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Advancing Care Excellence for Persons With Disabilities

Intellectual and Developmental Disability:
A Toolkit to Enhance Education of Health Care Professionals to Provide Quality Health Care to Persons With IDD

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Acknowledgments

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Introduction to Modules on Intellectual and Developmental Disability

This series of modules on intellectual and developmental disability (IDD) was developed as part of a project funded by the Administration for Community Living (ACL): *Partnering to Transform Health Outcomes with Persons with Intellectual and Developmental Disabilities* (PATH-PWIDD). The goals of the PATH-PWIDD project, which involves five universities, are the development, dissemination, and evaluation of high-impact interprofessional curricular materials and learning experiences for students across the health care disciplines. The impetus for the ACL grant is the lack of adequate education and training of health care professionals to provide quality health care to persons with IDD and the resulting inequities in health and health care experienced by many of the 7-8 million people in the United States with IDD.

These brief modules are designed to provide health care professionals, students in health care professions educational programs and their faculty members, clinicians, and others with basic but important information about IDD. The modules are ***not*** intended to be an exhaustive description of disabling conditions, that is, those disorders that result in IDD for affected persons. Rather, the modules focus on the effects of IDD on the lives, health, and health care of persons with IDD. One can know a great deal about disabling conditions but have little knowledge of or appreciation for the impact of the resulting disability on the lives, experiences, well-being, health, and health care of those affected. Biases on the part of health care professionals and students about persons with disability, including IDD, and their quality of life continue to be reported and identified as responsible, in part, for poor quality health care for the IDD population.

The following six modules comprise the series of modules on IDD developed by Villanova University M. Louise Fitzpatrick College of Nursing faculty to address the ACL project goals. The content of the modules is ***not*** limited to nursing specifically but focuses on health and health issues of persons with IDD of importance to professionals across the health care disciplines. Each module begins with an introduction to the topic and uses examples to illustrate the points in the module. Although the sequence in which these modules are reviewed is arbitrary and up to the reader, the author believes the sequence below is ideal.

- Communicating With Persons With Intellectual and Developmental Disability
- Attitudes, Bias, Ableism, and Stereotyping
- Social Determinants of Health, Intersectionality, and Models of Disability
- Intellectual and Developmental Disability – Part I: What It Is
- Intellectual and Developmental Disability – Part II: Select Health-Related Issues
- Important Differences Between Intellectual Disability and Autism Spectrum Disorder

We welcome feedback and comment on the modules; if you have feedback or comments to share, please contact Suzanne C. Smeltzer at **Suzanne.smeltzer@villanova.edu**.

Module 1

Communicating With People With Intellectual and Developmental Disability

Objectives:

At the end of this module, the learner will be able to:

- describe the importance of communication strategies to the care of individuals with intellectual and developmental disability (IDD).
- identify strategies to communicate with individuals with various types of disabilities and alternate approaches if needed.
- describe the communication-related rights of individuals regardless of the presence of a disability or its severity.

Introduction

As every health care professional knows, communication is essential to the accurate assessment, diagnosis, care, and treatment of all individuals seeking or receiving health care. Verbal and nonverbal communication is a *major* component of human interaction. It is of great importance in those circumstances in which health care professionals and people with intellectual, cognitive, or communication disability want or need to share information about the person's health, well-being, and health care. This module addresses the importance of communication in interacting with people with IDD, strategies to communicate effectively with them, and the communication rights of people with disabilities.

Overview

Failure of health care professionals to communicate effectively and appropriately with people with disabilities has been identified repeatedly as a major barrier to quality health care for this population (National Council on Disability, 2022; World Health Organization, 2011). Failure to communicate effectively with people with intellectual, cognitive, or communication disabilities can result in failure to identify and address health issues of concern to them, errors in diagnosis and treatment, errors and omissions in care, and, ultimately, inadequate health care and poor health status. Additionally, failure to communicate effectively may result in the person with a disability feeling ignored, excluded, and disrespected.

It is important to keep in mind that the inability of people with intellectual, developmental, cognitive, or communication disabilities to respond does not mean that they do not or cannot hear or understand what you are saying. Therefore, it is important to avoid saying anything that you would not want the person to hear and understand. Often individuals with these disabilities can understand more easily what is being communicated to them than they can respond and express themselves. It is also important to keep in mind that an individual may have other types of disability, such as psychiatric/mental health, physical, hearing, or visual disability. Therefore, these types of disability also need to be considered when determining and using communication approaches with persons with IDD and any other disability.

General Recommendations for Communicating With All Persons With Disabilities.

Before discussing recommendations for communication with individuals with intellectual, developmental, cognitive, or communication disabilities, it is important to consider and review general recommendations for communicating with *all* people with disabilities. The following recommendations, although they seem basic and obvious, are often not followed, something that is evident when people with a disability describe their interactions with health care providers. In fact, ineffective communication with and by health care clinicians is one of the most common barriers to quality health care identified by people with disabilities seeking care.

- Talk with people with a disability in the same way, and with a normal tone of voice (not shouting), as you would talk with anyone else.
- Talk to people with a disability as adults and talk to them directly, rather than to an accompanying person.
- Although there may be unusual circumstances when it is necessary to ask an accompanying person about an issue experienced by the person with a disability, this should be done *very rarely*, and the information should be confirmed with the person with a disability. If it is necessary to communicate with the accompanying person, ask what method the person with the disability uses to communicate and then use that method.
- When talking to someone with vision impairment, avoid being self-conscious about your use of wording such as "Do you see what I mean?".
- Ask the person with a disability if assistance is needed; do not assume that help is needed until you ask.
- Use "people-first language": that is, refer to "a person with a disability" rather than "the disabled person" or "the disabled." (Note that recently, there has been a change in how some people with disabilities prefer to be described. Some prefer to be referred to as "a disabled person," which puts the fact that the person has a disability up front and does not avoid *disability* as a negative term. This is referred to as "disability-first language" or "identity-first language." Because of these changes, it is always appropriate to ask what term the person with a disability prefers.)
- When communicating with someone with a disability, it is important to take steps to ensure that effective communication strategies are used. This includes sitting or standing at eye level with the person and making appropriate eye contact.

Strategies to Communicate With Persons with IDD, Cognitive, and Communication Disabilities

In addition to the above general recommendations for communicating with *all* people with disability, there are some specific recommendations to follow when interacting with someone with intellectual, cognitive, or communication disability.

- Treat and communicate with adults with intellectual, cognitive, or communication disability as adults.
- Adjust your method of communication as necessary depending on the individual's responses to you. Use simple, direct sentences or supplementary visual forms of communication, such as gestures, diagrams, or demonstrations, if indicated.
- It may be necessary to talk more slowly to be understood, but it is *not* necessary or effective to talk louder or to shout.
- Allow extra time and do not rush the person as he or she communicates information to you or responds to a question.
- Use concrete, specific language. Avoid abstract language and use simple wording.

- Ask one question at a time. Avoid sentences in which you ask for two responses at a time.
    - Problematic questioning: "How did you get hurt and how was your injury treated?"
    - Preferred questioning: "How did you get hurt?" After receiving a response, ask, "How was your injury treated?"
- Be prepared to repeat the same information or questions more than once in different ways. Those with intellectual, cognitive, or communication disabilities may learn and process information more slowly than other people. They may have difficulty with abstract concepts such as time, money, humor, etc.
- When possible, use words that relate to things you both can see. Avoid using directional terms such as right, left, east, or west.
- When asking questions, phrase them without suggesting desired or preferred responses as some people with intellectual, cognitive, or communication disabilities may tell you what they think you want to hear.
- If you are having difficulty understanding the person's responses, try using questions that require a "yes" or "no" response.
- Give exact instructions, for example, "You will see the nurse at 10:30," rather than "Come back to see the nurse in 15 minutes."
- Avoid giving too many directions at one time, which may be confusing. Give one instruction at a time in clear, concise wording.
- Eliminate extraneous noise, lights, distractions, and commotion when interacting with the person to avoid sensory overload.
- Provide information in written or verbal form if that is the person's preference.
- Recognize that the person may need to have directions repeated and may take notes to help remember directions or the sequence of tasks. He or she may also benefit from watching a task or procedure demonstrated.
- Do not pretend to understand if you do not. Ask the person to repeat what was said. Be patient, flexible, and supportive. Use an alternative method of communication if necessary. Let people with disabilities finish what they are saying or responding to you; do not interrupt or finish their sentences for them and don't assume you know what they are saying before they say it.
- Do not assume that the person will or will not be able to read; some may not read at all so it is important to ask. Some people with disabilities have low literacy levels or are not fluent in English, so information and instructions need to be provided at a level that is understood by them.
- Avoid jargon such as medical terms and other words and expressions that are unlikely to be familiar to people with intellectual, cognitive, or communication disabilities.
- Offer assistance if it seems needed but respect the person's wishes if your offer is not accepted.

Additional points to keep in mind when interacting with people with IDD and cognitive or communication disabilities are the following:

- Explain who you are and what you will be doing prior to touching the person. Ask permission before you touch the person.
- Be aware of and sensitive to nonverbal cues, behaviors, and facial expressions that may convey issues, problems, pain, or discomfort on the part of the person with an intellectual, cognitive, or communication disability.

- Note that behaviors, even those that are described as "challenging behaviors," are often meaningful and may be the only way some people with a disability are able to communicate. Be aware of behaviors and gestures the person is using to better understand what it is the person is communicating.
- Keep in mind that some people have more than one type of communication disability. In this case, adjust communication strategies and efforts to meet the individual's needs, preferences, and abilities.
- Be aware that some people with intellectual, cognitive, or communication disabilities are nonverbal; that is, they do not communicate using words. They may use alternate methods to communicate with others.
- Become familiar with and use alternative methods of communication if necessary (e.g., communication boards, picture books, electronic devices). If a person with an intellectual, cognitive, or communication disability uses one or more of these methods, be patient while the person communicates. Encourage the person to use the device when communicating with health care personnel.
- Share information you have learned about how the individual with an intellectual, cognitive, or communication disability communicates with others who are likely to interact with that individual. Document this information in appropriate records.

Communication With Family and Caregivers of Individuals With IDD

Although the previous discussion highlighted the importance of communicating directly with people with disabilities, including IDD, it is important to keep in mind the crucial role of family and other caregivers in their lives and to communicate with them as well. Family members and other caregivers, including direct support professionals (DSP) who provide care and oversight for people with disabilities, often have very close and long-standing relationships with them, a strong interest in their health and well-being, and extensive first-hand knowledge of subtleties of their disabilities as well as strategies that are most effective in caring for and communicating with them. Family members often assume full responsibility for the care and well-being of individuals with a disability and do so with inadequate resources or support. The role family and other caregivers have in their daily lives and care should be considered and acknowledged, along with their important contributions and insights into the individual's well-being.

If decisions about health care are needed and the person with IDD is an adult, one needs to determine if that individual or a family member or other person has the legal power and responsibility to make such decisions. It is important to determine if the adult with IDD has retained the ability to make health-related decisions with support from family, referred to as *supported decision-making*, or if a legal guardian has been appointed to make such decisions. Supported decision-making is recommended when possible to ensure that those with IDD can participate in making decisions, including those related to their own health, with the support of family or other support persons if necessary. In order to allow information to be shared with others, the adult with IDD who retains decision-making authority with the assistance of a support person may need to sign a HIPAA release form to enable the support person to have access to protected health information.

Summary

This module has addressed the importance of effective communication between people with disabilities, including IDD, and health care professionals as well as strategies to promote effective communication. Problematic communication remains a major barrier to individuals with IDD, cognitive, and communication disabilities in their quest for quality health care. Multiple strategies exist to assist health care professionals in communicating with them. Although these strategies may take more time, their use is essential to enable health care professionals to accurately assess, diagnose, care for, and treat individuals with intellectual, cognitive, or communication disabilities.

The Communication Bill of Rights identifies the rights of individuals with disabilities and should serve as a call to action to health care professionals across settings to ensure that they work to communicate effectively with those with disability in their care. Collaboration with experts in communication should be an early step in the process rather than one that is considered only after all other approaches are tried and fail. With advances in technology, communication approaches have become more available and more effective, but identifying the need to use technology or other approaches requires commitment on the part of health care professionals to communicate with those with disability, including those with severe disability, as outlined in the Communication Bill of Rights.

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Module 2

Attitudes, Bias, Ableism, and Stereotyping

Objectives

At the end of this module, the learner will be able to:

- To summarize research findings on attitudes, bias, ableism, and stereotyping toward persons with disability.
- To examine the consequences of negative attitudes, bias, ableism, and stereotyping on the health and health care of persons with disability in general and intellectual and developmental disability (IDD) specifically.
- To implement and evaluate strategies to minimize the negative attitudes, bias, ableism, and stereotyping that lead to barriers to health care for persons with IDD.

Introduction

This module addresses a key and pervasive barrier to quality health care encountered by many people with a disability: negative attitudes toward people with disabilities by health care professionals. Such negative attitudes are consequential in the health of people with disabilities and their satisfaction with the health care they receive as well as the quality of that care. Attitudes, bias, ableism, and stereotyping are discussed in this module along with the concepts of diversity, equity, and inclusion (DEI) and accessibility (A). Legal mandates to address the civil rights of people with disabilities in general and IDD specifically are identified, along with strategies to address those factors that result in their receiving poor health care.

Overview

Most people believe that our judgments of others are fair, objective, and unbiased. However, even members of health care professions have unconscious biases that affect how we interact and respond to other people. Such biases affect the health care we provide to people with disabilities and their resulting health status.

People with disabilities, including those with intellectual and developmental disabilities (IDD), experience health disparities, defined as differences in health status compared to that of people without disability. These disparities are due in part to health inequities, defined as unfairness and injustice, affecting the health care they receive (Kneipp et al., 2018). Although the history of how people with IDD have been viewed and treated around the world and in the U.S. over time is troubling (Conrad, 2020), improvements have been made in health care for this population. Further efforts are still needed to ensure that those with IDD live their lives to the fullest and reach their potential. The health professions are an important part of reaching those goals. Health care professionals' lack of information about IDD and negative attitudes serve as barriers to quality health care and result in compromised health for those with IDD. The effects of the barriers and the strategies used to address those barriers are discussed in this module.

Diversity, Equity, Inclusion, and Accessibility

In the aftermath of social unrest and calls for social justice, many schools, businesses, organizations, and government agencies developed or strengthened existing programs to ensure that they adequately address diversity, equity, and inclusion (DEI). Once considered an issue of concern limited to organizations' human resources departments, DEI efforts began to be addressed in strategic plans and made a priority by many organizations. Although efforts to address DEI go back to the 1960s, the need for them grew in importance in response to the blatant racism and social unrest that erupted in 2020. Of concern is that these DEI programs often fail to include disability as one of several areas where greater efforts are needed to ensure that disenfranchised groups are treated equitably. Although 62 percent of businesses report having DEI policies and practices, only 4 percent of them include disability in their DEI efforts (Relias, 2021, 2022).

Attention to disability in health care through DEI programs remains sparse. The unique needs and experiences of people with disabilities, including those with IDD, continue to be ignored and unaddressed in educational programs or clinical practice for the health care professions. Thus, despite the large and growing population of people with disabilities (> 70 million), the U.S. health care system and health care professions education have failed the quarter of the U.S. population with disability (National Council on Disability [NCD], 2022). Many health care professionals have little knowledge about disability in general and even less about IDD. They fail to communicate effectively with people with disabilities and have biased attitudes about them, their quality of life, and their general health needs. As a result, people with disability often use the health care system for emergencies only and are reluctant to access it for health promotion and disease prevention; thus, the system is a source of potential harm for this population (NCD, 2022).

President J. Biden issued an executive order on DEI, adding "A" for accessibility (DEIA) to address disability in the federal workforce. However, in 2025 attacks on DEI efforts across the U.S. and across organizations and agencies resulted in many DEI programs and efforts being dismantled. Despite these changes, health care systems and health professions would benefit from maintaining their efforts to address diversity, equity, inclusion, and accessibility that are so vital to the health care of individuals with disability, including those with IDD.

Attitudes, Bias, Ableism, and Stereotyping

Negative attitudes, bias, ableism, and stereotyping on the part of health care professionals have consistently been identified as major barriers to quality health care for people with disabilities. These factors have the potential to lead to significant discrimination and prejudice. Attitudes, bias, ableism, and stereotyping are terms key to this discussion and are defined in the following table along with examples related to disability.

Term	Definition	Examples
Attitude	A set of emotions, beliefs, and feelings about someone or something; attitudes can be negative or positive and can affect our behaviors toward someone or something.	• *Positive attitude*: believing that all patients with disabilities should be approached with a warm and inviting manner. • *Negative attitude*: seeing nothing wrong with ignoring the views and questions of patients with IDD because they are viewed as incapable of understanding accurate information.

Term	Definition	Examples
Bias	Tendency to favor or disfavor one group over another; may be conscious (explicit) or unconscious (implicit); although bias may favor or disfavor one group over another group, the term is often used to indicate unfair response to groups not seen favorably. *Conscious/explicit bias*: Intentional favoring or disfavoring of one group over another; aware of effect of actions. *Unconscious/implicit bias*: Unintentional favoring or disfavoring of one group over another without realizing it; unaware of effect of actions.	• Intentionally withholding accommodations for people with disabilities for health care visits because of the costs or efforts required. • Not providing information about health-related procedures and tests to patients with IDD because of belief that they will not understand the information.
Ableism	Stigma, prejudice, and discrimination specific to disability; refers to favoring able-bodied people and disapproval and negative views of people with disability; social prejudice against those with disabilities based on the belief that typical or "normal" abilities are superior and those with disability are "less than" and in need of "fixing." Objectivizing people with disability for the benefit of those without disability (referred to as "inspiration porn").	• Talking to people with disability as if they are children; talking *about* them rather than to them; speaking *for* them. • Assuming that we know what is best for those with disability without asking them. • Scheduling a health care visit or meeting without providing needed accommodation. • Assuming people with disability have a poor quality of life and depend on others to care for them. • Framing disability as either tragic or inspirational in news stories, movies, and other media. Praising people with disability (as heroes, extraordinary, or inspirational) for everyday activities.
Stereotyping	Oversimplified, fixed, and widely held beliefs about an individual based on one's views about an entire group of people. Stereotypes are often inaccurate, especially when they lead to judgments applied to people within that group. Can lead to diagnostic overshadowing (attributing all health issues to a person's disability and failing to diagnose and treat the actual disorder).	• Believing that people with IDD are unpredictable and prone to violence. • Assuming that people with disability are asexual. • Having low expectations about what people with IDD can achieve. • Attributing all health issues to a person's disability rather than to other possible causes and, as a result, not providing timely and appropriate treatment.

Attitudes refer to feelings or ways of thinking that affect how we engage with others. Attitudes are formed during childhood and are influenced by the world and people around us. If these attitudes are negative, they can be result in bias, ableism, stereotyping, prejudice, and discrimination.

Multiple studies conducted around the world indicate that society as a whole and many health care professionals across disciplines have negative attitudes toward people with a disability (Desroches et al., 2022; Iezzoni et al., 2021; Morin et al., 2018; NCD, 2009; Pelleboer-Gunnink et al., 2017). Further, people with intellectual disability and psychiatric/mental health disability are viewed more negatively than those with other types of disability. While most people would be reluctant to openly admit that they have negative attitudes toward people seen as different from themselves, such as people with a disability, unconscious or implicit negative attitudes can have devastating effects that result in discrimination, inferior health care, and health disparities.

Bias can be either explicit or implicit. Explicit biases are those at the conscious level, are deliberately formed, and easy to report, observe, or measure. In contrast, implicit attitudes are those at the unconscious level. Such attitudes are involuntarily formed and unknown to us. They are also much more difficult to report, observe, or measure. Because individuals are unaware of their implicit biases, these are more difficult to modify than the explicit biases an individual usually recognizes and acknowledges.

Ableism refers to valuing independence over interdependence, and viewing being able-bodied (the absence of disability) as the norm. The concept of ableism is consistent with the medical model of disability, which views disability as a defect or deficit to be overcome, resting with the individual and not related to environmental and social factors (Borowsky et al., 2021). Ableism results in persons with disability being devalued or diminished because of their disability.

Ableism includes negative perceptions of the quality of life of persons with disability, which has consistently and as recently as 2021 been perceived as poor by health care professionals (Iezzoni et al., 2021). Activities and equipment that are part of the daily life of persons with disability (e.g., wheelchairs, feeding tubes, respirators) are often viewed by health care professionals as indicators of poor quality of life (Janz, 2019), resulting in inadequate health care for people with disability. A major consequence of these negative perceptions and ableism became apparent during the COVID-19 pandemic, when people with disabilities were denied high-level health care and instead were identified as candidates for palliative and end-of-life care, based only on their having a disability (Fuentes et al., 2021; NCD, 2022). A bulletin issued by the Office of Civil Rights (2020) during the pandemic emphasized the need for fairness, equality, and compassion in treating people with disabilities, stating they have the same dignity and worth as everyone else. The Office of Civil Rights further stated that people with disabilities should not be denied health care on the basis of stereotypes, assessments of quality of life, or judgments about the person's relative "worth" based on age or the presence or absence of disability.

Stereotyping refers to having oversimplified and fixed beliefs about an individual based on one's views about an entire group of people. Stereotypes are often inaccurate, especially when they lead to judgments applied to people within that group. Stereotyping can lead to overshadowing (attributing all health issues to a person's disability and failing to diagnose and treat the actual disorder). Diagnostic overshadowing with failure to treat health conditions and delays in treatment have been identified as possible explanations for a 26-year shorter lifespan of people with IDD compared to those without disability. Other health disparities, such as poverty, unhealthy living environments, and challenges with communication and self-advocacy in this this population, also contribute to their shortened lifespan (Lauer & McCallion, 2015; Landes et al., 2020).

Despite the negative effects of such attitudes, bias, ableism, and stereotyping on the health and health care of persons with IDD, these factors can be changed through education, experience, and exposure of health care professionals to people with IDD (Crane et al., 2021; Smeltz et al., 2023). However, effort is needed to ensure appropriate education for members of society in general and for members of the health care professions specifically. Such efforts have been identified as essential by private, governmental, and national as well as international organizations, including the Centers for Disease Control and Prevention (2020), World Health Organization (2021), United Nations Department of Economic and Social Affairs (2006), the Institute of Medicine (2007), the U.S. Surgeon General's Office (2005), and the National Council on Disability (2022).

In addition, there are legal mandates to address these issues, including those of the Americans with Disabilities Act (1990), the Americans with Disabilities Amendments Act (2008), and the Developmental Disabilities Assistance and Bill of Rights Act of 2000.

Strategies to Address Attitudes, Bias, Ableism, and Stereotyping

A number of strategies have been identified to address the attitudes, bias, ableism, and stereotyping that result in poor health and health care for persons with IDD. Several strategies are the following:

1. Consider and reflect on your own bias about disability by asking yourself these questions:
    - When you first meet a person with IDD or another disability, do you see the disability before you see the person?
    - When you first think of a person with IDD, do you focus on what the person *can* do or what the person *cannot* do?
    - When you see or meet someone with IDD, do you direct your attention and conversation to that person or to an accompanying person?
    - When you think of a person with IDD, do you have pity for that person?
    - When you interact with a person with IDD in a health care encounter, do you provide the same quality of care that you give to other patients?
    - When you communicate with a person with IDD, do you talk to that person as an adult or as a child?
    - When you are providing care to a person with IDD, do you ask the same types of questions about health practices you ask of other patients?
    - When you see someone with IDD, do you consider that person's quality of life as poorer than that of persons without IDD?
2. Interact with people with IDD and establish a one-to-one relationship to get to know them as people with individual characteristics, interests, and preferences, discarding stereotypes.
3. Consider the perspectives of people with IDD to better understand their responses and the adaptive techniques they use to function in their environment.
4. Focus on what people with IDD *can* do rather than what they *cannot* do.

5. Learn about IDD and its diversity and the effects of negative attitudes, bias, ableism, and stereotyping on the health and health care of people with IDD.
6. Consider completing the Disability Attitudes Implicit Association Test (DA-IAT) to assess your own explicit and implicit attitudes toward people with disabilities. Available without cost at. https://implicit.harvard.edu/implicit/selectatouchtestv2.html

Summary

This module has summarized information about the attitudes, bias, ableism, and stereotyping that are major barriers to quality health care for people with IDD. In addition, strategies to address these issues have been presented. These strategies are essential for health care professionals across disciplines if the large and growing numbers of people with IDD are to receive the equitable and quality health care essential for them to live healthy lives and thrive.

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Module 3

Social Determinants of Health, Intersectionality, and Models of Disability

Objectives:

At the end of this module, the learner will be able to:

- describe social determinants of health and their impact on/relationship to disability.
- explore the effects of intersectionality on health care professionals' views of people with disability.
- compare models of disability and their impact on health care professionals' views of and interactions with people with disability.

Introduction

Social determinants of health (SDOH), intersectionality, and models of disability are key issues that can have a profound effect on the health, well-being, and health care of people with disabilities. This module addresses these issues as they relate to disability and to the ability of people with disabilities to receive health care that is at least comparable to the care provided to people without a disability. Each of these topics is addressed along with discussion of how they interact as areas in which students in the health care professions and professionals in practice can have an impact and improve the health of this population.

Social Determinants of Health

According to the World Health Organization (WHO, 2025), social determinants of health are nonmedical factors that influence outcomes; such factors can have a greater effect on health outcomes than lifestyle or the health care received by individuals. SDOH are the conditions in which people are born, live, grow, learn, work, play, pray, and age. SDOH determine if individuals or populations experience health inequities, defined as unfair, unjust, and avoidable differences in health status (WHO, 2025). SDOH are relevant to all individuals, groups, and populations.

As illustrated in the figure below, SDOH can be categorized as economic stability; education; social and community context, including socioeconomic status (SES); neighborhood and the built environment; and health and health care. These, in turn, are influenced by economic policies and systems, development agendas, social norms, social policies, and political systems. The five categories of SDOH reflect key issues that affect health.

World Health Organization (2025). *Social Determinants of Health*

Using one SDOH as an example, it is obvious that socioeconomic status influences access to a safe and healthy environment, education, meaningful employment, adequate nutrition, housing, and safe water and air. It may be less obvious that people with disabilities are at greater risk for poor health and inadequate health care compared to people without disabilities because of low SES, which can affect their access to health care, transportation, community support, employment, education, housing, communication, safe water, and nutritious food. Thus, even a single SDOH can serve as a major barrier to good health and health care for those with disability.

The term SDOH refers to nonmedical factors that influence health and includes factors that result in poor health outcomes, such as social disadvantage, risk exposure, and social inequity (Bharmal et al., 2015). These are factors that typically exist outside the delivery of health care but affect health status and the ability to obtain quality care. Another example is the lack of access to health care providers who are knowledgeable about disabilities and their effects on health, understand the effects of disability on one's daily life, and have positive attitudes toward this population. As lack of access has a negative effect on the interactions of health care professionals with people with disabilities, health care professionals need to consider and address all SDOH that affect one's health and well-being.

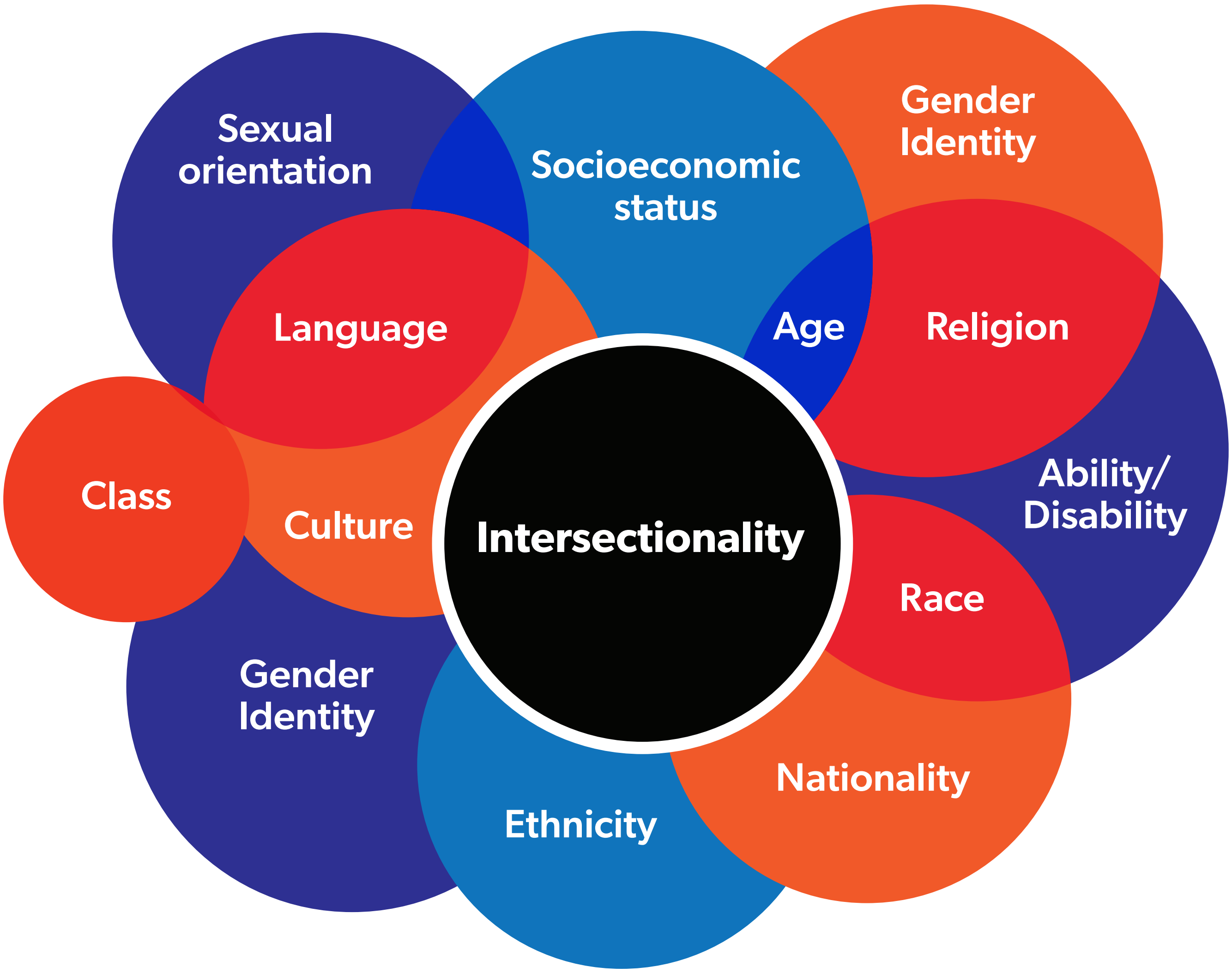
Negative attitudes on the part of health care professionals and their lack of knowledge about disability can result in their concluding that the health disparities experienced by people with disabilities are a direct result of their having a disability. Further, health care professionals may erroneously believe that people with disabilities have poor health, poor quality of life, and depression and do not contribute to society (Froehlich-Grobe et al., 2021). Health care professionals who view disability through the lens of the medical model of disability can also err in patient assessment, diagnosis, and treatment by attributing all health issues to disability, even if they are not remotely related to disability (diagnostic overshadowing). By emphasizing the importance of the environment as a key factor in disability, use of the social, biopsychosocial, or other comparable models of disability, rather than the medical model, helps health care providers avoid these issues (Froehlich-Grobe et al., 2021). The use of models other than the medical model is more likely to result in an accurate perspective of disability and its effects on the lives and health of those with disability. (See table on following page.)

Intersectionality

The concept of intersectionality builds on the concept of social determinants of health. It describes the ways in which one's multiple characteristics (e.g., gender, race, ethnicity, sexual orientation, gender identity, socioeconomic class, disability, religion) interact to form an individual's identity. These characteristics together may magnify the risk of discrimination and marginalization that an individual experiences. In other words, multiple forms of inequality reinforce one another and increase the scope of discrimination and its negative impact, leading to greater inequity and disparities. The intersection of identities (e.g., gender, race, ethnicity, religion, sexual orientation, and the presence of a disability) can limit one's ability to be fully included or accepted in society if others have negative assumptions about even one of these identities. When others have negative assumptions about more than one of these characteristics, the risk of discrimination or of being devalued and excluded increases.

When a person with a disability encounters a health care professional with many biases, there is greater opportunity for bias to occur because of intersectionality. If one assumes that only nondisabled people are "normal," those with disability may be perceived as not normal or deviant, resulting in discrimination and inequity in how they are treated by others in their everyday lives and by health care professionals. For example, a child with an intellectual disability who is a person of color, from a low socioeconomic group, and whose parents are immigrants and have limited literacy skills is at greater risk for poor quality health care than a child with an intellectual disability who is White, from the middle or upper socioeconomic class, and has parents who have high literacy skills. A recent study revealed that White children with disability (identified as children with "special health care needs") had a greater likelihood of having very good/excellent general and oral health and were less likely to experience barriers to care than a similar group of Black children (Dembo et al., 2022).

Because the intersection of multiple factors increases the risk of discrimination and poor health care, health care professionals must also consider the effects of race, ethnicity, gender identity, socioeconomic status, sexual orientation, and other characteristics on their interactions with individuals in their care, including those with disability. It is important to realize that one may perceive someone with a disability in a negative way without being aware of it (discussed in module on attitudes).



All of these identities have the potential to result in discrimination. Alone, each is a potential barrier to care; together, discrimination is likely to be compounded.

Models of Disability

Several models of disability have been developed to identify issues that need to be addressed to improve the lives of people with disabilities. As described above in the discussion of SDOH, use of models of disability other than the medical model is more likely to result in more accurate perspectives of disability and its effects on daily life, health, and health care. Models such as the social model and biopsychosocial model reflect the view that disability is much more than the underlying disorder or medical condition that leads to disability. Health care professionals who accept and use one of these models generally recognize that disability is far more than the disabling condition, that it includes the day-to-day experiences of the person with a disability. (See table on following page.)

Further, nonmedical models of disability acknowledge that experts in disability are those persons who have lived with disability, sometimes for their entire lives, and know what health issues are important to them. Health care professionals who have been reported to know little about disability (Iezzoni et al., 2021) are rarely experts on the experiences and lives of people with disabilities. While it is important and necessary for health care professionals to know about the underlying cause of disability (e.g., disease, trauma, genetic disorder), knowledge about underlying disorders is not sufficient for providing quality health care to the large and increasing population of people with disabilities.

The following table summarizes key points of several models of disability.

Comparison of Several Models of Disability

Medical Model	Social Model	Biopsychosocial Model
Developed by health care professionals (HCP)/medical professionals; focus is on pathology or impairment due to disease, trauma, or other health condition.	Developed by disability activists in response to medical model.	Developed to respond to limits of medical and social models of disability.
Disability viewed as problem of the individual; viewed as a deficiency or dysfunction; may result in individual with disability being blamed.	Disability viewed as socially constructed; due to physical, organizational, and negative societal barriers to be changed or eliminated.	Disability viewed as result of *both* biological factors and social *and* psychological factors; considers rather than ignores the functional impairment not addressed in the social model.
Disability seen as defect or abnormality.	Disability seen as difference or diversity.	Disability seen as interaction between 3 sets of factors: physical, psychological, and social or environmental factors.
Goal is to cure or "fix" the disability through medical interventions or by promoting change in the individual's behavior.	Goal is freedom from discrimination with the right to same opportunities and services as others with social change as the "fix" along with elimination of negative societal perceptions.	Goal is to address both underlying physical or biological issues *and* social, environmental and psychological factors.
Based on belief that HCPs are the experts on disability.	Based on belief that people with disability are experts on disability.	Acknowledges need for HCPs to address some aspects of disability, but views those with disability as experts on how disability affects them within their psychological and social environment.
Views those with disabilities as "tragic"; those who "overcome" disability as inspirational or heroic.	Views those with disability as not different from others; rejects views of medical model, including view that health and disability are mutually exclusive.	Addresses health and disability from biologic, individual, social, and environmental perspectives.
Reinforces negative stereotyping and prejudice toward people with disabilities.	Serves as framework for UN Convention on the Rights of Persons with Disabilities.	Serves as basis of the World Health Organization's International Classification of Functioning, Disability, and Health (ICF).

Summary

The intent of this module is to provide background about important issues related to disability, including the social determinants of health, intersectionality, and models of disability. These concepts provide a background necessary for health care professionals who want to make a difference in the health and health care of people with disabilities. Considering the social determinants of health and intersectionality in interaction with disability is an important step for health care professionals to identify and address factors that can interfere with quality health care for people with disabilities. Although health care professionals may not be able to remove all barriers that can have a negative impact on the health, well-being, and health care of people with disabilities, having an understanding of the factors that may come into play is an important first step in addressing those we can address.

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Module 4

Intellectual and Developmental Disability – Part I: What It Is

Objectives:

At the end of this module, the learner will be able to:

- describe overall characteristics of intellectual and developmental disability.
- compare and contrast levels of severity of intellectual disability, skills, and supports needed by individuals in each category.
- apply information about characteristics of individuals with intellectual disability by level of severity to design strategies to communicate with them about their health issues.

Introduction

This module introduces intellectual and developmental disability (IDD) and begins with an overview of what it is. Although IDD is the overall focus of the module, a special emphasis on *intellectual disability* (ID) is needed because it is a category of IDD and disability in general identified as most anxiety-provoking and challenging to health care professionals. The module addresses the prevalence and causes of intellectual disability followed by explanation of categories of severity. Common causes are discussed along with signs of intellectual disability and a summary of strategies to provide health care to affected individuals.

A second module (*Intellectual and Developmental Disability — Part II: Select Health-Related Issues*) discusses select health issues that health care professionals need to keep in mind when interacting with individuals with IDD: secondary conditions, causes of mortality ("Fatal 5 + 1"), aging with IDD, challenging behaviors, and abuse.

Overview

To understand intellectual disability, it is necessary to put it in the context of developmental disability. The term *developmental disability* is an umbrella term that includes disability that occurs before the age of 22, considered the developmental years. Developmental disability can affect intellectual or cognitive function only, physical function only, or both physical and intellectual and cognitive function. Although all types of developmental disability are important, the focus of this module is primarily on individuals with *intellectual disability*, with and without physical disability.

It is important to be aware of another term in use: *neurodevelopmental disorder*. This term refers to a group of conditions with an onset in the developmental years and includes intellectual disability as well as communication disorders, autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), and several specific neurodevelopmental disorders, such as tic disorders and specific learning disorders (Morris-Rosendahl & Crocq, 2019). It is also important to note that the American Psychiatric Association (2013) revised its language to remove the term *mental retardation* from its literature, as have most journals and organizations that previously used that term. The change in wording more accurately addresses intellectual disability without the negative connotation of the term. In the United Kingdom, the term *learning disability* is used instead of mental retardation.

Prevalence of Intellectual Disability

About one in six children in the U.S. (17.3% of children 3 to 17 years of age) has one or more developmental disabilities or other developmental delays (Centers for Disease Control and Prevention, n.d.). Approximately 7-8 million people, 10 to 13 of every 1000 children in the U.S. and 200 million people globally (1% - 3% of the global population) have an intellectual disability (Patel et al., 2020). ID is more common in low-income countries with few resources. Individuals with ID are living longer and the population of those affected, including those over 60 years of age, is increasing in size.

Characteristics of Intellectual Disability

Intellectual disability occurs before the age of 18 and involves impairments of general intellectual or cognitive abilities that further affect adaptive functioning in three domains. Intellectual function refers to general mental or cognitive capacity, such as the ability to learn, reason, and problem solve as well as the ability to understand reality and interact with it. Persons with ID (also referred to as intellectual developmental disorder) also have limitations in adaptive skills or domains (i.e., conceptual, social, and practical domains). These three domains, identified in the figure below, and limitations in each of these domains determine how well an individual with intellectual disability copes with everyday tasks.

The Three Adaptive Domains Affected in Intellectual Disability

Adaptive Behavior

Conceptual Behaviors

Language (receptive & expressive)
Reasoning
Reading & Writing
Basic math concepts
Knowledge and memory
Concept of time
Self-direction

Social Behaviors

IPR Skills
Social judgment
Empathy
Self-esteem
Wariness
Follows rules & laws
Able to maintain friendships
Vulnerable to victimization

Practical Behaviors

Activities of daily living
Self-care activities
School and Work skills
Health care: taking medication
Travel & Transportation
Reading & Writing
Knowledge and Memory
Use of phone & computer
Concept of time
Money management

Impairments in the three adaptive domains identified above accompany general intellectual impairment. The effects of those impairments are described in the following table. As noted, these effects depend on the *severity* of a person's cognitive limitations or level of intellectual function as well as the person's adaptive behaviors.

Impairments in Intellectual Functioning, Adaptive Domains and Consequences

Category of Domain	Specific Activities	Possible Consequences
Intellectual Functioning	General or global ability that enables an individual to understand reality and interact with it; mental capacity, such as learning, reasoning, problem solving	Impaired general mental capacity, such as learning, reasoning, and problem solving; severity of impairment of intellectual functioning is reflected in IQ scores.
Adaptive Behaviors	Group of conceptual, social, and practical skills learned and performed by people in their everyday lives.	Impaired adaptive ability refers to lack of competence in three areas: social, conceptual, and practical skills.
• *Conceptual Domain*	Language, reasoning, reading, math, basic math concepts, knowledge and memory, and self-direction.	Difficulty learning to talk, learn, lack of understanding of numbers and time, lack of self-direction.

Category of Domain	Specific Activities	Possible Consequences
• *Social Domain*	Empathy, social judgment, interpersonal communication skills, ability to make and maintain friendships.	Limited interpersonal skills, low self-esteem, unable to follow rules/obey laws, gullible and naïve; lack of wariness; at risk for being victimized; difficulty with social problem solving.
• *Practical Domain*	Self-management skills that include personal care, job responsibilities, money management, recreation, and organizing school and work tasks.	Difficulty with activities of daily living (preparing meals, school and work skills, health care, travel/transportation, schedules/routines, safety, use of money, use of phone and computer).

ID is identified by the presence of significant limitations in intellectual function and adaptive behavior. Although some types of ID may be recognized by the physical appearance of a young child along with atypical behaviors, others may not become obvious until a child begins school. ID is typically diagnosed by a multidisciplinary team with expertise in neurodevelopmental disorders based on clinical assessment and observation of the individual's behaviors and input from family members, teachers, or caregivers. Standardized tests used to assess intellectual functioning and adaptive behaviors are administered by qualified professionals; the tests used must be age appropriate and culturally sensitive. In addition, testing must take into account the mental age of the person, as well as motor, behavioral, or language variations and hearing and vision impairments (Patel et al., 2020). The Intelligence Quotient (IQ) is ***not*** the major criterion for diagnosing ID. However, IQ scores may be useful in determining supports likely needed by those with scores that are below 70.

The table below summarizes characteristics of persons with intellectual disability, the percent of people with intellectual disability, typical IQ test scores, and predicted level of skills and support required by level of severity. IQ scores in persons with intellectual disability typically are two standard deviations or more below the population mean of 100. This translates to IQ scores of 70 or below. Although persons with IQ scores below 70 *typically* have significant limitations in intellectual functioning, IQ scores may or may not correlate closely with level of adaptive ability (Patel et al., 2020). Individuals with good adaptive function but IQ scores below 70 are considered not to have intellectual disability (Lee et al., 2022). Because of wide variability in IQ scores and adaptive function, IQ scores in this population should be interpreted with caution.

Characteristics of Persons With Intellectual Disability by Severity

Severity	% of ID Population	Typical IQ Scores	Level of Skills and Deficits	Support Needed
Mild	85%	50-70	Take longer to learn to talk but communicate well once learned. May have difficulty reading and writing; socially immature; some difficulty with responsibilities of marriage or partnering. Benefit from specialized education. Fully independent in self-care as adult. If intellectual disability is very mild, it may not be recognized until the child is in school.	May require intermittent support during transitions or uncertainties.

Severity	% of ID Population	Typical IQ Scores	Level of Skills and Deficits	Support Needed
Moderate	10%	36-49	Independent living may be possible with moderate levels of support, such as in group homes. Slow in acquisition of language. Able to learn basic reading, writing, and counting skills. Can travel to familiar places and can participate in various social activities.	Some support needed in day-to-day activities, situations, and transitions.
Severe	3.5%	20-35	Noticeable motor impairment with impaired neurological development. Requires daily assistance with self-care and supervision to ensure safety.	Extensive support needed for daily activities.
Profound	1.5%	<20	Inability to understand or comply with instructions or requests; possible immobility, incontinence, very basic nonverbal skills. Unable to meet own needs independently. Requires 24-hour care (help and supervision)	Extensive support needed for all aspects of daily routines

Sources: National Academies of Sciences, Engineering, and Medicine. (2015). Mental Disorders and Disabilities Among Low-Income Children. National Academies Press; Lee, K., Cascella, M., & Marwaha, R. (2022). Intellectual Disability. NCBI Bookshelf. A service of the National Library of Medicine, National Institutes of Health. Patel, D. R., Cabral, M. D., Ho, A., & Merrick, J. (2020). A clinical primer on intellectual disability. Translational Pediatrics, 9(Suppl1), S23-S35. doi.org/10.21037/tp.2020.02.02

In contrast to common perceptions, the overwhelming majority of persons with ID (85%) have mild intellectual disability (Lee et al., 2022). Although those with mild ID are often a bit slower than average in learning new information or skills, most are able to live independently as adults with the right support. Many are able to read and write, make decisions including those that relate to their health, use phones and computers, attend school and be employed, maintain relationships, and live in their own homes and on their own in their communities. Others may need significant assistance and support to participate fully in their communities. Those with profound intellectual disability need full support and 24-hour care and supervision.

Causes of Intellectual Disability

Intellectual disability can be caused by a number of conditions that affect development of the brain in the prenatal period, during birth, or any time up to age 18. Although many causes have been identified, the cause is unknown in about one-third of those with ID, typically those with mild intellectual deficits (Patel et al., 2020). In contrast, the causes can be identified in 75% of persons with severe or profound levels of intellectual disability. Major causes of severe or profound ID include genetic abnormalities (chromosomal abnormalities and genetic syndromes including inborn errors of metabolism) and congenital brain malformation. Certain maternal infections or severe illness during pregnancy (e.g., hypertension, urinary tract infection, pre-pregnancy obesity, and pre-gestational diabetes) and obstetrical complications (e.g., placenta previa, placenta abruption), along with prenatal exposure to toxins, increase risks for intellectual disability. Other causes include injury at the time of birth (e.g., anoxia, premature birth and low birthweight), during early childhood or later (infection [e.g., meningitis, measles], traumatic brain injury, and exposure to toxins [e.g., lead, mercury]). The three most common causes of ID include fetal alcohol syndrome disorder, Down syndrome, and fragile X syndrome (Lee et al., 2022). Examples of causes of intellectual disability are identified in the following table.

Summary of Causes of Intellectual Disability by Categories With Examples

Environmental Factors	Specific Examples
Severe malnutrition, maternal illness, obstetrical complications	Maternal or childhood malnutrition, pre-gestational diabetes, diabetes, placenta previa, placenta abruption
Fetal exposure to toxins	Lead or mercury poisoning, alcohol (fetal alcohol syndrome), drugs (e.g., amphetamines, cocaine, teratogenic medications, radiation)
Fetal exposure to infectious agents	HIV, Rubella (German measles), Zika, cytomegalovirus
Exposure to toxins or infections after birth	Lead poisoning, meningitis, encephalitis
Trauma during or after birth	Brain injury during or after birth (e.g., anoxia), traumatic brain injury
Low birthweight, premature birth	
Metabolic disorders	Untreated hyperbilirubinemia in newborns
Genetic or Chromosomal Disorders	
Genetic mutations, additions, or deletions	Down syndrome, Fragile X syndrome, Klinefelter's syndrome
Inborn errors of metabolism	Phenylketonuria (PKU), galactosemia, Lesch-Nyhan syndrome
Other Causes	
Developmental disorders of brain formation	Microcephalus, hydrocephalus

Signs of Intellectual Disability

Intellectual disability may not be detected in individuals with mild ID during infancy and early childhood. The identification of ID depends in large part on its severity and a person's adaptive behaviors. Although signs of ID can vary considerably from one person to the next, there are some general signs that suggest intellectual disability and that should trigger an in-depth assessment. Signs of mild intellectual disability may not be obvious until the individual begins school. In individuals with more severe forms of ID, the signs will be detected early. The more severe the intellectual disability, the earlier it is likely to be detected (Patel et al., 2020).

In addition to the skills and deficits identified in the previous table (*Characteristics of Individuals With Intellectual Disability by Severity*), signs of ID may include the following:

- Failure of the person to meet intellectual developmental milestones.
    - Delays in language skills (speech or ability to speak clearly) or at all (severe intellectual disability)
    - Delays in motor skills (sitting, crawling, or walking compared to other children)
    - Delays in or difficulty eating and feeding self.

- Lack of interest, curiosity, focus, attention, or awareness of environment or others.
- Memory problems and inability to think logically.
- Inability to understand consequences of actions.
- Childish behavior inconsistent with chronological age.
- Difficulty learning, reading, and writing.
- Limited or immature ability to interact with others; inappropriate interaction with others.
- Inability to be fully independent (due to limitations in communication, self-care, or interaction with others).
- Maladaptive (self-harm) behavior in severe intellectual disability.
- Occurrence of challenging behaviors.

Issues to Consider in Caring for Individuals With Intellectual Disability.

A major issue repeatedly identified by individuals with ID, family members, and researchers is failure of health care providers to communicate directly with individuals with intellectual disability. Further, persons with ID and other types of disability are often assumed, incorrectly, to have health care needs and preferences that differ in major ways from those without disability. As a result, their primary health care needs are often overlooked or ignored and they do not receive health promotion services and preventive health screening. Further, their health status may not be assessed appropriately because of *diagnostic overshadowing* (i.e., attributing all issues to intellectual disability). Some individuals with ID may not receive even basic health care because health care providers believe, erroneously, that their quality of life is poor, they do not experience pain and discomfort, and they have a shortened life span because of their disability.

Essential to caring for individuals with ID is the realization that their basic health care needs do not differ from those of others. While they may have additional health care needs because of the effects of their disability, their basic health care needs are the same as those of others. It is also essential that health care providers communicate directly with persons with disability rather than accompanying persons and identify and establish communication strategies that are effective for them. Although many individuals with ID have a shorter life span than those without disability, this is often due to their failure to receive appropriate health care, delays in diagnosis and treatment of health problems, lack of accessible information about screening and detection, communication barriers, discrimination, and lack of knowledge about ID among health care professionals, rather than their underlying disability (Reppermund et al., 2020).

It is important for health care professionals to understand that although an intellectual disability is not always accompanied by physical effects, physical disability can occur along with intellectual disability and must be considered in interacting with and providing care for a person who experiences both intellectual and physical disability. A person with ID can also have a psychiatric-mental health disorder; that too must be considered when interacting with an individual with intellectual disability. Often persons with disability, including intellectual disability, are not correctly assessed for these disorders and, as a result, they do not receive appropriate treatment. Alternatively, some individuals with intellectual disability who exhibit challenging behaviors may be prescribed psychotropic medications inappropriately based on the assumption that their behaviors are indicative of psychiatric-mental health disorders rather than their efforts to communicate pain, discomfort, or other health-related issues (discussed in *Intellectual and Developmental Disability–Part II: Select Health-Related Issues* module).

Another issue important in caring for persons with ID is the need for health care professionals to communicate with the family members or caregivers of those with disability, but not to the exclusion of the person with disability. Family members and caregivers are often involved in providing care and support for the person with intellectual disability around the clock in their own environment; thus, their input is not only useful, it is essential. As discussed in Module 2, direct communication with the person with disability is key; however, communication with family members and caregivers is also important to ensure quality care to the person with disability during health care interactions and after the person returns to the previous environment with family members and caregivers.

Summary

This module provides an overview of the distinguishing features of intellectual disability, including impairments associated with intellectual disability by severity, causes of intellectual disability, signs of intellectual disability, and a brief overview of several important issues that need to be considered and addressed by health care professionals who interact with and provide health care to persons with intellectual disability. This module has not focused on assessment and diagnosis of intellectual disability, which is a high priority for those with signs of intellectual disability in order to initiate early interventions; it has instead focused on health issues of those who have a known diagnosis of intellectual disability.

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Module 5

Intellectual and Developmental Disability – Part II: Select Health-Related Issues

Objectives:

At the end of this module, the learner will be able to:

- describe select health-related issues that can occur with intellectual and developmental disabilities (IDD): secondary conditions, causes of mortality, aging with IDD, challenging behaviors, and abuse.
- identify implications of select health-related issues for interacting with and providing care for persons with IDD: secondary conditions, causes of mortality, aging, challenging behaviors, and abuse.

Introduction

This module builds on the information about IDD presented in *Intellectual and Developmental Disability – What It Is: Part I*. Part I presented an overview of IDD with an emphasis on intellectual disability. This module addresses several important issues that must be considered by health care professionals who interact with people with IDD. These include secondary conditions, aging with IDD, common causes of mortality in people with IDD, challenging behaviors, and abuse. Although not all people with IDD will experience these health issues, it is important for all health care professionals to be aware of the issues so that they can recognize them and initiate prompt assessment and care if indicated.

Overview

People with IDD often have complex health care needs because of the extent of the underlying causes of IDD and the physical and psychiatric/mental health issues that may occur along with IDD. Although some of the issues identified and discussed in this module are more likely to be seen by health care professionals whose area of practice or specialty is focused on IDD or neurological or neurodevelopmental disorders, *all* health care professionals need a basic level of awareness and understanding of these issues. Awareness of these issues will enable health care professionals to be alert to their possible occurrence and to be prepared to respond appropriately if they occur. An understanding of these issues may in turn reduce the anxiety and fear that many health care professionals experience if they lack knowledge about IDD. Knowledge about these issues will ultimately improve the health status and health care of people with IDD.

Secondary Conditions

Secondary conditions are any additional physical or mental health conditions that occur as a result of the primary disabling condition, although they are not diagnostic features of the primary disability. People with IDD can have multiple secondary conditions, which can increase the severity of the primary disability and reduce their independence and quality of life (Koritsas & Iacono, 2011). Secondary conditions may also increase the costs of treatment and care, but too often they are not treated or are treated late in their occurrence. Communication issues on the part of those with IDD may be a factor in the failure of health care professionals to identify the presence of these conditions.

In addition to secondary conditions, persons with IDD may also develop other health conditions independently of IDD (comorbidities). Having a disability, such as IDD, does not preclude a person from developing other health conditions that are common in the population at large (e.g., cardiac disease, cancer, arthritis).

Secondary conditions are diverse and may include medical complications (e.g., pressure ulcers and urinary tract infections), psychiatric/mental health disorders (e.g., depression and anxiety), decreased physical fitness, weight problems, and issues of personal hygiene/appearance, including dental and oral hygiene. Depending on the underlying type of IDD, contractures and joint and muscle pain may occur. Some secondary conditions associated with IDD may be associated with behavioral or lifestyle issues. The following chart lists the array of secondary conditions that may occur in persons with IDD.

Secondary Conditions in Intellectual and Developmental Disability

- Access barriers/problems
- Allergic reactions
- Arthritis
- Aspiration
- Balance problems/dizziness/vertigo
- Cardiovascular/circulatory problems
- Communication difficulties
- Contractures
- Decreased mobility
- Dehydration
- Dental and oral hygiene problems
- Depression
- Diabetes
- Fatigue
- Hearing problems
- Infection and sepsis
- Gastrointestinal tract dysfunction (constipation, bowel obstruction, gastroesophageal reflux disease)
- Joint and muscle pain
- Medication side effects
- Memory problems
- Nutritional deficits
- Osteoporosis
- Personal hygiene/appearance issues
- Physical deconditioning
- Pressure ulcers
- Respiratory problems
- Seizures
- Sleep problems/disturbance/sleep apnea
- Thyroid disorders
- Urinary tract dysfunction (infection)
- Weight issues

It is important to keep in mind that the development of secondary conditions is not inevitable with IDD; prevention, as well as assessment and early intervention, are important. It is also important to avoid diagnostic overshadowing, which can lead to lack of treatment, undertreatment, or incorrect treatment of secondary conditions. Depression and anxiety disorders tend to be underdiagnosed in people with IDD while psychiatric/mental health disorders tend to be over diagnosed (Gentile et al., 2014). Secondary conditions may result in increased barriers and decreased mobility in the lives of those with IDD.

Causes of Mortality

Consequences of lack of appropriate treatment for secondary conditions include possible increased morbidity and mortality. The following secondary conditions have been referred to as the “Fatal 5 + 1” because of the risk of morbidity and mortality if unrecognized and untreated: aspiration, constipation/bowel obstruction, seizures, dehydration, gastroesophageal reflux disease, and sepsis (Smith & Escudé, 2015). Because of the possibility of communication limitations, information about these issues may come from family members or other caregivers who report subtle changes in usual behavior, using wording such as, “She is just not acting right,” “He is not participating in activities that he usually enjoys,” or “She has stopped eating.” The occurrence of these and other changes should result in a careful assessment of the person with IDD to ensure identification and prompt treatment of serious conditions that may occur (Smith & Escudé, 2015).

Aging With IDD

Although people with IDD have historically had a shorter life expectancy than those without IDD, their life expectancy has improved in recent years so that it is similar to that of the general population. As a result, increasing numbers of people with IDD are aging. Their life expectancy ranges from the mid-50s for those with more severe IDD and those with Down syndrome to the early 70s for adults with mild/moderate IDD. Many individuals will need support and assistance as they transition to older age. The goals of persons aging with IDD are similar to those of other aging populations: 1) being as independent as possible while maintaining physical and mental health, 2) engaging with others (family and friends), and 3) contributing to their community and to society (Heller, 2019). Achieving these goals may be more difficult for persons with IDD who may not have participated regularly in health promotion activities such as healthy eating, exercise, and preventive health screening. Differences in early mortality suggest the need for health care professionals to be knowledgeable about the etiology of a specific patient’s IDD and identify strategies to decrease the patient’s risks.

Health issues that affect other aging populations also occur in those with IDD, but may have an earlier onset in persons with IDD and other disabilities. Such health issues include: cardiovascular diseases, obesity, diabetes, epilepsy, gastrointestinal and genitourinary tract disorders (e.g., constipation, incontinence), bone and joint disorders (e.g., osteoporosis; arthritis), and thyroid disorders. Individuals are also likely to experience a decline in hearing, vision, and overall intellectual capacity as they age. As with other groups, the risk of dementia increases with aging. It is important to note that persons with IDD may have limited access to quality health care and fewer financial resources and social supports than others (Heller, 2019). In addition, those aging with IDD are likely to have aging parents and siblings who have provided assistance and support to them over the years.

Loneliness and social isolation, issues for many people who are aging, may be important issues for people with IDD, particularly if they have had limited contact outside their home or family. Attention to healthy aging of those with IDD and the development of plans to guide decision-making should be the same as what is provided to other adults who are aging. This includes supported decision-making, self-determination, and person-centered advance care planning, strategies that involve the person with IDD in the planning process so that the person’s wishes and preferences are adequately addressed (McGinley et al., 2021). Person-centered planning is based on principles of social inclusion, choice, and independence and involvement of individuals with IDD in identifying and pursuing their goals (Heller, 2019; McGinley et al., 2021; Community Living British Columbia, 2017).

Challenging Behaviors

People with IDD may exhibit challenging behaviors. Although the term *problematic behaviors* was previously used to describe these behaviors, *challenging behaviors* is preferred because it has a less negative connotation. Challenging behaviors are defined as abnormal or atypical behaviors of intensity, frequency, or duration that may threaten the physical safety of the person or others, or inappropriate and disruptive behaviors resulting in exclusion from community events or facilities (Emerson, 2001).

It is important to keep in mind that all behavior serves a purpose, has a meaning and origin, and reflects the interaction of persons with the environment (Ali et al., 2014). Behaviors are often the only means those with limited communication skills have to indicate the presence of pain, discomfort, fear, anxiety, and other health-related issues that affect them. These behaviors occur more often in persons with low communication ability (Hofmann & Müller, 2022). It is estimated that severe forms of such behaviors occur in 5% to 10% of persons with IDD and usually in those with severe or profound IDD. A person may exhibit one type of challenging behavior or multiple types.

Challenging behaviors can be related to the presence of undiagnosed health-related conditions. In addition to occurring with pain and discomfort, these behaviors may also occur with stress, fear, psychological trauma, dissatisfaction with surroundings, lack of support, or inadequate services. Although such behaviors may also occur with mental illness and neuropsychiatric disorders, health care professionals should not assume that these behaviors indicate the presence of mental or psychiatric illness. The risk of diagnostic overshadowing, in which these behaviors are automatically and erroneously attributed to the disability or attributed to mental or psychiatric illness, is high. Diagnostic overshadowing may result in lack of treatment of an underlying physical health issue, such as an abscessed tooth, or inappropriate treatment. Overtreatment of nonexistent mental health issues rather than assessment of the underlying cause of challenging behaviors may lead to polypharmacy.

It is also important to consider that what may be challenging in one culture, environment, or setting may be viewed as more or less serious in other cultures, settings, or situations. Strange or new environments, such as acute health care facilities, can be overwhelming for people with IDD and may trigger challenging behaviors. Conversely, one-to-one care in the person's home environment might be less threatening, thereby reducing the negative impact of challenging behaviors. The following table identifies categories of possible challenging behaviors and several specific examples.

Categories and Examples of Challenging Behaviors

Behaviors	Examples
Aggression/aggressive behaviors	Verbal aggression, physical aggression, threats and physical violence, throwing objects, hitting others
Destructive behavior	Breaking or damaging objects in the environment, setting fires
Disruptive behavior	Repetitive stereotypical, purposeless behaviors (hand waving, body rocking); screaming, smearing feces, setting off fire alarms
Self-injurious behavior	Self-biting, head banging, scratching
Inappropriate behavior	Inappropriate sexual behaviors

Although a thorough functional behavior assessment of the person with IDD who exhibits significant challenging behaviors is necessary to make a correct diagnosis and develop effective interventions, such assessment may be beyond the expertise or scope of practice of most health care professionals. If challenging behaviors occur and interfere with the care of persons with IDD, discussion with those who know the person well (family members, caregivers, direct support professionals) may provide information about 1) what situations trigger challenging behaviors in a specific person, 2) what strategies have been effective in decreasing those behaviors so that needed care can be provided, and 3) what is the most effective communication strategy to use with a person who is exhibiting challenging behaviors so that appropriate care can be provided. Such strategies might be removal of distractions (e.g., noise, light, commotion), use of measures known to reduce the person's stress, and strategies to promote the person's comfort and sense of safety. Elimination of situations that trigger challenging behaviors has been found to be an effective strategy. It is important to determine if medication and behavioral intervention strategies have been used in the past and their effectiveness.

Restraining, use of seclusion, sedation, or isolation, or otherwise punishing the person with IDD who exhibits challenging behaviors takes away the person's autonomy, violates the person's civil rights under the Americans with Disabilities Act (1990), is very likely to increase the behaviors, and must be avoided. Further, these strategies increase the risk of injury and abuse, psychological trauma (including post-traumatic stress disorder), and even death (Williams & Grossett, 2011). Assessment of factors that precipitate challenging behaviors is far safer and more effective than efforts to restrain or punish the person exhibiting these behaviors. Before any effort is taken to restrain a person with IDD because of challenging behaviors, policies that address such restraint in an agency or other setting must be consulted and followed.

Abuse in Individuals With IDD and Implications

An important consideration in interacting with people with IDD is related to the possibility that they have been abused in the past with effects on their overall health. Compared to persons without IDD, those with IDD are (Lund, 2021; Disability Justice, 2022):

- More likely to be abused (4-10 times more likely).
- More likely to be sexually abused (5-7 times more likely).
- More likely to be abused by someone they know (e.g., a caregiver).
- More likely to be abused repeatedly by the same person.
- More likely to remain in abusive situations.

People with IDD are likely to be abused more frequently and for longer periods of time than those without IDD. They are less likely than others to have access to the law enforcement system, advocates, health care professionals, and social services, which leads to continued abuse.

Abuse can take many forms, including neglect, physical and/or sexual assaults, bullying, emotional abuse, exploitation, and use of restraints or other punitive actions in attempts to control or punish the person with IDD. Those who require assistance with personal activities (e.g., bathing, dressing, toileting) are at high risk for abuse, including sexual abuse. These abusive experiences are likely to decrease their sense of self-worth and dignity and instill fear in them and distrust of others. People with communication limitations are often unable to report abuse that has occurred, or they may not be believed if they do report it.

Cognitive, physiological, and behavioral effects of trauma may be the only indicators of abuse and should not be ignored. The following table provides examples of possible effects of abuse that may indicate the need for further assessment of the person with IDD, particularly if the effects represent regression of previous skills and adaptive behaviors.

Possible Effects of Trauma on Persons with IDD

Cognitive Effects	Difficulty acquiring new skills, difficulty processing new information, deterioration of previous communication skills.
Physiological Effects	Frequent abdominal pain or headaches, difficulty sleeping, loss of acquired developmental skills, bed-wetting and soiling.
Behavioral Effects	New onset of challenging behaviors, such as aggression, screaming, or crying excessively, irritability, verbally abusive behavior, being fearful, and avoidance of people or situations.

Because unwanted touch may trigger the occurrence of these responses, it is important to avoid touching someone with IDD without first explaining what part of the body will be touched along with the reason for the touching, and then obtaining permission from the person to do so. Failure to do so may trigger negative responses and behaviors in those who have experienced abuse in the past. To promote and maintain positive relationships that support the physical and emotional health of people with IDD and reduce experiences of trauma or sense of revictimization, health care professionals need to be thoughtful about their verbal and physical actions when interacting with and caring for people with IDD (Disability Justice, 2022).

Summary

This module has addressed several important and often sensitive and difficult-to-manage issues that may be factors in the reluctance of health care professionals to interact with people with IDD. It is important to understand the factors that may underlie the occurrence of challenging behaviors as well as the role of health care providers in providing safe health care in a safe environment with further assessment and referral when appropriate. Promoting the dignity and worth of those with IDD should be paramount when providing care. Multiple resources are available to assist people with IDD, family members and other caregivers, and health care providers in addressing these often difficult issues.

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Module 6

Important Differences Between Intellectual Disability and Autism Spectrum Disorder

Objectives:

At the end of this module, the learner will be able to:

- describe major differences in intellectual disability (ID) and autism spectrum disorder (ASD).
- identify common characteristics of ASD.
- explain the possible consequences of ID and ASD when they occur together.

Introduction

In this module, the distinction between intellectual disability and autism spectrum disorder (ASD) is discussed. Note that the focus of this module is on intellectual disability (ID) rather than intellectual and developmental disability (IDD), a broader term, in order to make a clear distinction between intellectual disability and ASD.

ASD, an umbrella term rather than a single disorder, is not an intellectual disability, but it often affects learning and can be accompanied by delays in adaptive capacity. Consequences of those delays, which can also occur with ID, include deficits in language, communication, and emotional responses. About 30% of people with ID have also been reported to have ASD (Thurm et al., 2019). Although both ID and ASD are neurodevelopmental disorders, there are important differences between them; however, the similarities in various features that may occur in ID and ASD may make it difficult to distinguish between these disorders. One important difference is that people with ASD may have normal or high-normal IQ scores while those with ID have IQ scores of 70 and below. When a person has both ID and ASD, the severity of ID and the issues that occur with ASD (e.g., deficits in communication, repetitive behaviors, limited interests, lack of social skills and interactions, delays in fine motor development) result in greater functional limitations than in ID or ASD alone (Thurm et al., 2019).

The National Institute of Mental Health (2022) describes ASD as a neurological and developmental disorder that affects how people interact and communicate with others, learn, and behave. It generally appears in the first two years of life, although it can be diagnosed at any age. The wide variations in type and severity of symptoms with ASD result in its being labeled a spectrum. Some defining characteristics of ASD are identified in the following chart:

Characteristics of Autism Spectrum Disorder (ASD)

- Lack of expressive verbal communication; 30% of people with ASD may be nonverbal or minimally verbal (Koegel et al., 2020)
- Repetitive or unusual behaviors (repeating words or phrases; having an interest in specific topics and inability to respond to or engage beyond those topics)
- Need for unvarying routine and difficulty coping with changes and transitions
- Increased sensitivity and aversion to sensory input (light, noise, temperature, touch)
- Limited eye contact with others and lack of social skills and ability to respond to others
- Inability to perceive, interpret, or respond to social cues and behaviors of others
- Delays in development of motor skills

Despite the importance of verbal communication, the absence of verbal communication in individuals with ASD does ***not*** mean that they are unable to process and interpret information. Nor do limited verbal skills mean that they cannot learn, comprehend, or communicate using alternate communication strategies. Many individuals with ASD clearly understand spoken words but may communicate using nonverbal strategies such as written words, pictures, flash cards, gestures, body language, and electronic and nonelectronic communication boards. They may be strong visual and auditory learners or demonstrate the ability to learn information in detail and retain it for an extended period of time. They may also excel in math, science, music, or art.

The changing definitions of neurodevelopmental disorders and the identification of features and overlap of expected symptoms of each type indicate the evolution in thinking about these disorders, their diagnoses, and treatments. The difficulty in distinguishing between these disorders in some people suggests there is a continuum of neurodevelopmental disorders. For example, symptoms of attention-deficit hyperactivity disorder (ADHD), another neurodevelopmental disorder, can include inattention and/or hyperactivity/impulsivity leading to impairments in many aspects of living. These behaviors are also common features of ASD and may also occur in persons with ID. Of importance is the need to ensure the safety of individuals with profound autism; 24-hour supervision is essential because of self-harm behaviors and serious risks associated with these behaviors.

Summary

This module provides a general overview of ASD and the major differences between ID and ASD, both neurodevelopmental disorders that affect the functioning of the neurological system and brain. It reviews the behaviors and characteristics that commonly occur with ASD and identifies important considerations when an individual has both ID and ASD.

Recognizing and acknowledging the differences between intellectual disability and ASD, the modules in this toolkit primarily address issues that are characteristic of ID or IDD more broadly, but may occur with ASD, which often include communication skills. Issues addressed in these modules may be relevant in persons with ASD as well as persons with intellectual disability, such as communication, social determinants of health, societal attitudes, bias, ableism, and stereotyping. Additionally, these modules address general and select health-related issues that may affect intellectual development in persons diagnosed with either IDD or ASD.

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