Relational Health: From research to practice with families of children with autism or hearing differences
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Intellectual Disability

Altered Immune System

Abnormal EEG

Genetic Abnormalities

Hyper-serotonemia

Neuroimaging: Altered brain region size

Genetics

Hyperactivity/Impulsivity

Agitation/Aggression

Language Impairment

Intellectual Disability

Genetic Abnormalities

Hyperactivity/Impulsivity

Behavioral Comorbidities

Agitation/Aggression

Anxiety

Medical Comorbidities

Severe Constipation

Seizure Disorder

Language Impairment

Cognitive Comorbidities

Developmental Macroencephaly

Biomarkers

Core ASD Symptoms

Impaired Social Communication & Interaction

Restricted/Repetitive Behaviors

Impaired Social Communication & Interaction

Restricted/Repetitive Behaviors

Cognitive Comorbidities

Behavioral Comorbidities

Medical Comorbidities

Biomarkers

Genetics

Hyper-serotonemia

Altered Immune System

Neuroimaging: Altered brain region size
Autism

• Reliably diagnosed at 18–24 mos.
• Impaired social cognition is an early indicator of ASD
Today

• Social cognition
  ➢ Shared emotion stage
    ➢ Mutual eye gaze and social responsiveness, in early intervention

• Pathways early autism intervention that bridges the research-to-practice gap
COGNITIVE DEVELOPMENT IN THE FIRST TWO YEARS OF LIFE
--Tomasello et al., 2005

SHARING EMOTION
2 mos. +

PURSUIT GOALS
6-10 mos.

JOINT ATTENTION
10-24 mos.
COGNITIVE DEVELOPMENT IN THE FIRST TWO YEARS OF LIFE
--Tomasello et al., 2005

Social Cognition

- SHARING EMOTION
  2 mos. +

- JOINT ATTENTION
  10-24 mos.
Sharing Emotion (2 months on)

Social smile

Face-to-face (dyadic) interaction

Mutual gazing

Social responsiveness

Reciprocal to vocalization & facial expressions

Reciprocal exchanges of shared emotions

Rohat & Striano, 1999; Rollins & Greenwald, 2013; Tomasello et al., 2005
Children with ASD show a decline in *eye gaze* between 2-6 mos

Based on Jones & Klin (2013)
Parent Mediated Early ASD Intervention

Naturalistic Development Behavioral Intervention

Focus on Shared Emotion skills of mutual gazing & social responsiveness
Manualized intervention in English and Spanish

Uses a coaching model
90 minutes, 1x/wk

Meets the service delivery model of TX IDEA Part C
Early Childhood Intervention
Coaching based on adult learning strategies

- Authentic learning
- Self-efficacy
- Adult learner
- Reflection
- Problem solving

Dunst & Trivette 2012; Friedman et al. 2012; Rush & Shelden 2011
The Coaching Model

**Problem**
Difficult for interventionists to transition from expert to coach

**Solution**
Integrate coaching strategies into intervention strategies and activities.

<table>
<thead>
<tr>
<th>Activity Sequence</th>
<th>Minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information sharing</td>
<td>10</td>
</tr>
<tr>
<td>Video observation</td>
<td>5</td>
</tr>
<tr>
<td>Reflection &amp; Evaluation</td>
<td>10</td>
</tr>
<tr>
<td>Clarification</td>
<td>15-20</td>
</tr>
<tr>
<td>New material</td>
<td>10-15</td>
</tr>
<tr>
<td>Demonstration</td>
<td>10-15</td>
</tr>
<tr>
<td>Parent Practice &amp; Problem Solving</td>
<td>10-15</td>
</tr>
<tr>
<td>Activity Plan</td>
<td>10-15</td>
</tr>
</tbody>
</table>

Rollins, et al., (2020)
Pathways 12 week RCT

(1) Is Pathways an effective ECI model?

(2) Is mutual gaze an important ingredient to intervention success?

Rollins, et al., (2020)
Units are Cumulative
<table>
<thead>
<tr>
<th>Unit</th>
<th>Pathways</th>
<th>Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Introduction of learning environments</td>
<td>Introduction of learning</td>
</tr>
<tr>
<td></td>
<td></td>
<td>environments</td>
</tr>
<tr>
<td>2</td>
<td>Face-to-face dyadic interactions &amp; social</td>
<td>Face-to-face dyadic interactions &amp;</td>
</tr>
<tr>
<td></td>
<td>sensory routines</td>
<td>social sensory routines</td>
</tr>
<tr>
<td>3</td>
<td><strong>Facilitate mutual gazing</strong></td>
<td><strong>Facilitate communication</strong></td>
</tr>
<tr>
<td>4</td>
<td>Use of animation</td>
<td>Use of animation</td>
</tr>
<tr>
<td>5</td>
<td>Imitation of the child</td>
<td>Imitation of the child</td>
</tr>
<tr>
<td>6</td>
<td>More toys added to the interaction</td>
<td>More toys added to the interaction</td>
</tr>
<tr>
<td>7</td>
<td>Facilitation of imitation; modeling and</td>
<td>Facilitation of imitation;</td>
</tr>
<tr>
<td></td>
<td>expansion of language</td>
<td>modeling and expansion of</td>
</tr>
<tr>
<td></td>
<td></td>
<td>language</td>
</tr>
</tbody>
</table>
Demographics similar to Texas statewide ECI

### Ethnicity
- Hispanic: 45%
- African American: 24%
- Caucasian: 9%
- Asian: 22%

### Chip Eligible
- CHIP eligible: 35%
- Not eligible: 65%

### Nonverbal IQ (M=65.9, SD=15)
Pre and Post Intervention

Parent-child interactions
- Social Eye Gaze
- Vocal-verbal reciprocity
- Intentional communication

Vineland II, Social Subscale
Residual Change Scores

- Better Post-intervention
- Worse Post-intervention

Error bars: 95% CI
Social Measures

Social Eye Gaze

Vineland Social (nonverbal IQ)

Pathways > Communication = SAU

Pathways > Communication = SAU

$F(2, 73) = 16.61, p < .0001, \omega^2 = .283$

$F(2, 75) = 6.06, p = .004, \omega^2 = .106$
Social Communication measures (nonverbal IQ)

**Vocal-Verbal Reciprocity**

Pathways = Communication > SAU

\[ F(2, 73) = 4.53, p = .014, \omega^2 = .084 \]

**Intentional Communication**

Pathways = Communication = SAU

\[ F(2, 73) = 1.69, p = .192, \omega^2 = .016 \]
After 12 weeks of Pathways
Key Findings

(1) Toddlers with ASD had maximal benefit when parents were coached on early shared emotions skills

(2) Pathways protocol for mutual gaze appears to be the key ingredient to social development

(3) Facilitating mutual gaze had cascading effects on communication

(4) Pathways is an effective early intervention model
Parenting Stress Model

Based on Adidin (2012)
Decrease in Parenting Stress (PSI-4)

\[ F (2, 58) = 3.24 \quad p = .046, \text{ partial } \eta^2 = .10 \]

Jones, & Rollins (2018)
Initial Parenting Stress & Change in Parent Responsivity (n=56)


$R^2 = .43$
Directions

• To evaluate the efficacy of Pathways in children 3-5 years of age.

• To evaluate the effectiveness of Pathways in Part C, ECI program
Acknowledgements

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• Students for their assistance with coding videos in the social communication lab.

• Renee Hoffman and Michelle Campbell of Pathways

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  • Cristina Rangel, M.S, CCC-SLP
  • Delayne, M.S., CCC-SLP
  • Megan Nauta, M.S., CCC-SLP
  • Sara Brantley, MED, BCBA
Relational health: From research to practice with families of children with autism or hearing differences

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Goals for today
To understand the effect of hearing differences on the child
To describe the effect of hearing differences on the family dynamic, including the parents and siblings
To apply knowledge of family systems to clinical interactions with children who have hearing differences

Hearing differences in children
- Sensorineural hearing loss occurs frequently
  - 2/4-5,000 newborn infants
  - 12,000 newborn infants/year
  - 4,000-6,000 infants and toddlers (0-3 years)/year with late-onset HL
  - 16,000-18,000 infants and toddlers with HL per year

CDC’s Hearing Screening and Follow-up Survey, 2009; National Center on Hearing Assessment and Management (NCHAM); White, 2004.

* In the United States

Effect of hearing differences on audibility

Auditory technology can mitigate effects of hearing loss on audibility.
Family systems theory

- Family members function in relation to one another
- Change in one family member produces changes in the others

Family systems: Parents

- Strengthened family bond
- Increased awareness to differences
- Better child adjustment
- Stress or worry about child's future
- Emotional disconnection from child
- Financial and time demands

Does a child's hearing status affect hearing-specific parenting stress?

<table>
<thead>
<tr>
<th>Child characteristics</th>
<th>M (SD)</th>
<th>Family Stress Scale (FSS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronologic age (years)</td>
<td>11.9 (2.3)</td>
<td>9 general and 7 HL-specific items</td>
</tr>
<tr>
<td>Age at hearing loss identification (years)</td>
<td>1.1 (0.9)</td>
<td>Child characteristics</td>
</tr>
<tr>
<td>Age at cochlear implantation (years)</td>
<td>2.7 (1.8)</td>
<td>Chronologic age, gender, maternal education, temperament (EATQ-R)</td>
</tr>
<tr>
<td>Cochlear implant experience (years)</td>
<td>9.2 (2.5)</td>
<td>Cochlear implant-related factors</td>
</tr>
</tbody>
</table>

Child's hearing status has little to no effect on general parenting stress.

- Parental distress
- Parent-child dysfunctional interaction
- Difficult child
- Total stress

- 0-50 Parental distress
- 0-20 Parent-child dysfunctional interaction
- 0-50 Difficult child
- 0-50 Total stress

Normative sample, Deaf or hard of hearing, Cochlear implant users, Autism

High parental stress: Parenting Stress Index (PSI) scores > 85.

- Parenting Stress Index (PSI)
- Early Adolescent Temperament Questionnaire (EATQ-R)
- Abidin, 1990;
- Lederberg & Golbach, 2002;
- Quittner et al., 1990,
- 1991;
- Wiseman et al., 2021.
... but similar levels pre- vs. post-implantation (albeit different stressors).

Hearing differences may exacerbate factors associated with parental stress.

Does a child’s hearing status affect the sibling with typical hearing?

<table>
<thead>
<tr>
<th>Child characteristics</th>
<th>Sibling</th>
<th>CI user</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean chronologic age (years)</td>
<td>11.6 (2.6)</td>
<td>11.9 (2.9)</td>
</tr>
<tr>
<td>Mean age difference (sibling – CI user, years)</td>
<td>0.3 (3.7)</td>
<td>0.3 (3.7)</td>
</tr>
<tr>
<td>% female</td>
<td>47%</td>
<td>47%</td>
</tr>
<tr>
<td>% older</td>
<td>56%</td>
<td>44%</td>
</tr>
</tbody>
</table>

Quantitative
- Sibling perspective of CI users (23 items) – Higher score = more positive
- Effect of hearing loss on sibling (16 items) – Higher score = more affected

Qualitative
- Open-ended items about growing up with CI user

Certain child-related factors coincide with higher levels of parental stress.

Family systems: Siblings

Open-ended items revealed some negative feelings by siblings with typical hearing.

| Sibling perspectives relate to the CI users’ communication skills. |
|------------------|------------------|
| Sibling perspective of the CI user | Effect of HL on the sibling |

Instead of feeling further apart from my brother, I feel closer to him.

Sometimes I want to hang out with my parents, but if something happens to my brother’s CI, they might not have the time to spend with me.

It makes me upset when she’s not acting normal with her friends … It’s hard for me to realize how much HL really affects her.
Siblings feel positively, but struggle with aspects of having a cochlear implant user in the family.

Family systems theory

Family systems theory

Clinical implications of this work

- Parental stress
  - Active listening
  - Cognitive reframing
- Sibling engagement
  - Sibling groups/camps
  - Dedicated time with parents
- Family focus
  - Family support groups/camps
  - Inclusion of extended family

Conclusion

Pediatric hearing differences have direct and indirect effects on the family dynamic.
These effects emerge in early childhood and can have long-lasting influences on all family members.
Clinicians should incorporate ways to engage the whole family to enhance well-being in all members.

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