Title: Health Care Decision Making in Context: Who and How?

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Introduction: Individuals with IDD likely need supports in order to make informed health care decisions (Wong et al., 2000). This presentation will explore different models of shared health care decision making, including both advantages and disadvantages for professionals of including the individual with IDD as active participant in health care. Using survey and direct assessment data from studies in FXS, we will examine the concept of decisional capacity for health care decision making, areas of strengths and weaknesses in health care understanding and maintenance, and predictors of health autonomy.

Method: A survey of over 600 parents who have a child with FXS assessed health care autonomy. A total of 156 individuals with FXS (81 male, 75 female) completed a large battery of measures assessed decisional capacity (modified MacCAT), and areas associated with decision making including overall cognition (Stanford Binet, 5th edition), ability to understand written and oral information (Woodcock Johnson, 3rd edition), anxiety and ADHD symptoms (Anxiety, Depression, and Mood Scales and Symptom Inventories), appreciation and reasoning (Delis-Kaplan Executive Function System), verbal and visual memory (Wide Range Assessment of Memory and Learning), autism status (Autism Diagnostic Observation System and Social Communication Questionnaire), and adaptive behavior (Scales of Independent Behavior- Revised).

Results: Survey results suggest that only 35% of adults are able to communicate directly with their primary care provider without a caregiver present. Most (over 75%) of adults with FXS are able to describe symptoms if not feeling well, but fewer than 7% are able to independently seek medical attention when needed. Data also suggests that adults with FXS have a limited understanding of medications (31% have no understanding, 18% need a lot of help). Direct assessment data indicated that females with FXS had better decision making ability than males, but both groups improved with repeated exposure to information. Predictors of decision making included overall cognition ($\beta = 0.17$), oral comprehension ($\beta = 0.18$), social avoidance ($\beta = 0.17$), general anxiety ($\beta = -0.22$), executive functioning ($\beta = -0.49$), and social communication ($\beta = 0.08$).

Discussion: Practical as well as ethical, legal, and social implications of the informed health care decision making process for individuals with FXS will be discussed, including possible ways to support more informed decision making.

References/Citations: