The Impact of Guardianship on the Rights of Adults with Developmental Disabilities: A Case Study

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Basic Human Rights

- Described by some as “needs” (Schultz, 1996)
- Include:
  - Welfare
    - physiological
    - safety
  - Independence
    - esteem
    - self actualization

* Maslow, 1943

Welfare needs must be fulfilled before independence needs

This framework of rights applies to all people, regardless of disability status
...special [needs] should not at all imply that human needs are higher or DIFFERENT for these individuals [with disabilities], but only the FACILITATION of their needs may demand difference... (Schultz, 1996, p. 277).
How Does Guardianship Facilitate Basic Human Rights?

• Welfare is safeguarded by guardianship
  “A court may appoint a guardian... only as necessary to promote and protect the well-being of the person.”

• Independence is fostered by guardianship
  “…the guardianship [shall] develop... independence in the incapacitated person.”

(Texas Probate Code, chapter 13, section 602)
A Legal Primer on Guardianship

• Types
  • Plenary or full guardianship
    • Guardian assumes the responsibility in all types of decision-making for the ward
  • Partial or limited guardianship
    • Guardian assumes some of these responsibilities

• Proceedings
  • Petitioner requests a guardian for the alleged ward
  • Proof to support guardianship is provided
## Legal Rights According to Texas Courts

<table>
<thead>
<tr>
<th>Getting married</th>
<th>Giving gifts</th>
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<tbody>
<tr>
<td>Entering a contract</td>
<td>Earning money</td>
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<tr>
<td>Choosing housing</td>
<td>Looking for a job</td>
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<tr>
<td>Choosing residential location, e.g. institution</td>
<td>Holding a job</td>
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<tr>
<td>Choosing to change residence, e.g. leaving an institution</td>
<td>Having a vocation</td>
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<td>Entering military service</td>
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Welfare Safeguarded

- Through removal of certain legal rights e.g. removal of the right to determine housing will prevent the ward from choosing unsafe housing.
Independence Fostered

• Through wards’ retention of certain legal rights
  e.g. Retaining the right to choose housing will allow the ward to decide independently where to live

• Legally
  • Independence required by Texas law for limited guardianship (TX probate code, ch. 13, section 602)

• In practice
  • Independence required in practice for both limited and full guardianship. (Missy Rainey, personal communication)
Research Need

• Potential threats to wards’ rights have already been studied (Millar, 2003; Payne-Christsiansen & Sitlington, 2008), e.g.
  • alternatives to full guardianship may not be considered
  • evidence may be insufficient
  • partial guardians may overstep authority
• There is a need for studies of guardianships in real-life contexts, to understand:
  - *why* guardianship decisions are made
  - *how* guardianship decisions are made
Strengths of Case Studies (Yin, 2003)

- Well suited to questions that ask “why” or “how”
- Deal with complex issues in context
- Consider multiple sources of information
- Answer some questions, while raising new questions and issues
Research Question

How does guardianship impact the rights of individuals with developmental disabilities?
A ward’s welfare and independence may be impacted by guardianship for reasons not yet considered in the literature
Unit of Analysis: Defining the Case

• One instance of guardianship, comprised of
  • guardian
  • ward
  • legal institution
Data Collection

• In-person *interview of guardian* (audio taped and transcribed)
• *Written questionnaire*
• Review of *court records* for guardianship proceedings
Participants

- Recruitment process
  - Contacts: employer with DSSW, ARC of Denton County, director and supervisor at SPHS clinic, an advocate…

- Nine potential participants
  - Seven declined to participate due to time constraints, content, and/or privacy concerns
  - Two agreed to participate.
    - 1. Companion care provider for adult with cerebral palsy; documentary film maker
    - 2. Former guardian of deceased ward; case over 20 years old
Anticipated Outcome

• Issues that impact wards’ rights may be uncovered, such as:
  • communication problems of ward or guardian
  • cultural background, especially regarding disabilities
  • attitudes toward people with disabilities
  • family income
  • educational and vocational backgrounds of guardian’s family
  • availability of guardianship training
  • availability of support services
  • personal health of guardian
  • etc
Dr. Olness, faculty mentor, utterly invaluable at each step
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