

Starfield Summit II: Health Equity Summit
Curriculum Toolkit

People with Disabilities (Developmental and Intellectual)

IGNITE Presentation by William Schwab, MD

Module by Sarah Davis, JD, MPA, Jennifer Edgoose, MD, MPH, Ronya Green, MD

Appropriate Audience: all learners

Related modules:

- Understanding Health Experiences and Values to Address Social Determinants of Health
- Identifying and Addressing Patients' Social and Economic Needs in the Context of Clinical Care
- Intersectionality: —The Interconnectedness of Class, Gender, Race and other Types of Vulnerability

Learning Objectives

After participating in this learning module, the participant will be able to:

1. Understand how individuals with developmental and/or intellectual disabilities (DD/ID) experience amplified disparities.
2. Identify barriers to providing high quality medical care for individuals with DD/ID, and responses.
3. Appreciate how obtaining officially recognized classification can promote advocacy for at-risk populations.

Background

People who have developmental and intellectual disabilities (DD/ID) are a unique and medically distinct population who have both the right and natural inclination to live in typical settings in the community. While they may have financial access to medical resources through government payers, that access is limited by physical, linguistic, cultural, and administrative barriers and the content of care received is adversely impacted by deficits in attitudes, skills, and knowledge among health care professionals.¹

Most people with DD/ID rely on others for assistance with daily activities, so the quality, configuration, and funding of the broader service system is a critical element of health and wellbeing. People with DD/ID rank high in poverty, unemployment, social isolation, and other health determinants. Race and ethnicity amplify some disparities. The home care workers who

Updated August 2, 2018

support them on a daily basis are also low income and disproportionately people of color and foreign-born US citizens.

People with DD/ID constitute 2% of the US population, but many of the factors that affect their health are generalizable to the health status of people who have acquired disabilities caused by the effects of chronic illness, injury, aging, and other factors, which represents 19% of the US population. This population also experiences significant disparities.

Ignite Video

Please follow the link below to view the full lecture given by Dr. Schwab (8min):

<https://www.youtube.com/watch?v=xVx8d3ne9bw>

Accompanying Slides

<https://static1.squarespace.com/static/56bb9997746fb9d2b5c70970/t/594976d51b10e371ac6f00d/1497986780594/2.2+Schwab+Presentation.pdf>

Possible Questions for Group Discussion

After watching the lecture, consider splitting your learners into smaller groups and facilitate discussion on the following questions. Consider handing out the concise American Academy of Developmental Medicine and Dentistry (AADMD) Health Disparities Consensus Statement (described on page 3) to guide discussion.

1. How might a person with an intellectual or developmental disability view health? In what ways might their preferences for health care differ from traditional care delivery?
2. What resources are available that can support a person with a disability in fulfilling their health goals?
3. What is the role of the person's advocate/attendee (family member, guardian, power of attorney for healthcare, home care worker, or social worker) in fulfilling health goals, and what might you consider when working with the advocate?
4. What are the barriers in our practice to providing care to patients with intellectual/developmental disabilities? Which of these barriers can we improve upon to meet the medical needs of this population?
5. What are the "right" indicators of health outcomes for people with intellectual/developmental disabilities?
6. What are the advantages to being classified as a "health disparities target group"?
7. Should individuals with intellectual/developmental disabilities be classified as a medically underserved population (MUP)?

Applying an Equity Lens in Professional Practice

As you reflect on the material in this module, consider how you will apply it in your professional practice by asking questions based upon the Equity and Empowerment Lens' 5Ps:

Purpose: What is my purpose towards considering individuals with DD/ID? What could you do differently? Propose an intervention.

People: How will communities with DD/ID be affected if I apply my intervention? Are their sub-groups of people with DD/ID who might be left out?

Place: As you probe for patients' priorities (patient-centered outcomes) how will you ensure individual patient's emotional safety?

Process: Are there empowering processes at every human touchpoint of your intervention for people with DD/ID?

Power: Who is accountable in your organization to ensure that people with DD/ID are included in development of interventions?

For more in depth discussion refer to:

- Havercamp SM, Scott HM. National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disabil Health J.* 2015 Apr;8(2):165-72.
 - This study compared the health of US adults with no disability to adults with intellectual and developmental disability and outlines significant disparities in health status, health risks and preventative health care.
- Health Disparities Consensus Statement. American Academy of Developmental Medicine and Dentistry (AADMD) website. <https://aadmd.org/articles/health-disparities-consensus-statement>. Accessed August 2, 2018.
 - This consensus statement was proposed by the AADMD to address health disparities for persons with neurodevelopmental disorders and intellectual disabilities.
- Bradley V. Exploring Health Disparities Among People with Intellectual and Developmental Disabilities. What Are the Issues and Do Race and Ethnicity Play a Role? Lecture presented at: National Association of State Directors of Developmental Disabilities Services Annual Meeting; November 13, 2014; Alexandria, VA. http://www.nationalcoreindicators.org/upload/presentation/FINAL_NASDDDS_2014_Health_Disparities.pdf. Accessed August 2, 2018.
 - This PowerPoint outlines the significant health and health care disparities experienced by individuals with DD/ID and advocates for their inclusion as a federally recognized medically underserved population.

Resources for further exploration:

Macro: In Health Care Transformation

- Statement from Robert Wood Johnson Foundation President and CEO Richard Besser, MD, on Potential Impact of the Graham-Cassidy-Heller-Johnson Legislation. Robert Wood Johnson Foundation website. <https://www.rwjf.org/en/library/articles-and-news/2017/09/statement-from-richard-besser-on-impact-of-graham-cassidy-bill.html>. Published September 21, 2017. Accessed August 2, 2018.
 - In proposals to dismantle the Affordable Care Act, consider the impact of eliminating important protections for those with pre-existing health conditions.

Meso: In Quality Improvement

Updated August 2, 2018

- Health Care For Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers Available at: <https://vkc.mc.vanderbilt.edu/etoolkit/>. Accessed August 2, 2018.
 - This toolkit provides a wealth of information to inform more intentional practices and policies by primary care clinicians to support people with DD/ID and their families.

Micro: In Clinical Encounters- Shared Decision Making

- Institute for Patient- and Family-Centered Care website. <http://www.ipfcc.org/>. Accessed August 2, 2018.
 - IPFCC “advances the understanding and practice of patient- and family-centered care. In partnership with patients, families, and health care professionals, IPFCC seeks to integrate these concepts into all aspects of health care.”

Words and Concepts Used in this Module that are Defined in the Guidebook

- Disability
- Developmental Disabilities
- Disparities (see Health Disparities)
- Health Disparity Populations
- Health Equity
- Intellectual Disabilities
- Medically Underserved Populations

References

1. US Home Care Workers: Key Facts. Paraprofessional Healthcare Institute (PHI) website. <https://phinational.org/sites/phinational.org/files/phi-home-care-workers-key-facts.pdf> Published 2017. Accessed September 26, 2018.

Module Writer

Jennifer Edgoose, MD, MPH

Department of Family Medicine and Community Health

University of Wisconsin School of Medicine and Public Health

Madison, WI

Copyright © 2018

Board of Regents of the University of Wisconsin System

University of Wisconsin School of Medicine and Public Health

This work is licensed under the Creative Commons Attribution-NonCommercial 4.0 International License.

To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc/4.0/>