As people with intellectual disabilities assume greater integration within their communities, they are afforded expanded opportunities for decision-making. People with intellectual disabilities seek the counsel of significant others, family members, and friends, when making difficult and complex decisions about health care choices, including end-of-life care and decisions related to life-sustaining treatments. The overwhelming majority of people with intellectual disabilities have the capacity to make their own decisions.

Project Overview

The project included three major activities:

1. Conduct a qualitative research study to provide evidence of the ethical principles surrogate decision-makers apply when making end-of-life decisions for individuals with significant intellectual disabilities.

2. Conduct a guided interview: healthcare decision-making.

3. Complete the considerations for quality of life worksheet.

Significant Findings

- During the study, we found differing interpretations of the application of best interest standards, as well as concerns among disability advocates of how the standard is applied.

- Guardians felt less confidence and higher distress in end-of-life scenarios than in general health care decision-making, and relied significantly on medical team guidance.

The End-of-Life Decisions web resource, including Ethics Work-up & Case Analysis, Guided Interview: Healthcare Decision Making, Annotated Reference Guide, Guardianship Statutes in the States, Glossary, and Question and Answer pages. Our web resource is located at:

http://gucchd.georgetown.net/UCEDD/complex/index.html

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