Adults Aging with Developmental Disabilities, Perceptions of Health

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Presentation

- Literature / Background
- Study:  *Family Quality of Life In The Context of Aging & Intellectual Disability*
- Health-Related Findings
- Implications
- Conclusion
Literature / Background

- Adults with DD
  - 1st Cohort to Age in Significant Numbers
- Scant Canadian Research on this Group
- Other Countries
  - Leading Cause of Death - CVD
  - Some Age-related Changes
    - Syndrome Specific - Predominately DS
    - Associated Conditions
  - Little - Nutrition, Exercise, Health Promotion
REFERENCES


Family Quality of Life Study

Purpose:
To Explore & Describe Perceptions of FQoL Held by Older-Aged Family Members
- Age Criteria: Person with DD, 40+

Mixed Methods
- Interviews (19)
- Focus Groups (7)
- FQoL Survey (Brown, et al 2006) (26)
FQoL Study

Interviews / Focus Groups
- Past, Present, Future Hopes

FQoL Survey – Parents / Siblings
- 9 Domains across 6 Dimensions
  - Health - Importance, Opportunity, Initiative, Attainment, Stability, Satisfaction

Data Analysis
- Qualitative / Quantitative
- Synthesis of Findings
Participants (44)

20 Parents
  - 60-91 yrs; MA 76.7 (SD 8.80)

12 Siblings
  - 43-69 yrs; MA 54.4 (SD 8.10)

12 Adults with ID
  - 43-60 yrs, MA 49.6 (SD 4.98)

Living Arrangement
  - Separate/Together

Abilities & Service Use
  - Varied
Highlights of Health Findings

Health Considered Very Important

- Changes in health status changed family priorities / focus / arrangements
  
  "You know with my parents aging… the emphasis is almost turning towards them and their care and their concerns." JI3S

- Sudden Changes for Co-Resident Members

Adults with DD

- Array of Conditions
  
  "You know you don’t know how they age. He’s 50…” IIP1

- Basic Understanding of Health
FQoL – Health Findings

Reliance on Others

Adults with DD
- Relied on Family or Agency Staff (e.g. Access, Follow Up, Lifestyle Choices)

Parents / Siblings
- Provided Support
- Relied on Agency Staff to Monitor Health of Relative with DD
FQoL – Health Findings

- Need for Information
  - Family Members, Adults with DD, Agency Staff
- Access Issues
  - Repeat Visits
  - Unrecognized, Untreated Conditions
  - Dental Care
- Consent for Treatment
  - Air of Competence
- Advance Directives / Future Planning
FQoL – Health Findings

Sedentary Lifestyle / Lack of Exercise

“I have numerous times suggested that somebody should be making sure these people are getting adequate exercise.” (Sibling)

Nutrition

e.g. Fast Food; Processed / Canned

Medications

“The medication he’s on, he must have a stomach of iron. They don’t seem to bother him. He’s certainly on a lot.” (Sibling)
Implications for

- Policy, Practice, Research, & Education
- Family Physicians
  - Other Healthcare Professionals
- Agency Staff
- Become familiar with DD & age-related changes
- Promote good health & best practices
- Monitor health
- Support access & provide follow-up
Conclusion

“He just might outlive all of us, the whole family” IIP9

- Emerging Population
- Many Issues & Concerns
- Critical Need for Research in a Canadian Context
  - One possible Research Tool:
    Rochester Health Status Survey – IV.
    Davidson et al
    Used to determine & track health status and health care utilization of adults with I/DD
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