

# Attitudes about the Levels of Input Adults with I/DD should have in Life-Course Decisions: Participatory Action Research in Rural Missouri

## Introduction

Participatory action research (PAR) provides a way for individuals with I/DD and their families to engage with their community, shape an agenda, and take action around issues that are important in their lives. Researchers involved with the National Training Initiative on Self-Determination had the opportunity to participate in a PAR project in the Spring of 2011 in Kirksville, Missouri.

## Research Problem

Adults with I/DD participated in self-advocacy training events. When they began using their new advocacy skills they received push back from some service providers. This prompted them, their family members, and some providers to ask: **What level of input do support providers believe I should have in decisions about my life?**

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## PAR Team

2 People with I/DD, 3 Family Members, 5 Support Providers, 2 University-Based Researchers

## Survey

The survey consisted of seven hypothesized domains (education, legal, relationships, daily living, health care, employment, and housing) and 38 questions. Each question reflected real experiences from the lives of PAR team members. The survey included a vignette about a young woman named Lisa. Her parents were trying to decide what level of guardianship, if any, they should have over Lisa's life. The person taking the survey is asked to help the parents make a decision by giving their opinion about the level of input Lisa should have in the life areas reflected in the 38 questions.

## Analysis

Exploratory Factor Analysis

## Results

Preliminary analyses of 133 responses reveal three predominant factors: Long-Term Decisions, Temporary / Day-to-Day, and Risky Behaviors.

### Long-Term Decisions (Medical & Financial):

The questions that best fit, statistically, in Factor 1 share a common theme of addressing broader adult-life decisions—specifically pertaining to medical and financial issues.

### Temporary / Day-to-Day Decisions:

These items address more short-term decisions such as altering one's clothing style or hair, who to socialize with, and changing jobs

## Results continued

### Risky Behaviors:

Several of these items involve decisions about issues typically considered risky, such as smoking or drinking, sexual relations and preferences, and living outside conventional social norms (such as on the streets).

### Actions

The action phase of the project has two components. First, the members of the PAR team reported the results of the survey to the organizations whose staff participated. The organizations as are currently using the results to identify training areas for support providers throughout their county. Second, the survey is now being used by organizations statewide as a pre- / post-training survey to measure impact.