

# Exploring Wellbeing Among Caregivers: A Comparison of Direct Support Professionals and Parents

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## Literature Review

Caregivers of adults with intellectual and developmental disabilities (IDD) often are Direct Support Professionals (DSPs) or family members (e.g., parents). Changes to policies and funding is shifting the field of primary caregivers, resulting in a growing number of adults with IDD living in their family homes with family members serving as primary caregivers (Heller, Caldwell, & Factor, 2007). Research with caregivers shows they are susceptible to both negative and positive outcomes. Little research to date has looked at comparing caregiver roles (i.e., DSPs and Parents) as well as both positive and negative outcomes of caregiving. The current study aimed to provide a clearer picture of the potential differences that exist between DSPs and Parents in regard to both negative and positive outcomes of caregiving. An additional aim was to better understand the caregiver and individual characteristics impacting caregivers' reports of burnout and positive contribution.

## Research Questions

- **RQ1.** Do significant relationships exist between caregivers' reports of burden and positive contribution?
- **RQ2.** Do DSPs and parents significantly differ in their reports of burnout and positive contribution?
- **RQ3.** Which caregiver characteristics and individual characteristics are most influential in predicting caregiver burden and positive contribution among DSPs and parents?

## Participants

- 120 adults receiving Home and Community Based Medicaid waiver services in Oklahoma and their Caregivers, including 60 Parents and 60 DSPs.
  - Note: If caregivers were both a Parent and DSP, they were categorized as a Parent only. Agency companions and foster parents were excluded from the sample.

## Measures

- The **Caregiver Survey** was used to gather caregiver demographic characteristics (i.e., age, gender, education, marital status) as well as:
  - **Caregiver Burden Scale** (Zarit et al., 1980)
  - **Positive Contribution Scale** (Behr et al., 1992) assessed six subscales of positive contribution: Happiness, Awareness, Personal growth, Learning, Understanding, and Strength.
  - **Coping Orientations to Problems** (Piazza et al., 2014) assessed positive coping strategies.
- The **National Core Indicators Adult Consumer Survey** assessed individual characteristics (i.e., mobility, behavioral challenges, mental health, & communication).

## Table

Means and Standard Deviations of Caregiver Characteristics, Individual Characteristics, Burden, and Positive Contribution Subscales by DSPs and Parents

Caregiver Characteristics	DSPs (n = 60)		Parents (n = 60)	
	M or %	SD	M or %	SD
<b>Marital Status</b>				
Married	38.3%		69.5%	
Other	61.7%		30.5%	
<b>Ethnicity</b>				
Caucasian	59.3%		82.8%	
Non-Caucasian	40.7%		17.2%	
<b>Gender</b>				
Female	80.0%		86.7%	
Male	20.0%		13.3%	
<b>Education Level</b>				
High School or Below	38.3%		25.4%	
Higher Education	61.7%		74.6%	
Age	45.52	14.30	53.09	12.43
Positive Coping Strategies	24.12	5.34	25.67%	4.87
<b>Individual Characteristics</b>				
<b>Mobility</b>				
With Aids or Assistance	40.0%		33.3%	
Without Aids or Assistance	60.0%		66.4%	
<b>Communication</b>				
Non Verbal	33.4%		28.4%	
Verbal	66.6%		71.6%	
Behavioral Challenges	1.38	1.94	1.00	1.49
<b>Dual Diagnosis</b>				
No Mood, Anxiety, Psychotic	53.4%		86.7%	
One of the three	23.3%		11.7%	
Two of three	20.0%		1.6%	
All three diagnosis	3.3%		0.0%	
<b>Outcome variables</b>				
Burden	18.91	12.81	30.70	16.80
<b>Positive Contribution</b>				
Happiness	17.15	2.22	17.39	2.65
Strength	13.40	2.76	14.01	2.33
Understanding	11.98	2.05	12.92	1.99
Awareness	3.01	1.01	3.05	0.79
Learning	17.15	2.70	17.59	2.32
Personal Growth	19.42	4.42	20.92	4.98

## Findings

**Preliminary analyses:** Compared to Parents, DSPs were more likely to be younger, part of a minority racial or ethnic group, single/not married and more likely to be caring for an individual with a dual diagnosis.

### RQ1: Correlations

- Burden and the Positive contribution of Happiness were negatively correlated ( $r = -0.34, p = 0.002$ ). Correlation coefficients for Burden and the five other Positive contribution subscales were not significant.

### RQ2: ANCOVAs (controlling for significant demographics)

- **Positive Contribution.** DSPs and Parents did not differ on six Positive contribution subscales
- **Burden.** Parents reported significantly greater levels of Burden than DSPs,  $F(1, 87) = 5.64, p = 0.02$ .

### RQ3: Regressions

- **Burden.** No caregiver or individual factors contributed significantly to Burden among DSPs or Parents.
- **Positive Contribution.**
  - DSPs' Strength on caregiving characteristics was significant,  $F(6,40) = 2.89, p < .05$ . DSPs part of a minority race/ethnicity reported greater Strength ( $\beta = -2.39, SE = .84, t = -2.85, p > .05$ ).
  - DSPs' Understanding on individual characteristics was significant,  $F(4, 49) = 3.47, p = .014$ . DSPs caring for individuals with mobility aids or assistance reported greater Understanding ( $\beta = -1.20, SE = 5.67, t = -2.11, p < 0.05$
  - Parents' Happiness on caregiver characteristics was significant,  $F(6, 45) = 2.53, p = .04$ . Parents' gender had a significant negative regression weight, indicating fathers reported lower Happiness than mothers ( $\beta = -2.39, SE = 1.01, t = -2.46, p < .05$ ).

## Conclusion

- Similar to previous research with families (Hastings & Taunt, 2002), the lack of significant relationships between Burden and the Positive contribution subscales suggest the outcomes are mutually exclusive and not on a continuum from negative to positive outcomes.
- Parents' higher levels of Burden seem to indicate the two caregiving roles are inherently different. Perhaps parents' inability to "clock out" from the responsibilities of caregiving results in more negative outcomes.
- Results specifically exploring DSPs' and Parents' positive contributions found distinct characteristics that may uniquely impact specific positive outcomes among each caregiver group.

## Limitations & Implications

- The current study included caregivers of individuals receiving Oklahoma waived services and supports. Findings may not be generalizable to caregivers of individuals not receiving funded supports.
- Further research should explore the role relationship quality between the caregiver and the individual may have on caregiver outcomes.



Funding for this research was provided through a contract with Oklahoma Developmental Disabilities Services and the Department of Human Development and Family Science at Oklahoma State University awarded to Oklahoma National Core Indicator Project PIs: Drs. Jennifer Jones and Kami Gallus

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