Exploring Relationships and Intimacy with Adults with Intellectual and/or Developmental Disabilities (I/DD)

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Exploring Relationships and Intimacy with Adults with Intellectual and/or Developmental Disabilities (I/DD)

Gabrielle Kennedy, OTS; Jazminne Orozco Arteaga, OTD, OTR/L; & Thais Petrocelli, OTD, MHA, OTR/L

BACKGROUND

The American Occupational Therapy Association (AOTA) defines intimate partner relationships as “engaging in activities to initiate & maintain a close relationship, including giving & receiving affection & interacting in desired roles…” (AOTA, 2020, p. 33).

Intimacy is associated with familiarity, privileged knowledge, emotional attachments, trust, & *sometimes* physical proximity or sexual activity. • Intimacy is not limited to romantic partnerships & can be expressed emotionally, intellectually, experientially, creatively, spiritually, & physically (Klausen, 2021).

Intimate partner relationships are regarded as a component of the occupation of social participation (AOTA, 2020).

PROBLEM

Adults with I/DD’s access to occupations related to intimacy, intimate partner relationships, & opportunities for sexual expression has been significantly limited due to various societal, cultural, institutional, & familial barriers (Bathje et al., 2021).

PURPOSE

Explore Relationships & Intimacy Address Gap in Services

Assess Needs Identify Barriers

Occupation-Based Tertiary Prevention Health Strategy

Develop Resources Support Community

Promote Inclusion Increase Access

METHODS

1. Community Partnership

2. Needs Assessment:
   • Observations & record reviews
   • Informal interviews
   • Staff surveys
   • Literature review

3. Develop Resources:
   • Staff member training videos
   • Community-centered resource guide
   • Internal needs assessment infographic
   • OT student presentation
   • Client assessment session

CLINICAL APPLICATION

Community Day Programming Advocacy Goals:

- Advocating for Population Members:
  • Communicate contextual impacts of occupational deprivation
  • Provide knowledge translation of needs assessment
  • Utilize & highlight Bill of Rights (San Diego Regional Center [SDRC], n.d.-b)

- Advocating for Community-Centered Collaboration:
  • Train staff members on methods for structured activities & groups
  • Include stakeholders’ perspectives in data collection for needs assessment
  • Support use of Person-Centered Thinking methods (SDRC, n.d.-a)

- Advocating for Occupational Therapy:
  • Education on scope of practice
  • Review of current curriculums/programs
  • Detail benefits of utilizing OT methods to explore relationships & intimacy

REFERENCES

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KAWA MODEL
A PICTURE STORY OF MY LOVE LIFE

Parts of the Kawa & What They Mean:

**Water**
the natural flow of my love life

**River Wall (Mud)**
the people & places in my love life
*examples:* romantic partners, TERI

**Rocks**
the problems making my love life harder
*examples:* busy schedule, no partner

**Driftwood (Logs)**
personality traits that affect my love life
*examples:* being considerate, being shy
INTRODUCTION

Definition of Key Terms

Intellectual and/or Developmental Disabilities (IDD)
A group of lifelong conditions that impact cognitive functioning, adaptive behaviors, development, nervous system, sensory system, and/or metabolism. Autism spectrum disorders, Down syndrome, and cerebral palsy are common types of IDD (National Institute of Health, 2003).

Intimacy
The feeling of being close, emotionally connected, and supported (State of Victoria, 2020). Intimacy is not limited to romantic partnerships and can be expressed emotionally, intellectually, spiritually, physically, etc. (Klausen, 2021).

Intimate Partner Relationships
"Engaging in activities to initiate and maintain a close relationship, including giving and receiving affection and interacting in desired roles. Intimate partners may or may not engage in sexual activity." (American Occupational Therapy Association, AOTA, 2020, p. 34).

Conservatorships
"When a judge appoints another person to act or make decisions for the person who needs help. Must be the least restrictive type of assistance needed to help a person lead a life of their choice." (Judicial Branch of California, 2023).

Let’s Talk About Relationships & Intimacy

Summary of the Problem:
The Persons with Developmental Disabilities Bill of Rights grants adults who have been diagnosed with IDD the right to make their own choices in their relationships (San Diego Regional Center [SDRC], n.d.-b). This bill of rights also outlines population members’ rights to dignity, social interaction, and community participation (SDRC, n.d.-b).

Unfortunately, adults with IDD encounter notable inequity when attempting to exercise these rights (Schmidt et al., 2020). This is because the population’s access to activities related to intimacy, intimate partner relationships, and opportunities for sexual expression has been significantly limited due to various societal, cultural, organizational, and familial barriers (Bethel et al., 2020).

“I think lots of people have stories about all of the barriers & how difficult & challenging it is... it doesn’t have to be challenging or hard. It can just be two people that love each other & that want to be together & have the support to be together.”

- Nicole

(BITTER ET AL., 2019)