Module 1: Introduction & Sensitivity Exercise

Module 2: Overview of Developmental Disabilities

Module 3: Who We Are
United Cerebral Palsy of New York City, Inc. (UCP of NYC) is the leading nonprofit agency in New York City providing direct services, technology and advocacy to children and adults with cerebral palsy and other disabilities. UCP of NYC offers a breadth of more than 75 comprehensive programs including medical, clinical, educational, technological, residential and rehabilitative services to over 14,000 New York City residents and families annually. Our services are delivered by a staff of more than 1,500 trained and dedicated individuals, including many employees who themselves have disabilities.

To learn more please go to:

www.ucpnyc.org
The mission of United Cerebral Palsy Of New York City is to create opportunities to lead independent and fulfilling lives.
Why HealthLink?

Due to the significant shortage of Nurses experienced and skilled in the needs of individuals with developmental disabilities who are also medically fragile, the NY State Developmental Disabilities Planning Council (DDPC), with input from the community, released a request for proposal to develop a curriculum to increase sensitivity and skills for nurses. In 2008, UCP of NYC won that 3-year grant and developed HealthLink for Nurses, a disability and sensitivity training curriculum.

In 2012, the Delaware DDPC released a request for proposal to utilize UCP of NYC’s HealthLink for Nurses to train Delaware nurses. Wesley College won that award and as a result, UCP of NYC’s curriculum is now being used in Delaware and across the country through this web training.

Since HealthLink was developed, over 1,000 Nurses and healthcare professionals have been trained nation-wide, increasing access to quality healthcare to 100’s of thousands of individuals with disabilities.
HealthLink’s Overarching Goal

Enhance the quality and availability of nurses who can provide health care for children and adults who are medically fragile with developmental disabilities.
INDIVIDUALS WHO ARE MEDICALLY FRAGILE

- Children and adults with intense health care needs, that is, those with one or more medical diagnosis impacted by the presence of a disability and resulting in increased severity and risk from complications
- Typically require complex health procedures, special therapy or specialized medical equipment to enhance or sustain their lives
- Not all people with developmental disabilities are medically fragile
Objectives

• Appreciate disability concepts

• Understand the functional consequences of illness related to social and environmental factors

• Recognize disparities in health care for people with disabilities

• Understand the roots of disability rights legislation

• Understand the nurse’s role in the provision of care

• Understand general principles and etiquette for interacting with persons with disabilities

• Critically reflect on personal attitudes and assumptions about people with disabilities and how these may impact on the delivery of care
Competencies

WHAT YOU WILL BE ABLE TO DO BY THE END OF THE TRAINING

• Explain
  – The role played by the physical and social environment in the disabling process
  – The differences between palliative and hospice care for individuals who are medically fragile

• Discuss
  – Existing health disparities from social and historical perspectives
  – Recommendations for preventive and wellness care
  – The person-first concept and provide examples of person-first language
  – Personal attitudes, assumptions and misconceptions about individuals with disabilities
Competencies

WHAT YOU WILL BE ABLE TO DO BY THE END OF THE TRAINING

• Identify
  – The hallmarks of patient- and family-centered care
  – At least four barriers to health care and strategies to surmount them

• Describe
  – The nurse’s role throughout the continuum of care
  – At least two ways nurses can assist people with disabilities to feel more comfortable during doctor visits

• Apply best practice principles to case study vignettes
How we will accomplish our goals

• Multi-dimensional disability training that incorporates:
  – Lectures
  – Case vignettes*
  – Interview with a person who has a disability
  – Group exercises and discussions*
  – Evaluation*

Only asterisk* items will be used in this online format
Topics

• Sensitivity Exercise
• Why this training?: Defining the Problem
• Overview of Developmental Disabilities
  – Disability rights history
  – What are developmental disabilities?
  – What makes a person with a disability medically fragile?
  – Models of disability
  – Secondary conditions
  – Service needs
  – Removing barriers to care
  – Best practices throughout the continuum of care
  – Disability-related myths & promoting change
Defining the problem

WHAT THE MEDICAL LITERATURE SAYS

- Inadequate care
- Well-meaning but insensitive health care providers
- Ineffective patient-provider communication
- Inaccessible medical equipment
- Lack of environmental accessibility
- Poorly coordinated care
- Lack of a long term focus on prevention
People with disabilities have...

- Higher than average
  - rates of chronic conditions
  - difficulties in accessing care
  - rates of hospitalizations
  - rates of preventable medical problems

- Lower
  - Rates of formal patient education
  - than average use of health care system for preventive care

- A preventable mortality rate 4 times higher than the general population
Children who are Medically Fragile

- Growing number of children living with chronic illnesses and complex medical conditions

- Advances in medical technology and treatment options now sustain infants’ lives

- Newborns routinely survive severe prematurity, traumatic births and congenital conditions, but remain dependent on comprehensive care throughout their lives
Life Expectancy

• Life expectancy in 2000 for people with intellectual disability:
  – Mild to moderate intellectual disability - 66 years
  – Severe intellectual disability – 53 years
  – General population - 77 years

• Many of these deaths are avoidable and unnecessary and result from numerous barriers to health care faced by people with developmental disabilities.
Barriers to Health Care

- Architectural
- Medical equipment
- Communication
- Economic
- Social policy
- Attitudinal
- Inadequate provider knowledge
Sensitivity Training

The following exercises are designed to provide an opportunity for you to perform everyday tasks in an uncommon way, that is, with a physical limitation, so that you can interact with individuals with disabilities with a higher degree of sensitivity to their needs and experiences.
This is an online offering; participate in Activity #1 and review Activities 2 and 3:

Activity #1
Get 3 socks along with a stack of 15 sheets of paper. Place the socks on the hand NOT used for writing, and place the other hand behind your back. One by one, remove 15 sheets of paper from the stack using the socked hand and place each individual sheet in a neat stack.

Activity #2
Give each person one index card with a directive written on it. Do not reveal what is written on the card to your partner or to others in the group. Read it privately and then place it face down on the table so that it cannot be seen. Each person will attempt to communicate nonverbally to their partner what is written on the care without mouthing the words. After 5 minutes, the roles will be reversed.

Activity #3
Give each person a cup of water. Remaining seated, clasp your hands behind your back while allowing your partner to help you drink a cup of water. You are unable to communicate verbally to your partner. After 5 minutes reverse roles.
Sensitivity Training Questions

• Physical Limitation Role:
  – What was it like for you to perform the task with a limitation?
  – What did you notice about your feelings and behavior?
  – What did you notice about your partner’s reactions, behavior and feelings toward you?

• Partner Role:
  – What was it like for you to be the “partner?”
  – What did you notice about your feelings and behavior?

• General Questions:
  – What did you learn about yourself in each role?
  – Was there anything that surprised you about your reactions during the exercise? Explain.
  – How do you think this experience will be relevant to you as a nurse?
Sensitivity Exercise “Take Away”

• Disability does not define a person

• Recognize personal attitudes, assumptions and perceptions—they are the foundation of our actions

• Disability is part of the human experience

• Use Person First Language - People with disabilities want to be seen as “people first” not in terms of their disability or condition
MODULE 2

Children and Adults who are Medically Fragile
Disability Rights History

• The era of institutionalization

• Pioneering Civil Rights Legislation:
  – The Americans with Disability Act – ADA

• The new philosophy: self-determination, independence, community inclusion
Institutionalization

- Willowbrook State School on Staten Island, New York opened its doors to residents in 1942
- A notorious example of the failure of institutions to meet the needs of the people they were intended to serve
- Finally closed in 1987
Institutionalization

Deplorable living conditions
Institutionalization

Abuse, injuries and experimentation were common

Control rather than treatment was the norm
AMERICANS WITH DISABILITIES ACT (ADA)

- The ADA, signed into law in 1990, was the nation’s first comprehensive civil rights law for people with disabilities and prohibited discrimination in employment, public services, public accommodations, telecommunications and other areas.

- Includes provisions on accessibility and equal opportunity in the most integrated setting.
The New Philosophy

• Focus on community integration, independence and self-determination.

• Affirms that all individuals with disabilities should experience the benefits of family and community living while receiving those services necessary to maintain health and fully develop their potential.
Where We Need to Go

• Architectural, attitudinal, social policy, economic and other barriers to full equality are still prevalent.

• Real issues of discrimination still remain and no where is this more evident than in the lack of access to health care.
Definition of Developmental Disability

- Lifelong physical and mental impairments that impact an individual’s cognitive, social, and/or physical development
  - Manifested prior to age 22
  - Requires ongoing individualized services and support

- Result in significant limitations in daily functioning in three or more of the following areas:
  - Self care
  - Receptive/expressive language
  - Learning
  - Mobility
  - Self-direction
  - Capacity for independent living
  - Economic self-sufficiency
Examples of Developmental Disabilities

• Intellectual Disability
• Cerebral Palsy
• Epilepsy
• Autism
• Spina bifida
• Other neurological impairments
International Classification of Functioning, Disability & Health

• More holistic model

• Emphasis on level of health & functioning

• Understands disability as an interaction between the individual and the environment

• Considers social and environmental barriers in determining level of functioning and ability to participate in the community

HealthLink
Prevalence of Developmental Disabilities in the U.S.

• 11.3 per 1000 in non-institutionalized population

• 15.8 per 1000 if institutionalized populations are included (nursing homes, group settings, psychiatric facilities, etc.)

• Source: Analysis of data from National Health Interview Survey-Disability Supplement (NHIS-D) 1994 – 1995 at Univ. of Minnesota’s Institute for Community Living.
Children with Special Health Care Needs

• “…those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”

• Nearly 14% of all children under the age of 18 in the USA in 2005

• Of these, no reliable data exists on those who are medically fragile

• Difficulty accessing health services for young people as they transition from pediatric or adolescent to adult health care
Risk Factors

- Developmental disabilities usually involve dysfunction of, or injury to, the central nervous system and can be caused by genetic, biological or environmental factors that can occur at any time before or during the birth process as well as post-natally.

- In some cases, a definitive cause may never be determined.
Risk Factors

• Premature birth
• Brain injury
• Lack of oxygen to the brain
• Defects in brain formation
• Maternal-fetal infections
• Abnormalities of chromosomes and genes
• Substance abuse during pregnancy, including alcohol intake and smoking
• Head trauma
Major Risk Factors

• Infections during pregnancy
  – Rubella, CMV, Herpes, Toxoplasmosis

• Insufficient oxygen reaching the fetus
  – Improper functioning of the placenta

• Preterm births, LBW (less than 3 1/3 lbs)
  – Tiny babies can suffer from bleeding into the brain or develop periventricular leukomalacia (PVL); alcohol/drug misuse and smoking
Major Risk Factors

• Asphyxia during labor and delivery
  – Only 5-10% of cases
• Blood clotting diseases (Thrombophilias)
• Severe jaundice
  – RH disease, untreated high bilirubin levels
• Other birth defects
  – Brain malformations, chromosomal and genetic defects, alcohol/drug misuse and smoking
• Post-natal acquisition
  – About 10%, during first few years of life from head injuries, meningitis
Secondary Conditions

• Medical, physical, cognitive, emotional or psychosocial complications resulting from a primary disabling condition

• Primary disabling conditions increase risk of secondary conditions

• Increases level of disability, which further impedes daily activities and quality of life

• Worsens with age in terms of number, severity, and impact on life activities

• Premature mortality

• Are often preventable medical conditions that are far more costly to treat than to prevent!
Examples of Secondary Conditions

- Neuromusculoskeletal conditions such as osteoporosis, contractures, scoliosis, arthritis
- Digestive difficulties
- Urogenital problems
- Respiratory problems
- Fatigue
- Endocrine problems like amenorrhea
- Early aging, including early onset AD in Down Syndrome
- Skin breakdown
- Cardiovascular diseases
- Thyroid problems
- Emotional & Psychosocial problems
- Dental problems and periodontal disease
- Polypharmacy
- Fungal infections
- Obesity
- Diabetes
Secondary Conditions

WOMEN WITH PHYSICAL DISABILITIES

- Women with physical disabilities have an average of 14 secondary conditions
- 8 times more likely to have osteoporosis
- 6 times more likely to have diabetes
- 4 times more likely to have depression
- almost 3 times more likely to have high blood pressure
- more than twice as likely to be obese
Service Needs

• Service needs vary widely.

• Depends on the type and severity of the functional impairments as well as individual differences such as health status and personal interests.

• Most individuals can live in the community and lead productive lives with services and supports that meet their individual needs and preferences.
Service Needs

Service needs can include Medical & Nonmedical Interventions

**MEDICAL**
- Adaptive equipment
- Augmentative communication devices
- Physical, occupational, speech therapy
- Proper positioning, lifting and transferring and feeding
- Proper positioning during GYN, dental and prostate exams
- Accessible medical equipment and medical suites
- Psychological or psychiatric services
- Specialty medical care based on secondary conditions and other medical problems
- Preventive services and exams
Service Needs

NON-MEDICAL

• Early Intervention and specialized education
• Architectural modifications in the home
• Residential placement
• Family support
• Skill development through day programs and habilitation training
• Health promotion programs sensitive to people with developmental disabilities
  – Accessible exercise and recreation facilities, smoking cessation
• Disability-sensitive patient education and written materials in alternative formats
Removing Barriers to Care

• Can patients in a wheelchair move easily throughout the facility?

• Can you communicate with patients who are nonverbal or hearing-impaired?

• Can you see the whole person and their abilities, not only their disability?

• Can patients using mobility devices step-up on to the exam table?

• Can you weigh people who can’t stand on a scale?

• Can you provide mammograms for women who use wheelchairs?
Removing Barriers to Care

Medical equipment often requires patients to stand or climb, and the inability to use that equipment can keep people from getting the medical care they need.
Removing Barriers to Care

Accessible Exam Table

Accessible Scale
Removing Barriers to Care

THE MOST ACCESSIBLE MEDICAL SUITES HAVE:

- Wheelchair accessible entrances, hallways, bathrooms, doorways, exam rooms and reception areas
- Adjustable-height examining and treatment tables
- Platform scale
- Staff trained to assist with lifting, transfers and dressing
- A Hoyer lift when staff are not able to assist with transfers
- Easily understandable written materials available in alternative formats
Removing Barriers to Care

NONPHYSICAL ACCESS ISSUES INCLUDE:

• problems with interpersonal communication
• inflexible scheduling and procedures
• inadequate facilities
• attitudinal barriers
Removing Barriers to Care

ATTITUDINAL BARRIERS

• Stigmatizing people with disabilities is an attitudinal barrier that is evident in how people think about, talk about and behave around people with disabilities.

• Stereotyping and infantilizing people with disabilities are just two ways that attitudinal barriers are expressed.

• Can you think of others?
Removing Barriers to Care

- It is important for health care providers to realize that stigmatization, shame, and fear of negative evaluation by others, can be part of everyday life for all people with disabilities.

- Successful access means successful use of services and leads to more positive outcomes.
Marlene is a 50 year old woman who uses a wheelchair because of a mobility impairment. The clinic where she receives her primary care schedules her for a gynecology appointment for severe vaginitis. Marlene arrives at the gynecologist’s office, registers at the desk, and joins five other patients in the waiting area where she waits 1.5 hours until she is finally called into the exam room. In the exam room, she is advised that the electric, height–adjustable exam table is not functioning. The nurse says, “Sweetie, can you get undressed and get on the table? If not, we’ll have to reschedule your appointment… the doctor will be here in five minutes.”
Marlene’s Story

TAKE AWAYS

• The provider communicated poorly and was not very sensitive to the patient.
• The office could have called Marlene in advance to let her know that the accessible table was broken.
• They might have tried to locate a Hoyer lift or staff to help transfer.
• The nurse called her “Sweetie”
• The nurse did not ask Marlene if she needed assistance undressing.
Communication Tips

• Take time to put the patient at ease

• Speak directly to the patient, even if they are accompanied by a person without a disability or a sign-language interpreter

• Be considerate of the extra time a patient with a disability may need to communicate, understand or get things done

• Listen without interruption

• Speak to adults as adults (avoid words like ‘sweetie’ or ‘honey’) and children as children
Communication Tips

• Be sensitive to non-verbal behavior as cues to the patient’s feelings and experience of pain

• Encourage use of augmentative communication device if patient uses one – allows direct patient-provider communication.

• Recognize that caregivers come to the medical setting with their own feelings and biases, which can mislead the practitioner

• Provide flexible scheduling procedures whenever possible
Communication Tips

• Interview in quiet, private location and avoid interruptions

• Sit at eye level during interviews with patients who use a wheelchair

• Ask the person with a disability if he or she needs any help – don’t assume help is needed

• See the whole person and their abilities, not just the disability

• Understand that lack of access to work, school, health care, or fun things to do can cause more problems than a disability itself
Person first language is the most appropriate terminology to use when communicating with or about people with disabilities – it puts the emphasis on the person, not the disability and is respectful and considerate.
Person First Language

**SAY**
- Person with a disability
- Person with a physical disability
- Person with cerebral palsy or visual impairment, etc.
- Person who uses a wheelchair
- Person with a hearing impairment, hearing loss, person who is deaf
- Accessible parking, accessible toilets, etc.

**AVOID**
- Victim, suffers from, deformed
- Crippled, the crippled, crippling, invalid
- Afflicted by / with or blind / can’t see
- Wheelchair bound, confined to a wheelchair
- Deaf and dumb, deaf mute
- Disabled toilets, handicapped parking, etc.
Implications for Nursing Practice

• What are the best practices in the care of children and adults who are medically fragile?

• And what are the implications for nursing practice?
Patient- and Family-Centered Care

- Adopts the patient’s and/or family’s perspective

- Views patients and/or family as equal partners in care
Patient- and Family-Centered Care

• Primary components:
  – Respect for patients’ values, preferences, needs
  – Coordination and continuity of care
  – Information, communication and education
  – Physical comfort
  – Emotional support and alleviation of fear and anxiety
  – Involvement of family, guardians, caregivers, friends
Best Practices in Care Coordination

INDIVIDUALS WHO ARE MEDICALLY FRAGILE

- Interdisciplinary team approach
- Individualized plan of care
- Meets education and training needs of the caregiver
- Ongoing treatment planning meetings to review and revise plan
- Intensive RN case management
- Electronic medical records
- Medical homes
Best Practices in Care Coordination

INDIVIDUALS WHO ARE MEDICALLY FRAGILE

- Recognizes responsibility of care often lies with family members, particularly when children, of any age, who are medically fragile live at home

- Understands the lives of family members caring for their child are far from normal: can lead to lost income, career opportunities, and leisure time as well as higher incidence of divorce, depression, social isolation and acting out among healthy siblings
FEATURES OF PALLIATIVE CARE

• Interdisciplinary team approach

• Seeks to prevent and relieve the symptoms produced by their conditions

• Prevention and relief of symptoms from complex, chronic, life-threatening medical conditions or their treatment

• Stresses pain management, optimum quality of life, and comfort care

• Helps patients who are medically fragile and their families live as normally as possible at home
Palliative Care

- Empathic, developmentally and culturally sensitive support
- Intensifies as needed with changing goals of care
- Most effective for children when combined with disease-modifying care at diagnosis
- Extends the hospice concept of care to embrace patients who experience pain or discomfort but who do not necessarily qualify for hospice services
Palliative Care

• Addresses psychological, social, spiritual and medical issues

• Timely and accurate information and support in decision making for patients/families

• Intensifies as appropriate with changing goals of care

• Gives support and information to families or individuals
MAJOR COMPONENTS OF HOSPICE CARE:

• May be provided at home or in a hospice center

• Primary medical provider coordinates care with patient, family and hospice team

• Addresses medical, emotional and spiritual needs of patient and family

• Hospice team assess home environment to assure meets patient and family needs
Implications for Nursing Practice

NURSES ROLE

• Coordinate care with other providers
  – Family members
  – Services coordinators
  – Health professionals

• Case management and advocacy
  – Talk with patient and their family to identify needed supports and connect them to programs/services within their home and community
Implications for Nursing Practice

NURSES ROLE

• Provide nursing assessment and develop a care plan with the interdisciplinary team
  – Design a patient and family-centered care plan that incorporates presenting medical problems while also considering the pre-existing developmental disability.
Implications for Nursing Practice

NURSES ROLE

• Teach about prevention
  – Help patient understand importance of engaging in activities and behaviors that promote health and wellness such as proper diet, exercise, smoking-cessation and prevention of sexually transmitted diseases.
  – Provide written materials in alternate formats.
  – Good curricula exist for teaching wellness.
Implications for Nursing Practice

NURSES ROLE

• Schedule preventive and restorative health screenings and services
  – Full immunizations; well baby/child/adolescent visits; GYN visits for birth control, Pap smears and mammograms; prostate screenings for men; colorectal exams; EKG; hearing, urine, glucose & bone density tests; vision screenings; mental health referrals, etc.
• Follow-up with phone call to assure follow-through with recommendations and treatment plan
Implications for Nursing Practice

NURSES ROLE

• Teach methods for health maintenance
  – Sufficient rest and fluid intake, handling medication side effects

• Promote accident prevention
  – Assure accessibility through use of shower grab bars, hand rails, increased lighting, area rug removal.
Implications for Nursing Practice

NURSES ROLE

• Monitor health status
  – Temperature control to avoid hypothermia
  – Skin integrity for those confined to a bed or who use a wheelchair
  – Changes in independent functioning
  – Assess need for home attendant services to assist with care

HealthLink
Implications for Nursing Practice

NURSES ROLE

• Educate about specific health issues
  – Increase patient’s awareness and understanding about their specific disability and their other medical conditions such as diabetes or seizures
  – Meet education and training needs of the family/caregiver

• Acknowledge personal preferences and choices
  – Prefers liquid medication to tablets
Implications for Nursing Practice

NURSES ROLE

• Medication management
  – Can be challenging for many reasons:
    • Lack of compliance with medication schedules.
    • Polypharmacy increases potential for side effects/drug interactions. Look for signs/symptoms, bring to attention of primary care practitioner for further evaluation.
    • Difficulty swallowing medications. Seek alternatives and discuss with pharmacist or MD.
    • Monitor for side effects or complications from medications
Implications for Nursing Practice

NURSES ROLE

• Awareness of special accommodation needs
  – Read medical history prior to visit; prepare adequately to provide reasonable accommodations according to patients physical and psychosocial needs.
  – Reasonable Accommodation Examples
    • space for a seeing eye dog
    • wheelchair accessible dressing
    • exam rooms and bathrooms
    • assistance with dressing and transfers
    • scheduling considerations for behavioral issues
    • extra time for the visit
Best Practice Case Vignettes
Vignette #1
Gail is a 40-year-old woman with normal cognitive ability but very limited mobility due to cerebral palsy (spastic quadriplegia). She is non-verbal because the CP has affected her speech, making it difficult for her to articulate words. She is accompanied on the doctor visit by her mother, her primary caregiver, who tends to infantilize her by not recognizing her cognitive capacity. The nurse is gathering preliminary data to develop a health history. She directs her questions to Gail’s mother, asking the typical history-taking questions. When she asks about Gail’s sleep and eating patterns, the mother responds that Gail has no trouble eating or sleeping. At this point, Gail makes a face. The nurse continues to address Gail’s mother. Finally, Gail utters a loud screech which catches their attention. The mother dismisses it by saying that it’s probably nothing, she does it occasionally.

What should the nurse do and why?

Vignette #2
Michael is a 10-year-old male with spina bifida and moderate mental retardation. He has a G-tube and a BMI of 17. According to the residential staff who accompanied him to the medical appointment, Michael ahs not been having regular bowel movements. The staff report that he has bowel movements every 3-4 days. Michael frequently complains of abdominal pain or exhibits severe behavioral outbursts that have become increasingly violent as his bowel habits worsen.

What can the nurse do to improve the outcome of this medical visit?
Vignette Answers

• Vignette #1
  Conversation should be directed at the individual receiving service. The parent, although present, may not respond as quickly if she were to observe that the questions are being directed at the patient. If the parent were still to answer first, it would be appropriate to readdress the question again to the patient and ask the patient if the response reflects what he or she wishes to say.

• Vignette #2
  Ask the patient or the staff what is currently being done when Michael does not move his bowels after 3-4 days. Ask to see if there are protocols in place to address the constipation issues. Michael’s behaviors may be due to the constipation that is causing him discomfort. The nurse must ask important and appropriate questions to get a good history from the patient or staff. It is important to find out what Michael is eating through the G-tube which also may be contributing to his constipation issues. Is Michaels’s fluid intake being monitored at home?
Trends in the Disability Field

- Scientific advances

- Use of assistive technology and accessibility modifications to support independence and productivity

- Shift from medical to social model, and from institutionalization to community and home-based care

- Emphasis on health and functioning rather than disability, and on wellness and health promotion

- Workplace accommodations to support employment of people with disabilities

- Wide range of service options such as special education services within schools and day habilitation programs
Myths

• Disability is exclusively a medical issue
• People with disabilities will never be able to live, work and be productive in society
• People with disabilities are not interested in sex and aren’t sexually active
• Everyone with a speech and language disorder has an intellectual disability
Myths

• Having a disability means you cannot be healthy

• People with disabilities always need help

• The lives of people with disabilities are totally different than those of people without disabilities

• The physical and social environment plays no role in disability
Myths

There’s nothing one person can do to help eliminate the barriers confronting people with disabilities…
Promoting Change

WHAT YOU CAN DO TO PROMOTE CHANGE

- Advocate for a barrier free environment in and outside the medical setting
- Learn about the ADA’s equal access provisions
- Understand reasonable accommodation for special needs
- Keep informed about disability-related disparities in health care
- Be aware of your attitudes, stereotypes and misconceptions
- Speak up when negative disability-related words or phrases are used
- Accept people with disabilities as individuals with the same needs and feelings as you
- Request courses on disability education be included in the required nursing school curriculum
- Do fieldwork and clinical rotations in settings that provide services for people who have developmental disabilities
Interview FAQ

• What kinds of activities can you do yourself?

• Who helps you with self-care issues?

• Do you go to medical appointments by yourself?

• Do you always understand the medical information that you get or receive from doctors and nurses?

• How should health professionals communicate with you?

• What can health professionals do to make you feel more at ease during exams?
Wake Up Call FAQ

• What did you learn that you didn’t know before?

• What stood out for you the most?

• How will it be helpful to you in working with people with disabilities?
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- Permission to use this HealthLink Curriculum for Nurses was approved by the United Cerebral Palsy of New York City.

- We request that you please take the necessary time to complete the Survey Monkey.

<a href="https://www.surveymonkey.com/s/DevelopmentDisabilities">Click here to take survey</a>
Thank you

Click here to take survey
Resources

• Center for Disability Issues and the Health Professions
  http://www.cdihp.org/about.html

• Center for Research on Women with Disabilities
  www bcm.edu/crowd

• DBTAC Northeast ADA Center
  http://www.ilr.cornell.edu/edi/dbtacnortheast/index.cfm, 1-800-949-4ADA

• My Child Without Limits
  www.myChildWithoutLimits.org

• Check out fieldwork, clinical rotations and volunteer opportunities at UCP of NYC
  www.ucpnyc.org

• Peruse the reference guide