Health Equity for Individuals with Disabilities

A Webinar from APHA Disability Section hosted by AUCD
The Role of Health Professionals in the application of Supported Decision-making

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1. Quick Poll

How familiar are you with Supported Decision-making?

A. I have never heard of SDM
B. I have heard of it, but do not know what it is
C. I am familiar with SDM, but have not used it in practice
D. I am very familiar with SDM and use it in practice
2. Quick Poll

How do you identify?

A. Medical / nursing professional
B. Allied health provider
C. Public health professional
D. Other
SECTION 1

The Purpose
The Purpose

1. Supported Decision-making (SDM) is an emerging research area within the field of disability studies.

2. Guardianship has been the standard for decades, though the law advocates for the principle of least restriction and the presumption of capacity.

3. Even when a less restrictive support system is identified, other environmental and/or social barriers continue to prevent the actualization of self-determination.

4. These barriers exist within the healthcare setting because health professionals are unfamiliar with the application of SDM and their roles in the process.
Goals for Today

1. Define major concepts around Supported Decision-making (SDM)
2. Introduce SDM as an alternative to guardianship
3. Identify the roles and responsibilities of health professionals in the successful implementation of SDM
4. Identify the system of supports available for healthcare settings
SECTION 1

Concepts of SDM
What is Decision-making

• The process of making choices among competing courses of action.¹

• Common practice for everyone.
  • Do I want to brush my teeth this morning?
  • What treatment plan should I follow?

• Considering what is best for you at a given moment in time.²
  • Goal driven
  • Beliefs and values-based
Decision-making Capacity

• “The ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision.”

• Based on 4 legal markers:

  - Understand relevant information
  - Appreciate the situation
  - Reason about options
  - Communicate a choice
## Capacity and Competency

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Competency</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Ability to make a decision</td>
<td>• Legal right to make decisions</td>
</tr>
<tr>
<td>• Time and decision specific</td>
<td>• Legal judgement</td>
</tr>
<tr>
<td>• Medical assessment</td>
<td>• Informed by capacity assessment</td>
</tr>
</tbody>
</table>
The Action

1. In context of autonomy, action is the step that follows the decision.

2. Once you have control over both the decision and the action, you are considered to be self-determined.
Self-determination

The attitudes and abilities required to make one’s own decision and to act on that decision “free from undue external influence or interference”. 6(p. 305)
Current Problem

- Special populations with a perceived limited capacity for decision-making have fewer opportunities to become self-determined.  

- People with schizophrenia, severe mental illness, older adults, and people with intellectual and/or developmental disabilities (IDD) fall into this category

- Guardianship has been the standard for formalized support, providing protection but not promoting autonomy.

- United Nations convention on the rights of persons with disabilities promotes alternatives to guardianship
Spectrum of Support

- Independence (Least restrictive)
- Formalized Supported Decision-making
- Limited Guardianship
- Agency Agreements (POA)
- Guardianship⁹ (Most restrictive)
Spectrum of Support

- Independence (Least restrictive)
- Agency Agreements (POA)
- Limited Guardianship
- Guardianship⁹ (Most restrictive)
The Shift
Social-ecological Model of Disability

- Environmental and Social Constraints
- Personal Factors

Fit?
The Shift toward SDM

1. Decision-making
   - Presumption of capacity
   - Principle of least restriction
   - Support the individual’s goal

2. Person-centered planning / Patient-centered care

3. **Goal**: To the highest extent possible, provide people the opportunity to become self-determined
Supported Decision-making

“Giving people with disabilities the supports they need and want to understand the choices they face so they may make life decisions for themselves”.

8(p.10)
Supported Decision-making

• The person/agent always makes the final decision

• SDM has rarely been formally implemented. However, the ideals are imbedded within guardianship and other alternatives and can be thought of similarly.

Are they capable? → What supports are needed to make them so?
SDM in a Healthcare Setting
Roles of Health Professionals

1. All health professionals play a role
   - Assess and treat patients
   - Research
   - Health promotion interventions

2. Formally on an SDM team or helping to build the team

3. Medical professionals have the extra responsibility of implementing capacity assessments when needed\textsuperscript{13}
Capacity Assessment

1. The initial assessment is done with all patients but certain signs may indicate the need for a formal analysis

2. Interview or Objective Assessment
   - MacArthur Competence Assessment Tool (MAC), 30 min.
   - Aid to Capacity Evaluation (ACE), 5-10 minutes

3. If the person shows poor capacity for decision-making, SDM should be implemented. Time and decision-specific

4. Partnership with legal team may be necessary, but only if SDM is not formalized and all other efforts do not provide enough support.
Responsibilities for SDM

• Communication with person is imperative
  • Consider the person’s preferred communication approach
  • Consider the person’s preferred level of involvement in decision-making process

• Consider the person’s beliefs, values, and goals

• Engage the supports around the person (natural and formalized) to elevate the person in meeting the steps of the decision-making process

• The ultimate decision is up to the person
Steps in the Decision-making Process

1. Understand relevant information
2. Appreciate the situation
3. Reason about options
4. Communicate a choice
System of Support within a Healthcare Setting
Instruction

1. Education for the patient
   - In school
   - In the healthcare setting

2. Health education for other supports (family, direct support staff)
Environmental Arrangements

1. Opportunities for choice

2. Accessible health care
   - Physical building
   - Communication
   - Time

3. Assessing capacity

4. Shared decision-making
Positive Supports

1. Improved capacity and positive attitudes

2. Training of the health providers and professionals
   - Professional education
   - Continuing education
   - Experiential opportunities

3. Advocacy within professional groups
Recommendations & Limitations

1. This is not black and white

2. Still growing in knowledge, newer area of research

3. Must assess the person’s needs continually
   - Decision and time specific

4. Need research on the application of SDM in a healthcare setting. We can not work to improve the system until we understand better how this will work.
Resources

3. Quick Poll

I can describe my role and responsibility as a health provider in the supported decision-making process.

- I agree
- I somewhat agree
- I somewhat disagree
- I disagree
Thank You!

If you have questions or would like more resources,
contact Mackenzie Jones at mgj4@iu.edu
or visit iidc.Indiana.edu
National Overview – TPSID, ThinkCollege

TPSID = The Model Comprehensive Transition and Postsecondary Programs for Students with Intellectual Disabilities

The Think College National Coordinating Center provides support, coordination, training, and evaluation services for TPSIDs.
Local Level Overview:

**FIU Embrace**

- **Medical and legal services**
- **2 non-degree inclusive postsecondary programs**
  - LIFE students – 18-22 years
  - PLUS students - 23-26 years
  - Certificate of completion
- **Goals**
  - Young adults experience college courses and develop skills
  - Find competitive, integrated, and paid employment
  - Live independently
Research Shows

Those who attend a postsecondary institute:

- More likely to be employed (83%), compared to those with lower levels of education (38-58%).
- Average hourly wages higher at $12.50 per hour versus $9.80 per hour
- However, face greater challenges during transition
- Impact graduation rates
- Support mechanisms are needed
- Mentoring is one such support mechanism which can support students at a PSE
Mentoring movement has largely overlooked one key group: young Americans with disabilities.

Many types of programs to support needs of youth with disabilities, but few include mentoring components.
Potential Outcomes for Mentored Young Adults (Mentees)

- Interest in continuing education
- Interest in having a job/career
- Independent living skills
- Motivation and self-esteem
- Lower stress & anxiety
- Involvement in community and extracurricular activities
Research suggests that quality mentoring relationships are associated with both favorable objective and subjective outcomes, including increased:

- Career satisfaction
- Recognition
- Networking opportunities
- Satisfaction from helping others
Funder: Florida Consortium on Inclusive Higher Education

Innovation: First program of its kind! Faculty mentors and mentees receive 1) **targeted training** (and a certificate) and 2) students **provide and receive mentorship** simultaneously.

Three new programs: For faculty mentors, student mentees and peer mentors.
The Embrace Mentoring Program (EMP)

35 students
34 faculty and staff mentors
Our Hypotheses

1. Enhanced Mentor & Mentee Skills
   - 6 workshops across a 9-month academic year
   - Certificate of completion

2. Improved effectiveness in role
   - Weekly mentoring sessions

3. Improved Outcomes
   - Employment, anxiety, academic and self-competence
Program Expectations

- **Frequency and Duration of Meetings**
  - Meet once a week for at least 1 hour.

- **Scope**
  - Academic guidance, goal setting and alignment with *STAR PCP*.

- **Data Collection**
  - Complete Weekly Faculty Mentor Log by Friday each week.
  - Complete all surveys available via online links in a timely manner.

- **Workshops**
  - 6 total = Attend 3 in the Fall and 3 in the Spring.
STAR Person-Centered Planning

'S's STAR Chart

Career Development and Employment
Academic Enrichment
Community and Engagement
Self-Determination

Susan's STAR Chart

Career Development and Employment
Academic Enrichment
Community and Engagement
Self-Determination

Works hard
Artistic
Likes to travel
Organized
Athletic
Good cook
Helpful
Courteous
Sharing apartment with friend
Has significant other
Sings in choir
Has full time daycare job
Loves music
Beautiful voice
Willing to listen
Friendly
Loves kids
Self-Determination
<table>
<thead>
<tr>
<th>Workshop</th>
<th>Mentor</th>
<th>Mentee</th>
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<tbody>
<tr>
<td>Workshop 1</td>
<td>Orientation</td>
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<tr>
<td>Workshop 2</td>
<td>Program Basics</td>
<td>Program Basics</td>
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<tr>
<td>Workshop 3</td>
<td>Disability Awareness &amp; Skills for Effective Mentoring</td>
<td>Mentee Needs &amp; Plan</td>
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<tr>
<td>Workshop 4</td>
<td>Employment Support</td>
<td>Essential Mentee Skills</td>
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<tr>
<td>Workshop 5</td>
<td>Communication &amp; Consultation</td>
<td>Communication &amp; Consultation</td>
</tr>
<tr>
<td>Workshop 6</td>
<td>Closing Ceremony</td>
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1 Knowledge acquisition assessed with a pre-post survey after each workshop # 2-5
What does this picture make you think of?
Questions for the First Mentor-Mentee Meeting

How will we communicate between our weekly sessions?

What things will we discuss at every meeting?

How will we give each other feedback?

Discuss setting goals

Ask mentor/mentee what he/she would like to get out of the mentorship program and why they opted to participate
Ground Rules

- No texting
- No hugging
- Show up for all your meetings
- Keep your mentor informed about any scheduling changes
- Come prepared to share what you did during the week to meet your goals
- Stay professional and keep boundaries. Your mentor wants to help you but they are not your friend, buddy or family member.
Weekly Mentoring Sessions

- Work on goals identified in STAR PCP
- Identify tasks to complete by next week’s session
- Examples of activities: resumes, using/writing email, installing apps for time management and learning to use it

This step is assessed with a weekly log completed by mentor after meeting with student
Mentees complete these at the beginning and end of the academic year.
Results Obtained So Far

- Mentors - statistically significant improvement in knowledge related to *benefits* of being a mentor, understanding *scope* of the program and *FERPA* obligations.

- Mentee - highlight *challenges* to assess levels of knowledge acquisition
Many parents and students have shared positive feedback about the support received from faculty and staff mentors.

Mentors enjoy discussing ideas of what is working with their student. Allows sharing of new ideas and opportunities.
- Involvement and contact between all key players in student’s life
- Examples of activities/skills to work on in meetings together
- Change how pre-post tests are conducted
- Possibly offer webinar sessions of workshops for mentors
- Roll-out of Peer Mentor Program fall 2019
Thank You!
Questions?
Assessment Practices and Care Continuity in Hospital-Based Treatment for Individuals with Intellectual and Developmental Disabilities
Context for this project

- American Dental Association Institute for Diversity in Leadership
Challenges with Dental Care

- Quality Care
- Comprehensive Care
- Care Continuity
Access to Care

“Set of dimensions describing the fit between the patient and the healthcare system”
—Penchansky and Thomas, 1981
Demand for Care

• Medical → Social Model of Care
Workforce Supply

- Specialty training
- Accreditation standards
- Continuing Education requirements
Today’s Equilibrium

- Gaps in training + changing demand = lack of quality and continuity in comprehensive dental care
Toward a better balance

- Assessment and treatment guidelines
- Interdisciplinary standards of care
- Referrals
- Continuity for comprehensive care
Starting where we are

- What are existing assessment and treatment protocols?

- Survey
- Interviews
Survey Results—Respondents

- 67 respondents from USA and Canada
- 33 Male and 34 Female
- Normal distribution from age 20-80 years
Survey Results—Training/Work

- Majority with training in Pediatric Dentistry or an hospital-based general dental program
- Mixture of academic and private practice work settings
Survey Results—Care Frequency

- 65% see I/IDD at least daily
- 24% see I/IDD at least weekly
- 8% see I/IDD at least monthly
- 3% see I/IDD at least yearly
Survey Results—Referral Sources

- Referred from general dentist (26%), primary care provider (26%), pediatric dentist (18%), specialty clinic (17%), and other sources (13%)
Survey Results—Assessment Tools

• 72% do not use any kind of behavioral assessment instrument to determine need for sedation
• 28% do use a consistent assessment
More than half require attendance of consultation, treatment, follow-up/post-op, and routine recall appointments.
Survey Results—Sedation

- Treatment—33%
- Routine recall—25%
- Consultation 17%
- Post-op/follow-up—13%
- Other—12%
Survey Results — Assessment Visit

- Consultation — 31%
- Routine recall — 27%
- Treatment — 23%
- Post-op/follow-up — 15%
- Other — 5%
Survey Results—Post-Treatment

- Establish as patient of record—72%
- Other—19%
- Send back to referring dentist—8%
- No action—2%
Survey Results—Payment

- Medicaid—30%
- Out of pocket—24%
- Private insurance—21%
- Medicare—14%
- Other—11%
Survey Results—Pre-Authorization

- Consultation—44%
- Routine recall—21%
- Treatment—18%
- Post-op/follow-up—11%
- Other—6%
Survey Results—Pre-Assessment

- Consultation—47%  (+3)
- Treatment—19%  (+1)
- Routine recall—19%  (-2)
- Post-op/follow-up—12%  (+1)
- Other—4%  (-2)
Interviews on Best Practices

- 34 individuals agreed to be interviewed
- 18 individuals participated in full interview
Key Emergent Themes

- Objective vs subjective information
- Utility of tool for referral and continuity
- Universal template with adaptable sections
- Importance of checklist
- Accessible overview
Implications for Health Equity

“Set of dimensions describing the fit between the patient and the healthcare system”

—Penchansky and Thomas, 1981
Questions or comments?

- Join the effort!
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Thank you!
Interested in Participating in Future Webinars? Contact us at:

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