Siblings of Adults with Intellectual Disabilities: Their Perspectives on Guardianship and Its Alternatives



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I. Introduction

- Siblings of adults with intellectual disabilities (IDD) often take on guardianship & other caregiving roles when their parents pass away
- These siblings often report being underprepared and uninformed about ways to support their brothers and sisters with IDD
- This study explored:
- Siblings' knowledge of guardianship & its alternatives
- Siblings' perspectives & opinions of guardianship & its alternatives
- Siblings' perspectives on their role as a guardian or supported decision maker



II. Methods

- · Interviews with 10 adult siblings
 - 7 females, 3 males
 - Ages 20-68 years old
 - Brothers & sisters with IDD had co-occurring disabilities
- Analyzed using combination of grounded theory & directed analysis
 - All transcripts were doublecoded by two researchers
 - Member checking was done

III. Results

- Siblings had a limited knowledge of guardianship & its alternatives
 - More familiar with guardianship, but still some misconceptions
- Viewed guardianship as "absolutely necessary" and alternatives as not feasible
- Willingly accepted their role as a guardian
 - "I've always planned on it"



IV. Conclusions

- Implication for schools & service agencies to fully inform families
- Implication for training people with IDD & their families
- Implications for family planning & clearer communication
- Future Research:
 - Compare siblings' views from the same family
 - Compare perspectives of siblings & their brothers/ sisters with IDD
 - Explore results of training on family's guardianship choices



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