



IASIDD 15TH WORLD CONGRESS
Global Partnerships: Enhancing Research, Policy and Practice
Melbourne 15-19 August 2016

Ethics and Human Rights Symposium on Supported Decision-Making

August 16, 2016 16:15 to 17:45

- 1. The US National Resource Center on Supported Decision-making: Assessment Development and Research in SDM**
Michael L. Wehmeyer & Karrie A. Shogren
- 2. Pioneering Supported Decision Making Practice in Australia**
Michelle Browning and Joanne Watson
- 3. Human Right to Legal Capacity: Respecting Autonomy and Providing Support**

Anna Arstein-Kerslake

**The National Resource
Center on Supported
Decision-Making: From
Theory to Practice**

*National
Resource Center
for Supported
Decision-Making*

*Tina Campanella
CEO, Quality
Trust*

*Principle
Investigator,
National
Resource Center
on Supported
Decision-Making*

NATIONAL RESOURCE CENTER ON SUPPORTED DECISION MAKING (SDM)

- Funded in 2014 by the Administration on Community Living
- Focused on Research, Training and Information Sharing about SDM
- Addressing the issues of people who are aging and people with disabilities
- Linking development and reform efforts throughout the country
- www.supporteddecisionmaking.org

MAJOR PARTNERS

- Burton Blatt Institute, Syracuse University
- Kansas University Center on Developmental Disabilities, University of Kansas
- Autistic Self Advocacy Network (ASAN)
- P2P USA/Family Voices
- ABA Commission on Law and Aging

SOME GOALS FOR THE PROJECT

- ▶ A national consensus on SDM
- ▶ Changing attitudes regarding decision making and capacity
- ▶ Local, State and National adoption of SDM as the preferred option for support
- ▶ Principles and tools for interdisciplinary support for across the lifespan with people of varying abilities, challenges and life situations.
- ▶ Increased collaboration and information sharing for implementing the principles of SDM.
- ▶ Availability of training and technical assistance network promoting practices consistent with SDM
- ▶ Development of assessments and supports to enable people with intellectual and developmental disabilities to maximally participate in the decision-making process

Assessment Development and Research in Supported Decision-Making

Karrie A. Shogren, Ph.D. (shogren@ku.edu)
Michael L. Wehmeyer, Ph.D. (wehmeyer@ku.edu)

Kansas University Center on Developmental Disabilities / Beach Center on
Disability, University of Kansas



Supported Decision-Making

- There is a need for frameworks that can be used, in practice, to promote the provision of supports for decision-making that enable people with disabilities to be agentic and maximally involved in decisions about their lives
 - Promotes self-determination and autonomy as well as, potentially, access to alternative legal arrangements

National Resource Center on Supported Decision-Making: ACL-funded Measurement Development

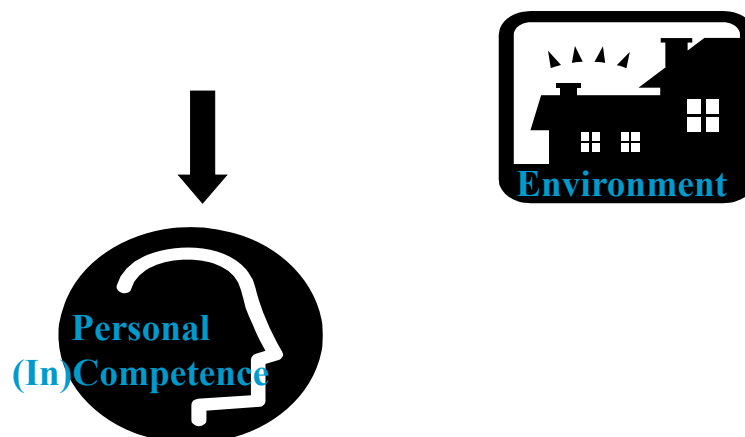
- Supported Decision Making Inventory System (SDMIS)
 1. Developing and piloting the SDMIS, which examines decision-making skills and abilities, environmental and decision contexts, and decision-making supports needed
 - a) Multistep process
 - Developed framework for measurement of supported decision-making
 - Conducted extensive literature review in three domains to be measured by the SDMIS (decision-making abilities, environmental demands for decision making, and supports needed for decision making).
 - Generated items/processes for assessment/measure
 - Pilot testing measure
 - Develop user's guide

A Framework for Research and Intervention Design in Supported Decision-Making

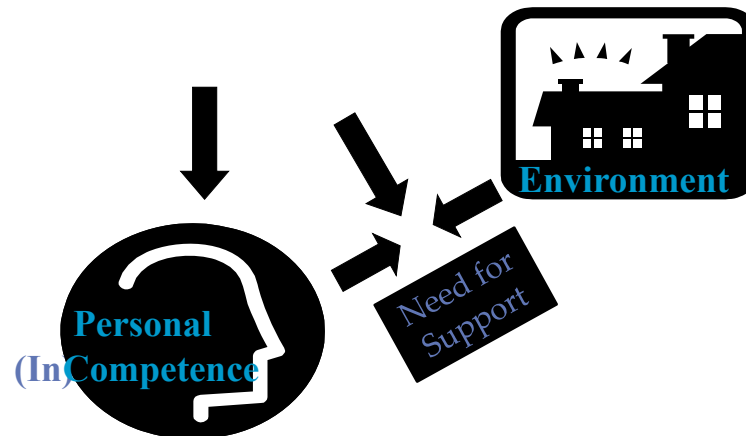
(Shogren & Wehmeyer, 2015)

- Three-pronged approach for designing assessments and interventions based on a social-ecological model of disability
 - Decision-making abilities
 - Environmental demands for decision making
 - Supports needed for decision making and factors that influence decision-making

Social-Ecological Understandings of Disability



Social-Ecological Understandings of Disability



Decision-Making Abilities

- Decision theorists define decision making as:
 - Choices among competing courses of action
 - Involves making judgement about which solution is best at a given time
- Steps to decision-making
 1. Identifying alternative courses of action
 2. Identifying the possible consequences of each action
 3. Assessing the probability of each consequence occurring
 4. Choosing the best alternative
 5. Implementing the decision

Environmental Demands for Decision-Making

- Understand the factors that impact decision making abilities and the demands of the environment for decision making (Shogren, Luckasson & Schalock, 2015)
 - Reviewed the literature to identify person and environmental factors that impacted decision-making
 - Identified key decision-making domains from the literature

Personal Factors	
Sociodemographic characteristics	Age, gender, education level, race/ethnicity, language
Decision-Making Experience	Exposure to previous decision-making opportunities, experience with previous interventions and outcomes
Disability characteristics	Cognitive functioning
Co-occurring conditions	Secondary medical conditions, medication side effects, behavioral support needs
Emotional factors	Perceived quality of life, level of stress, fear of making decisions, beliefs about decision-making capacity, concerns about impacting others
Environmental Factors	
Accessibility of information	Accessibility of information, manner of communication, complexity of intervention presented, time provided for communication, level of concreteness
Complexity of Decision	High vs. low stakes decisions, costs associated with recommendations, risk associated with decisions, timing of decisions (long term vs. crisis)
Relationships with Providers	Trust / existing relationship with medical or support provider, influence of support providers on decision-making (e.g., does the provider direct or facilitate)
Opportunities for Decision-Making	Degree to which personal preferences are respected in the environment, opportunity for choice in the environment, living in integrated settings (vs. congregate settings)
Family Attitudes about Decision-Making	Processes used by family of origin for making decisions, level of involvement of family in decision-making, attitudes toward decision-making of those with disabilities

Environmental Demands for Decision-Making

- Domains
 - Health
 - Financial
 - Legal
 - Relationships
 - Community Living
- Key Factors
 - Risk
 - Complexity
 - Opportunity

Needed Supports for Decision- Making

- Supports are defined as resources and strategies that enhance human functioning
 - Must be individualized and relate to specific need for supports
- To enable supported decision-making must create systems of supports that enable individualized supports for decision-making based on the needs of a person

Needed Supports for Decision-Making

- Reviewed the literature, focused on person-level supports for decision making
 - Communication and problem solving skills
 - Advocacy skills
 - Social networks
 - Person centered teams / planning
 - Decision making aids
 - Simplified info about medical decisions
 - Visual presentation of financial information

Supported Decision Making Inventory System

- Demographic Information
 - Are there any medical, behavioral, or other factors that may impact your decision making process?
 - Describe how decisions are typically made in your family / culture.
 - Who are the key people available to support you in making decisions?

Name	Relationship	How long have you known this person?	How often do you see this person?
1.			
2.			
3.			
4.			
5.			

Supported Decision Making Inventory System

- Section 1: SDM Personal Factors Inventory
 - Feelings
 - I feel like I am free to decide for myself how to live my life.
 - People in my life care about me.
 - Agency
 - I identify my preferences, interests, values, beliefs
 - I take action to achieve my goals
 - Experiences
 - To what degree have you had opportunities to be involved in decisions?
 - To what degree do you feel that you have been supported to successfully engage in the decision making process in the past?

Supported Decision Making Inventory System

- Section 2: SDM Environment
Demands Inventory
 - Environmental Domains
 - Health Relationships Financial
 - Legal Community Living
 - In **HEALTH** matters
 - To what degree are opportunities available for you to make high risk decisions?
 - To what degree are there supports available to enable you to make high risk decisions?
 - To what degree is accessible information available to you to make high risk decisions?

Supported Decision Making Inventory System

- Section 3: Decision Making
Autonomy Inventory
 - I know when a decision needs to be made.
 - Level of Autonomy (the degree to which you do this)
 - Level of Support Needed (the support you need to do this)
 - I know that decisions lead to achieving a goal.
 - Level of Autonomy (the degree to which you do this)
 - Level of Support Needed (the support you need to do this)

Supported Decision-Making: NIDILRR-funded Research

- Study 1: Examining Relationships Among Supported Decision Making, Self-Determination, and Outcomes
 - Explore the relationships among SDM, self-determination, choice opportunities, and satisfaction with life over time
 - Determine the personal (i.e., age, gender, disability type, level of support need, education status, employment status) and environmental factors (i.e., opportunities for choice, residential placement, and provider policies and practices regarding SDM) that mediate and moderate these relationships
 - Determine the personal and environmental factors that most strongly predict SDM and its effect on self-determination, choice opportunities, community living and participation, and satisfaction with life.

Supported Decision-Making: NIDILRR-funded Research

- Study 2: An Intervention Study and Evaluation of the Self-Determined Supported Decision Making Model.
 - Develop and evaluate the efficacy of an intervention, the *Self-Determined Decision Making Model* (SDDMM) to enable people to engage in self-regulated problem solving, goal setting, and goal attainment pertaining to making decisions in their lives.
 - Measure impacts on supported decision-making, self-determination, and outcomes