

Abstract

Title: It is what it is...enduring...always on-call: The Lived Experiences of Parenting Adult Children with Developmental/Intellectual Disabilities.

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Background/Significance: The parental home is the predominant place of residence for adults with developmental disabilities/intellectual disabilities (DD/ID) (Heller et al., 2007). More than 75% of the adult population with DD/ID, living in the US, continue to have their basic needs provided by parents (Williamson & Perkins, 2014). About 2.9 million adults with DD/ID live with a parent 55 years (Byun et al, 2006), with more than 25% of these parents older than 60-years (Braddock et al., 2013). The predominance of aging parents as the source of long-term care seems to be the result of such factors as lack of appropriate housing, services, and supports, as well as discrimination in general (AAIDD, 2013).

Aims: The study specific aims: 1. Describe the common meanings and shared practices of parenting an adult with DD/ID. 2. Understanding the challenges parents face in their current lives and the resources they use to meet those challenges. 3. Elucidate the practical advice they have for others who want to be supportive of the efforts of parenting an adult with DD/ID.

Methods: The methodological approach is a Heideggerian Hermeneutic approach using deWitt & Ploeg's (2006) framework for rigor. Data was collected through the interview of 22 New Mexican parents caring for adult children with developmental/intellectual disabilities using semi-structured, open-ended questions and a demographic survey. The inclusion criteria included English-speaking birth parents living in the Southwest who parent an adult with DD/ID over the age of 18 years, who stills lives at home.

Results: Three relational themes with supporting subthemes and one constitutive pattern.

Implications: Although more research studies have immerged about parenting and adult children with developmental/intellectual disabilities, little is known about the lived experiences of parenting adult children with developmental/intellectual disabilities in the United States, particularly living in the southwest. This research study reveals several state and federal policy pieces.