

Perspectives on Intimate Relationships and Self-Determination in Young Adults With Down Syndrome

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IMPORTANCE: Intimate relationships are significantly associated with quality of life for young people with Down syndrome (DS) (Haddad et al., 2018; Friedman et al., 2018). However, individuals with DS are often left out of the conversation regarding their relationships and sexual identity (Kammes et al., 2021; Healy et al., 2009).

OBJECTIVE: To explore 1) perceptions of intimate relationships as described by individuals with DS and their caregivers, and 2) the impact of self-determination and participation in life roles on relationship formation and maintenance.

DESIGN: Prospective descriptive study utilizing a mixed-methods approach.

PARTICIPANTS: Young adults (ages 18-30) with Down syndrome and their caregivers.

MEASURES: Qualitative data were collected using interview and focus group formats. Quantitative data was collected using a background questionnaire, the Role Checklist Version 3 (RCv3), and the ARC Self Determination Scale (ARC-SDS).

PROCEDURES: Participants with DS participated in one-on-one semi-structured interviews (guided by the ARC-SDS and RCv3) and a focus group with other young adults with DS (guided by Nominal Group Technique). Caregivers completed the background questionnaire and RCv3 based on their perceptions of their loved ones' roles. Additionally, caregivers participated in a one-on-one semi-structured interview.

RESULTS: Individuals with DS reported high self-determination on the ARC-SDS and a high level of satisfaction in their life roles on the RCv3. However, it was also noted that participants also reported strong agreeableness with others (e.g., "I usually agree with people when they tell me I cannot do something"). Individuals with DS expressed interest in developing intimate relationships and sexual identities but experienced difficulty identifying how to create and maintain these relationships. For the majority of participants, the maintenance of intimate relationships required caregiver support. Differences in how intimate relationships were perceived by young adults and their caregivers were noted. Caregivers expressed interest in supporting their adult children's self-determination and relationship building. However, caregivers also reported some difficulty teaching their loved ones about the nuances of intimate relationships.

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