr>
<td>GB</td>
<td>Head nodding</td>
<td>hand mouthing hand to head head banging</td>
<td><strong>hand mouthing head banging</strong></td>
</tr>
<tr>
<td>MR</td>
<td>hand flapping <strong>rocking</strong> <strong>leg shaking</strong> head nodding</td>
<td>hand mouthing <strong>hand to head</strong> <strong>head banging</strong> eye poking</td>
<td><strong>hand to head and head banging</strong></td>
</tr>
<tr>
<td>BD</td>
<td>hand flapping leg shaking head dropping</td>
<td>hand mouthing <strong>hand to head</strong></td>
<td><strong>hand mouthing</strong></td>
</tr>
<tr>
<td>HG</td>
<td>hand flapping rocking head nodding</td>
<td>hand mouthing eye poking</td>
<td>hand mouthing thumb biting</td>
</tr>
<tr>
<td>LH</td>
<td>rocking head nodding</td>
<td>hand mouthing <strong>hand to head</strong></td>
<td><strong>hand mouthing</strong></td>
</tr>
<tr>
<td>ML</td>
<td>hand flapping leg shaking head nodding</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>JC</td>
<td>hand flapping rocking head nodding leg shaking</td>
<td>hand mouthing</td>
<td><strong>hand mouthing</strong></td>
</tr>
<tr>
<td>Stereo</td>
<td>Proto-SIB</td>
<td>SIB</td>
<td>Tissue Dam.</td>
</tr>
<tr>
<td>--------</td>
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<td>-----</td>
<td>-------------</td>
</tr>
<tr>
<td>AB</td>
<td>hand flapping&lt;br&gt;rocking&lt;br&gt;head nodding&lt;br&gt;leg shaking</td>
<td>hand mouthing&lt;br&gt;hand to head&lt;br&gt;head banging&lt;br&gt;<strong>body hitting</strong>&lt;br&gt;arm banging</td>
<td>thumb biting&lt;br&gt;arm biting&lt;br&gt;hand to head&lt;br&gt;or head banging</td>
</tr>
<tr>
<td>ZS</td>
<td>hand flapping&lt;br&gt;jumping</td>
<td><strong>hand to head</strong></td>
<td>None</td>
</tr>
<tr>
<td>KF</td>
<td>hand flapping</td>
<td>head banging</td>
<td>None</td>
</tr>
<tr>
<td>AM</td>
<td>None</td>
<td>hand mouthing&lt;br&gt;<strong>head banging</strong>&lt;br&gt;<strong>hand to head</strong></td>
<td>None</td>
</tr>
<tr>
<td>RH</td>
<td>None</td>
<td>hand mouthing</td>
<td>None</td>
</tr>
</tbody>
</table>
Patterns for *emergence* of proto-SIB and SIB

- No change in topography or function, but the behavior occurred more frequently and with greater intensity
  - Hand mouthing turned into repetitive SIB
- Stereotypy (hand flapping, hand mouthing) occurred for several months before a new topography of proto-SIB or SIB emerged (head hitting, hand biting)
- One case of transition from SIB maintained by automatic reinforcement to Sr+ attention
Case Example of SIB Transitioning from Automatic to Positive Reinforcement-Attention

• Anna
  • 2 years old
  • Moderate to severe DD, visual impairment
  • Hypoxia during birth
  • Topographies:
    • Body Hitting
    • Head Hitting
    • Several other topographies = undifferentiated throughout longitudinal functional analysis
Percentage of 10-s Intervals

Alone/Ignore
Toy Play
Attention
Demand
Tangible

Sessions

Head Hitting

Body Hitting

Months

Percentage of 10-s Intervals

Alone/Ignore
Toy Play
Attention
Demand
Tangible
Summary: New Topographies and Functions

• No intensive function-based intervention, but they were receiving Part C “best practices”
  • 5 of 12 (42%) developed a new topography SIB
  • 11 of 12 = FA suggested all topographies automatic or undifferentiated throughout the study
  • 1 of 12 (8%) developed a social attention function after several months suggesting automatic function
• Now let’s compare the number of new topographies of functions for a similar cohort of participants that received an early intervention and prevention package.
Part III: Early Intervention and “Prevention” Analysis

Getting closer to the promised land of a large scale prevention study
Purpose

1. Can we intervene early and reduce SIB and proto-SIB maintained by automatic reinforcement?
2. Can we teach the participants to mand for functionally irrelevant social consequences that maintain many cases of SIB in older children with disabilities?
Participant Inclusion Criteria

- 12-48 months CA
- Moderate to profound developmental delays in cognition and communication
- Within 90 miles of study site
- Engaging in proto-SIB or SIB maintained by automatic reinforcement
- Added this requirement to compare to longitudinal FA study participants
Functional Analysis

(n=8)

Sr+/-

FCT + Parent Responsivity Training

Enriched Environment + Response Blocking

(n=8)

Automatic

Enriched Environment + Response Blocking

FCT + Parent Responsivity Training
SIB Early Intervention

• Weekly home visits (1 ½ - 2 hours)

• 5 or 10 min sessions conducted in-home by RA (training/modeling) or parent/grandparent
  • 2-3 sessions run per day – no monitoring from RAs

• Treatment analysis: Nonconcurrent multiple baseline with reversal design
Example Participant

• Sandy
  • 18 months CA (developmental skills 9-12 months)
  • Williams Syndrome
  • Body banging, hand mouthing, body hitting
    • All proto-SIB
**Participant Characteristics and Treatment Outcomes**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age in months</th>
<th>Diagnoses</th>
<th>% Intervals with SIB</th>
<th>M (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Baseline</td>
<td>EE+RB</td>
</tr>
<tr>
<td>SW</td>
<td>30</td>
<td>Moderate DD</td>
<td>5 (0-7)</td>
<td>0.6 (0-3)</td>
</tr>
<tr>
<td>AB</td>
<td>29</td>
<td>RS, Moderate DD</td>
<td>28 (6-42)</td>
<td>19 (5-35)</td>
</tr>
<tr>
<td>MD</td>
<td>30</td>
<td>WS, Severe DD</td>
<td>23 (16-67)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>SD</td>
<td>30</td>
<td>WS, Severe DD</td>
<td>8 (0-20)</td>
<td>1 (0-7)</td>
</tr>
<tr>
<td>SG</td>
<td>21</td>
<td>CdLS, Severe DD</td>
<td>83 (13-90)</td>
<td>10 (0-20)</td>
</tr>
<tr>
<td>AG</td>
<td>24</td>
<td>CdC, Moderate DD</td>
<td>17.9 (0-43)</td>
<td>8 (0-15)</td>
</tr>
<tr>
<td>RS</td>
<td>47</td>
<td>Moderate DD</td>
<td>49.3 (23-73)</td>
<td>9 (3.8-14)</td>
</tr>
<tr>
<td>DT</td>
<td>12</td>
<td>RS, Severe DD</td>
<td>74 (67-80)</td>
<td>47.6 (10-63)</td>
</tr>
</tbody>
</table>


- Mean reduction in proto-SIB and SIB from baseline levels was 82% (range, 33% to 97%)
- 5 of 8 met the goal of 80% or greater reduction in SIB
- 2 of 3 treatment failures = Rhett Syndrome
- All were effectively taught to mand for Sr+ attention/toys and Sr- escape that did not currently contribute to maintenance of SIB
Preliminary Prevention Results

- Intensive function-based interventions + Part C services
  - 1 of 8 (13%) developed a new topography of proto-SIB or SIB
    - Longitudinal assessment: 5 of 12 (42%) developed a new topography SIB
- None developed a social function
  - Longitudinal assessment study: 1/12 developed a social function
- Several limitations - messy data
  - Did not follow some the participants very long
  - No repeated FA probes every month - weak measure of potential change in function
  - No exact match for level of cognitive and communication functioning across groups, number and severity of topographies, etc.
Implications

• Prevention
  • Early intervention package for current topographies of SIB
  • Prevention of new topographies and functions?
    • Need a simultaneous control group with matched developmental levels AND number and severity of topographies and functions of SIB/proto-SIB
  • Findings could affect public policy and funding if (a) we can show that some forms functions of SIB can be prevented or minimized and (b) the financial cost of early intervention is less than waiting to treat.
  • BUT – this is an incredibly expensive group design study with massive amounts of direct observation data
    • Can’t conduct sample size determination because we don’t know enough about risk factors, or the proportion of early childhood SIB that resolves without intensive treatment.
Phase IV: Risk Factors for SIB

Going from “almost there” to what seems like “one step backwards”
SIB risk factor analysis through collaboration with the Ann Sullivan Center del Perú (CASP)
R21 Risk Factors Analysis

• Initial Screening (N=1000+ screened)
  • Scripted telephone interview by CASP veteran parents using the Parental Concerns Questionnaire (Mayo, et al., 2012)

• Participant Interdisciplinary Evaluation Visit (n=341)
  • Parent Interview
    1. Behavior Problem Inventory-01 (BPI-01) (Rojahn, et al., 2001)
    5. Behavioral History and Profile

• Child Testing
  1. Analogue functional analysis
     • Examined macro-to-micro agreement between BPI-01 and direct observations during FA
  4. Vision and Hearing Screening
  5. Developmental Pediatric Examination and History
  6. Other Specialty Exams as indicated (Pediatric Neurology, Genetics, Nutrition, Ophthalmology, Dentistry)

• Final N=180: Followed longitudinally for 18 months (6 mth. repeated assessment)
Multiple Regression Analysis of Risk Factors for SIB (Schroeder et al., in review)

**SIB R-square=.134**

<table>
<thead>
<tr>
<th></th>
<th>Unique Contribution</th>
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<tbody>
<tr>
<td>CSBS</td>
<td>.003</td>
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<tr>
<td>Bayley</td>
<td>.001</td>
</tr>
<tr>
<td>Age</td>
<td>.002</td>
</tr>
<tr>
<td>Gender</td>
<td>.014</td>
</tr>
<tr>
<td>Vision</td>
<td>.005</td>
</tr>
<tr>
<td>Income</td>
<td>.049</td>
</tr>
<tr>
<td>Mother Educ</td>
<td>.002</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>.038</td>
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</table>

Gravetter & Wallnau, 2010: Social Sciences

<table>
<thead>
<tr>
<th>Percentage of Variance Explained, $r^2$</th>
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</thead>
<tbody>
<tr>
<td>$r^2 = 0.01$</td>
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<tr>
<td>$r^2 = 0.09$</td>
</tr>
<tr>
<td>$r^2 = 0.25$</td>
</tr>
</tbody>
</table>

These risk factors accounted for more variability in stereotypy (0.356) and aggression (0.247)
### Number of Increasers vs. Decreasers as a Function of Diagnosis, Gender, and Age

<table>
<thead>
<tr>
<th></th>
<th>Increasers</th>
<th></th>
<th>Decreasers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>24 (40)</td>
<td></td>
<td>36 (60)</td>
<td></td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>23 (52)</td>
<td></td>
<td>21 (48)</td>
<td></td>
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<tr>
<td>At Risk for Autism</td>
<td>31 (42)</td>
<td></td>
<td>43 (58)</td>
<td></td>
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<tr>
<td><strong>Gender</strong></td>
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</tr>
<tr>
<td>Female</td>
<td>25 (37)</td>
<td></td>
<td>42 (63)</td>
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<tr>
<td>Male</td>
<td>53 (48)</td>
<td></td>
<td>56 (52)</td>
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<tr>
<td><strong>Age (mos.)</strong></td>
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<tr>
<td>4-12</td>
<td>12 (71)</td>
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<td>5 (25)</td>
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<tr>
<td>13-24</td>
<td>22 (45)</td>
<td></td>
<td>27 (55)</td>
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<tr>
<td>25-36</td>
<td>32 (42)</td>
<td></td>
<td>45 (58)</td>
<td></td>
</tr>
<tr>
<td>37-48</td>
<td>12 (34)</td>
<td></td>
<td>23 (66)</td>
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</tr>
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</table>
### Types of stereotypy that predict later SIB
Rojahn et al., in review

**Factor Loadings of the BPI-01 Stereotypy-item Rotated Component Matrix (n = 1,691)**

<table>
<thead>
<tr>
<th>Items (abbr.)</th>
<th>Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Arms/Hands</td>
</tr>
<tr>
<td>Waving/shaking arms</td>
<td>.616</td>
</tr>
<tr>
<td>Repetitive body movements</td>
<td>.690</td>
</tr>
<tr>
<td>Repetitive hand movements</td>
<td>.769</td>
</tr>
<tr>
<td>Complex hand and finger movements</td>
<td>.650</td>
</tr>
<tr>
<td>Sustained finger movements</td>
<td>.684</td>
</tr>
<tr>
<td>Gazing at hands/objects</td>
<td>.532</td>
</tr>
<tr>
<td>Waving hands</td>
<td>.629</td>
</tr>
<tr>
<td>Pacing</td>
<td>.317</td>
</tr>
<tr>
<td>Yelling/screaming</td>
<td>.158</td>
</tr>
<tr>
<td>Bouncing around</td>
<td>.165</td>
</tr>
<tr>
<td>Bursts of running around</td>
<td>.150</td>
</tr>
<tr>
<td>Clapping hands</td>
<td>.297</td>
</tr>
<tr>
<td>Grimacing</td>
<td>.171</td>
</tr>
<tr>
<td>Rocking back and forth</td>
<td>.373</td>
</tr>
<tr>
<td>Spinning own body</td>
<td>.088</td>
</tr>
<tr>
<td>Rolling head</td>
<td>.249</td>
</tr>
<tr>
<td>Whirling, turning around on spot</td>
<td>.127</td>
</tr>
<tr>
<td>Bizarre body postures</td>
<td>.269</td>
</tr>
<tr>
<td>Twirling things</td>
<td>.273</td>
</tr>
<tr>
<td>Spinning objects</td>
<td>.180</td>
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<tr>
<td>Manipulating objects</td>
<td>.412</td>
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<tr>
<td>Sniffing objects</td>
<td>.160</td>
</tr>
<tr>
<td>Sniffing own body</td>
<td>.110</td>
</tr>
<tr>
<td>Rubbing self</td>
<td>.242</td>
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a. Rotation converged in 7 iterations.
## SIB Factors

<table>
<thead>
<tr>
<th>Factors</th>
<th>Gross/Motor</th>
<th>Concealed</th>
<th>Oral</th>
</tr>
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<tbody>
<tr>
<td>Biting</td>
<td>.612</td>
<td>.161</td>
<td>.131</td>
</tr>
<tr>
<td>Head hitting</td>
<td>.682</td>
<td>.175</td>
<td>.279</td>
</tr>
<tr>
<td>Body hitting</td>
<td>.700</td>
<td>.115</td>
<td>.217</td>
</tr>
<tr>
<td>Scratching</td>
<td>.685</td>
<td>.100</td>
<td>-.008</td>
</tr>
<tr>
<td>Pinching</td>
<td>.747</td>
<td>.052</td>
<td>-.064</td>
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<tr>
<td>Hair pulling</td>
<td>.350</td>
<td>.329</td>
<td>-.001</td>
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<tr>
<td>Vomiting</td>
<td>.149</td>
<td>.568</td>
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<tr>
<td>Pica</td>
<td>.166</td>
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<tr>
<td>Stuffing objects</td>
<td>.142</td>
<td>.665</td>
<td>-.003</td>
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<tr>
<td>Pulling nails</td>
<td>.052</td>
<td>.422</td>
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<td>Stuffing fingers</td>
<td>.037</td>
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<td>Air swallowing</td>
<td>.019</td>
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<td>Drinking</td>
<td>.064</td>
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<tr>
<td>Teeth grinding</td>
<td>.180</td>
<td>-.008</td>
<td>.642</td>
</tr>
</tbody>
</table>

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.
a. Rotation converged in 4 iterations.
Best fitting model for latent Gross-Motor SIB for Lima, Peru participants
Summary and Next Steps for Birth-3 with Moderate to Profound DD

- High frequency hand mouthing and hand-to-head stereotypies/proto-SIB may be high risk for developing into SIB in toddlers with severe DD + specific genetic disorders
- Many topographies of emerging proto-SIB and SIB for birth-3 with severe DD + specific genetic disorders appear to be maintained by automatic reinforcement
- More sophisticated risk and protective factors algorithm before we can accurately predict development and maintenance of SIB
- Analysis of the conditions that will evoke more accurate measurement of SIB using indirect measures to supplement expensive direct observation prevention studies
- Continue to progress from a reactive model of assess and treat to a prevention model for high risk infants and toddlers
Collaborators and RAs

Faculty Collaborators

- Travis Thompson – U. of Minnesota
- Patricia Kurtz – KKI, JHU
- Steve Schroeder – University of Kansas
- Nancy Brady – University of Kansas
- Jim Halle – University of Illinois
- John Belmont – University of Kansas

Graduate Students

- Myungjin Kim – UIUC
- Carly Slavin – UIUC
- Anamarie Hayner - UIUC
- Mary Caruso – The Chicago School
- Anna Burns – UMBC
- Teresa Coffin – UMBC
- Christine Feaster – UMBC
- Eric Garnet – UMBC
- Jesse Guercio – UMBC
- Noelle Jaracho – KUMC
- Steve Lindauer – Faculty Kennedy Krieger Inst.
- Paige McKerchar – Jacksonville State U
- Reagan Mercer - UMBC
- Albee Ongsuco - UMBC
- Alice Owens – UMBC
- Stephanie Thorne – KU ABS
- Maria Valdovinos – Faculty Drake University
- Laura Grubb – TTU