

## Paper Session C2: Ethical Aspects of Clinical Decision-Making

### *Creating Clinical Scenarios To Test Decisions Made By Proxies For Those With Intellectual Disability.*

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**Purpose:** The goal of this study was to create “real world” clinical scenarios for testing proxy decision-making in intellectual disability (ID) by community residential agency directors. It builds on the work of a statewide survey that identified information sources and decision factors in proxy healthcare decision-making.

**Background:** Individuals with ID are often dependent on others (i.e. proxies) for help with healthcare decision making. Their healthcare opportunities vary, and are often fewer compared to other populations. Evidenced based models that specifically address the decision making needs of those with ID are lacking, therefore our research team planned to develop testable clinical scenarios through focus group discussions with proxy decision makers in the community.

**Methods:** A qualitative exploratory design using four focus groups with 17 community agency directors across one mid-Atlantic state. Discussions were audiotaped, transcribed and systematically coded for themes using MAXQDA software for qualitative analysis.

**Results:** The following themes were identified: the process of decision-making is inclusive and takes time and effort; a knowledge gap among health care workers exists, there is a stigma attached to this diagnosis, and aging is an emerging concern. Two scenarios were created based on the identified concerns surrounding end of life decision-making, and access to healthcare services, specifically dental care.

**Conclusions:** The clinical scenarios created related to chronic problems in accessing dental care and services, and for the emerging concerns and needs related to end of life decision making. A knowledge gap among health care workers in relation to this vulnerable population as well as the stigma associated with the diagnosis which included a lack of sensitivity to their many physical and psychosocial needs was also identified.

**Implications and Policy Recommendations:** Data can inform policy especially in a group of people whose needs are hidden by stigma and a lack of sensitivity.