



*Beyond Childhood:
College, Careers, and Relationships
for Adolescents and Adults with
Developmental Disabilities*



Creating a Medical Home - Ideas for Person-Centered Care

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Project Disclosure Statement

- ▶ We have no affiliation or financial interest related to the content of this activity.





Mitigating Potential Bias

- ▶ The information and recommendations involving clinical medicine is based on evidence that is currently accepted within the profession

Person-Centered Medical Home (PCMH)

What is it?

The medical home model holds promise as a way to improve health care in America by transforming how primary care is organized and delivered.

5 functions and attributes of the PCMH:

1. Comprehensive Care
2. **Patient-Centered**
3. Coordinated Care
4. Accessible Service
5. Quality and Safety





Objectives



1. Discuss barriers for persons with IDD transitioning from pediatric to adult health care
2. Define Shared Decision Making (SDM) and some tools to support SDM.
3. Know resources to inform evidence-based practice for caring for persons with IDD in primary care



Objective 1: Let's Talk about Barriers

- ▶ What is the evidence for disparity for persons with disabilities?
- ▶ What are the barriers to health care for individuals with disabilities
- ▶ What is the Disability Rights Movement - and what does it have to do with health care?

Disability ≠ Poor Health, But Disparities Are Large

Measure	Americans with disabilities	Americans without disabilities
Fair or poor self-rated health	41.7%	8.7%
14 or more physically unhealthy days in the past 30 days	31.5%	4.8%
14 or more mentally unhealthy days in the past 30 days	31.7%	6.3%

Measure	Kansans with disabilities	Kansans without disabilities
Fair or poor self-rated health	42.7%	7.7%
14 or more physically unhealthy days in the past 30 days	33.1%	4.3%
14 or more mentally unhealthy days in the past 30 days	27.2%	6.0%

Sources: Centers for Disease Control and Prevention, Disability & Health Data System (DHDS). 2017. URL: <https://www.cdc.gov/ncbddd/disabilityandhealth/dhds.html> and 2017 Kansas BRFSS, <http://www.kdheks.gov/brfss/Survey2017/DataTableList2017.htm>

Disease Prevalence

Condition	Kansans with disabilities	Kansans without disabilities
Stroke	7.4%	1.4%
Heart Attack	9.2%	2.4%
High cholesterol	47.3%	29.7%
Hypertension	51.1%	26.7%
Asthma	16.2%	6.7%
Diabetes	21.4%	6.8%
Depression	42.1%	4.0%

Source: 2017 Kansas BRFSS, <http://www.kdheks.gov/brfss/Survey2017/DataTableList2017.htm>



Barriers to Health for People with Disabilities

- In addition to barriers experienced by nondisabled people, those with disabilities experience other barriers:
 - Environmental
 - Lack of facilities that meet accessibility guidelines
 - Lack of affordable and accessible transportation
 - Lack of knowledgeable professionals
 - Lack of financial resources
 - Programmatic
 - Lack of sufficient appointment times that do not accommodate
 - Online systems that are not accessible
 - Attitudinal
 - Belief that people with disabilities cannot be healthy

The Disability Rights Movement

- Replaces previous models of disability with the civil rights and the social models
- Seeks to level the playing field
- Unites disability constituencies to address common concern: discrimination
- Works to institute public policy and legislation that removes barriers



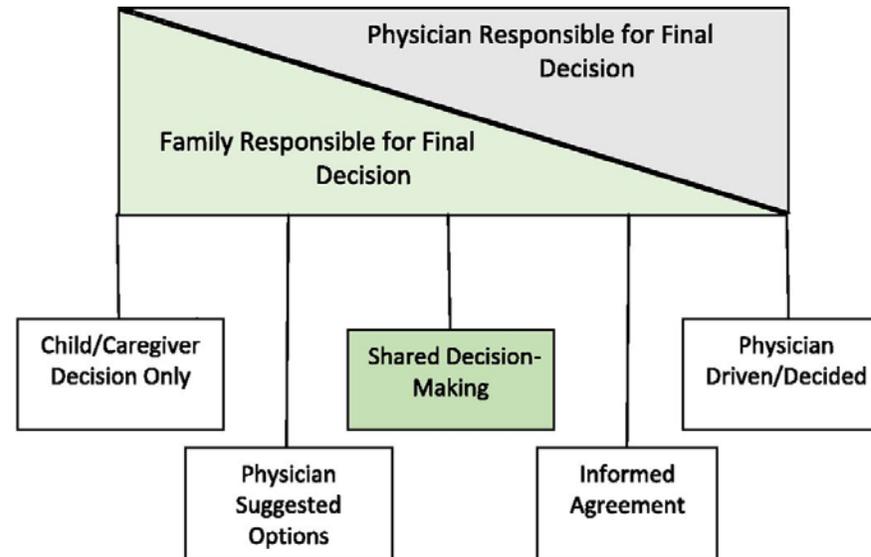


Social vs Medical Model (More on this later)

- The social model of disability proposes that what makes someone “disabled” is not their medical condition, but the attitudes and structures of society.
- Disability does not need to be “fixed;” instead, physical and social barriers need to be addressed.
- Barriers accessing health care and physical activity are among the many that people with disabilities may encounter.
- Other barriers include lower income, lower educational levels, and lower employment levels.

Objective 2: What is Shared Decision Making?

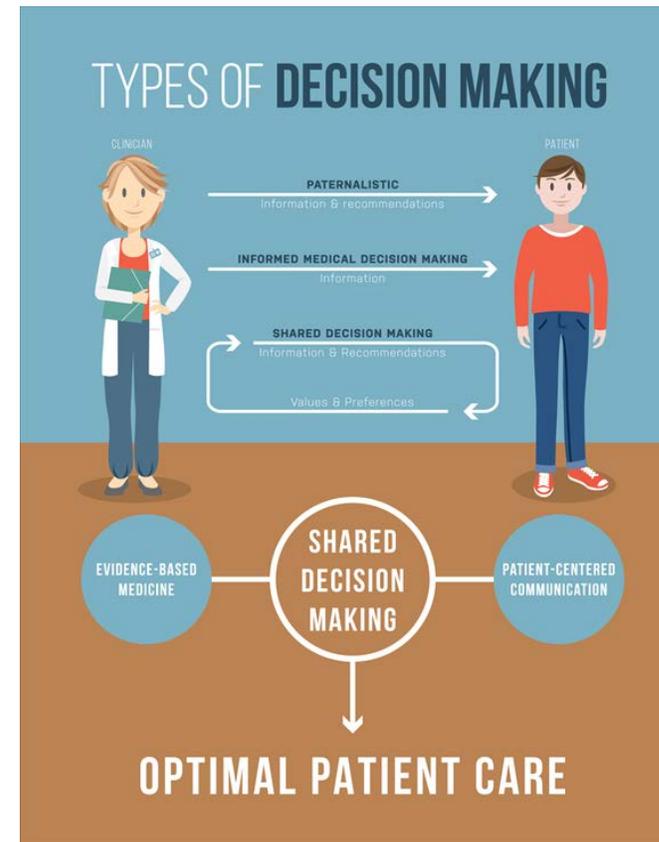
- ▶ What is the definition of Shared Decision Making?
- ▶ What is the history of Shared Decision Making in healthcare in the United States?
- ▶ What are the barriers to Shared Decision Making for persons with IDD?



(Consumerism) ← **Autonomy** ← ----- → **Beneficence** → (Paternalism)

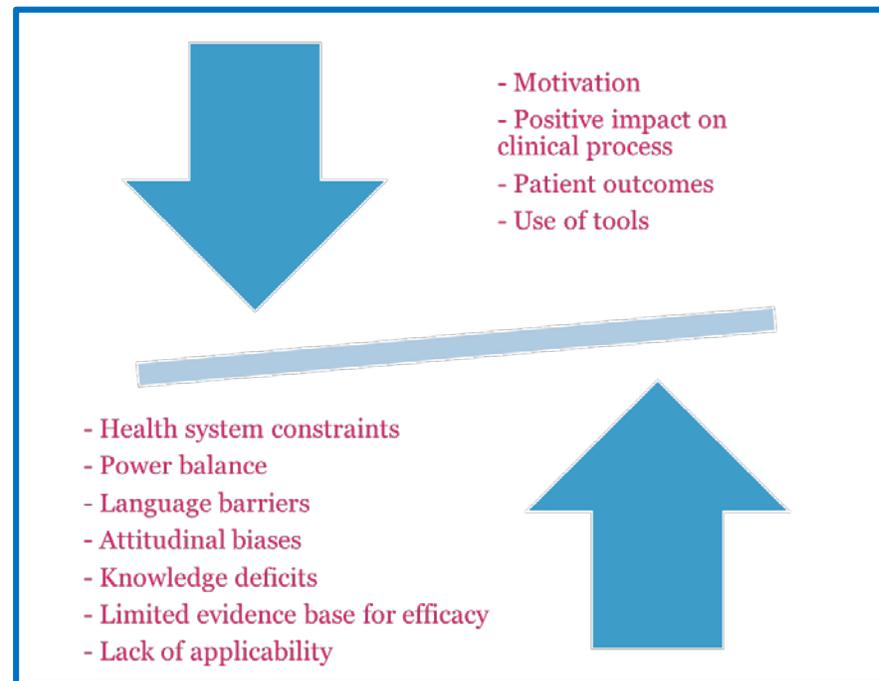
Definition of SDM:

- ▶ Shared decision making is a key component of patient- centered **health care**.
- ▶ It is a process in which clinicians and patients work together to make **decisions** and select tests, treatments and care plans based on clinical evidence
- ▶ that balances risks and expected outcomes with patient preferences and values.



Barriers to SDM for persons with IDD

- ▶ Provider Knowledge
- ▶ Health System Constraints
- ▶ Family Issues
- ▶ Complexity of IDD





AUCD's H.E.A.T. Initiative

- ▶ Although 20% of adults in the US have a disability, with 1 in 6+ having DD, there is currently no training standard on DD for physicians at all levels of training.
- ▶ The AUCD's Keep the HEAT On (Health is for Everyone Action Team) builds on successful adoption of the American Medical Association's (AMA) resolution to include education about the unique needs of people with Developmental Disabilities (DD) at undergraduate, graduate and continuing medical education for physicians.
- ▶ Keep the HEAT On will be a second phase of a multiyear effort to better understand DD competency in medical education, learning from previous efforts, and linking these learnings into a shared action plan to include DD in medical education.



Objective 3: Resources to help!

- ▶ Review the 2018 Canadian Consensus Guidelines for Primary Care of Adults with Intellectual and Developmental Disabilities
- ▶ Explore the IDD Toolkit (www.iddtoolkit.org) and some tools to address barriers in primary care

Canadian consensus guidelines - 2018

- ▶ Update on 2011 Canadian consensus guidelines
- ▶ Systematic review and update with 45 primary care providers from urban and rural areas across Canada
- ▶ Notes the change in focus in family medicine from approaches to care based exclusively on the medical model of disability...to approaches that incorporate insights from the social model of disability.
- ▶ Tools in the IDD Toolkit were developed in Canada to complement these Consensus guidelines.



The IDD Toolkit

www.IDDtoolkit.org

- ▶ General issues
- ▶ Physical health
- ▶ Health watch tables
- ▶ Behavior and mental health issues



References and Resources

- ▶ Sullivan WF, Diepstra H, Heng J, Ally S, Bradley E et al. Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines. *Canadian Family Physician*. Vol 64: April 2018, pp. 254 - 278.
- ▶ Adams RC, Levy SR, COUNCIL ON CHILDREN WITH DISABILITIES. Shared Decision-Making and Children with Disabilities: Pathways to Consensus. *Pediatrics*. 2017; 139 (6): e20170956.
- ▶ <https://pcmh.ahrq.gov/page/defining-pcmh>
- ▶ www.IDDtoolkit.org



Thank You

