Caregivers of Children with Developmental Disabilities:
Exploring Perceptions of Health-Promoting Self-Care

Emily Auerbach, M.A.
Taylor Koriakin, M.A.
Sandra Chafouleas, Ph.D.
Conference Session Objectives

• List at least three challenges that impact caregivers of children with developmental disabilities (DD).

• Identify the 6 domains of health and well-being that caregivers used to assess their health-promoting self-care behaviors.

• Discuss how the Transtheoretical Model might be used to inform self-care intervention for caregivers of children with DD.
Getting to know our audience

In what field related to mental health do you currently work?

Specifically, in what capacity do you work with families/caregivers?
Background

• Approximately half of informal caregivers present with at least one chronic condition impacting personal health and affects their caregiving (Family Caregiver Alliance, 2012).

• Psychological distress and health-risk behaviors among the most frequent negative influences on caregiver health

• Caregivers of children with DD report high levels of stress and greater levels of depression and anxiety

Beach, Schulz, Yee, & Jackson, 2000; Family Caregiver Alliance, 2012; Khanna, Jariwala, & Bentley, 2013; Lindo, Kliemann, Combes, & Frank, 2016; Miodrag & Hodapp, 2010; Pinquart & Sorensen, 2007
• Primary caregivers must be able to engage in self-care to be able to provide the best possible care in order to facilitate positive child outcomes.

• Many families with a child with DD experience financial and physical stress at greater levels than families not living with a child with DD (Lindo et al., 2016).

• Thus, the means by which primary caregivers receive support for their mental and physical health must be easy to use, efficient, and attainable.
Putting it all together

Parent Health and Well-Being → Quality of Parent Involvement in Care of Child → Child Outcomes
Putting it all together

Barriers to Parent Health
- Lack of social support
- Time
- Financial Strain

Lower Quality of Parent Involvement in Care

Poorer Child Outcomes
Supports that Promote Parent Health

Self Care Practices

Higher Quality of Parent Involvement in Care

Positive Child Outcomes

Social support

Self Care Practices

Supports that Promote Parent Health

Spirituality /religion

Putting it all together
Purpose of this Exploratory Study

- Determine health-related concerns of caregivers of children with DD
- Evaluate readiness to change health behaviors
- Explore perceptions of utilizing technology to facilitate behavioral changes in self-care
Participants

• 13 parents of children with DD
  • Primarily mothers
  • Range of education levels from high school diploma to advanced graduate degrees

• Child characteristics
  • Variety of disability types: ASD, Intellectual Disability, ADHD, developmental disability, and cerebral palsy
  • Age range from early childhood to young adulthood
Our Exploratory Domains of Well-Being

- Love
- Eat
- Sleep
- Learn
- Work
- Play
How is Your Well Being?

- Take a moment to look at your handout
- For each domain, mark if you are:
  - Far from goal
  - Almost at goal
  - At goal

<table>
<thead>
<tr>
<th></th>
<th>Far From Goal</th>
<th>Almost At Goal</th>
<th>At Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eat</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Play</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Love</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learn</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## How Our Participants Compare

<table>
<thead>
<tr>
<th></th>
<th>Far From Goal (N=13)</th>
<th>Almost At Goal (N=13)</th>
<th>At Goal (N=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eat</td>
<td>8</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Sleep</td>
<td>6</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Work</td>
<td>4</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Play</td>
<td>3</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Love</td>
<td>3</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Learn</td>
<td>2</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
What are your top 3 wellness priorities?

<table>
<thead>
<tr>
<th>Love</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Learn</td>
<td></td>
</tr>
<tr>
<td>Eat</td>
<td></td>
</tr>
<tr>
<td>Play</td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td></td>
</tr>
<tr>
<td>Sleep</td>
<td></td>
</tr>
</tbody>
</table>
Our Participants’ Top 3

<table>
<thead>
<tr>
<th></th>
<th>Top 3 Endorsed (N=13)</th>
<th>1 (N=13)</th>
<th>2 (N=13)</th>
<th>3 (N=13)</th>
<th>4 (N=13)</th>
<th>5 (N=13)</th>
<th>6+ (N=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eat</td>
<td>10</td>
<td>2</td>
<td>6</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Sleep</td>
<td>8</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Play</td>
<td>8</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Love</td>
<td>6</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Work</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Learn</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>
Participant Barriers to Health-Promotion
Participant-Identified Barriers

**Related to Caregiving**

- Expenses related to raising a child with DD.
- Minimal time and/or ability to sleep, exercise, or focus on eating a healthy, balanced diet.
  - Specifically, time and energy were barriers to engaging in these behaviors.
- Feelings of hopelessness, anxiety, and being overwhelmed.

**Other Barriers**

- Being a single parent
- Low socioeconomic status
- Chronic health problem
Your turn...

Can you identify any other barriers to caregiver well being that you have experienced/witnessed in your clients?
How can we facilitate reducing these barriers?
One Possibility: Changing Caregiver Behavior

• The Transtheoretical Model and Stages of Change (TTM) can be used to identify readiness to change behavior (Prochaska & DiClemente, 1984; Prochaska, DiClemente, & Norcross, 1992).

• TTM involves stage-matched behavior change strategy selection using four dimensions of consideration:
  1. processes of change
  2. stages of change
  3. pros and cons of change
  4. levels of change
The Transtheoretical Model

Stage 1: Precontemplation
- Not ready to change behavior

Stage 2: Contemplation
- Has the knowledge to change behavior

Stage 3: Preparation
- Preparing to change behavior

Stage 4: Action
- Actively working on a change in behavior

Stage 5: Maintenance
- Behavior has been changed and is being maintained

(Prochaska & DiClemente, 1983; Prochaska, DiClemente, & Norcross, 1992)
Stages of Change

Precontemplation → Contemplation → Preparation → Ready → Action → Maintenance
What Stage are You in?

- Going back to the handout...
- For your top 3 areas, note which stage of change you are in
## Participant Readiness To Change

<table>
<thead>
<tr>
<th>Activity</th>
<th>1 (N=13)</th>
<th>2-3 (N=13)</th>
<th>4-5 (N=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eat</td>
<td>5</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Sleep</td>
<td>4</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Work</td>
<td>5</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Play</td>
<td>1</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Love</td>
<td>1</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Learn</td>
<td>1</td>
<td>3</td>
<td>9</td>
</tr>
</tbody>
</table>

Note. Readiness to Change: 1 = precontemplation, 2-3 = contemplation/preparation, 4-5 = action/maintenance.
What other possibilities exist to help facilitate self-care behavior change for caregivers of children with DD?
Possibilities within Technology-Mediated Platforms?

• 9 participants were interested in a user-friendly form of technology (i.e. application or website) to promote their health and well-being.

• Areas of participant need for technology included:
  • resources for social support, such as an online support group
  • a tool to assist with time-management
  • a list of community resources
SUMMARY: Considerations and Future Directions for Supporting Caregiver Health

- Facilitating caregiver self-awareness of their health – and self-care as an intervention with dual benefit to self and child.
- Understand individual need varies, and thus, consider a variety health-promoting areas for intervention.
- Exploring possibility of technology as an option for addressing potential burden of access.
Thank you. Questions & Comments?

Contact:
Sandra Chafouleas
sandra.chafouleas@uconn.edu