Redefining Support for Families of Children with Autism

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Learning Objectives

1. Define family occupations and family quality of life.

2. Articulate differences between family occupations and family mental health for families raising a child with a disability compared to families with children who are typically developing.

3. Understand the impact of family mental health on outcomes for a child with a disability.

4. Discuss barriers to considering family occupations and family mental health within daily practice.

5. Develop strategies for applying communication pertaining to family occupations and family mental health within daily practice.

What is Family Quality of Life?

- "Impacts (either positive or negative) experienced by families as a result of supports and services for themselves and/or their children with disabilities"
- Influenced by:
  - Perceived stress, depression, or caregiving burden by parents
  - Family functioning (e.g. communication, cohesion, flexibility, role performance, coping processes)
  - Eco-cultural adaptations to family's routine
- An assessment of Family QoL: The Beach Center Family Quality of Life Scale)

(Summers et al., 2005)

What are Family Occupations?

- Occur when a family is engaged in a shared occupation
- Participation does not need to be parallel or equal among family members
- Purposes for participating and personal experiences of family occupations may vary among participants
- Provides family with the time and space to create experiences of togetherness
- Culture leads to idealized images of family participation which guide the behavior of families to participate in family occupations

(Segal, 1999)

What are your Family Occupations?

https://www.polleverywhere.com/free_text_polls/orWcSLrAemDcmRy9gAaPS?preview=true&controls=none

Parenting Stress in Mothers and Fathers of Toddlers with Autism Spectrum Disorders: Associations with Child Characteristics

Participants: Mothers and Fathers of 54 Toddlers with ASD

Mothers	Fathers
● Higher rates of stress and depression ● More likely to be involved in everyday activities of child with ASD ● More affected by child's inability to eat, sleep, self-regulate emotions	● Increased difficulty interacting with child with ASD ● More affected by externalized behaviors (e.g. tantrums, loud/peculiar vocalizations or mannerisms)

(Davis & Carter, 2008)

Types of Strain among Family Members of Individuals with Autism Spectrum Disorder Across the Lifespan

Caregiver strain: perception of how a caregiver's life has been impacted by caring for an individual with ASD

- Objective strain: degree to which caregiving activities impact work, finances, routines, etc.
- Subjective strain: degree to which caregiving activities impact the caregiver emotionally
  - Externalized: e.g. embarrassment, anger
  - Internalized: e.g. feeling tired, worried about future

(Shivers, Krizova, & Lee, 2017)

Types of Strain among Family Members of Individuals with Autism Spectrum Disorder Across the Lifespan

Survey of 193 family caregivers considering caregiver strain, objective responsibility, needs of individual with ASD and coping strategies of family members

- Moderate level of all three types of strain, not correlated to age of individual with ASD
- Highest mean level of subjective internalized strain
- Strain decreased when caregiver had shared responsibility for community interaction
- Maladaptive coping strategies influence how caregiver feels about individual with ASD as seen through correlation with subjective externalized strain

(Shivers, Krizova, & Lee, 2017)

Childhood Caregiving Roles, Perceptions of Benefits, and Future Caregiving Intentions among Typically Developing Adult Siblings of Individuals with Autism Spectrum Disorder

Sibling-Focused Parentification	Parent-Focused Parentification
● Parents become more available to reciprocate care, resulting in positive developmental outcomes ● Protective factor against stress, anxiety	● Occurs in families with high levels of parental conflict ● Interferes with child's social development, can lead to increased anxiety and stress

(Nuttall, Coberly, & Diesel, 2018)

Childhood Caregiving Roles, Perceptions of Benefits, and Future Caregiving Intentions among Typically Developing Adult Siblings of Individuals with Autism Spectrum Disorder

Benefit Finding

- Ability to identify positive contributions to self-development resulting from challenging life experiences
  - E.g. empathy, compassion, responsibility
- Results in development of prosocial behaviors, positive familial relationships, fosters intention to provide future caregiving

(Nuttall, Coberly, & Diesel, 2018)

Childhood Caregiving Roles, Perceptions of Benefits, and Future Caregiving Intentions among Typically Developing Adult Siblings of Individuals with Autism Spectrum Disorder

- Population: 108 college students between ages of 18-25
- Results:
  - Mean level of intention for future caregiving involvement=5.98/7
  - Individuals who reported higher levels of parent-focused parentification perceived fewer benefits associated with their role in family, expressed less intention to provide caregiving involvement for sibling with ASD in future

(Nuttall, Coberly, & Diesel, 2018)

Impact of Family Mental Health on Outcomes for Individuals with ASD

- Higher levels of parenting stress reduces effectiveness of early teaching interventions for children with ASD (Osborne et al., 2008)
- Mother-reported stress strongly related to child gains in family-oriented training programs for children with ASD (Robbins et al., 1991)
- Hypotheses for this phenomenon:
    - Child with ASD follows parents' modeling of coping mechanisms (Reaven, 2011)
    - Parent's emotion co-regulation strategies impact treatment efficacy (Ting & Weiss, 2017)

Examining the Relationship Between Parental Symptomatology and Treatment Outcomes in Children with Autism Spectrum Disorder

29 children between the ages of 7 and 12 with ASD participated in a manualized group psychotherapy program (Resilience Builder Program)

- Manualized group psychotherapy program for youth with prominent psychosocial and social competence deficits.
- Focused on adaptability, flexibility, emotional and behavioral regulation, optimism, frustration tolerance, and social skills
- 1 hr, 1x/week for 12 weeks

(Reid, Esalbon, Mendoza, Albord, & Rich, 2019)

Examining the Relationship Between Parental Symptomatology and Treatment Outcomes in Children with Autism Spectrum Disorder

Post-Treatment Communication Outcomes

Parental Interpersonal Sensitivity Symptoms (p=0.024)

Parental Hostility Symptoms (p=0.023)

Post-Treatment Emotional Control Outcomes

Parental Anxious Symptoms (p=0.005)

Parental Obsessive-Compulsive Symptoms (p=0.023)

Parental Depressive Symptoms (p=0.034)

Post-Treatment Internalizing Problems Outcomes

Parental Depressive Symptoms (p=0.041)

Parental Anxious Symptoms (p=0.004)

(Reid, Esalbon, Mendoza, Albord, & Rich, 2019)

Sib20
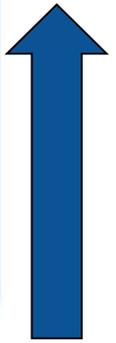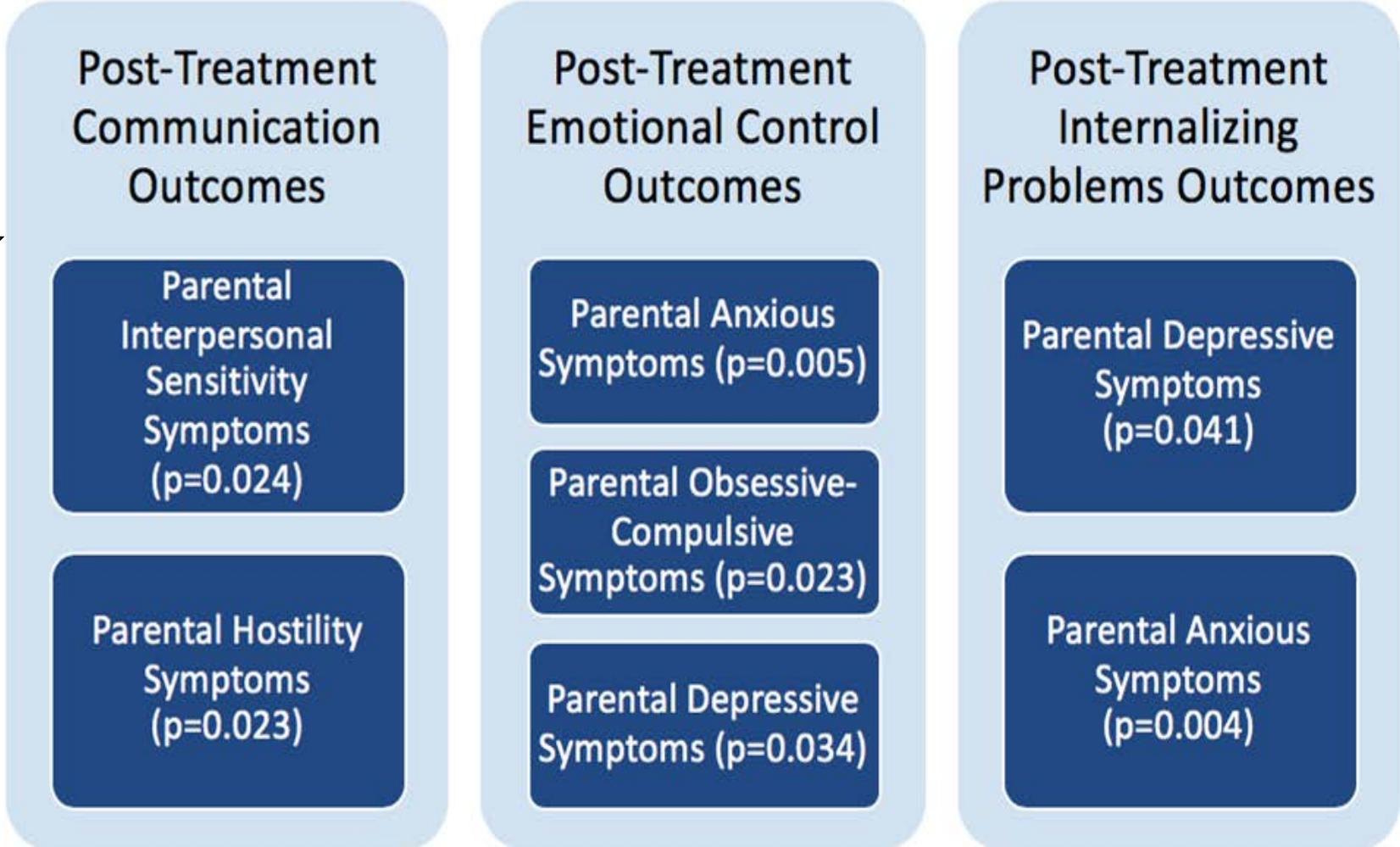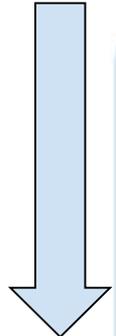
- Facebook group for individuals in their 20's with sibling(s) who have a disability
- Part of the Sibling Support Project
  - Founded in 1990
  - First national program dedicated to the support of siblings of individuals with disabilities
  - Consists of online support groups, workshops for school-aged siblings of individuals with disabilities, conducts research

Poll Everywhere: Slb20

What family occupations did you and your nuclear family engage in frequently during your childhood?

Sib20 Survey: Simple, Sibling-Centered Activities

"Family activities were kept **simple** [because] we all had very different hobbies and patience levels."

"All activities we did were very **thoroughly planned out** and often more of a hassle than they were worth. Everything **revolved around** trying to calm and control my sister."

"Doing "family" things were always **oriented around doing things my sister wanted**, or around sitting in a dark room and not talking to each other."

"**[T]raveling and vacationing [are] difficult** when the sibling is very anxious and attached"

Slb20 Survey: "Divide and Conquer" Approaches

"My parents took a **"divide and conquer"** approach [...] my dad would ski the harder slopes with me, and my mom would take my sister around the easier slopes [...] then that night my mom would go out to dinner with me, and my dad would stay at the hotel with my sister and watch a movie. [...] the parent spending time with me was getting the better end of the deal, which felt good, but it also felt like **[I] had a responsibility to be "easy" because this was their "break."**"

"We couldn't really go out to dinner together except a few places that my sister had decided she liked [...] hearing "Oh I'd love to try this new place but your sister will throw a fit, let's go for lunch next weekend when she and your dad are on a hike!" **sort of undermined the "family" part of it**."

Sib20 Survey: Miscellaneous

"At times my sister and I would say of our younger brother with Autism **"It's all about him!"** And there were phases where that was fairly accurate."

Reflection: Feelings of jealousy

"It was incredibly hard to think of three things, especially because my brother is severely autistic and nonverbal so **there weren't many things we all did together** that I remember."

Reflection: Lack of meaningful, shared family activities

"Please give all of us support but **mental health support** so parents don't get overwhelmed and end up taking it out on their typical children."

Reflection: Need for increased mental health support

Proposed Edits to the OTPF

Includes increased focus on providing services at the group and population level

- 5 new tables
  - Table 1--Clients: Person, Group, Population
  - Table 3--Examples of Occupations for Persons, Groups, and Populations
  - Table 7--Performance Skills for Persons (with examples of effective and ineffective performance skills)
  - Table 8--Performance Skills for Groups
  - Table 11--OT Process for Persons, Groups, and Populations

(AOTA Commission on Practice, 2019)

Vision 2025

- Developed following the Centennial Vision
- Four Pillars:
    - Effective
    - Leaders
    - Collaborative
    - Accessible
- Increased focus on people, populations, communities
- Aims to encourage practitioners to think big and be comfortable being trail blazers

(American Occupational Therapy Association, 2018)

Emerging Research on Interventions for Families

- Parent-Child Interaction Therapy (Agazzi, Tan, Ogg, Armstrong & Kirby, 2017; Iida et al., 2018)

- Self-Narratives (Trzebiński, Wolowicz-Ruskowaska, & Wójcik, 2016)

- Peer-Support Programs (Niinomi et al., 2016)

- Psychoeducation Approaches (Hemdi & Daley, 2017)

- Gratitude Interventions (Timmons & Ekas, 2018)

- Mindfulness Interventions (Jones et al., 2016; Raulston et al., 2019; Singh et al., 2019)

- Acceptance and Commitment Therapy (Lunsky, Fung, Lake, Steel, & Bryce, 2017)

An Inclusive, Family-Centered Model

(Addon, 2019)
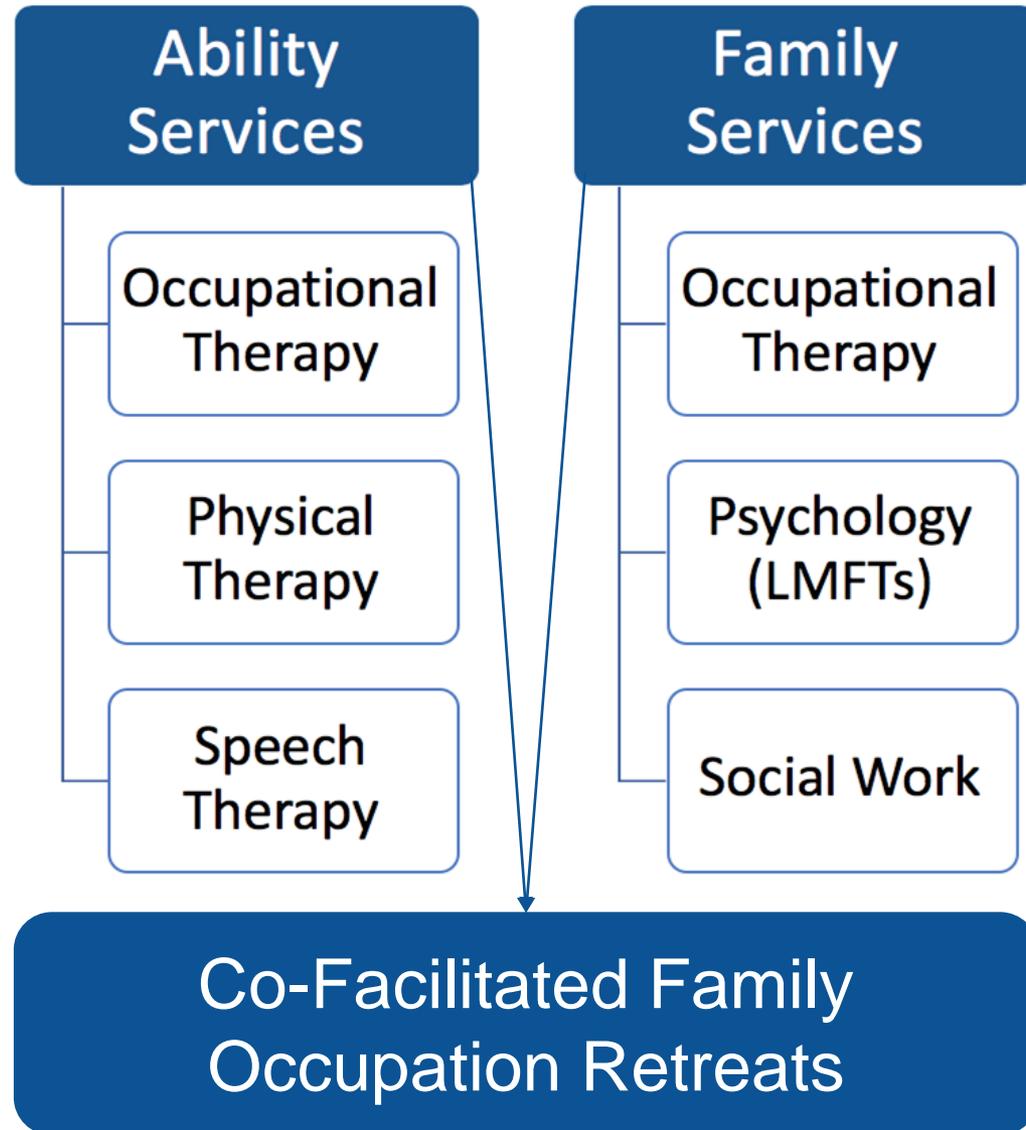
Family Services

Occupational Therapy	Psychology (LMFTs)	Social Work
Sibling Groups	Individual Psychotherapy	Individual Counseling
Father Groups	Marriage Counseling	Group Counseling
Mother Groups	Family Sessions	Information Sessions

(Addon, 2019)

An Inclusive, Family-Centered Model

(Addon, 2019)
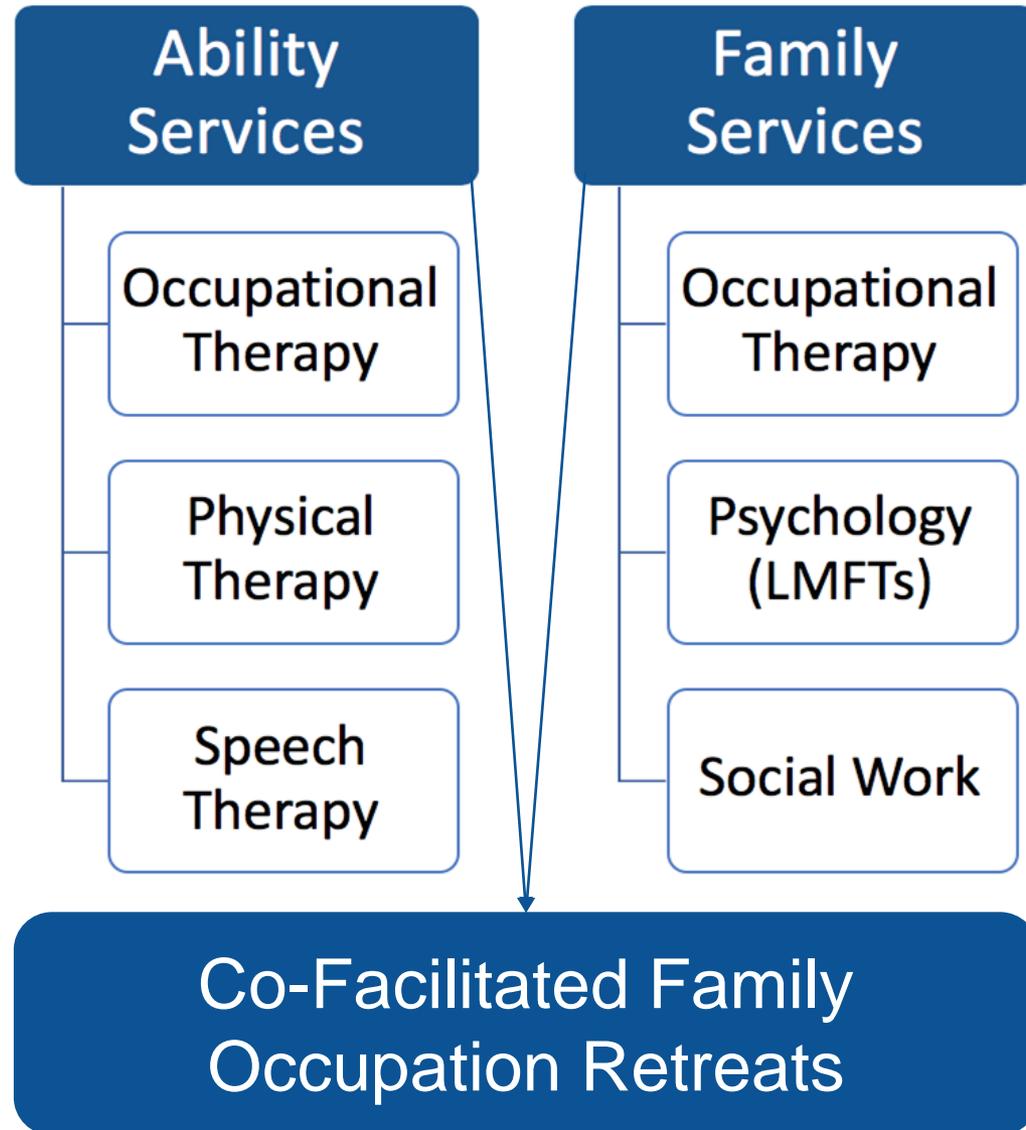
Strategies to Incorporate Family Mental Health into Practice

Utilize Family QoL measures during initial evaluations to develop goals based on the needs of the full family unit

- e.g. The Beach Center Quality of Life Scale (Summers et al., 2005), Family Adaptability and Cohesion Scale (Olson et al., 1992)

Ask about the family's current participation in family occupations and their desire to engage in new family occupations

Be familiar with support group services in your area and online resources for families of individuals with disabilities.

Barriers to Including Family Mental Health in Practice

- Limited research pertaining to sibling and father roles within families of individuals with ASD
- Limited evidence exploring interventions for family members of individuals with ASD
- Limited research considering family experiences of individuals with other types of disabilities
- Limits imposed by scope of practice in certain settings (e.g. schools)

"Are we creating supports to help the family participate together in positive health promoting daily life activities or are the interventions we provide interfering with shared family occupations?"

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Beth Werner DeGrace, PhD, OTR/L, 2004

Group Discussion

- Introduce yourself to your neighbors!
- How do you currently address family mental health and family occupations in your practice?
- What barriers do you perceive to be limiting our capacity as occupational therapy practitioners to impact family mental health for families raising a child who has autism? What can we do to modify these barriers?
- Major takeaway(s) from this presentation.

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