Introduction:
Families of individuals with intellectual and developmental disabilities (IDD) have experienced many stressors associated with transitions across the lifespan. For many families, transitions began with initial diagnosis of their relative with IDD, and then moved to institutionalization of the family member, followed by the trend of deinstitutionalization (Berry, 1995). One way to understand how families adapt to transitions is to explore meaning making surrounding those transitions. As the field of IDD continues to move toward a strengths-based approach when researching families of individuals with IDD, the family resilience model (FRM; Henry, Morris, & Harrist, 2015), used to understand how families adapt and make meaning throughout their lifetime of transitions of their family member with IDD.

Current Study:
The current study is part of a larger, two-phased mixed method study examining the impact and experiences of parents and siblings whose relative with IDD transitioned from Oklahoma’s state-run institutions. The phenomenological method and retroductive analysis were used to explore the following question: How do families of relatives with intellectual disability make meaning over a lifetime of risk and transitions (e.g., initial diagnosis, institutionalization, and deinstitutionalization)?

Sample and Procedures:
Participants included 23 family members (n=10 mothers, n=6 sisters, n=3 fathers, n=3 brothers, n=1 brother-in-law) across 19 interviews. Ages of participants ranged from 51 to 85 years (M=65.33, SD=9.01). Family members had a median income of $50,000 - $59,000. Ages of relatives with IDD ranged from 35-70 years (M=52.31, SD=10.03) and total time living in an institution ranged from 27 to 58 years (M=43.32, SD=7.99). Measures included semi-structured open-ended interviews with 47 questions for parents and 43 questions for siblings. Interviews ranged from 26 to 139 minutes and were conducted in the family member’s home, work place, or restaurant of family member’s choice.

The 19 qualitative interviews were analyzed using Colaizzi’s (1978) seven-step phenomenological method to ensure trustworthiness and rigor. A research supervisor and external auditor were also utilized to promote trustworthiness and rigor (Creswell, 1998).

Results:
Eight salient themes and eight subthemes emerged across family members’ experiences of transitions throughout the lifespan.

1. “I can deal with what I know, I have a hard time dealing with what I don’t know.”

2. “I think we got to be more caring”

3. “Gods Plan”

4. Shifting Family Roles

5. Listening to the Experts

6. Strong Sibling Connection

7. “I just want him to be happy”

8. Higher Power Taking Care of Relative

Discussion:
The study can inform professionals and policy makers who assist families during times of transition on what meaning families place on specific transitions, and professionals and policy makers can assist families in positive adaptation through their influence.

Understanding how families make meaning can assist professionals working with families in other transitions unique to individuals with disabilities such as transitioning out of the school system, employment transitions, and moving into the community.

Professionals must remain cognizant of the multiple and frequent transitions families experience across their lifespans, and the meanings they place on adaptations to the transitions.

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