

Complex Moral Issues: End-of-Life Decisions for Adults with Significant Intellectual Disabilities

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.

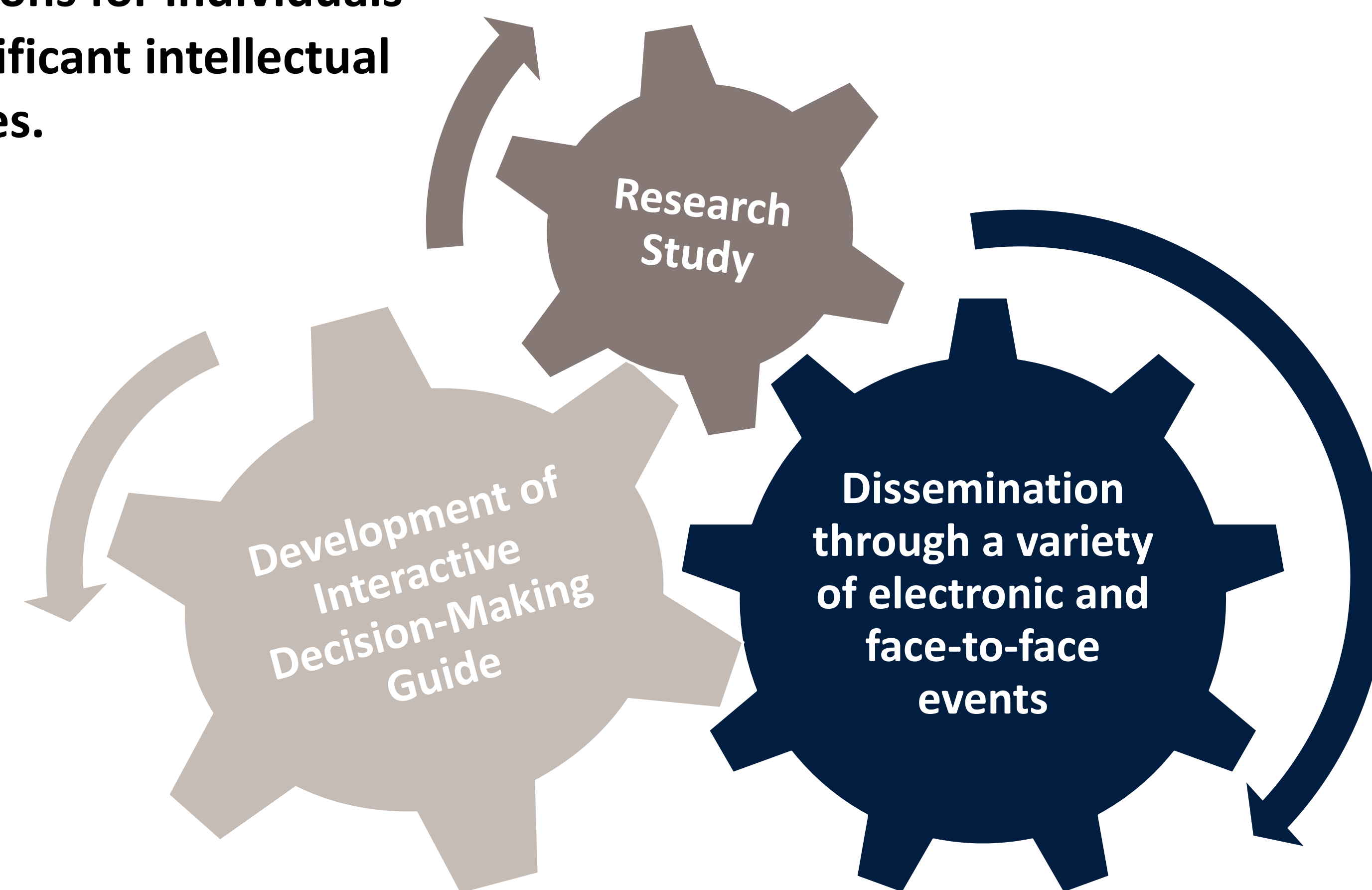
WHY....The End-of Life Project?

There are a small group of people with intellectual disabilities who have never been able to express their intentions about end-of-life care and life-sustaining treatments. This is due to the extent of their cognitive disability and concomitant restrictions upon their ability to communicate abstract and complex messages. Their guardians need clear information about how to make decisions on their behalf.

Project Overview

The project included Three Major activities:

We conducted 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.



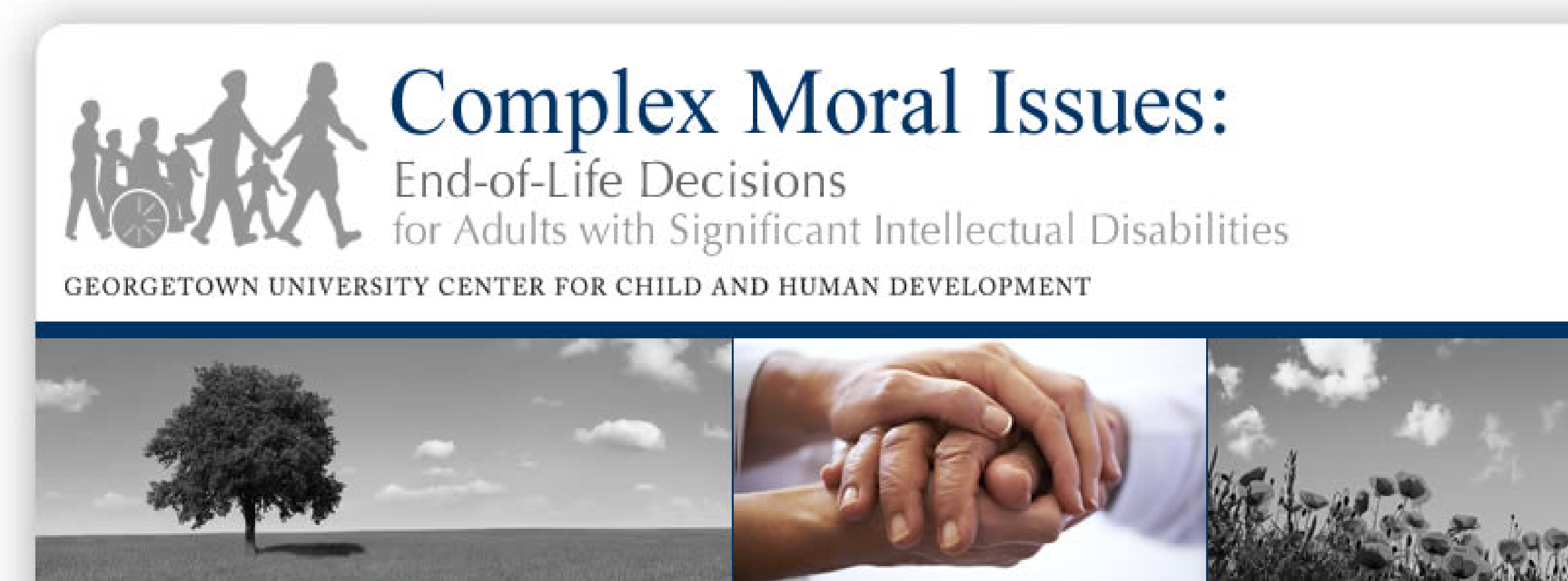
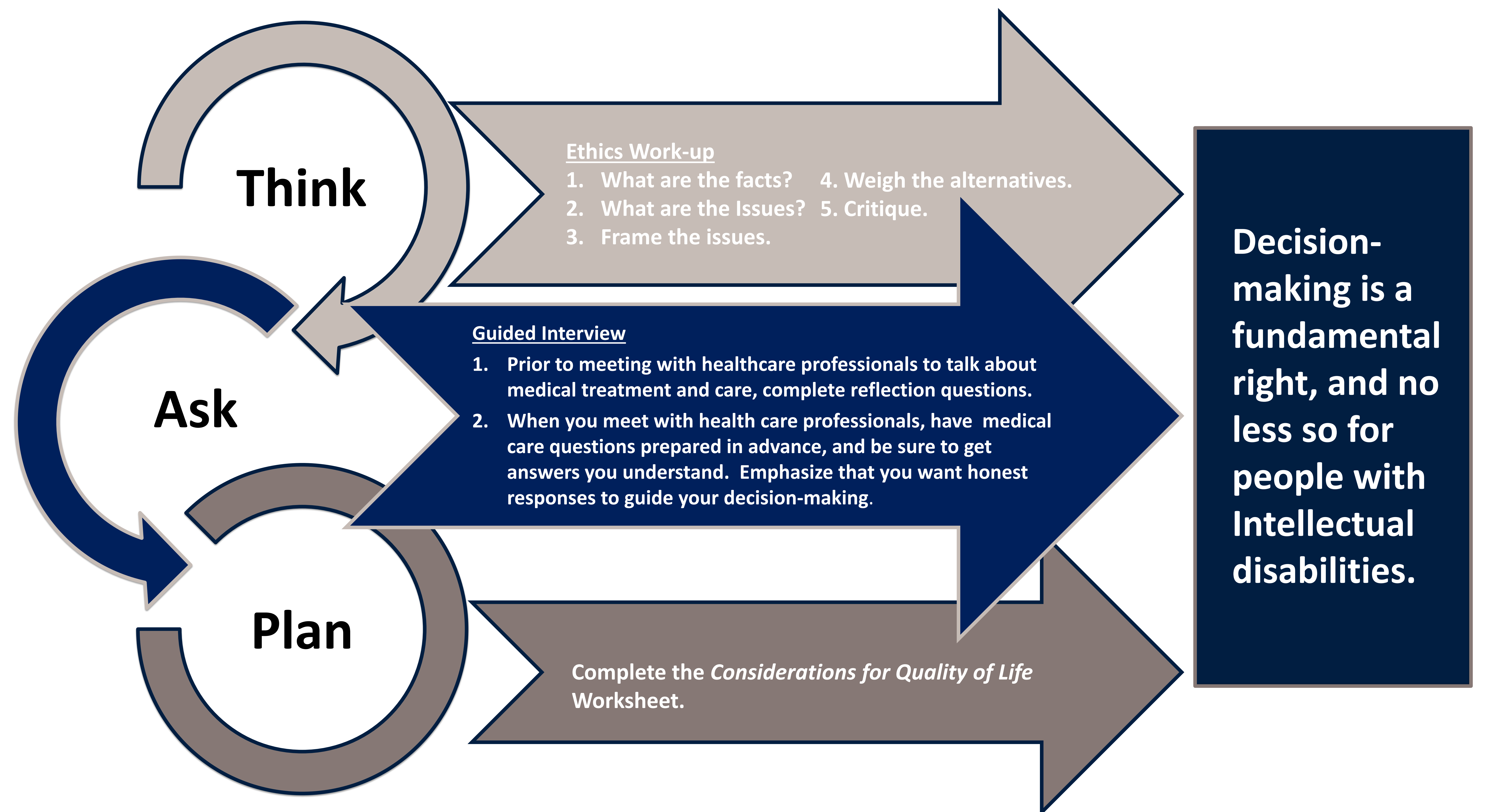
Two unique features of End-of-Life Decision-Making were explored:

- Complexity in identifying the best interest issue, and
- Developing an understanding of how these decisions are made.

Significant Findings

- During the study, we found differing interpretations of the application of best interest standard, 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.

FRAMEWORK FOR END-OF-LIFE DECISION-MAKING GUIDE FOR GUARDIANS



The End-of Life Decisions web resource, includes 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://gucchdgeorgetown.net/UCEDD/complex/index.html>

Partners



GEORGETOWN UNIVERSITY LAW CENTER

This work was supported by Georgetown University through a grant to the Georgetown University School of Nursing and Health Studies.