

Building Capacity among Pediatric Residents to Promote Health Advocacy among Persons with Developmental Disabilities

CURRICULUM



RRTC

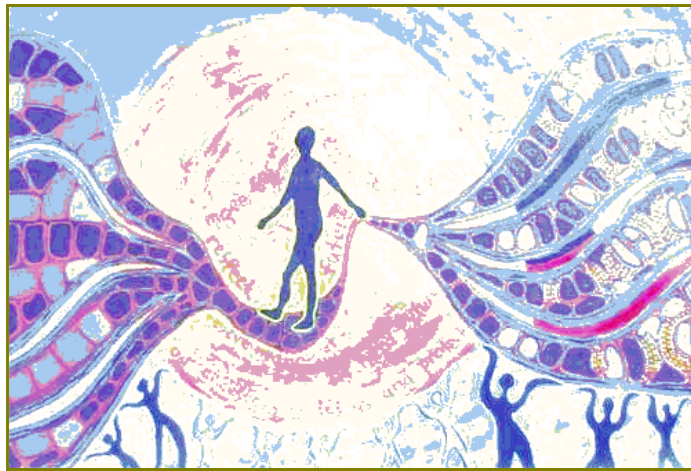
**ADD Rehabilitation Research and Training Center on
Aging with Developmental Disabilities**

UIC Department of Disability
UNIVERSITY OF ILLINOIS
AT CHICAGO and Human Development
COLLEGE OF APPLIED HEALTH SCIENCES

In Collaboration with the UIC Division of Specialized Care for Children
and the American Academy of Pediatrics

In Partnership with Illinois Council on Developmental Disabilities

Building Capacity among Pediatric Residents to Promote Health Advocacy among Persons with Developmental Disabilities



A Project of the
Rehabilitation Research and Training Center on Aging with Developmental Disabilities

In Collaboration with the
UIC Division of Specialized Care for Children
and
the American Academy of Pediatrics

Through a Partnership with
Illinois Council on Developmental Disabilities

**Beth Marks, RN, PhD
Jasmina Sisirak, MPH
Ann Cutler, MD**

The contents of this curriculum do not necessarily represent the policy of the Illinois Council on Developmental Disabilities and should not be viewed as an endorsement by the State government.

RESEARCH TEAM

Beth Marks, RN, PhD, Principal Investigator
Jasmina Sisirak, MPH, Co-Investigator
Ann Cutler, MD, Co-Investigator
Tamar Heller, PhD, Co-Investigator

ACKNOWLEDGMENT

We would like to acknowledge the work conducted by the dedicated project staff of the RRTCADD. The work on the Resource List and the Adapted Health Care Tool Kit was done by Orlando Torres, Yen-Ching Ming, MS entered the survey data and Erika Magallanes and Barbara Cole provided organizational assistance. Additionally, we would like to thank all the participating pediatric residency sites: Judy Fregetto, MBA, MPH and Frank Belmonte, MD, Advocate Lutheran General Children's Hospital; Michael Lotke, MD, Children's Hospital/Mount Sinai Hospital Medical; Mary Kate Fleming and Barbara Bayldon, MD, Children's Memorial Hospital; Alejandro Clavier, MD, UIC College of Medicine at Chicago; Lawrence Roy, MD, Mary Jones, MD, and William Frese, MD, UIC College of Medicine at Chicago/Christ Hospital Program; Peter J. Smith, MD, University of Chicago Medical Center and Stroger Hospital of Cook County Pediatric Residency Program. Finally we would like to thank our Host Sites for providing constant feedback and support to the project: Sarah Triano and Amber Smock, Access Living; Jane Doyle, PhD and Cynthia Witherspoon, Center for Independent Futures; Peter J. Smith, MD and Pam Shapiro, NP, RN, Illinois Center for Rehabilitation and Education-Roosevelt; Vladimir Cuk, MS, The Institute on Disability and Human Development; Lawrence C. Vogel, MD, Chicago Shriners Hospital for Children; Nicole Lange, Debbie Victor, Serena Prather, and Sue Mukherjee, MD, The Rehabilitation Institute of Chicago; Tanya Melich-Munyan, The Chicago Lighthouse for the Blind; Darcy Contri, RN, BSN, MPH, UIC Division of Specialized Care for Children

SUGGESTED CITATION

Marks, B., Sisirak, J. & Cutler, A. (2007). *Building Capacity among Pediatric Residents to Promote Health Advocacy among Persons with Developmental Disabilities*. Chicago: Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago.

ADDITIONAL COPIES

For additional copies, contact The Clearinghouse on Aging and Developmental Disabilities, Rehabilitation Research and Training Center on Aging with Developmental Disabilities (MC 626), Department of Disability and Human Development, University of Illinois at Chicago 1640 West Roosevelt Road, Chicago, IL 60608-6904 or call 1-800-996- 8845 (voice), 1-800-526-0844 (TTY), e-mail: rrtcamr@uic.edu, or fax: 312-996-6942. URL: www.rrtcadd.org.

PREFACE

Medical students, residents and other health care providers often receive less than three hours of education regarding health care issues and needs of people with disabilities including people with developmental disabilities and special health care needs (DD/SHCN). While only 15% of General Practitioners report that they would prefer not to work with people with DD, 93% feel that they would be able to provide better care if they had further training and education in the care of people with DD. Furthermore, 76% feel inadequately trained in DD, 68% know little about available resources, 66% lack experience, 60% state that their prior training is inadequate, and 38% do not feel confident in treating people with DD. Among pediatricians and residents, 80% report having no training in prescribing wheelchairs, braces, and communication devices for people with DD. **This lack of knowledge and experience among physicians in working with people with DD/SHCN often translates into negative attitudes further compromising the provision of culturally appropriate, accessible, acceptable, and equitable health care.**

Compared to the general population, people with DD/SHCN experience earlier age-related health conditions and poorer health status that could be addressed more effectively if their health care providers had adequate knowledge and resources available. Data also demonstrates higher rates of obesity, and, poor nutrition among adults with DD. Additionally, people with DD/SHCN have frequently not been taught how to communicate early signs and symptoms of chronic conditions to their health care providers, resulting in under-diagnosis, mis-diagnosis, or less chance of receiving prompt treatment.

Physicians have a key role in motivating the development of the skills and confidence necessary for people with DD/SHCN to address the social, economic, and environmental *determinants of health* and improve *their health*. By fostering partnerships between physicians and people with DD/SHCN through targeted training efforts, an infrastructure can be created that will support adolescents with DD/SHCN and their caregivers in becoming partners with their physicians to receive equitable, accessible, acceptable, and culturally relevant care that protects and promotes their health as they transition into adulthood.

A systematic overhaul is necessary to establish effective policies and programs that will provide health care services for adolescents and young adults with DD/SHCN. We must begin to target training efforts directed toward pediatric residents who play a pivotal role in being able to effectively communicate with adolescents with DD/SHCN and their families. This curriculum has the potential to improve pediatric residents' capacity to serve this population by helping them gain a comprehensive understanding of their unique needs not only during their residency training period, but also in their future practices throughout Illinois. With the partnerships in place and materials developed, this project will also better enable future pediatric resident training programs in Illinois to address health advocacy needs of adolescents and young adults with DD/SHCN.

The Building Capacity among Pediatric Residents to Promote Health Advocacy among Persons with Developmental Disabilities Curriculum is based on the successful outcomes of the innovative Building Capacity among Pediatric Residents to Promote Health Advocacy among persons with DD project at the University of Illinois at Chicago (UIC). This 2.5 hour curriculum has four components. The goals of the program are to: 1) observe good models of communication with pediatric patients with DD and their families; 2) learn ways to promote physical activity and healthy food choices and other preventive measures to decrease co-morbidities; 3) promote building self advocacy skills with patients and improve health literacy; and 4) increase awareness of available resources in the community to meet the needs of children and adolescents with DD/SHCN.

TO ORDER VIDEOS USED IN THIS CURRICULUM

BEYOND DISABILITY: THE FE FE STORIES

Home video \$30, Institutions \$125 / Available in VHS or DVD

The Empowered Fe Fes (slang for female), a group of young women with disabilities, hit the streets of Chicago on a quest to discover the difference between how they see themselves and how others see them. Their revelations are humorous, thought provoking and surprising. As the young women grapple with issues as diverse as access, education, employment, sexuality and growing up with disabilities, they address their audience with a sense of urgency, as if to say, "I need to tell you so you'll see me differently." (26 minutes)

Awarded **Spirit Award** and **Achievement Award** by the SUPERFEST International Disability Film Festival

WHY THEY GOTTA DO ME LIKE THAT? THE EMPOWERED FE FES TAKE ON BULLYING

Home Video \$30, Institutions \$125

Young women with disabilities show us how we can work together to understand and stop school-based discrimination, particularly against people with disabilities. The Fe Fes offer tongue-in-cheek dreamscapes depicting everyday bullying along with solutions that can be used by any student, teacher or administrator. (12 minutes)

- Awarded **Honorable Mention** at Picture This... Film Festival in Calgary, Canada

DOIN' IT: SEX, DISABILITY, AND VIDEOTAPE

Home video \$30, Institutions \$150

DOIN' IT: SEX, DISABILITY, AND VIDEOTAPE The Empowered Fe Fes, a peer group of young women aged 16 to 24 with different disabilities, strike again with their second video production, an insightful investigation into the truths about sex and disability. In the video, the Fe Fes educate themselves about sex from many angles by talking with activists and scholars. The viewer tags along on a date between a woman with a disability and her able-bodied boyfriend, exploring relationship issues of dating with a disability over a candle-lit dinner. (35 minutes)

- Awarded **Best Documentary** in the Central Illinois Feminist Film Festival
- Awarded **Best Documentary (Short)** in the San Francisco Women Film Festival

Shipping/Handling: \$5 per item, \$15 institutional (within the US)

Beyondmedia Education

www.beyondmedia.org (to order online)

7013 N. Glenwood Ave., Chicago, Illinois 60626 USA

Tel: 773-973-2280, Fax: 773-973-3367, email: beyond@beyondmedia.org

Health Advocacy Curriculum

Building Capacity among Health Care Providers to Promote Health Advocacy among People with Developmental Disabilities

I. Health Care Interactions: Charity to Advocacy

A. Definitions

1. Developmental Disabilities
2. Mental Retardation
3. Intellectual Disabilities

B. Historical Perspectives

1. The Rise of the Institutions
2. Parents' Movement
3. Independent Living Movement
4. Self-Advocacy Movement
5. Community Integration

C. Models of Disability

1. Medical Model
2. Rehabilitation Model
3. Social Model
4. Interface Model

II. Health Promotion: Beyond Illness Care

A. Factors Contributing to Health Status

1. Biological/Physiological
2. Socioeconomic and Environmental
3. Access to Health Care
4. Behavioral

B. Nutrition-Related Issues

1. Diet and Nutrition
2. Barriers to Nutrition
3. Prevalence of Obesity: Young Adults

C. Physical Activity and Fitness

1. Missed Opportunities for Play
2. Physical Activity
3. Barriers to Physical Activity

D. Sexuality

1. Promoting Sexuality
2. Peer Support
3. Structural Barriers to Sexuality Development
4. At-Risk Situations
5. Attitudinal Barriers to Sexuality Development
6. Mentoring and Sexuality Education

E. Psychosocial Well-Being

1. Features of Violence
2. Bullying among Children and Adolescents with Disabilities

Health Advocacy Curriculum

III. Universal Design: More Than Ramps

A. Physical/Environmental Access

1. What is Universal Design for Access
2. Universal Design for Office Space, Examination Room, and Washrooms
3. Strategies to Address Physical Access to Medical Equipment

B. Communication Strategies: Giving and Receiving Information

1. Using Person First Language
2. Interacting with People with Disabilities
3. Boundaries: Whose Body Is It?
4. Opening Communication
5. Creating Respectful Interactions: Meeting People with Disabilities
6. Behavioral Expressions
7. Identifying Communication Styles
8. Augmentative Communication
9. Accessible Materials and Content
10. Clear Communication: Culturally Competent Care

IV. Health Advocacy: Culturally Relevant Care

A. Health Advocacy

1. The Problem is Not My Disability
2. Health Advocacy: Triad Approach
 - a. Becoming a Self-Advocate
 - b. Caregiver/Support Person

B. Health Literacy and Health

1. Health Literacy: Key to Advocacy
2. Health Literacy and Health

C. Resources

1. Negotiating at an Uneven Table
2. What About College?
3. Transition: Notes from Patients...
4. Health Care Transition
5. Transition Resources for Everyone
6. Techniques for Better Health Outcomes: A 2-Way Street

D. Community-Based Advocacy Organization (Host Sites)

1. Identifying Advocacy Organizations in Your Community
2. Centers for Independent Living
3. Community Resource List

Building Capacity among Pediatric Residents to Promote Health Advocacy among Persons with Developmental Disabilities

List of Handouts

- | | |
|-------------------|---|
| Handout 1 | Models of Disability |
| Handout 2 | Content Areas for Sexuality Education Activities |
| Handout 3 | The Principles of Universal Design |
| Handout 4 | Selected ADA Requirements for Health Care Providers |
| Handout 5 | Assistive Technology |
| Handout 6 | Transition Checklist and Timeline for Medical Care Providers |
| Handout 7 | Health Care Checklist – Transition Planning for the Future |
| Handout 8 | Teen Transition Facts for Health Professionals |
| Handout 9 | Attention Families of Teenagers with Special Needs – Transition Issues for Adolescents with Special Needs |
| Handout 10 | Health Care Toolkit |
| Handout 11 | Ask Me 3: Good Questions for Your Good Health |
| Handout 12 | What Else Can You Do to Increase Your Patients' Understanding? |
| Handout 13 | Host Sites |
| Handout 14 | Resource List |

Health Advocacy Curriculum

Building Capacity among Health Care Providers to Promote Health Advocacy and Transition among People with Developmental Disabilities

University of Illinois at Chicago
Department of Disability and Human Development
Rehabilitation Research Training Center on
Aging with Developmental Disabilities

In Collaboration with

UIC Division of Specialized Care for Children
American Academy of Pediatrics



Health Advocacy Guiding Principles

- ❑ People with disabilities have a right to receive health education and services.
- ❑ People can contribute to their own well-being by becoming knowledgeable about their health and health resources, and by becoming active participants in health related activities.
- ❑ Collaborative support from pediatricians, families, and service and health care providers can maximize individual involvement in the planning and implementation of health-related goals.
- ❑ The strategies used to promote health advocacy are characterized by processes of choice, self-determination, self-efficacy, and self-advocacy.

Curriculum Components

I. Health Care Interactions: Charity to Advocacy

II. Health Promotion: Beyond Illness Care

III. Universal Design: More Than Ramps

IV. Health Advocacy: Culturally Relevant Care

Curriculum Components

Health Care Interactions: Charity to Advocacy

Learning Objective: Participants will review the historical factors that impact attitudes, beliefs, and treatment of people with I/DD.

Health Promotion: Beyond Illness Care

Learning Objective: Participants review determinants of health, including promotive, preventive, and primary health care areas. Training will identify areas of health promotion that will address many of the chronic health conditions being experienced by people with DD/SHCN.

Universal Design: More Than Ramps

Learning Objective: Participants will review strategies that can be used with people with I/DD gain the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

Health Advocacy: Culturally Relevant Care

Learning Objective: Participants identify appropriate environmental supports to advocate for health, communicate and promote benefits of health promotion activities, and increase awareness of available resources in the community for their clients.

New Generation: Disabled and Proud



Beyond Media Education

Empowered Fe Fes (Fe Fe is a slang for female) are a group of young women with disabilities who meet to talk about issues such as the following: dating and sexuality, Human Rights, and becoming independent. For eight years Access Living in Chicago has been running the only program for teenage girls with disabilities in the United States, the Empowered Fe Fes.

For More Information:

Beyond Media Education (www.beyondmedia.org)

BEYOND DISABILITY: THE FE FE STORIES The Empowered Fe Fes (slang for female), a group of young women with disabilities, hit the streets of Chicago on a quest to discover the difference between how they see themselves and how others see them. Their revelations are humorous, thought provoking and surprising. As the young women grapple with issues as diverse as access, education, employment, sexuality and growing up with disabilities, they address their audience with a sense of urgency, as if to say, "I need to tell you so you'll see me differently." (Video, 26 minutes)

I. Health Care Interactions: Charity to Advocacy

OBJECTIVE

Review historical perspectives
of definitions and attitudes
toward people with disabilities.

I. Health Care Interactions: Charity to Advocacy

DEFINITIONS

Mental Retardation (MR)

The label "Mental Retardation" is no more...

the new name is...

Intellectual and Developmental
Disabilities (IDD)

In February 2007, American Association on Mental Retardation (AAMR), the world's oldest organization representing professionals in developmental disabilities, officially changed its name to the American Association on Intellectual and Developmental Disabilities (AAIDD). For all those who ask, "What's in a name?" Steven J. Taylor, editor of *Intellectual and Developmental Disabilities Journal* (AAIDD publication) says, "The term *intellectual and developmental disabilities* is simply less stigmatizing than *mental retardation*, *mental deficiency*, *feeble-mindedness*, *idiocy*, *imbecility*, and other terminology we have cast aside over the years." However, Taylor acknowledges that the crux of the issue here goes beyond language and terminology into the deeper issues of inclusion and acceptance of people with intellectual disabilities in society. He explains, "Anyone who believes that we have finally arrived at the perfect terminology will be proven wrong by history. I am sure that at some future point we will find the phrase *intellectual and developmental disabilities* to be inadequate and demeaning."

Reference(s): AAIDD (www.aaid.org)

Intellectual Disabilities (ID) Defined

- ▣ A disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills.
- ▣ This disability originates before age 18.

Five Assumptions Essential to the Application of the Definition

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve.

Reference(s): American Association on Mental Retardation (AAMR 1992); Diagnostic and Statistical Manual (DSM IV 1994); International Classification of Diseases (ICD 10 1994); American Psychological Association (APA 1996)

International Perspectives for ID

- ▣ *...no one definition of intellectual disabilities has gained universal acceptance*
- ▣ *generally accepted that the term intellectual disabilities encompasses any set of conditions...*
 - *resulting from genetic, neurological, nutritional, social, traumatic or other factors occurring prior to birth, at birth, or during childhood up to the age of brain maturity, and*
 - *affecting intellectual development.*

Reference(s): Summative Report to the World Health Organization by the International Association for the Scientific Study of Intellectual Disabilities 2000

Developmental Disability (DD)

Severe, chronic disability that:

- a) is attributed to a mental or physical impairment or combination of mental and physical impairments;
- b) is manifested before the person attains the age of 21;
- c) is likely to continue indefinitely;
- d) results in substantial functional limitations in three or more of the following major life activity areas: self care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self sufficiency; and,
- e) reflects the person's need for a combination and sequence of special and interdisciplinary or generic care, treatment, or other services which are of lifelong or extended duration and individually planned and coordinated.

A person with a developmental disability may not have an intellectual disability. By definition, a person with an intellectual disability always will have a developmental disability.

Includes person with CP, autism, epilepsy

Reference(s): PL 95-602 Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendment of 1978, Section 119, 29 USC 794

Special Health Care Needs

Children with Special Health Care Needs (SHCN):

- ▣ *have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition, and*
- ▣ *require health and related services of a type or amount beyond that typically required by children.*

Reference(s): Adopted by the American Academy of Pediatrics (October 1998). McPherson M, Arango P, Fox HB, A new definition of children with special health care needs. Pediatrics 1998; 102:137-140

When I Became Disabled: Feeling Attitudes Change...



Beyond Media Education

For More Information:

Beyond Media Education (www.beyondmedia.org)

BEYOND DISABILITY: THE FE FE STORIES The Empowered Fe Fes (slang for female), a group of young women with disabilities, hit the streets of Chicago on a quest to discover the difference between how they see themselves and how others see them. Their revelations are humorous, thought provoking and surprising. As the young women grapple with issues as diverse as access, education, employment, sexuality and growing up with disabilities, they address their audience with a sense of urgency, as if to say, "I need to tell you so you'll see me differently." (Video, 26 minutes)

I. Health Care Interactions: Charity to Advocacy

DISABILITY RIGHTS MOVEMENT: HISTORICAL PERSPECTIVES

Attitudes and Advocacy

**In the early 19th century,
living conditions for persons with
disabilities were harsh.**

□ Housing

- Poorhouses/Almshouses
- "Warning out"
- "Passing on"

□ Education

- Early training schools aimed to help people become "productive" members of their communities
- Training schools became asylums providing custodial care for people with disabilities who were "patients"



Graphic Source: Parallels in Time

Persons who lived in poverty, whether it was due to being widowed, orphaned, alcoholic, or because of physical or mental disabilities, often were put into **poorhouses**, or **almshouses**. Wealthier parents tended to keep their children with disabilities at home. "Warning out" – unwanted newcomer was informed that he or she was not welcome in their town. "Passing on" – unwanted people were loaded onto a cart and dropped off in the next town.

•Industrialization: Extreme Wealth and Extreme Poverty: people speaking out on the conditions of persons with disabilities and others who were oppressed or neglected. By mid 19th century, social reformers were alerting society to the horrible living conditions of its many outcasts.

•Dorothea Dix - spent two years visiting jails, almshouses, poorhouses, and asylums across the United States. Since it was unthinkable in 1848 for a woman to address Congress, Dix had Samuel Gridley Howe, a well-known social reformer, present her speech. Her appeal was that the United States set aside 5 million acres of land throughout the nation to accommodate persons with disabilities –passed by both houses of Congress but vetoed by President Pierce. Through her appeals, Dix helped prepare the way for public institutions.

•Edouard Seguin – considered the first great teacher in the field of disabilities. He believed that intellectual disability was caused by a weakness of the nervous system, and could be cured through a process of motor and sensory training.

•Strong educational focus: physical training to improve motor and sensory skills, basic academic training and instruction in social and self-help skills to help people be productive members of their communities.

•First U.S. Government census to determine the number of people with ID.

•From training school to asylum: Training schools gave people with ID knowledge and tools to be productive members of society. Economic troubles during Civil War in 1857 diminished employment opportunity for returning students. Competition was too high and many students with disabilities who returned to their communities looking for work usually ended up in poorhouses or jails. At the same time, demand for placement in training schools was increasing but the commitment to training decreased. Education was abandoned and replaced by custodial institutional living.

•Institutions became medically oriented; persons with disabilities viewed as patients who were sick and needed to be cured. Medical experiments were also conducted to cure people.

Reference(s): Parallels in Time (<http://www.mncdd.org/parallels/index.html>)

Parallels and Consequences

- ▣ Immigration (1900's)
- ▣ Overcrowding in Cities (1900s)
- ▣ Labeling (1900s)
- ▣ Segregation (1920s)



•**Fear and suspicion**, worsening conditions: overcrowding, people could spend their entire day in one room and sleep on the floor.

•**Labeling** - Fear, suspicion, and worsening conditions; superintendents

•**Segregation** – Popular belief was that mental retardation and mental illness were completely genetic and caused many social ills such as poverty, drunkenness, prostitution, crime and violence. The response was to segregate or sterilize people who were labeled mentally retarded or mentally ill so that they could not reproduce or destroy the gene pool. Pictures of people who committed criminal acts such as arson, murder, or other violent crimes were often drawn in newspapers to suggest the presence of mental retardation.

Reference(s): Parallels in Time (<http://www.mncdd.org/parallels/index.html>); Webster's New World Medical Dictionary

Deadly Consequences: Eugenics

■ USA

- First country to undertake compulsory sterilization programs for the purpose of eugenics
- Sterilized over 64,000 individuals from 1900s through the 1970s

■ Nazis

- Nazis targeted people with disabilities for euthanasia
- 400,000 compulsory sterilization
- 100,000 children and adults with disabilities were killed
- Inhumane medical experiments



"You are bearing this too," informing the 'German worker' that a hereditarily ill person costs 50,000 RMs to maintain until he or she has reached the age of 60.

(from *Death and Deliverance - 'Euthanasia' in Germany 1900-1945* by Michael Burleigh)

•**Eugenics** - meaning normal genes, eugenics aims to improve the genetic constitution of the human species by selective breeding. The Nazis notoriously engaged in negative eugenics by genocide. The word "eugenics" was coined by Sir Francis Galton (1822-1911) to denote scientific endeavors to increase the proportion of persons with better than average genetic endowment through selective mating of marriage partners. The practice of eugenics was first legally mandated in the United States in the state of Indiana, resulting in the forcible sterilization, incarceration, and occasionally euthanasia of the mentally or physically handicapped, the mentally ill, and ethnic minorities (particularly people of mixed racial heritage), and the adopting out of their children to non-disabled, Caucasian parents. Similar programs spread widely in the early part of the twentieth century, and still exist in some parts of the world. No experiment in eugenics has ever been shown to result in measurable improvements in human health. Eugenics was a crucial component used to control sexuality and fertility among individuals with I/DD (especially women). Sterilization continues under the guise that it will prevent expressions of sexuality and reproduction, diminish chances of sexual exploitation, or reduce likelihood of acquiring sexually transmitted diseases at the onset of puberty.

•The first country to concertedly undertake compulsory sterilization programs for the purpose of eugenics was the [United States](#).

•The principal targets of the American program were the [mentally retarded](#) and the [mentally ill](#), but also targeted under many state laws were people who were deaf, blind, had [epilepsy](#), and had physical deformities.

•In Germany, the American eugenics programs were frequently invoked as models. Nazis quoted American geneticists who expressed support for their sterilization policies. The German sterilization program was followed in 1939 by a euthanasia program designed to rid the nation of its mental patients, now characterized as "useless eaters." (The technology of the gas chamber was first developed in connection with this program.) Racist measures had been imposed shortly after Hitler came to power.

•Laws and extralegal actions directed against Jews, Gypsies, the offspring of German mothers and black French soldiers, homosexuals, and other social and political "deviants" followed, culminating in the program of mass extermination known as the Holocaust.

•**Social Control** - Individuals with I/DD have been portrayed as sexually threatening requiring professional management and control. During much of the twentieth century, extreme methods of social control were employed in the U.S. and Europe to reduce perceived threats to the social order from marginalized individuals.

Reference(s): *Parallels in Time* (<http://www.mncdd.org/parallels/index.html>); Paul, D. (1995). *Controlling Human Heredity*. pp. 84-91; Albrecht, G. L. (Ed.) (2005) *Encyclopedia of Disability*. Thousand Oaks: Sage Publications.

Relics from the Institutions



Photo 1: Numbered grave marker used for deceased residents in institutions

Photo 2: Residents in an institution restrained with shackles

Photo 3: Resident in an institution bound in a straight jacket

1820 - 1870 Most people with disabilities lived with their families and in their communities—those who were destitute ended up in the almshouse.¹ A very small number of disabled people found not only work and a supportive community but sometimes fame and fortune by exhibiting themselves in sideshows.

1870 - 1930 In this age of institution building, people with disabilities lived in insane asylums, hospitals, state schools, and homes for the "feeble-minded."¹

1930 - 1970 Medical advances promised to eliminate many disabilities by either curing people of their disabilities or helping them to "overcome" their disability.¹ While this promise was overstated, disabled people did indeed become rarer on our streets; many people were warehoused in institutions or shunted to special schools, or kept out of sight at home. The physical environment was often inaccessible; few role models existed for people growing up with disabilities; and, doctors often passed their preconceptions about disability to their patients.

Parents' Advocacy Movement

- ❑ Forming support and advocacy groups (1940s-1950s)
- ❑ Improving conditions in state institutions (1960s-1970s)
- ❑ Creating community services, education, and employment (1960s-1970s)
- ❑ Initiating legislation (1960s-1970s)
- ❑ To support families, physicians continued to urge parents to place their children in institutions (1946-1967)



Forming support and advocacy groups (1940s-1950s)

Parents of children with disabilities begin to form support and advocacy groups because few supports and services were available in the community.

- 1933 Council for the Retarded Child
- 1936 Children's' Benevolent League, later became Washington Association for Retarded Citizens. The Association for Retarded Citizens is now Called ARC. The ARC continues to be one of the largest voluntary organizations comprised of family, friends, self-advocates and professionals.
- 1947 The Parents' movement was promoted by professional association AAMD.
- 1950 Parents' 1st National Conference: the "retarded child" was recognized as being a human being...

Improving conditions in state institutions: Although the parents' movement was successful in having more money put into public institutions, many parents still faced long waiting lists and overcrowded conditions.

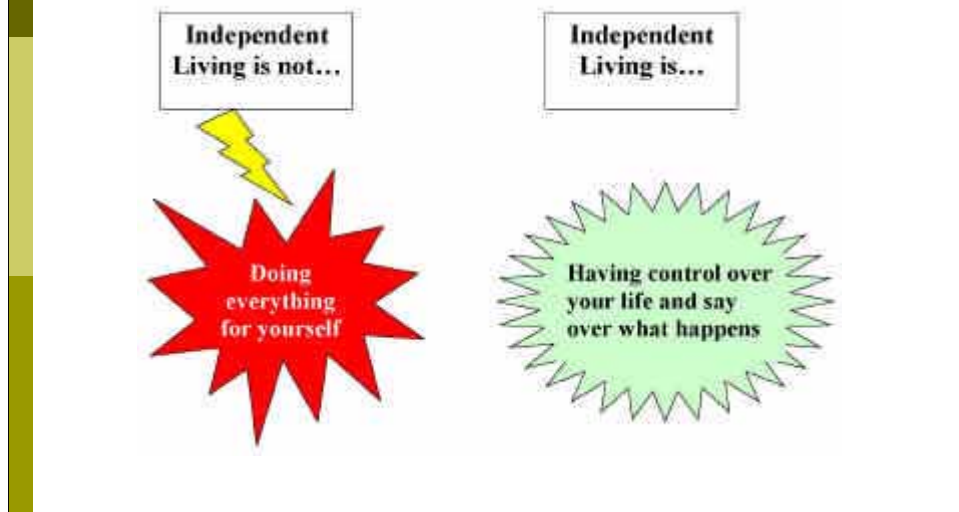
Creating community services, education and employment: Many parents did not want to place their children in large institutions and started their own services in homes, church basements, vacant buildings, and newly built schools. Services included education, sheltered work, daytime activity centers, recreation, camps, and various residential models.

Initiating legislation: In 1962, a report of the President's Panel on Mental Retardation concluded that the quality of services in state institutions should be upgraded. President Kennedy's sister, Rosemary, had mental retardation. Until she was in her twenties, Rosemary lived with her family and enjoyed the same lifestyle as her brothers and sister. The parents' movement had effectively brought mental retardation and other disabilities out into the open. Eunice Kennedy Shriver wrote an article about their sister Rosemary and the adjustments that the family made.

Medical/Health Professionals: Between 1946 and 1967, the number of persons with disabilities in public institutions increased from 116,828 to 193,188, a rate increase nearly twice that of the general population. To release stress from families physicians believed that this was better for the child. Doctors are viewed as experts and parents viewed as in need of help.

Reference(s): Parallels in Time (<http://www.mncdd.org/parallels/index.html>)

Independent Living Movement



1960s-1970s – People with disparate disabilities began sharing a common identity and a need to claim their human and civil rights. By creating community groups they started identifying and addressing barriers and taking active roles in decisions affecting their lives. Similar to other minority groups, during the past 20 years, people with disabilities are gaining more control over definitional issues by renaming themselves in accordance to their own perspective. This process serves to reclaim a sense of individual identity and empower a sense of group identity. As people share their experiences of stigma and isolation, attitudinal and architectural barriers, not the intrinsic limitations related to the disability, are viewed as central to disablement. People no longer want to be viewed merely as a “pathological” condition.

The concept of independent living is opposite that of the institutions, and a movement away from dependency on parents and professionals. Independent living means the opportunity to make decisions that affect one's life, being able to pursue activities of one's own choosing. Independent living does not necessarily mean living alone. Rather, it has to do with self-determination: making choices, being allowed to fail, and having access to appropriate services. Independent Living Movement created Centers of Independent Living (CIL) (information and referral services, independent living skills training). CILs became mandated by the Rehabilitation Act, section 504. Each county in the US should have a Center for Independent Living and they should be run by people with disabilities. In Chicago: Access Living (Chicago metro); Progress Center (Suburban Cook County).

Reference(s):

- Southampton Centre for Independent Living Ltd (www.southamptoncil.co.uk)
- Parallels in Time (<http://www.mncdd.org/parallels/index.html>);

Self-Advocacy: People First Movement

**"We are
people first."
"We are tired of
being treated
like children by
so-called
normal people."**

– Author Unknown



Self-advocacy is a civil rights movement that represents individuals of all races, colors, and religions who have been systematically neglected, abused, incarcerated, and misunderstood for most of history. It includes the values that all people share the same basic desires to be full participants in society, society's myths, fears, and stereotypes make being disabled most difficult, and there is no honor or tragedy in disability. Its goals include the following:

- advocating for one's self, standing up for one's rights; end to prejudice and segregation; access to education, jobs, transportation; and self determination

These are core beliefs, values, and principles of self-advocacy, as defined by Inclusion International [formerly the International League of Societies for Persons with Mental Handicaps (ILSMH)].

- Being a person first and making own decisions;
- Believing in one's value as a person and having other people believe in you as a person;
- Empowerment and equal opportunity; Learning and living together;
- Institutions are bad for people; and
- Not labeling people.

Reference(s):

- University of Miami, Department of Pediatrics
(<http://peds2.med.miami.edu/HistoryDisabilityArt/index.htm>)
- Inclusion International (www.inclusion-international.org)

Reclaiming Identity and Language



Because people with disabilities have frequently grown up in isolation from each other, they often have not had an opportunity to develop a sense of subculture or shared experiences of social stigma, isolation, and second-class citizenship. Consequently, many people with disabilities do not identify themselves as having a disability due to shame and fear of negative treatment from others.

Part of the advocacy movement among people with physical disabilities has focused on the concepts of labeling and reclaiming language. Hence, in this cartoon the artist is Crippen. People with physical disabilities are reclaiming the word “cripple” within the context of “Crip Culture.”

Reference(s): Russell, M. (1998). *Beyond Ramps: Disability at the End of the Social Contract*. Common Courage Press.

Key to Community Integration: Disability Legislation

- ▣ The **Rehabilitation Act of 1973** (Section 504)
- ▣ The Education For All Handicapped Children Act of 1975 (reauthorized in 2004 and renamed the Individuals with Disabilities Education Act "**IDEA**")
- ▣ The American with Disabilities Act (**ADA**) of 1990

Legislative Initiatives

1. A little-noticed provision of the 1973 **Rehabilitation Act, Section 504** (a paragraph 42 words long), proved to be watershed legislation for the disability community. Section 504 guarantees access to all **Federally-financed institutions**, schools, hospitals, and transportation systems. In 1977, the lack of implementation of Section 504 mobilized the disability community to stage protests until implementation was guaranteed. Independent Living Movement created Centers of Independent Living (CIL) (information and referral services, independent living skills training). CILs became mandated by the **Rehabilitation Act, section 504**. Each county in the US should have a Center for Independent Living and they should be run by people with disabilities.
2. The **Education For All Handicapped Children Act of 1975**, which guaranteed public education to children with disabilities for the first time. It was re-authorized in 1997 and renamed the Individuals with Disabilities Education Act (IDEA). IDEA guarantees children the right to free, appropriate education.
3. In 1990, congress enacted the **American with Disabilities Act (ADA)**. The ADA is a sweeping mandate to end discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications. The **ADA** which stands with women's suffrage and the **Civil Rights Act of 1964** in the effort to bring fundamental rights and equality to all Americans. For the disability community and parents of children with disabilities, these events are the equivalent of Brown versus Board of Education, and the repeal of Jim Crow laws. Although not all Americans with disabilities know about these events, they deeply feel the consequences of the revolution: they, and their families, recognize that some profound change in the early 1980s allowed them to have access to the world, far more easily than previously - curb cuts, handicap parking places, bathrooms, and more--their expectations and sense of possibility grew. As a civil rights law, the ADA focuses on arbitrary, unjust, and outmoded societal attitudes and practices that prohibit and/or restrict access for people with disabilities, and seeks to eliminate practices that make people unnecessarily different. According to ADA, a person with a disability is someone who meets at least one of the following criteria: a) has a physical or mental impairment that **substantially limits** one or more major life activities, such as, caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, or working; b) has a **history or record of such an impairment**; or, c) is **perceived by others** as having such an impairment.

The legal changes over the past 30 years continue to have a dramatic impact on the lives of persons with disabilities. Unfortunately, despite the creation of laws protecting the rights of people with disabilities, people are still deprived of many opportunities due to unnecessary barriers and fears. The 1998 National Organization on Disability/Harris Survey found that people with disabilities continue to lag well behind Americans without disabilities in many key areas of community life, such as, securing jobs, pursuing post-secondary education, and, obtaining accessible public transportation and health care.

Reference(s): A Guide to Disability Law (www.usdoj.gov/crt/ada/cguide.htm); P.L. 101-336. U.S. Department of Justice, Civil Rights Division, Disability Rights Section

For More Information: Disability and Business Technical Assistance Center (DBTAC) (www.adata.org/)

Mapping the Future...

Disability Rights Movement



Access Living Metropolitan Chicago

For More Information:

Access Living of Metropolitan Chicago

Community Integration: Benefits

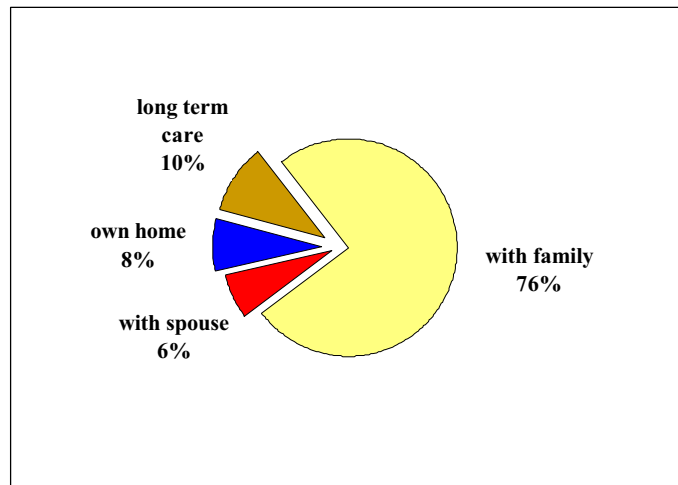
Positive Outcomes of Deinstitutionalization

- ▣ Quality of environment judged to be better
- ▣ Community services better than institutional services
- ▣ Staff seen as having positive impact
- ▣ Positive impact on family and parents
 - Increase in frequency of visits
 - More comfortable visiting in home

Reference(s):

- Kim, S., Larson, S. A., & Lakin, K. C. (2001). Behavioural outcomes of deinstitutionalisation for people with intellectual disability: a review of US studies conducted between 1980 and 1999. *Journal of Intellectual & Developmental Disability*, 26(1), 35-50.
- Larson, S. A., & Lakin, K. C. (1991). Parent attitudes about residential placement before and after deinstitutionalization: a research synthesis. *Journal of the Association for Persons with Severe Handicaps*, 16(1), 25-38.

Where Do People Live



Reference(s):

- Fujiura, G. (1998). Demography of family households. *American Journal on Mental Retardation*, 103, 225-235.
- Fujiura, G. (2001). Family demography: Emerging policy challenges. Paper presented at the Invitational Research Symposium on Aging with Developmental Disabilities: Promoting Health Aging, Family Support, and Age-Friendly Communities. Chicago.

Status of Deinstitutionalization

STATES WITHOUT INSTITUTIONS	WHO'S NEXT?	WHO'S NOT?
Alaska	Minnesota	Texas
District of Columbia	Oregon	California
Hawaii	Montana	New Jersey
Maine	Wyoming	Illinois
New Hampshire	Idaho	Ohio
New Mexico	Nevada	
Rhode Island	Colorado	
Vermont	Arizona	
West Virginia	North Dakota	
	Delaware	

Since the 1970s, most states have aggressively reduced their reliance on institutional settings for persons with I/DD in favor of smaller, community-based options. Although the advantages of community integration for persons with I/DD from both functional and theoretical perspectives have been frequently noted in the literature, most states in the United States continue to utilize state institutions for persons with I/DD. The federal government does not dictate to states which settings they must provide to persons with I/DD; states have great latitude in deciding whether to utilize institutional or community services. More traditionalistic states used institutions more. Furthermore, participation in the **HCBS Waiver*** was inversely correlated with state institution utilization; higher state funding for the Waiver was associated with lower rates of utilization. State wealth was positively associated with use of state institutions for persons with I/DD. Wealthy states could afford to operate dual systems of care (institutions- and community-based supports).

Political culture of the state is a determinant of how many resources will be allocated to institutional versus community living. Where people live depends on what kind of social services they will be getting. In Illinois 57% of people with I/DD live in settings of 7 or more residents. Only Arkansas and Missouri have larger proportion of consumers that live in settings of 7 or more residents.

*Home and Community Based Services (HCBS) Medicaid Waiver Programs allow eligible individuals to either remain in their own homes or live in a community setting, rather than an institutional setting such as: a hospital, nursing home or intermediate care facility for the developmentally disabled.

Reference(s):

- Braddock, D.(2005). State of the States in Developmental Disabilities, (www.cu.edu/ColemanInstitute/stateofthestates/index.html)
- Braddock, D., & Fujiura, G. (1987). State government financial effort in mental retardation. *American Journal of Mental Deficiency*, 91, 450–459.
- Rizzolo, M. C., Heller, T., Braddock, D. (2005). Determinants of State Utilization of Public Institutions for Persons with Intellectual Disabilities in the United States. *Journal of Policy and Practice in Intellectual Disabilities* 2(1), 60–62.

Institutional versus Home and Community-Based Services

The Average Cost of Care in the United States

- | | |
|--|---|
| ▣ Average state institution cost per participant \$146,325 | ▣ Average waiver* cost per participant \$37,784 |
|--|---|



On average four people can receive care compared to one person in a state institution.

*Home and Community Based Services (HCBS) Medicaid Waiver Programs allow eligible individuals to either remain in their own homes or live in a community setting, rather than an institutional setting such as: a hospital, nursing home or intermediate care facility for the developmentally disabled.

Reference(s): Braddock, D.(2005). State of the States in Developmental Disabilities, (www.cu.edu/ColemanInstitute/stateofthestates/index.html)

I. Health Care Interactions: Charity to Advocacy

MODELS OF DISABILITY

We need to replace our current view of disability with a framework incorporating the socio-political, economic, and cultural factors affecting people with disabilities. This framework can broaden our understanding of disabilities beyond a view that disabled people are objects of pity or in need of fixing, and allow us to perceive disabled individuals as valuable citizens whose skills and talents are needed and wanted by the community.

"In the efforts to serve people who are marginalized within a community, the professional model of service often breaks down the sense of community and the belief among community members that they can support and care for each other." -Jane Doyle

The idea of multidisciplinary care and working within a different paradigm and including multiple people including CILs, etc.

Disability Models: Impact on Care

Model	View of Disability	Impact on Care	Limitations
Medical Model	Disability caused by disease or trauma and seen as deficiency/ abnormality	Provided and controlled by professionals	Focus limited to cure or normalization of the individual; decision-making limited to professionals
Rehabilitation Model	Based on medical model; with adequate effort on the part of the person, the disability can be overcome	Provided and controlled by professionals	Fails to consider reality of permanent disability
Social Model	Disability is a difference and is socially constructed; a consequence of society's lack of awareness about those who may require some modifications to live full, productive lives; interaction between the individual and society	Individual, an advocate, or anyone affecting the arrangements between the individual and society	Ignores or dismisses disease or injury as a part of the experience
Interface Model	Seen as neither the medical diagnosis nor solely the environment; life experience in which the person with a disability is in control and empowered; disability interfaces between a person's medical diagnosis and environmental factors that affect disability	Provided by health care provider in conjunction with individual preferences; recognizes reality that disability may be a consequence of disease or trauma	New model; has not been widely adopted or used

Handout: Disability Models

Medical Model

Disability is caused by disease or trauma and its resolution or solution is intervention provided and controlled by professionals.

Rehabilitation Model

Based on medical model and the belief that with adequate effort on the part of the person, the disability can be overcome.

Social Model

Disability is socially constructed and a consequence of society's lack of awareness and concern about those who may require some modifications to live full, productive lives.

Interface Model

Disability exists at the meeting point or interface between the person's medical diagnosis and the environmental factors that affect disability.

Biopsychosocial Model

Disability arises from a combination of factors at the physical, emotional and environmental levels.

"...the medical model [has become] the institutionalized expression of societal anxieties about people who look-different or function differently. It regards them as incompetent to manage their own lives, as needing professional, perhaps lifelong, supervision, perhaps even as dangerous to society." (Paul Longmore)

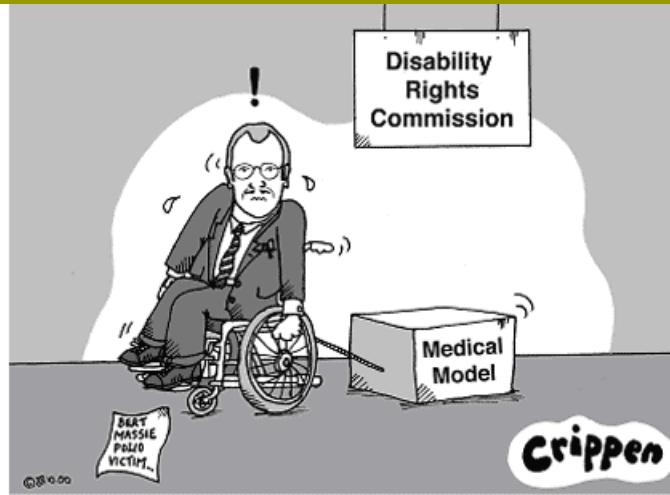
Handout: Models of Disability (Smeltzer, 2007)

Reference(s): Smeltzer, S.C. (2007). Improving the health and wellness of persons with disabilities: A call to action too important for nursing to ignore. *Nurs Outlook*, 55: 189-195.

Table 1. Models of Disability

Model of Disability	Description	Comment
Medical Model	The medical model or illness approach is based on the view that disability is caused by disease or trauma and its resolution or solution is intervention provided and controlled by professionals. ¹ Disability is perceived as deviation from normality and the role of persons with disability is to accept the care determined by and imposed by health professionals who are considered the experts. ^{24,47-48} In this model, disability is considered as residing within the individual.	This approach to disability has been rejected by many individuals with disability and disability advocacy groups, ^{24,47-48} because it does not cover the full spectrum of issues related to living with a disability. Further, it ignores the ability of many individuals to live full and successful lives and to be independent, the impact of a disability on access to health care, and the need to modify how care is delivered because of a disability. The medical model reinforces the view that physicians, nurses and other health care professionals are best qualified to make key decisions about health issues. Individuals with disabilities are often regarded as tragic. ^{15,23,51}
Rehabilitation Model	The traditional rehabilitation model is based on the medical model and the belief that with adequate effort on the part of the person, the disability can be overcome. Persons with disabilities are often perceived as having failed if they do not overcome the disability. ^{15,51} Similar to the medical model, the rehabilitation model suggests that care and support are determined by professionals.	This approach often fails to consider the reality of permanent disability. Because this model shares many characteristics of the medical model, it has been rejected by many people with disabilities. ⁴⁷⁻⁴⁹
Social Model	The social model of disability views disability as socially constructed and a consequence of society's lack of awareness and concern about those who may require some modifications to live full, productive lives. ⁴⁹ The model, referred to by some as the barriers model, views the medical diagnosis, illness or injury as having no part in disability. Rather, society is considered the cause of disability, which is considered a consequence of an environment created for the able-bodied majority.	This model has been criticized because it ignores or dismisses disease or injury as part of the picture, although such factors and their consequences may have a major role in the life of a person with a disability ⁴⁹ and may require intervention by health care providers at times. People with disabilities are encouraged to see any problems they encounter as emerging from barriers and negative attitudes of others in their social environment. ^{47,49,52}
Interface Model	The interface model is based on the premise that disability exists at the meeting point or interface between the person's medical diagnosis and the environmental factors that affect disability. Disability is seen as neither the medical diagnosis nor the environment alone. In this model those individuals with disability define their own problems and seek solutions, which may include intervention by health care professionals including nurses. However, these interventions are designed collaboratively by those with disabilities and health care professionals. Disability is viewed as a life experience in which the person with the disability is in control and empowered. ⁵¹	The interface model, developed by a nurse with a disability, identifies the role of the nurse that is congruent with the preferences of persons with disability but simultaneously recognizes the reality that disability may be a consequence of disease or trauma, areas in which nurses commonly practice. ⁵¹ The model strongly suggests the need for nurses and nurse educators to address disability if nurses are to have a positive and empowering impact in their interaction with persons with disability in their care. The interface model is not well-known and, to date, has not been adopted by many nursing or other health care groups or organizations.
Biopsychosocial Model	The biopsychosocial approach or model of disability views disability as arising from a combination of factors at the physical, emotional and environmental levels. ¹	This approach or model takes the focus beyond the individual and addresses issues that interact to affect the ability of the individual to maintain as high a level of health and well-being as possible and to function within society. This approach is consistent with the WHO's revised definitions of disability. ¹⁶ It recognizes that disabilities are often due to illness or injury and does not dismiss the importance of the impact of biological, emotional and environmental issues on health, well-being, and function in society. ⁵⁰ Critiques of this model have suggested that the disabling condition, rather than the person and the experience of the person with a disability, is the defining construct of the biopsychosocial model. ¹⁷

Models of Disabilities



... Don't look now Bert, but your handicap is showing !

II. Health Promotion: Beyond Illness Care

OBJECTIVE

Review determinants of health and issues related to nutrition, physical activity and fitness, and sexuality.

People with disabilities lack education around health promotion. Currently, we have been focusing on illness care. When children with disabilities grow up they do not have necessary knowledge or skills to advocate for health care services or manage their health care issues. Consequently, they are at increased risk for chronic health conditions.

II. Health Promotion: Beyond Illness Care

FACTORS CONTRIBUTING TO HEALTH STATUS

Most health activities take place at home, work, recreational activities, not within doctors office.

Disability and Poor Health Status

While a large proportion of persons who are in bad health end up with a disability, a large proportion of persons with disabilities end up with bad health.



Biological/Physiological Factors

Men and women with I/DD who have syndrome-related conditions are predisposed to certain health conditions based on their type of disability.

- ❑ Down Syndrome
- ❑ Fragile X
- ❑ Prader-Willi
- ❑ Cerebral Palsy
- ❑ Epilepsy
- ❑ Severe Intellectual Disability and Non-Ambulatory

•Down Syndrome: Atlanto-axial issues, research has shown that children with Down syndrome have calorie needs that are lower than those of their peers. On average they burn 200 to 300 calories less per day. This is probably not going to change in their adulthood, Gastroesophageal Reflux Disease, mitral valve issues

•Fragile X: heart complications

•Prader-Willi: pica, overeating

•Cerebral Palsy: osteoporosis

•Epilepsy: osteoporosis

Impact of Socioeconomic and Environmental on Health

Living in specific residential settings and participating in day programs can impact health status.

- ❑ Limited **social support**.
- ❑ **Negative attitudes** from caregivers and lack of training for caregivers (e.g., the benefits of health promotion).
- ❑ **Violence** toward persons with disabilities.

Access Barriers to Health Care



Beyond Media Education

Factors that impede access to health care:

Programmatic Issues

Attitudes (e.g., health care professionals, fear of examination)

Physical

Communication

Economic

Health literacy

For More Information on the Video:

Beyond Media Education (www.beyondmedia.org)

BEYOND DISABILITY: THE FE FE STORIES The Empowered Fe Fes (slang for female), a group of young women with disabilities, hit the streets of Chicago on a quest to discover the difference between how they see themselves and how others see them. Their revelations are humorous, thought provoking and surprising. As the young women grapple with issues as diverse as access, education, employment, sexuality and growing up with disabilities, they address their audience with a sense of urgency, as if to say, "I need to tell you so you'll see me differently." (Video, 26 minutes)

Health Behaviors and Health Status

For persons with I/DD, cardiovascular disease (CVD) is one of the most common causes of death.

- ❑ Adults living in community settings have the highest CVD risk of all adults with I/DD.
- ❑ CVD is strongly associated with health behaviors - specifically poor nutrition and lack of physical activity.

Unlike many acute health conditions, chronic conditions are generally not caused by infections. The onset of chronic diseases is often the result of health behaviors. While genetics and environmental toxins can also influence the development of chronic disease, behavior is the primary contributor to chronic disease for most people. For the general population and for persons with I/DD, the combination of sedentary lifestyles, high fat diets, and low fruit and vegetable diets is a major contributor to increased risk for acquiring chronic health conditions.

Diet and physical activity patterns are driving the current epidemic of overweight and obesity in the U.S. People who are overweight or obese have an increased risk of developing heart disease, high blood pressure, diabetes, arthritis-related disabilities, and some cancers. Physically inactive people are almost twice as likely to develop heart disease as active people. This makes inactivity as important a risk factor for heart disease as smoking, high blood pressure, or high cholesterol. Diabetes and colon cancer are also linked to inactivity.

II. Health Promotion: Beyond Illness Care

NUTRITION-RELATED ISSUES

Diet and Nutrition

Our knowledge of disability and nutrition is next to nothing!

- ❑ Limited research data suggests the following:
 - 93% adults with I/DD living in the community have a high fat diet
 - 63% of adults with I/DD do not consume enough fruits and vegetables



- ❑ Today, people with I/DD are increasingly living in community settings, such as, group homes and apartments; and they are gaining the freedom to have more responsibility for food choices.
- ❑ How does this relate to children? Food is used as reward/behavior modification; children often do not have an opportunity to learn and experiment with food.

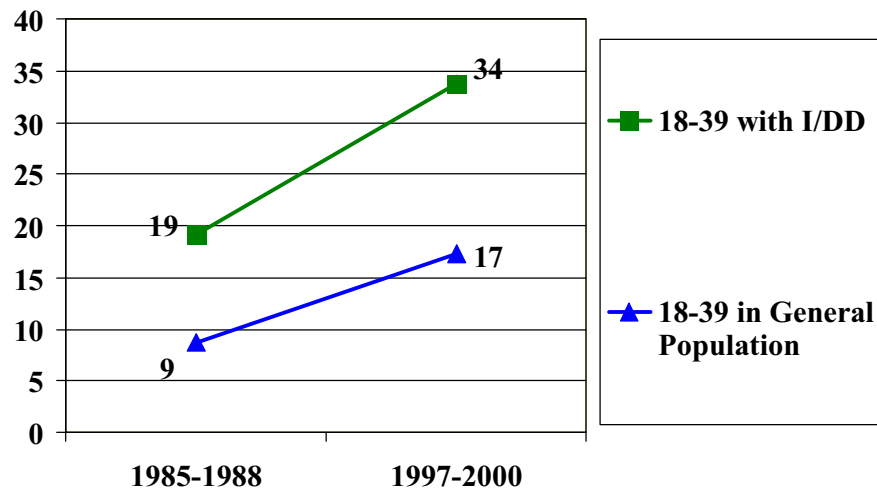
Reference(s): Draheim, C. C., Williams, D. P., & McCubbin, J. A. (2002). Physical activity, dietary intake, and the insulin resistance syndrome in nondiabetic adults with mental retardation. *American Journal of Mental Retardation*, 107(5), 361-375.

Barriers to Nutrition

- Health or Disability Related Issues
 - Dental, oral, health issues
 - Chewing and swallowing
 - Food sensitivities
 - Medication use
- Knowledge of food preparation
- Supports
- Cost

Today, people with I/DD are increasingly living in community settings, such as, group homes and apartments; and they are gaining the freedom to have more responsibility for food choices. But, have not been given the opportunity to gain skills.

Prevalence of Obesity: Young Adults



Compared to their counterparts in the general population, a smaller proportion of women and young adults with intellectual disability maintained their weights in the healthy weight range.

- Compared to their counterparts in the general population, fewer young adults with intellectual disability maintain their weights in the healthy weight range.

- Up to 75% of persons with I/DD are estimated to be either overweight or obese.

- Percentage of **healthy weight adults** with I/DD has declined significantly from 48% in 1985-1988 to 34% in 1997-2000.

- Individuals with particular syndromes have a higher prevalence of being overweight and obese (Down Syndrome; Prader-Willi).

- Living arrangement is related to obesity rates among persons with I/DD. Adults living in the community have the highest rates of obesity.

Reference(s): Yamaki, K. (2005). Body weight status among adults with intellectual disability in the community. *Mental Retardation*, 43(1), 1-10.

II. Health Promotion: Beyond Illness Care

PHYSICAL ACTIVITY AND FITNESS

Physical Activity

- ❑ 10% of adults with I/DD engage in physical activity a minimum of three days a week compared to about 15% of adults in the general population.
- ❑ 50% of adults with I/DD engage in no exercise compared to 25% of adults in general population.
- ❑ Most leisure-time activities are sedentary, such as watching television or listening to the radio.



General Population

More than 60 percent of U.S. adults do not engage in the recommended amount of activity. Approximately 25 percent of U.S. adults are not active at all.

Reference(s):

- Rimmer, J. H., & Yamaki, K. (2006). Obesity and intellectual disability. *Mental Retardation & Developmental Disabilities Research Reviews*, 12(1), 22-27.
- Frey, G. C., Buchanan, A. M., & Sandt, D. D. R. (2005). "I'd rather watch TV": an examination of physical activity in adults with mental retardation. *Mental Retardation*, 43(4), 241-254.
- Melville, C. A., Hamilton, S., Hankey, C. R., Miller, S., & Boyle, S. (2006, 25 September). The prevalence and determinants of obesity in adults with intellectual disabilities. (Publication. Retrieved 2007, 20 March, from Obesity Reviews (OnlineEarly Articles): <http://www.blackwell-synergy.com/doi/full/10.1111/j.1467-789X.2006.00296.x?prevSearch=allfield%3A%28The+prevalence+and+determinants+of+obesity+in+adults+with+intellectual+disabilities%29>.
- Physical Activity and Health: A Report of the Surgeon General (<http://www.cdc.gov/nccdphp/sgr/adults.htm>)

Missed Opportunities for Play



Beyond Media Education

Kids with disabilities often miss opportunities for play which is the foundation for lifelong social and physical activity.

For More Information:

Beyond Media Education (www.beyondmedia.org)

BEYOND DISABILITY: THE FE FE STORIES The Empowered Fe Fes (slang for female), a group of young women with disabilities, hit the streets of Chicago on a quest to discover the difference between how they see themselves and how others see them. Their revelations are humorous, thought provoking and surprising. As the young women grapple with issues as diverse as access, education, employment, sexuality and growing up with disabilities, they address their audience with a sense of urgency, as if to say, "I need to tell you so you'll see me differently." (Video, 26 minutes)

Barriers to Play and Physical Activity

- ▣ Little support for engaging in play activities, physical activity, or exercise
- ▣ Inaccessible equipment
- ▣ Lack of confidence to perform exercise
- ▣ Cost

II. Health Promotion: Beyond Illness Care

SEXUALITY

It's All In The Person



Beyond Media Education

For More Information:

Beyond Media Education (www.beyondmedia.org)

DOIN' IT: SEX, DISABILITY, AND VIDEOTAPE The Empowered Fe Fes, a peer group of young women aged 16 to 24 with different disabilities, strike again with their second video production, an insightful investigation into the truths about sex and disability. In the video, the Fe Fes educate themselves about sex from many angles by talking with activists and scholars.

Promoting Sexuality

People with I/DD have been routinely and systematically denied the right to develop and express their sexuality.

No group in this country faces the sort of sexual and reproductive restrictions disabled people do: we are frequently prevented from marrying, bearing and/or rearing children, learning about sexuality, having sexual relationships and having access to sexual literature... (Barbara Faye Waxman, 1991, p. 85-6)

Reference(s): Waxman, B.F. It's time to politicize our sexual oppression. *In* The Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of the Disability Rag. B Shaw (ed). The Advocado Press: Louisville, KY, 1994, pp 82-87

Peer Support



Beyond Media Education

While people in the general population receive their sex education from a variety of sources, including parents and friends, individuals with physical and I/DD are more likely to receive their knowledge only from formal educational programs and the media. Furthermore, individuals with I/DD are much less likely to discuss their thoughts, feelings and experiences with family and friends. According to McCabe, “the whole topic of sexuality is less likely to be normalized, because it is not discussed” p. 167. For persons with I/DD, attitudes of parents, teachers, and staff present significant barriers to developing a healthy sexual identity, which in turn serves to deny them of their humanity.

Reference(s): McCabe, M.P. (1999). Sexual knowledge, experience and feelings among people with disability. *Sexuality and Disability*, 17, 157-170.

For More Information:

Beyond Media Education (www.beyondmedia.org)

DOIN' IT: SEX, DISABILITY, AND VIDEOTAPE The Empowered Fe Fes, a peer group of young women aged 16 to 24 with different disabilities, strike again with their second video production, an insightful investigation into the truths about sex and disability. In the video, the Fe Fes educate themselves about sex from many angles by talking with activists and scholars.

Structural Barriers to Sexuality Development

Policies in schools, community-based, and residential and worksite settings often prevent sexual expression.

- ❑ **Social isolation** and parental overprotection may inhibit development as sexual and social beings.
- ❑ Children and adolescents in mainstreamed school settings may have **little contact** with individuals who they could expect to form more intimate relationships, including friendships and partnered-type relationships.
- ❑ Children and adolescents in segregated settings **may be denied opportunity** to form intimate relationships and enjoy little or no time to see or visit with friends outside of school settings.

Reference(s): Ailey, S. Marks, B.A., & Hahn, J.E. (2003). Promoting Sexuality Across the Lifespan for Individuals with Intellectual and Developmental Disabilities. *Nursing Clinics of North America*, 38(2), 229-252.

At-Risk Situation



Beyond Media Education

CDT (Cook-DuPage area Transportation) is the paratransit service for people with disabilities in the Cook-DuPage area

Issues related to consent.

For More Information:

Beyond Media Education (www.beyondmedia.org)

DOIN' IT: SEX, DISABILITY, AND VIDEOTAPE The Empowered Fe Fes, a peer group of young women aged 16 to 24 with different disabilities, strike again with their second video production, an insightful investigation into the truths about sex and disability. In the video, the Fe Fes educate themselves about sex from many angles by talking with activists and scholars.

Attitudinal Barriers to Sexuality Development

Parents and health professionals often have attitudes and practices that deny or impede adolescents with disabilities the right to healthy sexual expression.

- ❑ Parents are less likely to allow their children with disabilities to associate with peers outside of school hours than are parents of their non-disabled peers.
- ❑ Adolescents with disabilities often have limited circles of friends and social contacts.

Individuals with physical disabilities and individuals with I/DD often acquire sexual knowledge, experience, and feelings from different sources than their non-disabled peers. While people in the general population receive their sex education from a variety of sources, including parents and friends, individuals with physical and I/DD are more likely to receive their knowledge only from formal educational programs and the media. Furthermore, individuals with I/DD are much less likely to discuss their thoughts, feelings and experiences with family and friends. According to McCabe, “the whole topic of sexuality is less likely to be normalized, because it is not discussed” p. 167. For persons with I/DD, attitudes of parents, teachers, and staff present significant barriers to developing a healthy sexual identity, which in turn serves to deny them of their humanity.

Reference(s):

- ❑ Ailey, S. Marks, B.A., & Hahn, J.E. (2003). Promoting Sexuality Across the Lifespan for Individuals with Intellectual and Developmental Disabilities. *Nursing Clinics of North America*, 38(2), 229-252.
- ❑ McCabe, M.P. (1999). Sexual knowledge, experience and feelings among people with disability. *Sexuality and Disability* 17:157-170.

Mentoring



Beyond Media Education

Traditional assessments for abuse may not capture abuse being experienced by people with disabilities who are often abused by caregivers (including family members and paid professionals).

For More Information:

Beyond Media Education (www.beyondmedia.org)

DOIN' IT: SEX, DISABILITY, AND VIDEOTAPE The Empowered Fe Fes, a peer group of young women aged 16 to 24 with different disabilities, strike again with their second video production, an insightful investigation into the truths about sex and disability. In the video, the Fe Fes educate themselves about sex from many angles by talking with activists and scholars.

Sexuality Education Programs

Education and training around sexuality issues must begin in infancy and continue through adulthood.

- Learning to enjoy sexuality requires the presence of several factors:
 - Developing a positive self-esteem
 - Making choices
 - Giving consent
 - Receiving information
 - Experiencing mutuality
 - Experiencing pleasure
 - Having legal recourse if abuse is experienced

Handout:

Table 1. Content Areas Health Education Activities – Infancy to 3 Years of Age

Table 2. Content Areas – 3 to 5 Years of Age

Table 3. Content Areas – 5 to 8 Years of Age

Table 4. Content Areas – 8 to 11 Years of Age

Table 5. Content Areas – 12 to 18 Years of Age

Table 6. Content Areas – Adults

Reference(s): Ailey, S. Marks, B.A., & Hahn, J.E. (2003). Promoting Sexuality Across the Lifespan for Individuals with Intellectual and Developmental Disabilities. *Nursing Clinics of North America*, 38(2), 229-252.

Content Areas for Sexuality Education Activities

Infancy to 3 Years of Age

Sex and Sexuality	<ul style="list-style-type: none">➤ Teach parent(s)/caregiver(s) that curiosity about genitals is a part of normal development.➤ Instruct parent(s)/caregiver(s) to teach child:<ul style="list-style-type: none">■ certain body parts are private,■ behaviors that need to be done in private and what can be done in public (e.g., pull down pants only in bathroom), and,■ self-pleasuring is a normal part of self-exploration.
Body Part Identification	<ul style="list-style-type: none">➤ Ask parent(s)/caregiver(s) if they are comfortable discussing correct names for body parts with their child.➤ Instruct parent(s)/caregiver(s) to begin teaching child the appropriate names of all body parts in play with the child.
Sexual Abuse	<ul style="list-style-type: none">➤ Ask parent(s)/caregiver(s) if:<ul style="list-style-type: none">■ they are comfortable discussing stranger safety with their child,■ someone has hurt their son/daughter, and,■ they are worried that someone is or may hurt their son/daughter.➤ Instruct parent(s)/caregiver(s) to:<ul style="list-style-type: none">■ teach child good touch/bad touch and■ listen to their son/daughter when they try tell them something.➤ Evaluate child for signs and symptoms of abuse.

Reference: Ailey, S. Marks, B.A., & Hahn, J.E. (2003). Promoting Sexuality Across the Lifespan for Individuals with Intellectual and Developmental Disabilities. *Nursing Clinics of North America*, 38(2), 229-252.

Content Areas for Sexuality Education Activities

Table 2. Content Areas – 3 to 5 Years of Age

Sex and Sexuality	<ul style="list-style-type: none"> ➤ Instruct parent(s)/caregiver(s) to: <ul style="list-style-type: none"> ■ answer child's questions truthfully and directly and ■ discuss issues in language that the child understands.
Body Part Identification	<ul style="list-style-type: none"> ➤ Instruct parent(s)/caregiver(s) to: <ul style="list-style-type: none"> ■ continue teaching child the correct names of all body parts that are visible with appropriate terms (e.g., penis, vagina, breast), ■ use age-appropriate books to teach child names of body parts, ■ avoid cute names that may confuse child, and, ■ help child to differentiate between boys and girls.
Sexual Abuse	<ul style="list-style-type: none"> ➤ Continue asking parent(s)/caregiver(s) if they have any questions or concerns about sexual abuse and sexual abuse prevention. ➤ Instruct parent(s)/caregiver(s): <ul style="list-style-type: none"> ■ to identify signs of abuse and ■ continue listening to their son/daughter when they try tell them something. ➤ Ask child if: <ul style="list-style-type: none"> ■ anyone ever touched you in a way you didn't like, and, ■ anyone ever tried to hurt you. ➤ Teach child: <ul style="list-style-type: none"> ■ concepts of stranger safety, ■ his/her body belongs to him/her, and, ■ he/she has a right to tell others not to touch his/her body if they do not want to be touched. ➤ Evaluate child for signs and symptoms of abuse.
Relationships	<ul style="list-style-type: none"> ➤ Instruct parent(s)/caregiver(s) to: <ul style="list-style-type: none"> ■ demonstrate qualities of healthy relationships, such as love, respect, communication, friendship, and affection between adults, ■ teach about the different kinds of families that children have, and, ■ concretely discuss various sexual orientations and other differences.

Reference: Ailey, S. Marks, B.A., & Hahn, J.E. (2003). Promoting Sexuality Across the Lifespan for Individuals with Intellectual and Developmental Disabilities. *Nursing Clinics of North America*, 38(2), 229-252.

Content Areas for Sexuality Education Activities

Table 3. Content Areas – 5 to 8 Years of Age

Sex and Sexuality	<ul style="list-style-type: none"> ➤ Teach parent(s)/caregiver(s) that sexuality: <ul style="list-style-type: none"> ▣ exists in children with disabilities, ▣ develops in children with disabilities, ▣ includes physical expressions of love, affection, and desires, and, ▣ consist of gender identity, friendships, self-esteem, and body image. ➤ Encourage child to ask trusted adults questions about sex and sexuality. ➤ Teach child basic health and safety, cleanliness and hygiene. ➤ Remind child that masturbation should be done in private.
Body Part Identification/ Bodily Changes	<ul style="list-style-type: none"> ➤ Instruct parent(s)/caregiver(s) to: <ul style="list-style-type: none"> ▣ discuss information given to child at school, ▣ answer child's questions, ▣ continue teaching the correct names for all body parts using age-appropriate books, ▣ begin talking about the occurrence of changes during adolescence as questions arise, and, ▣ discuss menstruation as situation arises.
Sexual Abuse	<ul style="list-style-type: none"> ➤ Continue to ask child if they have been: <ul style="list-style-type: none"> ▣ touched you in a way you didn't like or hurt you or ▣ hurt by anyone. ➤ Ask parent(s)/caregiver(s) if they have any concerns or questions. ➤ Reinforce with child: <ul style="list-style-type: none"> ▣ concepts of stranger safety, ▣ his/her body belongs to him/her, ▣ good touch/bad touch, and, ▣ no one has a right to touch him/her without permission.
Childbirth	<ul style="list-style-type: none"> ➤ Teach basic concepts of where babies come.
Relationships	<ul style="list-style-type: none"> ➤ Demonstrate qualities of healthy relationships, such as love, respect, communication, friendship, and affection between adults. ➤ Teach about the different kinds of families that children have.
Sexually Transmitted Diseases (STDs)	<ul style="list-style-type: none"> ➤ Teach child: <ul style="list-style-type: none"> ▣ basic information regarding STDs and ▣ concepts of avoiding contact with blood and other body fluids.

Reference: Ailey, S. Marks, B.A., & Hahn, J.E. (2003). Promoting Sexuality Across the Lifespan for Individuals with Intellectual and Developmental Disabilities. *Nursing Clinics of North America*, 38(2), 229-252.

Content Areas for Sexuality Education Activities

Table 4. Content Areas – 8 to 11 Years of Age

Sex and Sexuality	<ul style="list-style-type: none"> ➤ Teach parent(s)/caregiver(s) and child that information is power and lack of information puts children at risk for abuse. ➤ Instruct parent(s)/caregiver(s) and child about: <ul style="list-style-type: none"> ➤ Physical & emotional changes that occur during puberty, ➤ menses for girls and “wet dreams” for boys, and ➤ the normalcy of sexual feelings. ➤ Teach child to discuss sexual issues with appropriate family members or other identified adults. ➤ Teach parent(s)/caregiver(s) the need to: <ul style="list-style-type: none"> ➤ provide accurate information about sex, sexual relationships, reproduction, sexually transmitted diseases, and sex abuse ➤ discuss information that child learned at school, and, ➤ provide clarification as needed.
Body Part Identification/ Bodily Changes	<ul style="list-style-type: none"> ➤ Teach child to continue discussing sexual issues with appropriate family members or other identified adults. ➤ Instruct parent(s)/caregiver(s) to: <ul style="list-style-type: none"> ➤ continue talking about the occurrence of changes during adolescence and ➤ discuss menstruation as situation arises.
Sexual Abuse	<ul style="list-style-type: none"> ➤ Teach parent(s)/caregiver(s) and child how to avoid sexual abuse and the need to report any sexual abuse or exploitation.
Self-Esteem	<ul style="list-style-type: none"> ➤ Teach child: <ul style="list-style-type: none"> ➤ to focus on his/her strengths and not on his/her weaknesses and ➤ that all people have some things that make them different from others.
Pregnancy, Contraceptives, and Pregnancy, STDs	<ul style="list-style-type: none"> ➤ Instruct parent(s)/caregiver(s) and child about: <ul style="list-style-type: none"> ➤ safe sex and contraception, ➤ the consequences related to decision making in that unprotected sex may lead to pregnancy STDs, ➤ basic information regarding STDs, and, ➤ reinforce concepts of avoiding contact with blood and other body fluids.
Relationships, Dating and Intimacy	<ul style="list-style-type: none"> ➤ Reinforce teaching about families and acceptance of various sexual orientations and other differences. ➤ Discuss dating and relationship issues.

Reference: Ailey, S. Marks, B.A., & Hahn, J.E. (2003). Promoting Sexuality Across the Lifespan for Individuals with Intellectual and Developmental Disabilities. *Nursing Clinics of North America*, 38(2), 229-252.

Content Areas for Sexuality Education Activities

Table 5. Content Areas – 12 to 18 Years of Age

Sex and Sexuality	<ul style="list-style-type: none"> ➤ Ask adolescent if he/she has concerns about sex or sexuality. ➤ Give adolescent permission to discuss issues regarding safe sex and contraception with a parent or other identified adult, such as a nurse or physician. ➤ Teach adolescent to: <ul style="list-style-type: none"> ■ say “no” to sex and ■ delay having sex until he/she’s mature enough to handle responsibilities.
Body Part Identification/ Bodily Changes	<ul style="list-style-type: none"> ➤ Reinforce with adolescent girls: <ul style="list-style-type: none"> ■ if sexually active, the need, for annual pelvic exam and Pap smear, STD screening and ■ breast self exam. ➤ Reinforce with adolescent males testicular self-exam.
Sexual Abuse	<ul style="list-style-type: none"> ➤ Continue teaching strategies to avoid sexual abuse and the need to report any sexual abuse or exploitation. ➤ Reinforce teaching regarding sexual exploitation and the adolescent’s right to say “no” to unwanted sex.
Self-Esteem	<ul style="list-style-type: none"> ➤ Teach adolescent: <ul style="list-style-type: none"> ■ feelings about ourselves influence the activities that we engage in and these activities affect maintain, improve, or harm our health & ■ to engage in sex when he/she able to handle responsibilities.
Pregnancy, Contraceptives, Pregnancy, Abortion, and STDs	<ul style="list-style-type: none"> ➤ Ask adolescent if he/she: <ul style="list-style-type: none"> ■ is having sex, ■ uses contraceptives, ■ has ever been pregnant, ■ has had an STD, and, ■ ever had sex with anyone who had an STD. ➤ Discuss with adolescent in a frank, open, non-threatening manner: <ul style="list-style-type: none"> ■ information about contraception, safe sex, pregnancy, abortion, & STDs, ■ basic childcare and development as well as the responsibilities of being a parent, ■ if he/she is planning to have a baby, discuss taking a daily folic acid supplement before and during pregnancy, and, ■ information about STDs.
Relationships, Dating, Intimacy, and Marriage	<ul style="list-style-type: none"> ➤ Ask adolescent if he/she: <ul style="list-style-type: none"> ■ is having sex ■ is dating, and, ■ dates more than one person. ➤ Teach adolescent about: <ul style="list-style-type: none"> ■ peer pressure and resisting when necessary ■ importance of interpersonal relationships, and, ■ importance of communication in an adult relationship including the ability to discuss sexual behaviors with that person. ➤ Reinforce the values of the family, culture, or religion that the adolescent is a part of, and help them to define their own values.

Reference: Ailey, S. Marks, B.A., & Hahn, J.E. (2003). Promoting Sexuality Across the Lifespan for Individuals with Intellectual and Developmental Disabilities. *Nursing Clinics of North America*, 38(2), 229-252.

Content Areas for Sexuality Education Activities

Table 6. Content Areas – Adults

Sex and Sexuality	<ul style="list-style-type: none"> ➤ Ask adult if he/she has concerns about sex or sexuality. ➤ Provide opportunity for adult to discuss issues regarding safe sex and contraception with appropriate individuals.
Body Part Identification/ Bodily Changes	<ul style="list-style-type: none"> ➤ Reinforce with women the need for: <ul style="list-style-type: none"> ■ pelvic exam, Pap smears, and STD screening if necessary and ■ breast self exam. ➤ Reinforce with men the need for testicular self-exam.
Sexual Abuse	<ul style="list-style-type: none"> ➤ Continue teaching strategies to avoid sexual abuse and the need to report any sexual abuse or exploitation. ➤ Reinforce teaching regarding sexual exploitation and the adult's right to say "no" to unwanted sex.
Self-Esteem	<ul style="list-style-type: none"> ➤ Teach adult: <ul style="list-style-type: none"> ■ our feelings about ourselves influence the activities that we engage in and these activities affect maintain, improve, or harm our health, ■ we have high self-esteem when we feel competent and lovable, ■ we have low self-esteem when we feel incompetent and unloveable, ■ with high self-esteem, people generally have good relationships, and, ■ people with low self-esteem may be overallly influenced by others instead of making their own decisions.
Pregnancy, Contraceptives, Pregnancy, Abortion, and STDs	<ul style="list-style-type: none"> ➤ Ask adult if he/she: <ul style="list-style-type: none"> ■ needs to practice safer sex (why or why not), ■ negotiates safe sex with his/her partners, ■ is planning on becoming pregnant, ■ uses contraceptives, ■ has an STD, Herpes, HIV, Hepatitis C, or HPV, and, ■ ever had sex with anyone who had an STD. ➤ If adult has an STD, ask if he/she tells new sexual partners about these STDs. ➤ If planning to become pregnant, discuss the need to: <ul style="list-style-type: none"> ■ eat a balanced diet of healthy foods, ■ engage in regular physical activity, and ■ avoid tobacco, alcohol, and drugs before and during pregnancy.
Relationships, Dating, Intimacy, and Marriage	<ul style="list-style-type: none"> ➤ Discuss with adult: <ul style="list-style-type: none"> ■ importance of interpersonal relationships, ■ importance of communication in an adult relationship including the ability to discuss sexual behaviors with that person, and, ■ concerns about dating.

Reference: Ailey, S. Marks, B.A., & Hahn, J.E. (2003). Promoting Sexuality Across the Lifespan for Individuals with Intellectual and Developmental Disabilities. *Nursing Clinics of North America*, 38(2), 229-252.

II. Health Promotion: Beyond Illness Care

PSYCHOSOCIAL WELL-BEING

Features of Violence for People with Disabilities



Rehabilitation Institute of Chicago

For More Information:

Kirschner, K. et al. (2001). Learning to Act in Partnership - Disabled Women Speak with Health Professionals. (VHS Video). Rehabilitation Institute of Chicago
(<http://www.ric.org/pros/education/CatalogofEducationalMaterials.aspx>)

Bullying



Beyond Media Education

For More Information:

Beyond Media Education (www.beyondmedia.org)

WHY THEY GOTTA DO ME LIKE THAT? THE EMPOWERED FE FES TAKE ON BULLYING Young women with disabilities show us how we can work together to understand and stop school-based discrimination, particularly against people with disabilities.

Bullying among Children with Disabilities

**Over 30% of all youth are bullied –
children with disabilities are at
even greater risk of being bullied.**

- Children who are bullied are more likely to:
 - have low self-esteem,
 - experience feelings of fear,
 - have nightmares, sleeplessness, headaches, stomachaches, fatigue, poor appetites,
 - be absent from school and dislike school, and
 - be depressed, lonely, anxious, and, think about suicide.

People with disabilities can be depressed; but not all people with disabilities are depressed.

Reference(s):

- Bullying Among Children and Youth with Disabilities and Special Needs (http://stopbullyingnow.hrsa.gov/HHS_PSA/pdfs/SBN_Tip_24.pdf);
- Roles for Health and Safety Professionals in Bullying Prevention and Intervention (http://stopbullyingnow.hrsa.gov/HHS_PSA/pdfs/SBN_Tip_16.pdf)

III. Universal Design: More Than Ramps

OBJECTIVE

Identify concepts related to universal design and strategies to achieve physical, communication, and programmatic access.

Recent studies find that a "substantial portion of primary care physicians' offices are not in compliance with the ADA":

1. 18% of the primary care physicians in this study were unable to serve their patients with disabilities in the last year for reasons that could be interpreted as non-compliant with the ADA (e.g., physical barriers and inaccessible equipment),
2. 22% were improperly referring patients with disabilities although they generally treat such patients, and
3. 13% of the physicians' offices had a low level of compliance in regard to structural features that enhance the accessibility.

Reference: E.W. Grabois, M.A. Nosek, C.D. Rossi 1999 article "Accessibility of primary care physicians' offices for people with disabilities. An analysis of compliance with the Americans With Disabilities Act" in Archives Family Medicine Jan-Feb;8(1): 44-51.

Universal Design: Accessibility for All



Access Living Metropolitan Chicago

For More Information:

Access Living of Metropolitan Chicago

What is Universal Design?

Universal Design designs environments and products to be usable by as many people as possible regardless of age, ability, or situation.

- ❑ International terminology: *Design For All*, *Inclusive Design*, and *Barrier-Free Design*
- ❑ Common symbols include:



Universal design is not a fad or a trend but an enduring design approach that originates from the belief that the broad range of human ability is ordinary, not special. Universal design accommodates people with disabilities, older people, children, and others who are non-average in a way that is not stigmatizing and benefits all users. After all, stereo equipment labels that can be read by someone with low vision are easier for everyone to read; public telephones in noisy locations that have volume controls are easier for everyone to hear; and building entrances without stairs assist equally someone who moves furniture, pushes a baby stroller, or uses a wheelchair. Designing for a broad range of users from the beginning of the process can increase usability of an environment or product without significantly increasing its cost. It results in easier use for everyone and it reduces the need for design modifications later when abilities or circumstances change.

Universal design is assuming growing importance as a new paradigm that represents a holistic and integrated approach to design ranging in scale, for example, from product design to architecture and urban design, and from simple systems such as those that control the ambient environment to complex information technologies.

Universal design is not a synonym or a euphemism for accessibility standards. Universal design can be distinguished from meeting accessibility standards in the way that the accessible features have been *integrated* into the overall design. This integration is important because it results in better design and avoids the stigmatizing quality of accessible features that have been added on late in the design process or after it is complete, as a modification.

Universal design also differs from accessibility requirements in that accessibility requirements are usually prescriptive whereas universal design is performance based. Universal design does not have standards or requirements but addresses usability issues. The Principles of Universal Design, published by the Center for Universal Design in 1997, articulate the breadth of the concept and provide guidelines for designers.

Handout: The Principles of Universal Design POSTER

Reference(s): The Center for Universal Design (www.design.ncsu.edu/cud/about_ud/udprinciples.htm)

Universal Design Education Online (<http://www.udeducation.org/learn/aboutud.asp>)

THE PRINCIPLES OF UNIVERSAL DESIGN

Version 2.0 (4/97)

1

EQUITABLE USE

The design is useful and marketable to people with diverse abilities.



- GUIDELINES**
- 1a.** Provide the same means of use for all users; identical whenever possible; equivalent when not.
 - 1b.** Avoid segregating or stigmatizing any users.
 - 1c.** Make provisions for privacy, security, and safety equally available to all users.
 - 1d.** Make the design appealing to all users.

- EXAMPLES**
- Power doors with sensors at entrances that are convenient for all users
 - Integrated, dispersed, and adaptable seating in assembly areas such as sports arenas and theaters

5

TOLERANCE FOR ERROR

The design minimizes hazards and the adverse consequences of accidental or unintended actions.



- GUIDELINES**
- 5a.** Arrange elements to minimize hazards and errors; most used elements, most accessible; hazardous elements eliminated, isolated, or shielded.
 - 5b.** Provide warnings of hazards and errors.
 - 5c.** Provide fail safe features.
 - 5d.** Discourage unconscious action in tasks that require vigilance.

- EXAMPLES**
- A double-cut car key easily inserted into a recessed keyhole in either of two ways
 - An "undo" feature in computer software that allows the user to correct mistakes without penalty

2

FLEXIBILITY IN USE

The design accommodates a wide range of individual preferences and abilities.



- GUIDELINES**
- 2a.** Provide choice in methods of use.
 - 2b.** Accommodate right- or left-handed access and use.
 - 2c.** Facilitate the user's accuracy and precision.
 - 2d.** Provide adaptability to the user's pace.

- EXAMPLES**
- Scissors designed for right- or left-handed users
 - An automated teller machine (ATM) that has visual, tactile, and audible feedback, a tapered card opening, and a palm rest

6

LOW PHYSICAL EFFORT

The design can be used efficiently and comfortably and with a minimum of fatigue.



- GUIDELINES**
- 6a.** Allow user to maintain a neutral body position.
 - 6b.** Use reasonable operating forces.
 - 6c.** Minimize repetitive actions.
 - 6d.** Minimize sustained physical effort.

- EXAMPLES**
- Lever or loop handles on doors and faucets
 - Touch lamps operated without a switch

3

SIMPLE AND INTUITIVE USE

Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.



- GUIDELINES**
- 3a.** Eliminate unnecessary complexity.
 - 3b.** Be consistent with user expectations and intuition.
 - 3c.** Accommodate a wide range of literacy and language skills.
 - 3d.** Arrange information consistent with its importance.
 - 3e.** Provide effective prompting and feedback during and after task completion.

- EXAMPLES**
- A moving sidewalk or escalator in a public space
 - An instruction manual with drawings and no text

7

SIZE AND SPACE FOR APPROACH AND USE

Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.



- GUIDELINES**
- 7a.** Provide a clear line of sight to important elements for any seated or standing user.
 - 7b.** Make reach to all components comfortable for any seated or standing user.
 - 7c.** Accommodate variations in hand and grip size.
 - 7d.** Provide adequate space for the use of assistive devices or personal assistance.

- EXAMPLES**
- Controls on the front and clear floor space around appliances, mailboxes, dumpsters, and other elements
 - Wide gates at subway stations that accommodate all users

4

PERCEPTIBLE INFORMATION

The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.



- GUIDELINES**
- 4a.** Use different modes (pictorial, verbal, tactile) for redundant presentation of essential information.
 - 4b.** Maximize "legibility" of essential information.
 - 4c.** Differentiate elements in ways that can be described (i.e., make it easy to give instructions or directions).
 - 4d.** Provide compatibility with a variety of techniques or devices used by people with sensory limitations.

- EXAMPLES**
- Tactile, visual, and audible cues and instructions on a thermostat
 - Redundant cueing (e.g., voice communications and signage) in airports, train stations, and subway cars

THE PRINCIPLES WERE COMPILED BY ADVOCATES OF UNIVERSAL DESIGN, IN ALPHABETICAL ORDER:

Betty Rose Connell, Mike Jones,
Ron Mace, Jim Mueller,
Abir Mullick, Elaine Ostroff,
Jon Sanford,
Ed Steinfeld, Molly Story,
and Gregg Vanderheiden.

NOTE

The Principles of Universal Design are not intended to constitute all criteria for good design, only universally usable design. Certainly, other factors are important, such as aesthetics, cost, safety, gender and cultural appropriateness, and these aspects must also be taken into consideration when designing.

© Copyright 1997 NC State University,
Center for Universal Design, College of Design

THE CENTER FOR UNIVERSAL DESIGN

Box 8613 • Raleigh, NC • 27695.8613

1.800.647.6777 Info Request Line

919.515.3082 Voice and TTY

919.515.8951 FAX

<http://www.design.ncsu.edu/cud>

THE PRINCIPLES OF UNIVERSAL DESIGN

Version 2.0 (4/97)

UNIVERSAL DESIGN : The design of products and environments to be usable by all people, to the greatest extent possible, without adaptation or specialized design.

The authors, a working group of architects, product designers, engineers and environmental design researchers, collaborated to establish the following Principles of Universal Design to guide a wide range of design disciplines including environments, products and communications. These seven principles may be applied to evaluate existing designs, guide the design process, and educate both designers and consumers about the characteristics of more usable products and environments.

1

EQUITABLE USE

The design is useful and marketable to people with diverse abilities.

2

FLEXIBILITY IN USE

The design accommodates a wide range of individual preferences and abilities.

3

SIMPLE AND INTUITIVE USE

Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.

4

PERCEPTIBLE INFORMATION

The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.

5

TOLERANCE FOR ERROR

The design minimizes hazards and the adverse consequences of accidental or unintended actions.

6

LOW PHYSICAL EFFORT

The design can be used efficiently and comfortably and with a minimum of fatigue.

7

SIZE AND SPACE FOR APPROACH AND USE

Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.



Universal Design in Action



Access Living Metropolitan Chicago

For More Information:

Access Living of Metropolitan Chicago

III. Universal Design: More Than Ramps

PHYSICAL/ENVIRONMENTAL ACCESS

Universal Design aims to design communication, products, and environments to be usable by all people, to the greatest extent possible, without adaptation or specialized design. This concept is also referred to as *Inclusive Design*, *Design-For-All*, *Lifespan Design*, *Barrier-Free Design*, or *Human-Centered Design*. The underlying premise is the following: if it works well for people across the spectrum of functional ability, it will work better for everyone. For example, medication labels that can be read by people with low vision are easier for everyone to read; minimizing external noises for classroom setting makes it easier for everyone to hear; and building entrances without stairs is useful for people who are pushing strollers, carrying groceries, or using a wheelchair.

The usability of a communication strategy, product, or environment can be enhanced by including designs for a broad range of users that incorporate the five senses: seeing, touching, smelling, tasting, and hearing.

Physical/Environmental Access

- ❑ What physical/environmental modifications would you need to make in your office including principles of Universal Design?
- ❑ How usable are your health care services and facilities to people with disabilities?
 - Can you weigh people who can't stand on the scale?
 - Can your patients to move freely throughout your facility?

You may consider the following questions to guide you in making modifications related to content, physical/environmental, and communication.

Universal Design: Physical Access



Access Living Metropolitan Chicago

For More Information:

Access Living of Metropolitan Chicago

The RERC on Accessible Medical Instrumentation (RERC-AMI)

<http://www.marquette.edu/news/articles/692.html>

RERC-AMI is guided by the vision that all persons should have access to healthcare instrumentation and services and to employment in healthcare professions regardless of disability.

The U.S. Department of Education's National Institute on Disability and Rehabilitation Research has granted \$4.5 million to Marquette University and its partners to establish the Rehabilitation Engineering Research Center (RERC) on Accessible Medical Instrumentation.

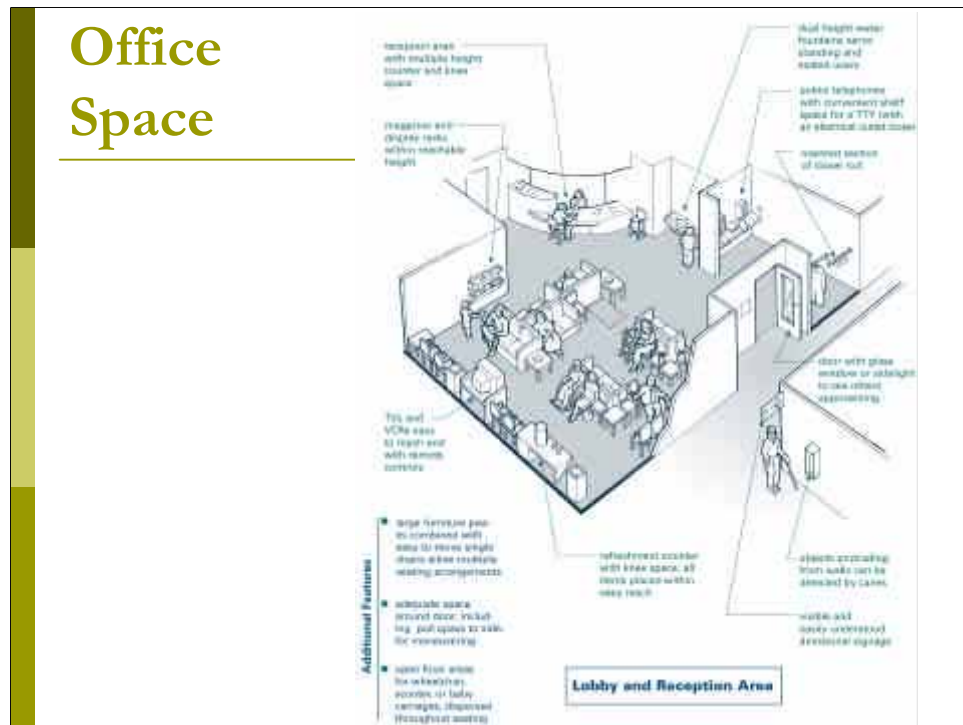
This RERC is the first to specifically address the critical need for new medical instrumentation that advances the ideal of healthcare that is universally accessible to all people. "A key element of the American promise is that every citizen - no matter their race, creed or physical condition - has the right of equal access to services and employment," said U.S. Congressman Tom Barrett (WI). "By answering questions and shedding light on this important issue, Marquette and its partners will discover better ways to give individuals with disabilities greater access to healthcare, and use this federal investment to help thousands of people strengthen their connections to the healthcare field." This five-year grant is awarded to Marquette University and will be managed through its Department of Biomedical Engineering. Project partners in Milwaukee include the University of Wisconsin-Milwaukee's Center for Rehabilitation Sciences and Technology and IndependenceFirst, the metro-Milwaukee area independent living center.

This RERC will evaluate methods and technologies to increase the usability and accessibility of healthcare equipment for people with disabilities as patients and as healthcare providers. It will work closely with consumers, healthcare practitioners, hospitals and medical device manufacturers to increase access to and utilization of medical instrumentation and services by persons with disabilities. RERC-AMI are to:

- Increase knowledge of, access to, and utilization of healthcare instrumentation and services by individuals with disabilities.
- Increase awareness of and access to employment in the healthcare professions by individuals with disabilities.
- Serve as a national center of excellence for this priority area.

The Co-Directors of this project are Jack Winters (Marquette University, jack.winters@marquette.edu) and Molly Follette Story (Human Spectrum Design, L.L.C., molly@humanspectrumdesign.com). Dissemination and training activities are directed by Brenda Premo (CDIHP, bpremo@westernu.edu).

Office Space



Reference(s):

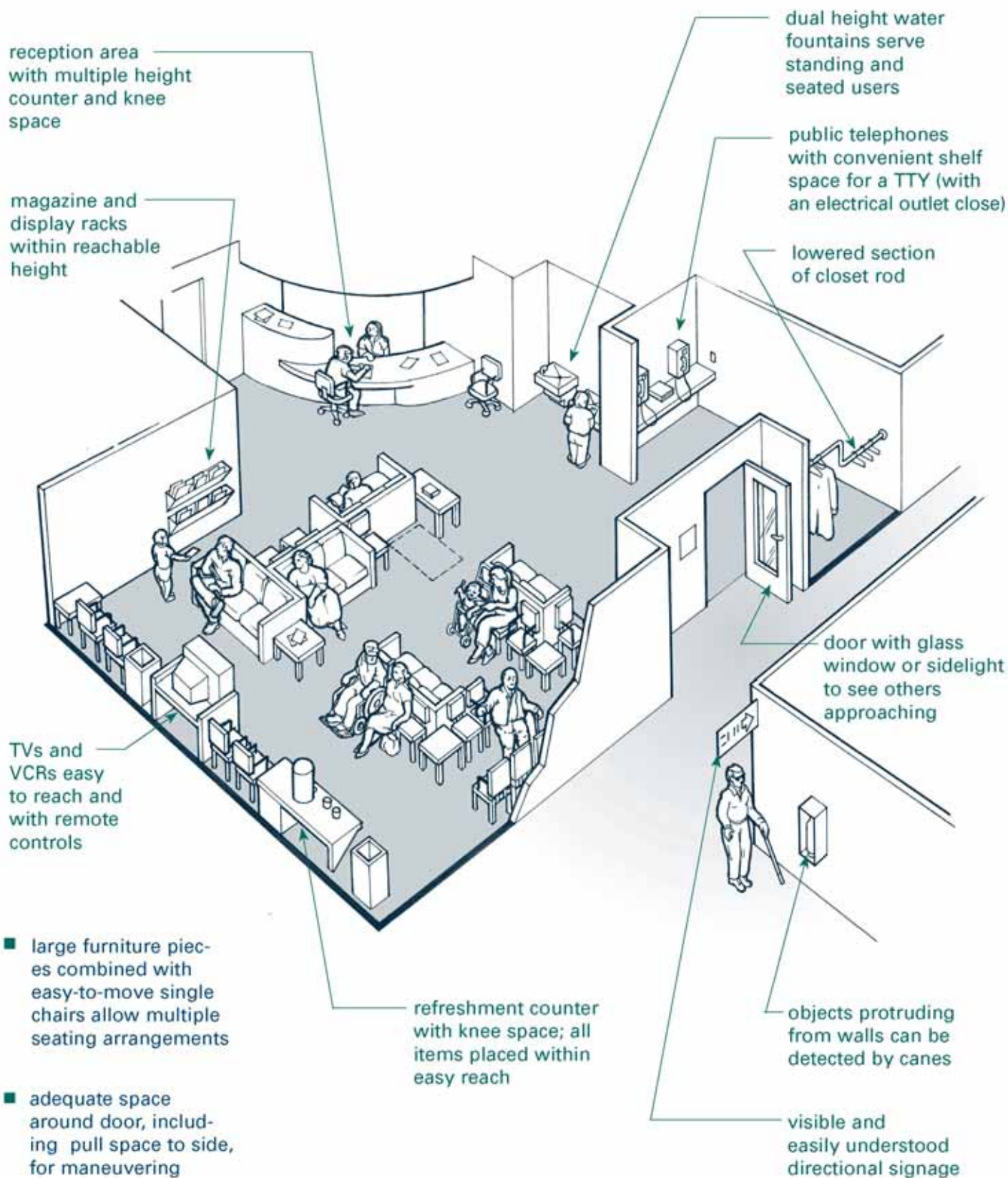
NCODH and the Center for Universal Design at N.C. State University.
 Removing Barriers to Health Care: A Guide for Health Professionals
 (<http://www.fpg.unc.edu/~ncodh/removingbarriers/removingbarrierspubs.cfm>)

For More Information:

ADA Standards for Accessible Design
 (<http://www.usdoj.gov/crt/ada/stdspdf.htm>)

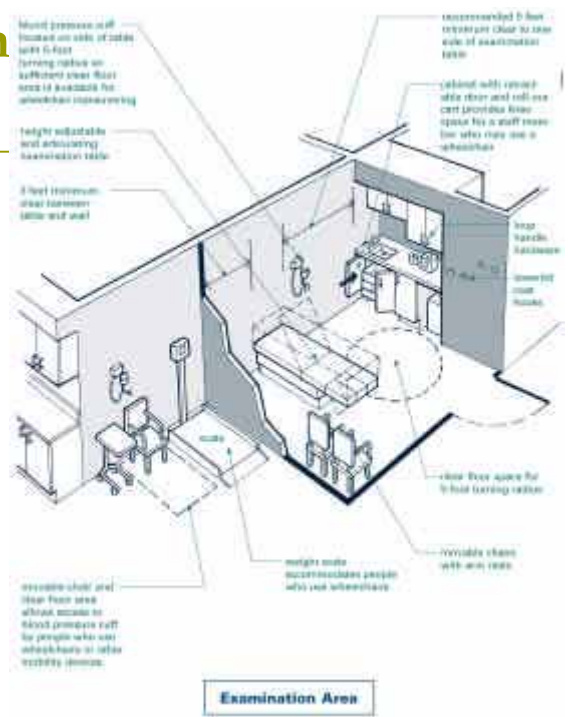
The Center for Universal Design, North Carolina State University
 (www.design.ncsu.edu/cud)

- large furniture pieces combined with easy-to-move single chairs allow multiple seating arrangements
- adequate space around door, including pull space to side, for maneuvering
- open floor areas for wheelchair, scooter, or baby carriages, dispersed throughout seating



Lobby and Reception Area

Examination Room



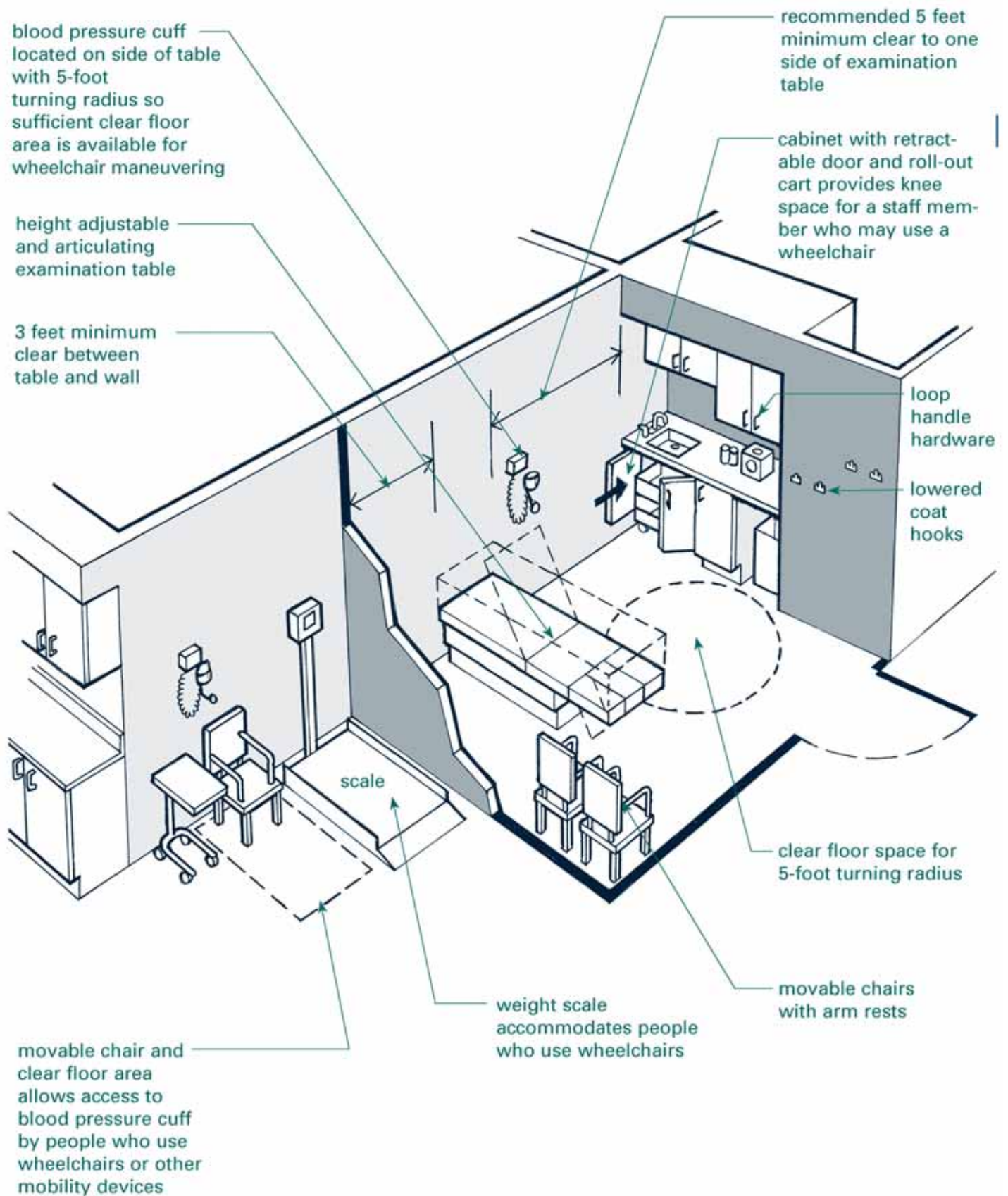
Reference(s):

NCODH and the Center for Universal Design at N.C. State University.
 Removing Barriers to Health Care: A Guide for Health Professionals
 (<http://www.fpg.unc.edu/~ncodh/removingbarriers/removingbarrierspubs.cfm>)

For More Information:

ADA Standards for Accessible Design
 (<http://www.usdoj.gov/crt/ada/stdspdf.htm>)

The Center for Universal Design, North Carolina State University
 (www.design.ncsu.edu/cud)



Addressing Physical Access



Learning to Act in Partnership

For More Information:

Kirschner, K. et al. (2001). Learning to Act in Partnership - Disabled Women Speak with Health Professionals. (VHS Video). Rehabilitation Institute of Chicago
(<http://www.ric.org/pros/education/CatalogofEducationalMaterials.aspx>)

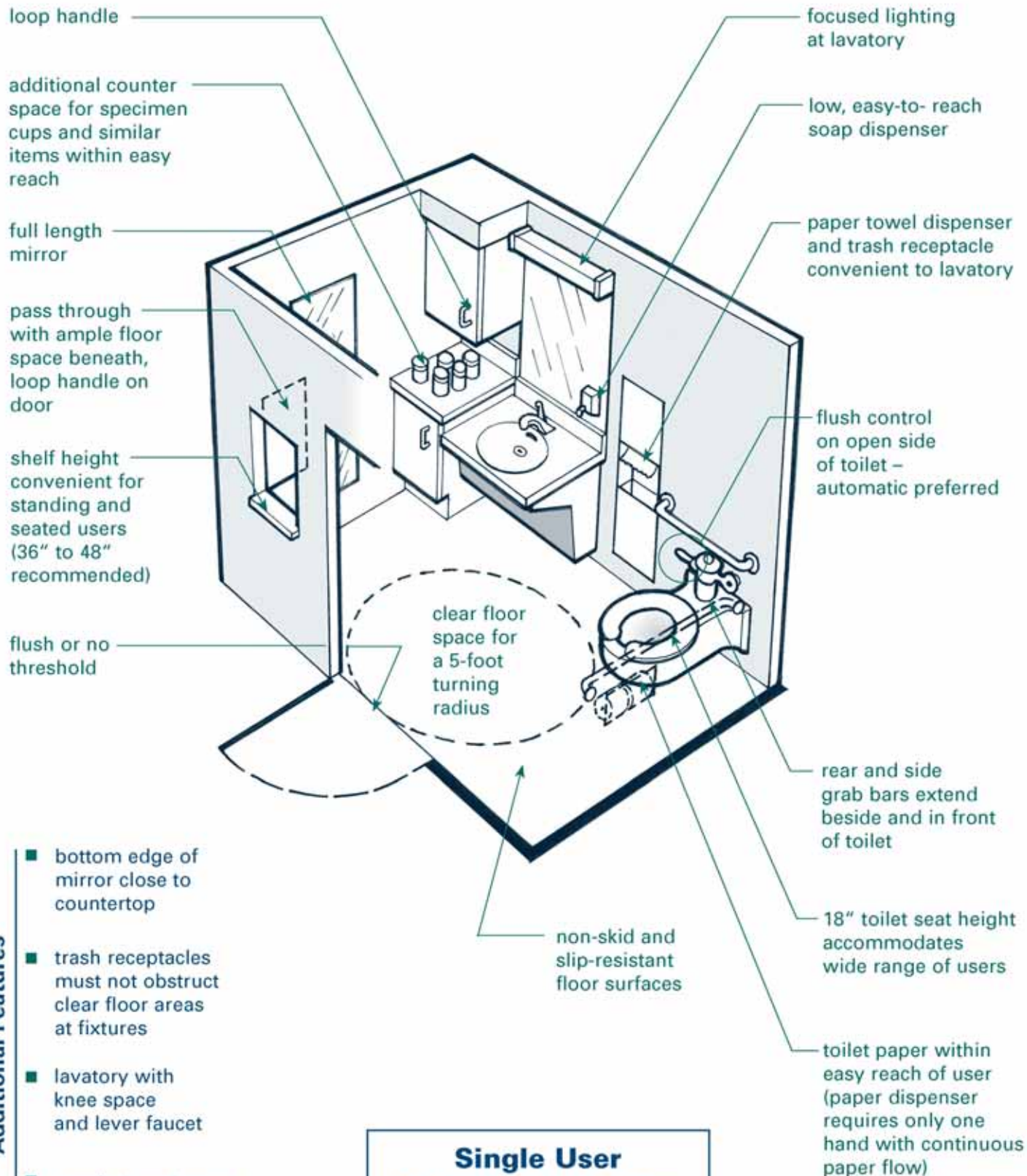
[illegible]

NCODH and the Center for Universal Design at N.C. State University.
Removing Barriers to Health Care: A Guide for Health Professionals
(<http://www.fpg.unc.edu/~ncodh/removingbarriers/removingbarrierspubs.cfm>)

ADA Standards for Accessible Design
(<http://www.usdoj.gov/crt/ada/stdspdf.htm>)
The Center for Universal Design, North Carolina State University
(www.design.ncsu.edu/cud)

Additional Features

- bottom edge of mirror close to countertop
- trash receptacles must not obstruct clear floor areas at fixtures
- lavatory with knee space and lever faucet
- reach to seat cover dispenser must not be obstructed by toilet



**Single User
Patient Toilet Room**

III. Universal Design: More Than Ramps

COMMUNICATION STRATEGIES: GIVING AND RECEIVING INFORMATION

Using Person First Language

Instead of using	Use
Crippled with, suffering from, or afflicted with	Has, with
Handicap	Disability
Handicapped person	Person with a disability, Individual with a disability
Normal, healthy, able-bodied	Nondisabled
Disease, defect	Condition
Confined to a wheelchair, in a wheelchair	Wheelchair user, uses a wheelchair

When in doubt, ask a person what language to use.

Person-first language is a linguistic technique used when discussing disabilities to avoid perceived and subconscious dehumanization of the people having the disabilities. It may also occasionally be used to refer to other identities such as ethnicity or nationality. Its use is controversial in a small number of contexts. It is an example of political correctness.

The technique is to use the term "person with a disability", putting the person first, rather than "disabled person", which puts the disability first. The word ordering is thought to carry implications about which part of the phrase is more important. Many people with disabilities have expressed unease at being described using person-second terminology, seeing it to devalue them as people, with the implication that the most significant facet of their existence is their disability. Person-first terminology is therefore widely preferred in the discussion of most disabilities.

Reference(s):

State governors committee on employment of people with disabilities. (n.d.). *VII. Interacting with people with disabilities*. Retrieved December 2002 from the American Federation of State, County, and Municipal Employees website: <http://www.afscme.org/publications/3118.cfm>

Interacting with People with I/DD

ADA removes many barriers – however, ADA cannot eradicate invisible attitudinal hurdles.

- ❑ Many people without disabilities feel uncomfortable around persons with disabilities.
- ❑ Sometimes, individuals avoid people with disabilities or be awkward around them.
- ❑ Much of this discomfort is due to misunderstanding and lack of contact with people with disabilities.
- ❑ Common feelings include:
 - uneasiness, paternalism and objectification
 - assumptions about emotions and abilities

Social Uneasiness: A sense of awkwardness and uncertainty as to how to speak and act in the presence of people with disabilities.

Paternalism and Objectification: A feeling that people with disabilities are dependent and helpless and therefore in need of special treatment or charity. Treating people with disabilities as objects who do not have personal space.

Assumptions about Emotions: Assumptions about how people with disabilities feel about their conditions, specifically that they feel sorry for themselves or that they are bitter.

Assumptions about Abilities: Assumptions about what people with disabilities can or cannot do.

When in doubt, ask a person what language to use.

Reference(s): Community Resources for Independence
(www.crinet.org/interact.php)

Boundaries: Whose Body Is It?



Beyond Media Education

For More Information:

Beyond Media Education (www.beyondmedia.org)

DOIN' IT: SEX, DISABILITY, AND VIDEOTAPE The Empowered Fe Fes, a peer group of young women aged 16 to 24 with different disabilities, strike again with their second video production, an insightful investigation into the truths about sex and disability. In the video, the Fe Fes educate themselves about sex from many angles by talking with activists and scholars.

Opening Communication...

- 1. In order to achieve full access, how can we arrange your appointment to best meet your needs?**
- 2. What are your communication needs?**
- 3. How can I best work with you to meet your needs?**

Universal Design: Communication Access



Access Living Metropolitan Chicago

For More Information:

Access Living of Metropolitan Chicago

Creating Respectful Interactions: Meeting People with Disabilities

Gestures for showing respect and easing feelings of awkwardness:

- ❑ Ask if assistance is wanted.
- ❑ Look directly at an individual.
- ❑ Treat people as people.
- ❑ Do not assume that a person with a disability is more fragile.
- ❑ Identify yourself and anyone else who may be with you.
- ❑ Try to be seated to facilitate eye contact when conversing with a wheelchair user or a person of short stature.

Feel free to **offer assistance** to a person with a disability or **ask** how you should act or communicate, but **do not automatically assume that the person needs assistance**. Wait until the offer is accepted. Then, the individual can let you know what action he or she prefers.

Look directly at an individual with a disability when addressing him or her, even if a companion or sign language interpreter is present. Avoiding eye contact sometimes increases tension. Persons with hearing impairments may rely on speech reading and may need to look directly at your face.

Adults should always be treated as adults.

Do not assume that a person with a disability is **more fragile** or sensitive than others. These feelings may make you reluctant to ask certain questions that should be asked.

When meeting a **person with a visual disability**, always **identify yourself** and anyone else who may be with you.

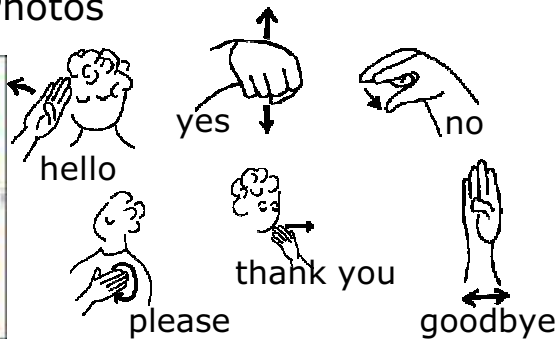
When **conversing with a wheelchair user or a person of short stature**, **try to be seated** to facilitate eye contact.

Reference(s): Community Resources for Independence
(www.crinet.org/interact.php)

Behavioral Expressions

All human behavior communicates something to others

- Motoric □ Sign Language □ Pictorial
- Gestural □ Objects □ Written
- Vocalization □ Photos



Understanding the Use of Nonverbal or Behavioral Communication

For a person who has difficulty vocalizing what it is that he or she wishes to communicate, the use of nonverbal or behavioral communication may take a more primary role in how that person communicates.

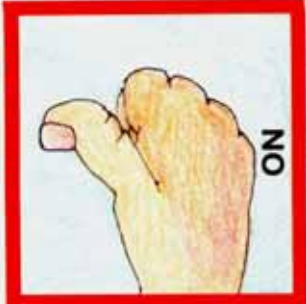
- **Motoric:** Direct physical manipulation of a person or object (e.g., taking a person's hand and pushing it towards a desired item; giving a cup to a caregiver to indicate, "Want milk").
- **Gestural:** Pointing, showing, gaze shift (e.g., the person looks or points to a desired object and then shifts his gaze to another person, thereby requesting that object).
- **Vocalization:** Use of sounds, including crying, to communicate (e.g., an individual says "ah-ah-ah", to draw another person's attention to him).
- **Sign language:** Communication with a conventional sign language system.
- **Using objects:** The individual hands an object to another person to communicate (e.g., the person hands a cup to his parent to indicate "drink").
- **Using photos:** Use of two-dimensional photographs to communicate (e.g., the individual points to, or hands photographs of various objects, actions or events to communicate his desires).
- **Pictorial:** Use of two-dimensional drawings which represent objects, actions or events (e.g., a child hands a line drawing of a "swing" to his parent to indicate that he wants to swing).
- **Written:** Use of printed words or phrases to communicate (e.g., the individual writes, "too loud" to indicate that the noise level in the environment is bothering him).

Audiotape (e.g., visual disabilities), Augmentative communication device, Braille (e.g., visual disabilities), Computer Disk (e.g., visual disabilities), Interpreter, Nonverbal communication, Sign cards, Sign Language, Speech

Reference(s):

- Stokes, S. (n.d.). Developing expressive communication skills for non-verbal children with autism. Wisconsin Department of Public Instruction Website (<http://www.cesa7.k12.wi.us/sped/autism/nonverbal/non11.htm>)
- Venkatagiri, H.S. (2002). Clinical implications of an augmentative and alternative communication taxonomy. *Augmentative and Augmentative Communication*, 18(1), 1-24.
- Health Care Communications Board, Joan Green, Greenhouse Publications, www.greenhousepub.com/index.html.
- American Sign Language Series III Lesson 1: Simple Answers and Beginning Phrases www.lesstutor.com/eesASLsimple.html

TOUCH FOR "NO"



No = eyes closed

Health Care Communication Board

For Medical, Physical and Emotional Information

Greenhouse Publications



INSTRUCTIONS: Have patient touch pictures to request wants and needs.

If unable, caregiver touches pictures and gets yes/no response from patient.

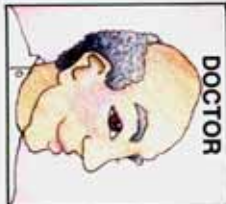
Yes = thumbs up, nod, or eyes wide open;

No = thumbs down, nod or eyes closed.

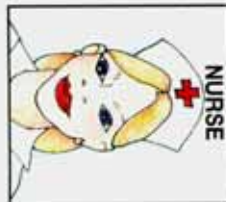
TOUCH FOR "YES"



Yes = eyes wide open



DOCTOR



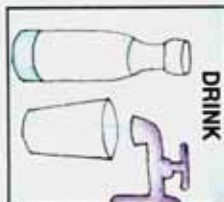
NURSE



MEDICINE



EAT



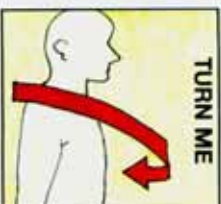
DRINK



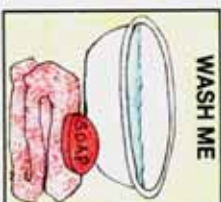
TOILET



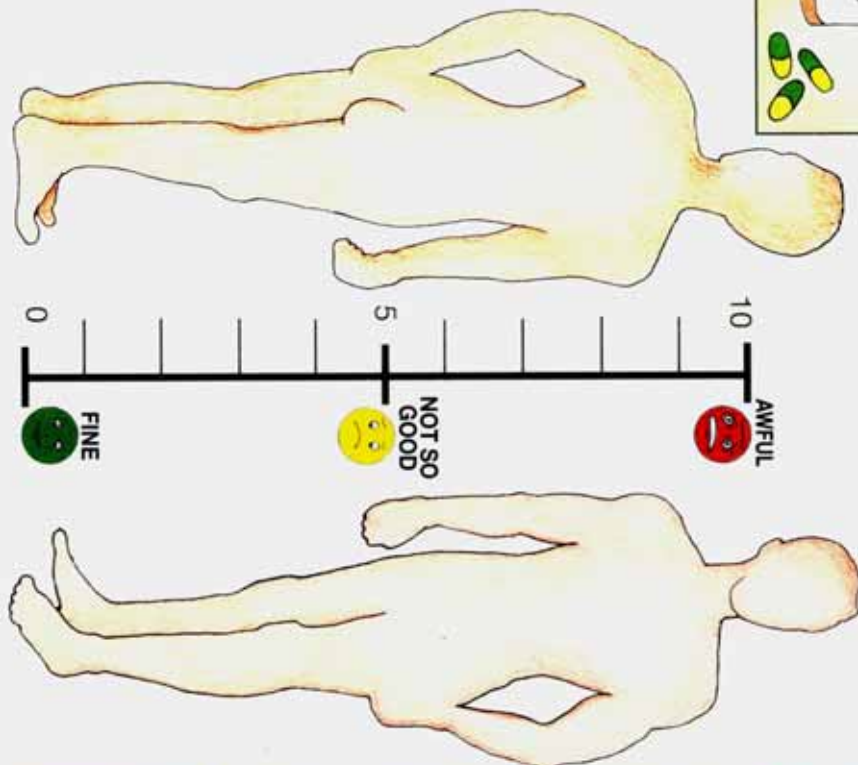
URINAL



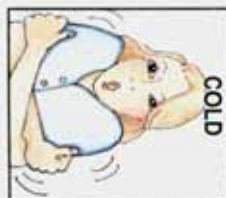
TURN ME



WASH ME



HOT



COLD



CHEST PAIN



CAN'T BREATHE



CHOKING



SUCTION ME



NAUSEOUS



HEADACHE



DIZZY



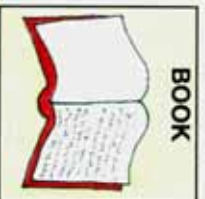
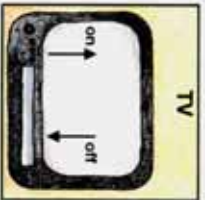
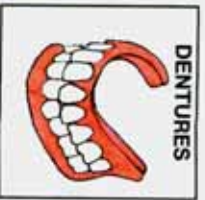
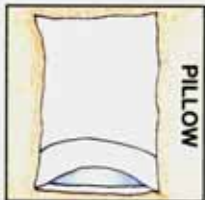
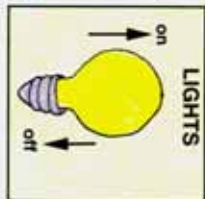
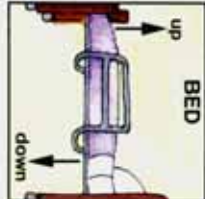
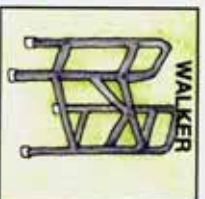
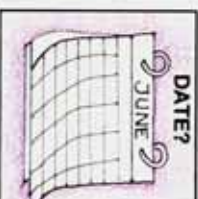
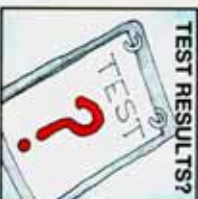
ITCHY



BURNS



NUMB



A B C D E F G H I J K L M
N O P Q R S T U V W X Y Z



Identifying Communication Styles

Determine a person's preferred method of communication as early as possible.

- ❑ Do not assume what a person can do.
- ❑ Consider the need for extra time.
- ❑ Ask questions requiring short answers or head nods.
- ❑ Use universal communication strategies
 - Move away from a noisy source to a quiet environment.
 - Talk directly to a person in a well-lighted area with hands and other objects away from your mouth.
 - If you do not understand, do not pretend that you did.
 - Consider speech-to-speech relay service for phone communication
- ❑ Make sure communication device is within client's reach.

Communication/speech (e.g., people may use augmentative communication devices), Energy (or stamina), Hearing, Learning/memory, Mental health issues (mood, behavioral), Mobility, Vision

- Never assume person with a speech disability has a cognitive disability just because he or she has trouble speaking.
- Move away from a noisy source to a quiet environment for communicating with a person.
- Talk directly to a person with a speech disability if he/she has a companion/attendant – do not ask the companion about the person.
- Be considerate of the extra time it might take for a person with a disability to finish a sentence or complete a task. Let the person with the disability set the pace in walking or talking. When conversing with a person who has speech disability, do not interrupt or finish sentences for that person.
- If you do not understand what the person has said, do not pretend that you did. Ask the person to repeat it. Smiling and nodding when you have no idea what the person said is embarrassing to both parties. Instead, repeat what you have understood and allow the person to respond.
- If you have difficulty conversing on the phone with a person, suggest use of a speech-to-speech relay service so that a trained professional can help you communicate with the person. Either you or the person can initiate the call free of charge via the relay service.
- If person uses a communication device, make sure it is within his or her reach. If there are instructions visible for communicating with the person, take a moment to read them.
- Do not make assumptions about what a person can or cannot do based on disability.
- Consider asking questions that require short answers or can be answered by nods of the head or gestures if that is the individual's most comfortable method of communication. Also, reduce number of questions, provide yes/no questions with pictures, use either/or questions, or provide two options in a question.
- When speaking to a person with a hearing impairment who uses speech reading, be sure to stand in a well-lighted area (not backlit, and keep hands, other objects and food away from your mouth when speaking).

•**Reference(s):** University of Kentucky Engaging Differences Project (http://www.uky.edu/TLC/grants/uk_ed/interactiontips6.html); American Federation of State, County and Municipal Employees, AFSCME (<http://www.afscme.org/publications/3118.cfm>); Community Resources for Independence (<http://www.crinet.org/interact.php>)



ASSISTIVE TECHNOLOGY

WHAT IS ASSISTIVE TECHNOLOGY?

Assistive technology is any service or tool that helps the elderly or disabled do the activities they have always done but must now do differently. These tools are also sometimes called “adaptive devices.”

Such technology may be something as simple as a walker to make moving around easier or an amplification device to make sounds easier to hear (for talking on the telephone or watching television, for instance). It could also include a magnifying glass that helps someone who has poor vision read the newspaper or a small motor scooter that makes it possible to travel over distances that are too far to walk. In short, anything that helps the elderly continue to participate in daily activities is considered assistive technology.

Just as older people may have many different types of disabilities, many different categories of assistive devices and services are available to help overcome those disabilities. These include the following:

- **Adaptive switches.** Modified switches that seniors can use to adjust air conditioners, computers, telephone answering machines, power wheelchairs, and other types of equipment. The tongue or the voice might activate these switches.
- **Communication equipment.** Anything that enables a person to send and receive messages, such as a telephone amplifier.
- **Computer access.** Special software that helps a senior access the Internet, for example, or basic hardware, such as a modified keyboard or mouse, that makes the computer more user friendly.
- **Education.** Audio books or Braille writing tools for the blind come under this category, along with resources that allow people to get additional vocational training.
- **Home modifications.** Construction or remodeling work, such as building a ramp for wheelchair access, that allows a senior to overcome physical barriers and live more comfortably with a disability or recover from an accident or injury.
- **Tools for independent living.** Anything that empowers the elderly to enjoy the normal activities of daily living without assistance from others, such as a handicapped-accessible bathroom with grab bars in the bathtub.
- **Job-related items.** Any device or process that a person needs to do his or her job better or easier. Examples might include a special type of chair or pillow for someone who works at a desk or a back brace for someone who does physical labor.
- **Mobility aids.** Any piece of equipment that helps a senior get around more easily, such as a power wheelchair, wheelchair lift, or stair elevator.
- **Orthotic or prosthetic equipment.** A device that compensates for a missing or disabled body part. This could range from orthopedic shoe inserts for someone who has fallen arches to an artificial arm for someone whose limb has been amputated.
- **Recreational assistance.** New methods and tools to enable people who have disabilities to enjoy a wide range of fun activities. Examples include swimming lessons provided by recreational therapists or specially equipped skis for seniors who have lost a limb as a result of accident or illness.
- **Seating aids.** Any modifications to regular chairs, wheelchairs, or motor scooters that help a person stay upright or get up and down unaided or that help to reduce pressure on the skin. This could be

something as simple as an extra pillow or as complex as a motorized seat.

- **Sensory enhancements.** Anything that makes it easier for those who are partially or fully blind or deaf to better appreciate the world around them. For instance, a telecaption decoder for a TV set would be an assistive device for a senior who is hard of hearing.
- **Therapy.** Equipment or processes that help someone recover as much as possible from an illness or injury. Therapy might involve a combination of services and technology, such as having a physical therapist use a special massage unit to restore a wider range of motion to stiff muscles.
- **Transportation assistance.** Devices for elderly individuals that make it easier for them to get into and out of their cars or trucks and drive more safely, such as adjustable mirrors, seats, and steering wheels. Services that help the elderly maintain and register their vehicles, such as a drive-up window at the department of motor vehicles, would also fall into this category.

WHAT ARE THE BENEFITS OF ASSISTIVE TECHNOLOGY?

For many seniors, assistive technology makes the difference between being able to live independently and having to get long-term nursing or home-health care. For others, assistive technology is critical to the ability to perform simple activities of daily living, such as bathing and going to the bathroom.

According to a 1993 study conducted by the National Council on Disability, 80 percent of the elderly persons who used assistive technology were able to reduce their dependence on others. In addition, half of those surveyed reduced their dependence on paid helpers, and half were able to avoid entering nursing homes. Assistive technology can also reduce the costs of care for the elderly and their families. Although families may need to make monthly payments for some pieces of equipment, for many, this cost is much less than the cost of home-health or nursing-home care.

HOW CAN I TELL IF ASSISTIVE TECHNOLOGY IS RIGHT FOR ME?

Seniors must carefully evaluate their needs before deciding to purchase assistive technology. Using assistive technology may change the mix of services that a senior requires or may affect the way that those services are provided. For this reason, the process of needs assessment and planning is important.

Usually, needs assessment has the most value when it is done by a team working with the senior in the place where the assistive technology will be used. For example, an elderly person who has trouble communicating or is hard of hearing should consult with his or her doctor, an audiology specialist, a speech-language therapist, and family and friends. Together, these people can identify the problem precisely and determine a course of action to solve the problem.

By performing the needs assessment, defining goals, and determining what would help the senior communicate more easily in the home, the team can decide what assistive technology tools are appropriate. After that, the team can help select the most effective devices available at the lowest cost. A professional member of the team, such as the audiology specialist, can also arrange for any training that the senior and his or her family may require using the equipment needed.

When considering all the options of assistive technology, it is often useful to look at the issue in terms of high-tech and low-tech solutions. Seniors must also remember to plan ahead and think about how their needs might change over time. High-tech devices tend to be more expensive but may be able to assist with many different needs. Low-tech equipment is usually cheaper but less adaptable for multiple purposes. Before buying any expensive piece of assistive technology, such as a computer, be sure to find out if it can be upgraded as improvements are introduced.

Whether you are conducting a needs assessment or trying to make a decision after such an assessment, it is always a good idea to ask the following questions about assistive technology:

- Does a more advanced device meet more than one of my needs?
- Does the manufacturer of the assistive technology have a preview policy that will let me try out a device and return it for credit if it does not work as expected?
- How are my needs likely to change over the next six months? How about over the next six years or longer?
- How up-to-date is this piece of assistive equipment? Is it likely to become obsolete in the immediate future?
- What are the tasks that I need help with, and how often do I need help with these tasks?
- What types of assistive technology are available to meet my needs?
- What, if any, types of assistive technology have I used before, and how did that equipment work?
- What type of assistive technology will give me the greatest personal independence?
- Will I always need help with this task? If so, can I adjust this device and continue to use it as my condition changes?

HOW CAN I PAY FOR ASSISTIVE TECHNOLOGY?

Right now, no single private insurance plan or public program will pay for all types of assistive technology under any circumstances. However, Medicare Part B will cover up to 80 percent of the cost of assistive technology if the items being purchased meet the definition of “durable medical equipment.” This is defined as devices that are “primarily and customarily used to serve a medical purpose, and generally are not useful to a person in the absence of illness or injury.” To find out if Medicare will cover the cost of a particular piece of assistive technology, call 1-800-MEDICARE (1-800-633-4227, TTY/TDD: 1-877-486-2048). You can also find answers to your questions by visiting the website at <http://www.medicare.gov/> on the

Internet.

Depending on where you live, the state-run Medicaid program may pay for some assistive technology. Keep in mind, though, that even when Medicaid does cover part of the cost, the benefits usually do not provide the amount of financial aid needed to buy an expensive piece of equipment, such as a power wheelchair. To find out more about Medicaid in your State call the toll free number for your State. A list of toll free numbers can be reached through the following website:
<http://www.cms.hhs.gov/medicaid/tollfree.pdf>

Seniors who are eligible for veterans’ benefits should definitely look into whether they can receive assistance from the Department of Veterans Affairs (DVA). Many people consider the DVA to have a model payment system for assistive technology because the agency has a structure in place to pay for the large volume of equipment that it buys. The DVA also invests in training people in how to use assistive devices. For more information about DVA benefits for assistive technology, call the VA Health Benefits Service Center toll-free at 1-877-222-VETS or visit the department’s website at:
http://www.va.gov/health_benefits/

Private health insurance and out-of-pocket payment are two other options for purchasing assistive technology. Out-of-pocket payment is just that; you buy the assistive technology yourself. This is affordable for small, simple items, such as modified eating utensils, but most seniors find that they need financial aid for more costly equipment. The problem is that private health insurance often does not cover the full price of expensive devices, such as power wheelchairs and motor scooters.

Subsidy programs provide some types of assistive technology at a reduced cost or for free. Many businesses and not-for-profit groups have set up subsidy programs that include discounts, grants, or rebates to get consumers to try a specific product. The idea is that by offering this benefit, the program sponsors can encourage seniors and people with disabilities to use an item that they otherwise might not consider. Obviously, elderly people should be careful about participating in subsidy programs that are run by businesses with commercial interests in the product or service because of the potential for fraud.

WHERE CAN I LEARN MORE ABOUT ASSISTIVE TECHNOLOGY?

Most states have at least one agency that deals specifically with assistive technology issues. The Assistive Technology Act (Tech Act) provides funds to states for the development of statewide consumer information and training programs. A listing of state tech act programs is available at: http://www.abledata.com/text2/state_technology_assistance_proj.htm

Some area agencies on aging (AAA) have programs or link to services that assist older people obtain low-cost assistive technology. You can call the Eldercare Locator at 1-800-677-1116 or visit the website www.eldercare.gov to locate your local AAA. In addition local civic groups, religious and veterans' organizations, and senior centers may be able to refer you to assistive technology resources.

THE FOLLOWING RESOURCES PROVIDE INFORMATION ON ASSISTIVE TECHNOLOGY PRODUCTS AND SERVICES.

DisabilityInfo.gov
<http://www.disabilityinfo.gov/>

This site is designed to serve as a "one-stop" electronic link to an enormous range of useful information to people with disabilities and their families.

ABLEDATA

<http://www.abledata.com/>
800/227-0216 or 301/608-8998
TTY 301/608-8912

ABLEDATA is a federally funded project whose primary mission is to provide information on assistive technology and rehabilitation equipment available from domestic and international sources to consumers, organizations, professionals, and caregivers within the United States.

The Rehabilitation Engineering Research Center on Technology for Successful Aging

University of Florida
<http://www.rerc.ufl.edu/>

The primary focus of the Center is to promote independence and quality of life for older people with disabilities through technology - devices that can make everyday tasks easier to complete. The Public Info section provides useful consumer information.

Doodads, Gadgets, and Thingamajigs

<http://www.ndipat.org/products/dodads/ddtoc.htm>
This publication provides information on the many uses of assistive technology. It also provides a list of possible resources.

Solutions: Assistive Technology for People with Hidden Disabilities

<http://www.uiowa.edu/infotech/Solutions.pdf>
This resource guide provides information on adapted devices for people who have memory problems.

FOR MORE INFORMATION

AoA recognizes the importance of making information readily available to consumers, professionals, researchers, and students. Our website provides information for and about older persons, their families, and professionals involved in aging programs and services. For more information about AoA, please contact: US Dept of Health and Human Services, Administration on Aging, Washington, DC 20201; phone: (202) 401-4541; fax (202) 357-3560; Email: aoainfo@aoa.gov; or contact our website at: www.aoa.gov

Augmentative Communication Device



Preservice Health Training Modules

It is important for the physician to find out the person's **preferred method of communication** as early in the examination and use it throughout the visit.

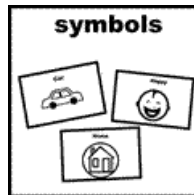
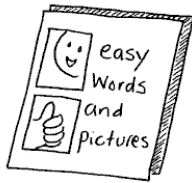
- When interacting with a person with a speech disability, never assume that the individual has a cognitive disability just because he or she has trouble speaking.
- Move away from a noisy source and try to find a quiet environment for communicating with the person.
- If the person with a speech disability has a companion/attendant, talk directly to the person. Do not ask the companion about the person.
- Be considerate of the extra time it might take for a person with a disability to finish a sentence or complete a task. Let the person with the disability set the pace in walking or talking. When conversing with a person who has speech disability, do not interrupt or finish sentences for that person.
- If you do not understand what the person has said, do not pretend that you did. Ask the person to repeat it. Smiling and nodding when you have no idea what the person said is embarrassing to both parties. Instead, repeat what you have understood and allow the person to respond.
- When you have difficulty conversing on the phone with the person, suggest the use of a speech-to-speech relay service so that a trained professional can help you communicate with the person. Either you or the person can initiate the call free of charge via the relay service.
- If the person uses a communication device, make sure it is within his or her reach. If there are instructions visible for communicating with the person, take a moment to read them.
- Do not make assumptions about what a person can or cannot do based on his or her disability.
- Consider asking questions that require short answers or can be answered by nods of the head or gestures if that is the individual's most comfortable method of communication.
- When speaking to a person with a hearing impairment who uses speech reading, be sure to stand in a well-lighted area (not backlit, and keep hands, other objects and food away from your mouth when speaking).

Reference(s):

- University of Kentucky Engaging Differences Project (http://www.uky.edu/TLC/grants/uk_ed/interactiontips6.html); American Federation of State, County and Municipal Employees, AFSCME (<http://www.afscme.org/publications/3118.cfm>); Community Resources for Independence (<http://www.crinet.org/interact.php>)
- Preservice Health Training Modules: Interactive Cases for Medical Students. (2002). Interdisciplinary Human Development Institute, University of Kentucky

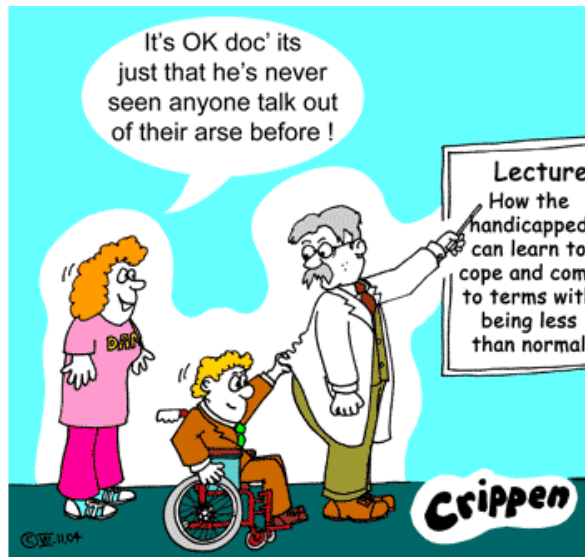
Accessible Materials and Content

- Purchase accessible brochures.
- Identify materials that present information in the following format:
 - simple backgrounds with high contrast
 - consistent page layout with clear, uniform font size and style (Arial or Times New Roman)
- Incorporate sensory health messages
- Multi-modal communication (visual, audio, tactile)



Content modifications need to be made in the spirit of not disadvantaging, stigmatizing, or privileging any group of participants. Teaching strategies are aimed at providing the same means of use for all participants. Conversely it's important to not segregate or stigmatize any group of participants; and to make the exercise and health education program appealing for all participants.

Crippen: “Shifting the Paradigm”



Clear Communication: Culturally Competent Care

*If there's communication, there can almost always be accommodation.**

- ❑ Clear communication includes a triad approach (adolescents with disabilities, parents/caregivers, and physician).
- ❑ Culturally competent provider care (e.g., knowledge, attitudes, practice oriented toward universal design)

Universal access is the necessary first step toward effective accommodations in your health education and fitness program. Obstacles may include stairs, narrow entryways, desks at the wrong height, and inaccessible washrooms.

For More Information:

Kirschner, K. et al. (2001). Learning to Act in Partnership - Disabled Women Speak with Health Professionals. (VHS Video). Rehabilitation Institute of Chicago
(<http://www.ric.org/pros/education/CatalogofEducationalMaterials.aspx>)

Attitudinal Barriers: Creative Solutions



For More Information:

Kirschner, K. et al. (2001). Learning to Act in Partnership - Disabled Women Speak with Health Professionals. (VHS Video). Rehabilitation Institute of Chicago
(<http://www.ric.org/pros/education/CatalogofEducationalMaterials.aspx>)

IV. Health Advocacy: Culturally Relevant Care

OBJECTIVE

Identify community-based and web-based resources to advocate for culturally relevant care.

Culturally Competent Care

Disability is a normal part of life experienced by almost everyone at some point.

Like race and gender, disability is now seen as a natural part of the human experience.

Persons with disabilities are identifying themselves as members of a socio-cultural group across diagnostic boundaries: in other words a ***cultural minority*** – social, political, and economic barriers are viewed as a large part of daily concerns, not just intrinsic limitations of disability. The 1998 N.O.D./Harris national survey data documented that 84% of disabled people (compared to 81% in 1994 & 74% in 1986) feel a sense of identity with others who have disabilities.

IV. Health Advocacy: Culturally Relevant Care

HEALTH ADVOCACY

The Problem is Not My Disability



For More Information:

Kirschner, K. et al. (2001). Learning to Act in Partnership - Disabled Women Speak with Health Professionals. (VHS Video). Rehabilitation Institute of Chicago
(<http://www.ric.org/pros/education/CatalogofEducationalMaterials.aspx>)

Health Advocacy: Triad Approach

- 1. Adolescent with a Disability**
- 2. Parent/Support Person**
- 3. Health Care Provider**

Everyone has a role and everyone has responsibilities in advocating for health related issues.

Becoming a Self-Advocate

- ▣ Identify health-related needs.
- ▣ Understand rights and responsibilities.
- ▣ Develop skills to identify, analyze, and make informed decisions concerning health choices.
- ▣ Participate in health care activities.

One's health and health care issues can have a major impact on one's ability to go to school, work, and play, and obtain housing. Adolescents need to learn how to develop goals, make decisions, solve problems, communicate effectively, and obtain self-care, independent living, and social skills.

Learning to Take Charge



Beyond Media Education

For More Information:

Beyond Media Education (www.beyondmedia.org)

WHY THEY GOTTA DO ME LIKE THAT? THE EMPOWERED FE FES TAKE ON BULLYING Young women with disabilities show us how we can work together to understand and stop school-based discrimination, particularly against people with disabilities.

Caregiver/Support Person

- Help an adolescent express their views
- Support them in expressing themselves
- Speak on their behalf (ideally with their permission and at their request)
- May include a variety of persons who fill many different roles:
 - **Family:** Parent, sibling(s), or other relatives
 - **Professional:** Patient-care advocate or guardian
 - **Volunteer:** Friend or Neighbor

Depending on the age of adolescent it's important to ask who the support person is.

Personal Care Assistant



Preservice Health Training Modules

Reference(s): Preservice Health Training Modules: Interactive Cases for Medical Students. (2002). Interdisciplinary Human Development Institute, University of Kentucky.

Health Care Provider

- ▣ Promote resilience/flexibility in families and their children/youth (start early)
- ▣ Focus on strengths, capacities and opportunities rather than limitations or deficits
- ▣ Develop partnerships with families, children / young people, community resources, and other professionals
- ▣ Support a vision of a future which can include work and life in the community
- ▣ Support ideas for residential and financial independence and personal life choices

Keep appropriate information and referral resources up-to-date and available to youth and their families

•Help them learn about medical problems. Begin this early in a child's life. Encourage the child to tell you the next time he/she visits something about their condition, for instance tell me next time how your leg braces help you walk.

•For example, ask the child in his/her own words what he is doing in physical therapy. Build on this each visit by asking how does the stretching exercise help you?

Physician Advocacy: Sterilization



Beyond Media Education

Importance of verbally reconsenting people and ensuring that adolescents understand the procedures that they are undertaking and the present and future ramifications of these procedures on their body. In lay language. Do not use terms such as tubal ligation or hysterectomy but “tying of the tubes” “taking your womb out” look up lay terms. Don’t use medical terminology but ask question regarding terms that are familiar to them.

For More Information:

Beyond Media Education (www.beyondmedia.org)

DOIN' IT: SEX, DISABILITY, AND VIDEOTAPE The Empowered Fe Fes, a peer group of young women aged 16 to 24 with different disabilities, strike again with their second video production, an insightful investigation into the truths about sex and disability. In the video, the Fe Fes educate themselves about sex from many angles by talking with activists and scholars.

IV. Health Advocacy: Culturally Relevant Care

HEALTH LITERACY AND HEALTH

Health Literacy: Key to Advocacy

- ❑ No longer centered on individuals.
- ❑ More than being able to read pamphlets and successfully make appointments.
- ❑ Current focus is on improving person's access to health information and his/her capacity to use it effectively.

Health literacy is crucial to empowerment.

Health literacy has evolved from a more passive role for patients to a more comprehensive, holistic definition that moves individuals to being an active participant in making informed health care decisions. Not everyone can necessarily read or remember when to take their medication but we can put in systems in place e.g. pictures or cues for remembering what their medications look like and when to take them.

Health Literacy: Evolving Definition

Health literacy redefined by WHO in 1998:

“... represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health...”

“The **ability** to read and comprehend prescription bottles, appointment slips, and other essential health-related materials required to successfully function as a patient” (American Medical Association, 1992)

“The **capacity** to obtain, interpret and understand basic health information and services and the competence to use such information and services to enhance health” (Department of Health and Human Services, 2000)

“The **degree** to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” (*Healthy People 2010*, 2000)

Reference: Health Promotion Glossary, 1998)

Health Literacy and Health

Low health literacy directly related to:

- Overall health status
- Increased hospitalizations
- Incorrect medication use
- Greater severity of illness
- Poorer knowledge of health status
- Poorer disease and treatment knowledge
- More negative health care perceptions and experiences

–Literacy is linked to personal and cultural identity (determinants include education, early childhood development, aging, personal capacity, living and working conditions, gender, culture).

–With proper tools, individuals can be moved from a *received ability to read and write* to an individual's *capacity to use those skills* to shape the course of his/her own life.

–Literacy can be one means of personal empowerment *to say his/her own word, to name the world, and to gain control over one's own health.*

Reference(s): Health Promotion Glossary, 1998; Freire, Pedagogy of the Oppressed, 1993

IV. Health Advocacy: Culturally Relevant Care

RESOURCES

Negotiating at an Uneven Table

37% of high school graduates with disabilities have attended a postsecondary school, compared with 68% of high school graduates without disabilities.

- ❑ Transition planning for adolescent must begin early and include family/support people and other health professionals.
- ❑ Managing one's health care is critical in being able to complete postsecondary school, secure employment, and achieve some form of independent living.

Students with disabilities are more likely to drop out of high school than youth in the general population.

- More than one-third (36%) of all youth with disabilities served in publicly mandated special education programs drop out of high school prior to graduation. This is a significantly higher drop out rate than the national average of 12%.

Even when they graduate from high school, students with disabilities are less likely to attend any type of post secondary school.

- 3 to 5 years after graduating from high school, only 37% of youth with disabilities had ever attended any kind of post secondary school, compared with 68% of high school graduates in the general population.

Students with disabilities are less likely to be employed than non-disabled peers.

- Nearly 1 in 5 youth with disabilities was not employed and not looking for work 3 to 5 years after exiting high school. A 1992 survey of 13 million working-age people in the U.S. revealed that only 34% of adults with disabilities worked full or part time, compared to 79% of adults without disabilities.

Youth with disabilities are achieving lower levels of independent living than youth in the general population.

- The percentage of youth with disabilities achieving some form of independent living within 5 years after leaving secondary school was 37%, compared with 60% of youth in the general population.
- White youth were significantly more likely to be living independently than African-American youth with disabilities, 42% vs. 26%.

Reference(s):

- The National Longitudinal Transition Study, SRI International (1987, 1990)
- National Organization on Disability/Harris Survey (1998)
- Kaye, H. S. (1997). Disability Statistics Abstract Education of Children with Disabilities, *Number 19*

What About College?



Beyond Media Education

For More Information:

Beyond Media Education (www.beyondmedia.org)

BEYOND DISABILITY: THE FE FE STORIES The Empowered Fe Fes (slang for female), a group of young women with disabilities, hit the streets of Chicago on a quest to discover the difference between how they see themselves and how others see them. Their revelations are humorous, thought provoking and surprising. As the young women grapple with issues as diverse as access, education, employment, sexuality and growing up with disabilities, they address their audience with a sense of urgency, as if to say, "I need to tell you so you'll see me differently." (Video, 26 minutes)

Transition: Notes from Patients...

I wish my doctor would have provided resources about...

- ❑ **Health Care**
 - Medical supply companies
 - Strategies to transition adolescent to adult provider
 - Referrals to other doctors
- ❑ **Educational/Employment/Financial/Health Insurance**
 - Peer mentoring opportunities
 - Vocational rehabilitation
 - How to transition off private insurance parents (SSI, student health plans)
- ❑ **Cultural**
 - Peer support/learning about identity, culture, and disability pride
 - Home modification
 - In-home support
 - Assistive technology

References:

- Gill, C.J. (1993). When is a woman not a woman. *The Disability Rag ReSource*, pp. 26-27.
- Iezzoni, L.I. (2006). Going beyond disease to address disability. *New England Journal of Medicine*, 355(10), 976-979.
- Gill, C.J. (1996). Becoming Visible: Personal Health Experiences of Woman with Disabilities. In [D. M. Krotoski](#), [M. A. Nosek](#), [M. A. Turk](#) (Eds.) *Women With Physical Disabilities: Achieving and Maintaining Health and Well-Being*, pp.5-14, Paul H. Brookes Publishing Co.

Health Care Transition

The purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems (Blum et al, 1993).

- ❑ 16% of respondents in a National Survey of Children with Special Health Care Needs (2002) reported that health care transition had been comprehensively addressed and
- ❑ 30% reported that their doctor had talked about shifting care to an adult provider.

The Role of the Pediatric Health Care Provider

1. Assist the youth with finding adult providers.
2. Relate to the youth as an individual and allow the youth to make decisions, ask questions about their care.
3. Educate the youth about their condition.
4. Provide information about adult services, settings and adult role expectations and give opportunities to practice adult behaviors related to decision-making, acquiring information and giving consent.
5. Meet or talk with adult service providers, (ideally with the youth present) to ensure continuity of care.
6. Summarize pertinent medical information from childhood to be passed on to adult care providers.

Reference(s):

- Transition Information Sheet For Medical Care Providers, UIC Division of Specialized Care for Children

Transition Resources for Everyone

Over 500,000 adolescents with special health care needs will turn 18 each year.

- ❑ Transition Checklist and Timeline for Medical Care Providers
- ❑ Health Care Checklist: Transition Planning for the Future
- ❑ Teen Transition Facts for Health Professionals
- ❑ Families of Teenagers with Special Needs Transition: Issues for Adolescents with Special Needs

Strategies For Effective Transition Planning

Transition plans can be developed by utilizing a transition planning checklist that follows normal adolescent development from the age of 11 through age 22. Transition planning should proceed at the youth's pace according to their physical and cognitive abilities, psychological, emotional and behavioral stability, family and social supports and general health.

Within this framework, strategies can be divided into four (4) main content areas: Medical Care, Education, Employment and Recreation.

A Health Care Checklist can also be utilized to assess the health care skills of the youth. The youth can complete the checklist and discuss the areas that need improvement. A plan can then be developed to address these concerns before the youth turns 18.

Handout(s):

- **Transition Checklist And Timeline For Medical Care Providers**, UIC Division of Specialized Care for Children
- **Health Care Checklist: Transition Planning for the Future** (for parents), UIC Division of Specialized Care for Children
- **Teen Transition Facts for Health Professionals**, The Illinois Chapter of the American Academy of Pediatrics
- **Families of Teenagers with Special Needs Transition: Issues for Adolescents with Special Needs**, The Illinois Chapter of the American Academy of Pediatrics

Reference(s):

- Transition Information Sheet For Medical Care Providers, UIC Division of Specialized Care for Children



Instructions: To assist adolescent patients and their families in the transition process the following checklist and timeline should be applied as appropriate to each adolescent patient. The timeline should be modified as developmentally appropriate for each individual.

MEDICAL CARE	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
Meet privately with the adolescent for part of the office visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Encourage the adolescent to assume increasing responsibility for his/her medical care management</i>				
<ul style="list-style-type: none">Assure the adolescent understands his/her health condition and medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none">Encourage the adolescent to ask questions during each office visit and to make his/her appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none">Provide parents with the opportunity to discuss their feelings about loss of control, concerns about the future and increasing the adolescent's independence.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none">Send copies of reports, letters and tests to the adolescent and family.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none">Encourage the adolescent to maintain a personal health record book to keep track of medical appointments, health information, history, medications, treatments and medical care providers.			<input type="checkbox"/>	<input type="checkbox"/>
<i>Provide anticipatory guidance</i>				
<ul style="list-style-type: none">Nutrition and fitness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none">Sexuality and relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none">Substance abuse and smoking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none">Genetic risks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Assess the adolescent's and the family's readiness for transfer to an adult health care provider</i>				
<ul style="list-style-type: none">Initiate discussion about transfer to an adult health care provider.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none">Discuss choices for adult care and assist in identifying possible care providers.			<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none">Encourage patient to meet and interview adult providers.			<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none">Initiate communication with the adult provider that the family and adolescent has selected.			<input type="checkbox"/>	<input type="checkbox"/>
<i>Implement the transfer to an adult care provider</i>				
<ul style="list-style-type: none">Transfer medical records.			<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none">Discuss nuances of care with the adult provider.			<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none">Follow-up after the transfer.			<input type="checkbox"/>	<input type="checkbox"/>

TRANSITION CHECKLIST AND TIMELINE – PAGE 2 (Optional)

LEGAL ISSUES	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
<p>Assess the adolescent's/young adult's ability to make independent decisions regarding medical care, finances and other adult concerns for determining whether there is a need for guardianship/conservatorship.</p> <ul style="list-style-type: none"> Initiate referral for assessment of competence if needed. Provide medical documentation. Follow-up on the process with the family. 			<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
EDUCATION				
<ul style="list-style-type: none"> Advise families that at age 18 a student will have the right to make all decisions regarding his/her education unless other legal actions have been taken. Encourage the adolescent to participate in his/her Individualized Education Program (IEP) planning process and/or 504 Plan. Make sure the adolescent and family are aware of the federal law regarding transition planning at age 14 for students with IEP/504 Plans. Discuss with the adolescent plans for further education beyond high school. 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
EMPLOYMENT				
<ul style="list-style-type: none"> Initiate discussion of different routes to employment such as higher education, technical training or supported employment. Encourage the adolescent and family to explore community vocational opportunities and to become familiar with vocational services, even if further education is planned. Encourage the adolescent and family to contact local and state agencies involved in employment services and financial support of work incentives. 	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
RECREATION				
<ul style="list-style-type: none"> Discuss in-home and community recreation options. Help families develop strategies to foster friendships and avoid social isolation. Share health care information that may affect the adolescent's ability to participate in recreational activities. 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Adapted from the Institute for Community Inclusion at Children's Hospital, Boston: Provider Transition Checklist and Timeline

HEALTH CARE CHECKLIST



As adolescents become adults, they must assume responsibility for their health care. Assuming responsibility for one's own health care, as developmentally able, is part of growing up, becoming independent from one's family, and finding a place in the adult community.

Your son/daughter will soon become a young teenager. Teenagers and young adults need to learn how to make appointments, talk to doctors, and get the information they need to make good decisions. It can seem overwhelming at first, but lots of other people have the same questions you do.

We understand taking control of one's own health care is a big step! Adolescents with special health care needs, chronic illnesses, physical or developmental disabilities, may find this difficult and the sooner you start, the more time you will have to get ready for this transition.

DSCC has included a checklist that you can use as an ongoing measurement of the independent skills your child achieves. Achieving these skills will better prepare your child for the adult world.

Adapted from the State of Washington's Adolescent Health Transition Project; California's HRTW Transition Health Care Assessment and Massachusetts' PACER Center Health Care Skills Checklist.

Health Care Skills	Can do Already	Need Practice	Plan to Start	Accomplish
<u>Understand Medical Condition:</u>				
Describe chronic illness or disability.				
Identifies changes/symptoms caused by his/her medical condition.				
Understands implications of chronic illness/disability on daily life.				
<u>Manage Your Own Health Care Needs:</u>				
Makes own medical appointments.				
Can tell when changes/symptoms require medical attention.				
Refills medications and supplies.				
Can tell when to replace durable medical equipment.				
Able to hire personal care assistants and is responsible for their supervision.				
Responsible for managing daily treatments.				
Can name medications, what they're for, or carries information in a wallet/purse.				
Can arrange transportation to medical office.				
Knows/carries a list of health emergency phone numbers in wallet/purse.				
Able to seek help and knows what to do in a medical emergency.				
Has identified a physician for adult care.				
Discusses role of general health maintenance.				
Has considered genetic counseling if appropriate.				

Health Care Skills	Can do Already	Need Practice	Plan to Start	Accomplish
<u>Communicates Effectively:</u>				
Prepares and asks questions of medical providers.				
Responds to their questions.				
Accesses information and answers to health related concerns.				
<u>Knowledge of Health Insurance:</u>				
Is aware of medical coverage numbers or carries information in a wallet/purse.				
Can name health care insurance coverage and aware of eligibility requirements.				
Carries an insurance card or copy of it.				
<u>Resources:</u>				
Is aware of income assistance (SSI), other public services and how to access them.				
Able to use community transportation when needed.				
Is aware of services available through Division of Rehabilitation (DRS) and how to apply.				
Is aware of the services he/she should receive through the school to help with transition to adult life.				
Is aware of the employment incentives offered by Social Security and how to apply.				
<u>Health Records:</u>				
Accesses medical records.				
Uses a method for keeping track of doctor appointments.				

- Foster self-reliance, independence, and survival skills.
- Know their medication dosages, take charge of their therapies, see the medical professionals alone when appropriate, and play an active role in decision-making.
- Work on their disability identity by learning about medical problems to the best of their ability, meeting teens and adults with similar health problems and needs, and learning how to identify symptoms that need medical attention.

Teen Issues - Encourage the Parent/Guardian to:

- Respect the teen's privacy.
- Realize that teens with special needs, like all adolescents, are vulnerable to early sexual activity, pregnancy, sexually transmitted diseases, substance abuse, sexual abuse and exploitation.
- Address these sexual issues with the teen early and often and in a way that they can understand. Parents should be forthright on sexual issues.
- Gradually step back from the parental authoritarian role and move from a role of supervisor to monitor to consultant.
- Recognize the teen's gradual need for increasing amounts of independence and separation.

Adult Medical System...the Primary Care Provider Should:

- Discuss regularly with the teen and family the timing of transition to an adult health care provider.
- Recommend adult primary care physicians and adult specialists who understand the teen's special needs and disability.
- Encourage the family to get recommendations from other families for the best adult health care for their teen.
- Suggest several adult primary care providers who accept Medicaid, where applicable.

- Advise the teen and family that once the teen is in the adult medical system, the teen may have to assume more responsibility for his/her own medical care.

Guardianship

- Advise the family that at the teen's 18th birthday, the parents/guardians are no longer the teen's legal guardian.
- Recommend that the parents/guardians consider going to the county court house and filing a guardianship petition if the teen is incapable of taking care of his or herself.
- Advise the parents/guardians that they may need to contact a lawyer with expertise in guardianship.
- For more information about guardianship, the family may contact the Illinois Guardianship and Advocacy Commission at 312-793-5900.

Federal, State, and Local Resources

- Contact the local public school to request transition planning as provided for by the Federal IDEA Amendment of 1990 (Public Law 101-496).
- Illinois DHS Office of Rehabilitation Services (ORS) - 800-275-3677.
- Illinois DHS, Disability Services - 800-843-6154.
- Patient Training and Information Centers in Illinois:
 - 1) Designs for Change - 312-857-9292
 - 2) Family Resource Center on Disabilities - 312-939-3513
 - 3) Family Ties Network - 217-544-5809
 - 4) National Center for Latinos with Disabilities - 800-532-3393
- Illinois Vocational Curriculum Center - 800-252-4822.
- Division of Specialized Care for Children (DSCC) - 800-322-3722.

CS 04/17/00



TEEN TRANSITION FACTS FOR HEALTH PROFESSIONALS



Developed by
The Illinois Chapter of the
American Academy of Pediatrics
312-733-1026 or info@illinoisAAP.com

TEENS WITH DISABILITIES AND THEIR FAMILIES MAY NEED HELP FROM HEALTH PROFESSIONALS FOR A SUCCESSFUL TRANSITION INTO ADULTHOOD. THIS PAMPHLET HAS INFORMATION AND SUGGESTIONS THAT SHOULD HELP HEALTH PROFESSIONALS PROVIDE THIS IMPORTANT SERVICE.

School Issues

Special Education - Facts and Suggestions for Parents/Guardians and their Teens

- Special education services are available to eligible teens until age 21 years.
- Eligibility for special education services depends on the severity of each teen's disability. If in the school's opinion, the teen's disability does not interfere with the education of the student, the school may deny these services. There is an appeal process.
- If the teen appears likely to meet special education eligibility, two possibilities should be considered depending on the level of services required. If the services needed are minor (e.g., a second set of books, use of the elevator, etc.), suggest that the parents/guardians call the school counselor or principal and request the needed services without an Individualized Education Plan (IEP). If the services needed are major, suggest that the parents/guardians request an evaluation by the school for an IEP.

- Students who receive special education services with an IEP can remain in school until age 21 if necessary. Students with disabilities who do not receive special education with an IEP cannot remain in school until age 21 but must graduate once they have earned sufficient credits for graduation.

- Beginning at age 14 years, students with disabilities who receive special education services as part of their IEP will have yearly transition planning; students with disabilities, without special education services at school, may not receive any transition planning assistance. Transition issues include basic adult survival skills, education after high school, earning a living, accessing government support, finding adult health care, and much more.

- Teens should be urged to accompany their parents/guardians to IEP meetings.

- The IEP meetings should be monitored by the parents/guardians to ensure that the evaluation and choices are presented to the teen in a manner that he/she understands.

- Additional resources for transition advice includes vocational counseling from the Office of Rehabilitation Services (ORS) in the Illinois Department of Human Services (IDHS). In order for the teen to receive ORS vocational services, he/she must be a junior in high school [exceptions for earlier services: teens with blindness or hearing loss and teens needing a Personal Assistant (PA)]. The parents/guardians and teen must fill out the ORS application before the teen can undergo a pre-vocational evaluation.

- Home Services Program provides PAs for home care for the severely disabled child, teen, and adult under age 65. Potential recipients must initially apply for Medicaid.

- Information about transition and education rights is available in Illinois at four Parent Training and Information Centers (PTIs) - **see back page under Local, State, and Federal Resources.**

- Advise the family that after age 21, there is no entitlement to adult services including educational, vocational, residential, or other disability services. However, other services may be available and should be sought.

Medical Insurance Issues/SSI

- Determine how long the teen can remain on the family health insurance policy.

- Review the advantages between the benefits on the family health insurance policy compared to Medicaid. Family insurance is dependent upon where the parents/guardians work and on eligibility criteria which will specify the teen's maximum age of coverage, whether the policy applies only while the teen is still in school, and whether the policy allows a dependent child with a disability to be covered after age 18 years.

- With regards to Medicaid, once the teen is 18 years old, he/she may apply for both Medicaid and Supplemental Security Income (SSI) based upon his/her own income, not the family income.

REPEAT: PARENTS/GUARDIANS' INCOME IS NOT COUNTED AFTER THE TEEN REACHES AGE 18.

- If the teen begins working and has health care benefits, be sure that the policy provides adequately for the teen's special needs? Which doctors can be utilized? Are prescriptions, therapies, and equipment covered? If on Medicaid, the teen should be aware of the income limitations before losing eligibility.

- If a teen chooses Medicaid for their health insurance benefits, he/she is not required to sign up for a Medicaid Managed Care plan but can use the traditional fee-for-service coverage.

- Young adults with severe disabilities may be eligible for SSI from the Federal Government. SSI eligibility changes when a young adult reaches their 18th birthday. If a young adult has been receiving SSI under the eligibility guidelines for children, his/her "case" will be transferred to the SSI program for adults and eligibility to continue to receive SSI will be redetermined. Other young adults with severe disabilities who previously were not eligible for SSI due to their parent's income, should be sure to apply for SSI within 30 days before their 18th birthday. Once a young adult reaches age 18, the Social Security Administration counts only their own income and assets. Parents' income and assets are no longer counted. For more information, contact the Chicago and SSI Coalition at 312-223-9600.

Teen Issues - Encourage the Teens to:

- Look to the future with their dreams and plans, asking regularly: What are you going to do with the rest of your life?

- Parents should ask the child's doctors for the names and telephone numbers of "adult doctors" who know about the kind of special needs of the child.
- Parents should ask other families for names of "adult doctors" who understand about the disability needs of the teenager.
- If the child will go on Medicaid at age 18, parents should ask the doctors their child sees now if they accept Medicaid or not (they do not have to do so). If not, ask them for names of doctors and clinics that accept Medicaid.
- If patients need to change doctors/clinics/hospitals, parents should call them ahead of time and ask for an appointment to come in with the teenager to meet each other and talk about medical and special needs.

Guardianship

- If the teen will not be able to make decisions about medical care independently, parents will need to go to court to obtain guardianship once the child reaches age 18. If parents do not do this, only the child will be asked to give consent for medical care, hospitalizations, surgery and treatments. Parents will NOT be asked for their permission and will NOT have the right to decide about the child's medical care, money or living arrangements.
- Guardianship is handled by the Circuit Court in the county of residence, and families must pay a fee in order to get guardianship. Parents can find out what the cost will be by contacting their county's courthouse. Families can file for guardianship on their own; a lawyer is not required.

Parents and caregivers can get more information about guardianship from the Illinois Guardianship and Advocacy Commission at 312-793-5900 or 866-274-8023 or gac.state.il.us.

Getting Help with Transition

- If you need help with transition you should:
- Start with the teen's school, and find out the

name and number of the vocational or transition coordinator. Talk with them before the IEP meeting and work on transition plans together.

- Call the Illinois Department of Human Services, Office of Rehabilitation Services (ORS) at 800-275-3677, and ask for the ORS counselor assigned to help people in the area where you live.
- Talk to your service coordinator or case manager in any programs that are already helping your child, and ask for help with transition.
- Talk with other parents of young adults with special needs, find out what they are doing about transition, and ask for their ideas.

State and Local Resources

- Public schools provide transition planning under the Federal Individuals with Disabilities Act (IDEA) Amendment of 1990 (Public Law 101-496).
- Illinois Department of Human Services (DHS) Office of Rehabilitation Services (800-275-3677)
- Illinois Vocational Curriculum Center (800-252-4822)
- Division of Specialized Care for Children (DSCC) (800-322-3722)
- Benefits Planning, Assistance and Outreach Projects: Mayor's Office for People with Disabilities (312-746-5743 for Chicago residents); the DHS Department of Mental Health (866-390-6771) or Office of Rehabilitation Services (800-807-6962 voice, 866-44-8018 TTY)

What makes a difference?

- having high expectations
- having clear, caring and consistent rules
- believing disability is a natural part of life and not a handicap

What makes the biggest difference?

- planning ahead
- being assertive
- stressing self-determination

ATTENTION

FAMILIES OF TEENAGERS WITH SPECIAL NEEDS

Transition Issues for Adolescents with Special Needs



developed by the
Illinois Chapter of the
American Academy of Pediatrics

1358 W. Randolph, Suite 2 East
Chicago, IL 60607
312-733-1026
Fax 312-733-1791
info@illinoisaaap.com
www.illinoisaaap.org



American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

Illinois Chapter

THIS IS CALLED TRANSITION PLANNING

School Issues

- Students who receive special education services (they have an Individualized Education Plan, or IEP) can stay in school until they earn enough credits to graduate from high school, or until they turn 21 years of age.
- If parents want their teenager to stay in school until age 21, they must decide this ahead of time and write this into the IEP when he becomes 16 years old.
- Students with special needs who DO NOT have IEPs (mostly students with long-lasting illnesses) cannot stay in school until age 21. They graduate when they earn enough credits to get their high school diplomas.
- Children with special needs ages 3-21 years have the right to special education services in school. (This means that any child who needs special education services can get them free of charge from the public schools.)
- AFTER AGE 21, ADULTS HAVE NO RIGHT TO EDUCATION OR ANY OTHER SERVICES FOR PEOPLE WITH DISABILITIES. Families who plan ahead can often get these services, since many programs have waiting lists.
- Plans for transition need to be written into the child's IEP each year, starting at age 14 years, 6 months.
- Illinois has three "Parent Training and Information Centers" (PTIs) that give families free help in learning about special education rights and getting ready for transition. The three PTIs are:
 - 1) Designs for Change: 312-236-7252 (voice),

- 2) Family Matters: 866-436-7842 (voice) or www.fmptc.org (statewide except Chicago)
- 3) Family Resource Center on Disabilities: 800-952-4199 (voice), 312-939-3519 (TTY) or www.frccd.org

Medical Issues

Families need to make two kinds of decisions about medical care for their teenagers with special needs:

- 1) How will the medical care be paid for?
- 2) Where will the teenager go in the future to get care?

Paying for Medical Care

- If the teenager prior to age 18 is covered by the parents' insurance from work, she may remain covered under the parents' fully insured (not self insured) group health plan after she reaches the age at which dependent coverage is usually terminated. The dependent adult will not be issued a separate policy but can remain on the parents' policy, provided that it remains in force.
- If the teenager goes to work, she needs to find out if the job offers health insurance. If insurance is offered, then parents need to find out how much it will cost each month and if the desired doctors and hospitals are covered by the insurance.
- Young adults with special needs can sign up for Medicaid when they turn 18, and the Illinois Department of Public Aid will count only the teen's income, if any, with a resource/asset limit of \$2,000. **PARENTS' INCOME AND RESOURCES ARE NOT COUNTED ONCE THE CHILD TURNS 18.**
- Many programs for adults with disabilities require the participants to be on Medicaid.
- If a teen receives Medicaid and also gets a job, it is very important to report all income and have an

understanding of the Social Security and Medicaid work incentives. A law, the Ticket to Work-Work Incentives Improvement Act (WIIA), finalized in December 1999, has allowed for new and improved work incentives that assist people with disabilities who want to work while maintaining access to health care. Under this law, working people with disabilities, who may not be eligible for Social Security cash programs, can still apply for Medicaid through the Health Benefits for Workers with Disabilities program by calling 800-226-0768.

- Young adults with severe disabilities may be eligible for SSI (Supplemental Security Income) from the Federal Government. SSI eligibility changes when a young adult reaches his 18th birthday. If a young adult has been receiving SSI under the eligibility guidelines for children, the "case" will be transferred to the SSI program for adults, and eligibility to continue to receive SSI will be redetermined. Other young adults with severe disabilities who previously were not eligible for SSI due to their parents' income must apply for SSI within 30 days before their 18th birthdays. Once a young adult reaches age 18, the Social Security Administration counts only his own income and assets. Parents' income and assets are no longer counted.

For more information on the Ticket to Work-WIIA or SSI, contact Health and Disability Advocates at 312-223-9600 (voice), 800-427-0766 (TTY) or www.hdadvocates.org.

Where to go for Medical Care

- Many doctors and therapists who take care of children and teens with special needs only see patients up to age 18 or 21.
- Parents will need to ask each doctor and therapist until what age they will continue to see the child, and tell the child about this.

Techniques for Better Health Outcomes: A 2-Way Street

80% of information provided by health professionals is forgotten as soon as the patient walks out of the office; **50% of what patients** do remember is recalled incorrectly

- ❑ **Health Advocacy Toolkit**
- ❑ **Ask Me 3**
 - *What is my main problem?*
 - *What do I need to do?*
 - *Why is it important for me to do this?*
- ❑ **“Teach Back” Method**

Handout(s):

- 1) Wisconsin Council on Developmental Disabilities Health Care Tool Kit - This Tool Kit helps patients prepare for the office visit with their doctor and includes a set of forms for tracking health care concerns and interventions.
- 2) Ask Me 3 Brochure (www.askme3.org)
- 3) “Teach Back” Method - Help Your Patients Succeed (www.pfizerhealthliteracy.com/pdf/help-your-patients.pdf)

YOUR Health Care Tool Kit



Your **INTRODUCTION** *to the* **HEALTH CARE PROVIDER**

Date _____

Hello, Dr. _____

Specialty _____

I am _____

Accompanied by _____

What you should know about me and how my disability affects me:

The support person with me is a(n)...

- ☐ attendant ☐ community case manager
☐ family member ☐ guardian ☐ job coach ☐ residential support person
☐ other (Please specify) _____

I live in... ☐ a group home ☐ a supported living apartment

☐ my family home ☐ my own home ☐ other (Please specify) _____

I walk with... ☐ no assistance ☐ some assistance ☐ total assistance

I walk with... ☐ a brace(s) ☐ a walker ☐ a wheelchair ☐ a prosthesis

I speak with... ☐ no assistance ☐ some assistance ☐ total assistance

I communicate with (check all that apply) ...

- ☐ a communication board ☐ a communication book ☐ a computer
☐ gestures/facial expressions ☐ information in writing ☐ interpreter services
☐ lip-reading ☐ pictures ☐ sign language
☐ other (Please specify) _____

I hear with... ☐ no assistance ☐ some assistance ☐ total assistance

I have a hearing aide or a cochlear implant in... ☐ both ears ☐ my left ear

☐ my right ear Please specify type: _____

I see with... ☐ no assistance ☐ some assistance ☐ total assistance

I wear... ☐ contact lenses ☐ glasses ☐ prosthesis

Your Health Care Toolkit

Your **INTRODUCTION** *to the* **HEALTH CARE PROVIDER**

For the exam table/chair...

- ☐ I would like help to get in the chair/exam table.
☐ I would like to be examined in my wheelchair/chair.

I use adaptive equipment...

- ☐ no ☐ yes If yes, please specify type: _____

I transfer with...

- ☐ no assistance ☐ some assistance ☐ total assistance

I am best assisted by a... ☐ 1 or 2 person lift ☐ pivot transfer

- ☐ other (Please specify type) _____

In personal care, I need the following (check the appropriate boxes):

My personal care:

	No Assistance	Partial Assistance	Total Assistance
Bowel Management Program			
Hygiene			
Intermittent Catheterization Program			
Toileting			

Medical History:

I am allergic to the following medications:

Doctors I've seen in the past two years:

Serious illnesses I've had in the past / other known medical information:

Your **INTRODUCTION** *to the* **HEALTH CARE PROVIDER**

Medications I'm taking now

Medicine	Directions/Dosage	Purpose	Prescribed by:

Immunization Record

Immunization	Date	Immunization	Date

MEDICAL *for the Health Care Provider*

Date _____

Hello, Dr. _____

Specialty _____

I am _____ Accompanied by _____

I am a new patient: ☐ no ☐ yes

I AM HERE BECAUSE:

<input type="checkbox"/> I NEED A CHECK UP You treated me for _____ _____ I <input type="checkbox"/> did <input type="checkbox"/> did not take the medicine. I didn't take it because _____ _____ I <input type="checkbox"/> did <input type="checkbox"/> did not do what you told me. I didn't do it because _____ _____ I feel: <input type="checkbox"/> better <input type="checkbox"/> worse	<input type="checkbox"/> I AM HAVING PROBLEMS I'm having problems with _____ _____ <input type="checkbox"/> I've had pain. <input type="checkbox"/> I feel sick. Where? _____ How long? _____ Other concerns or changes: _____ _____ I have treated myself at home by _____ _____
---	--

Patients that ask their physicians three questions can help better understand and act on health information, which can lead to better health outcomes.

**Ask
Me
3**

During my doctor visit today, I will Ask 3 questions to better understand my health.

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

- I don't need to feel rushed or embarrassed if I don't understand something. I can ask my doctor again.
- When I Ask 3, I am prepared. I know what to do for my health.

Information **FROM** the **HEALTH CARE PROVIDER**

Date _____

Dr. _____

Specialty _____

Contact Person _____

Phone (____) _____

Did you know that most patients forget up to 80% of what their doctor tells them as soon as they leave the office, and nearly 50% of what they do remember is recalled incorrectly?

- The **Teach Back Method** allows physicians to help their patients remember their medical instructions. This method involves patients repeating in their own words what they need to do when they leave the office.

- An example of how a physician can use the **Teach Back Method** is as follows:

“I want to be sure that I did a good job explaining your blood pressure medication because this can be confusing. Can you tell me what changes we decided to make and how you will now take the medications?”

- The **Ask Me 3** promotes patients to ask their health care providers three simple but essential questions in every health care interaction.

1. What is my main problem? _____

2. What do I need to do? _____

3. Why is it important for me to do this? _____

How soon should I see you again? _____

Our next appointment date is: _____

IV. Health Advocacy: Culturally Relevant Care

COMMUNITY-BASED ADVOCACY ORGANIZATIONS (HOST SITES)

Identifying Advocacy Organizations in Your Community

- ❑ National Council on Independent Living (NCIL) for your local Center for Independent Living (www.ncil.org)
 - NCIL advances independent living and the rights of people with disabilities through consumer-driven advocacy.
- ❑ The ARC (www.thearc.org)
 - The ARC is a collective of community organizations committed to providing supports and services, across the life span to individuals with disabilities.

Additional national and state advocacy organizations include the following:

People First, Self Advocates Becoming Empowered (SABE), Illinois Voices, I-SAIL (Illinois Self-Advocates in the Lead) , University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD), State Developmental Disability Councils, Illinois Lifespan (www.illinoislifespan.org)

Handout(s): List of local Host Sites

Access Living of Metropolitan Chicago

Center for Independent Futures

The Chicago Lighthouse for People Who Are Blind or Visually Impaired

Illinois Center for Rehabilitation & Education-Roosevelt

Rehabilitation Institute of Chicago (Transitions Program, Adult Spina Bifida Clinic)

Shriners Hospitals for Children, Chicago

Children's Hospital Spina Bifida Clinic

Centers for Independent Living



For More Information:

Kirschner, K. et al. (2001). Learning to Act in Partnership - Disabled Women Speak with Health Professionals. (VHS Video). Rehabilitation Institute of Chicago
(<http://www.ric.org/pros/education/CatalogofEducationalMaterials.aspx>)

Community Resource List

- 1. Disability Culture**
- 2. Health Promotion**
- 3. Universal Design**
- 4. Health Advocacy**

Handout: Resource List.

Building Capacity among Pediatric Residents to Promote Health Advocacy among Persons with Developmental Disabilities

Resource List



**University of Illinois at Chicago
Department of Disability and Human Development
Rehabilitation Research Training Center on
Aging with Developmental Disabilities**

**In Collaboration with
UIC Division of Specialized Care for Children
American Academy of Pediatrics**

Table of Contents

Disability Culture.....	3
Associations and Organizations.....	3
Disability History and Culture	5
Health Advocacy	8
Education	8
Employment	10
Health Care.....	14
Housing	16
Mentoring	20
Personal Assistance	21
Respite.....	22
Recreation.....	24
Self-Determination	25
Transportation.....	26
Travel	27
Health Literacy and Communication.....	28
Articles/Resources	28
Health Promotion	29
Articles/Resources	29

Disability Culture

Associations and Organizations

Reference/Contact Information	Comments
<p>Accessibility of Primary Care Physicians' Offices for People with Disabilities.</p> <p>archfami.ama-assn.org/cgi/content/abstract/8/1/44</p>	<ul style="list-style-type: none">• This article investigates if primary care physicians are in compliance with the Americans with Disabilities Act of 1990 (ADA) and to what extent offices of primary care physicians are usable for persons with disabilities.
<p>Ethel Louise Armstrong Foundation, Inc.</p> <p>www.ela.org/</p>	<ul style="list-style-type: none">• The mission of this foundation is to promote, through grants and scholarships, the inclusion of people with disabilities in the areas of arts, advocacy and education.
<p>Physicians as Leaders in Improving Health Care: A New Series in Annals of Internal Medicine.</p> <p>www.annals.org/cgi/content/full/128/4/289</p>	<ul style="list-style-type: none">• The goal of this series in Annals is to describe a new knowledge base that will help physicians participate effectively in the redesign of the health care system. The series is intended to raise the curiosity of physicians about the skills they will need to become more active and influential citizens of the health care community in accomplishing improvements. These skills will help physicians better deploy their clinical expertise and professional purpose in a debate that has heretofore been informed primarily by economics.
<p>The Association For Persons with Severe Handicaps</p> <p>Voice: (202) 263-5600 Fax: (202) 637-0138</p> <p>tash.org/index.html</p>	<ul style="list-style-type: none">• TASH is an international association of people with disabilities, their family members, other advocates, and professionals fighting for a society in which inclusion of all people in all aspects of society is the norm. TASH is an organization of members concerned with human dignity, civil rights, education, and independence for all individuals with

disabilities.

- We actively promote the full inclusion and participation of persons with disabilities in all aspects of life. TASH believes that no one with a disability should be forced to live, work, or learn in a segregated setting; that all individuals deserve the right to direct their own lives. TASH's mission is to eliminate physical and social obstacles that prevent equity, diversity, and quality of life.

The International Center for Disability Resources on the Internet

www.icdri.org/index.html

- Founded in 1998, The International Center for Disability Resources on the Internet (ICDRI) is a non-profit center based in the United States.
- Our overarching vision is the equalization of opportunities for persons with disabilities. As an internationally recognized public policy center organized by and for people with disabilities, ICDRI seeks to increase opportunities for people with disabilities by identifying barriers to participation in society and promoting best practices and universal design for the global community.
- ICDRI's mission includes the collection of a knowledge base of quality disability resources and best practices and to provide education, outreach and training based on these core resources. ICDRI makes this information available in an accessible format through our web site.

Quality Mall Newsletter

QualityMall.org

- Comprehensive website with Department topics relevant to people with disabilities, ranging from *Sexuality, Cultural Diversity, Funding Opportunities, Nominate a New Product*, and much more!

**Mayor's Office for People with Disabilities
(MOPD)**

www.cityofchicago.org/Disabilities

- MOPD services and programs include:

Disability Resources - Information & Referral, Independent Living Programs, Case Management Services, Assistive Technology Programs, Homemaker & Personal Assistance Services, and Emergency Home-delivered Meals.

Employment Services - Employment Counseling and Training to Job Seekers, Consultation and Technical Assistance to Employers, Social Security Administration Benefits Planning, Assistance, Outreach for work incentives programs.

Training - Independent Living Skills, Disability Etiquette.

Teletypewriter (TTY) Training

Recreation Programs.

Architectural Services - Site Surveys, Technical Assistance,

Consultation and Plan Review - Information about Accessibility Laws.

Public Information and Education - Disability Awareness, Special Events, Workshops and Seminars, Publications, Community Outreach.

Youth Programs - Disabled Youth Peer Development Initiative (DYPDI), Substance Abuse/AIDS Prevention Program for the Hearing Impaired (SAAPPHI).

Disability History and Culture

Reference/Contact Information	Comments
<i>No Pity: People with Disabilities Forging a New Civil Rights Movement</i> by Joseph P. Shapiro. (1993). Random House, Inc.: New York.	<ul style="list-style-type: none">• Information about the social and political barriers and the disability rights movement.
<i>Deaf in America; Voices from a Culture</i> by Carol	<ul style="list-style-type: none">• This book discusses how deaf culture

Padden and Tom Humphries (1988). Harvard University Press: Boston.	works, what it means to its members, how they define themselves within it, and how they interact with the world outside.
<i>The Question of David: A Disabled Mother's Journey through Adoption, Family, and Life</i> by Denise Sherer Jacobson (1999). Creative Arts Book Company: Berkeley, CA.	<ul style="list-style-type: none"> This book is a wonderful book written by a woman with cerebral palsy, who adopts a baby boy with her husband who also has cerebral palsy.
<i>Women with Physical Disabilities: Achieving and Maintaining Health and Well-Being</i> edited by D. M. Krotoski, M. A. Turk, & M. A. Nosek (1996). Paul H. Brookes: Baltimore.	<ul style="list-style-type: none"> Addresses a broad range of issues, including sexuality and reproduction; love, marriage, and relationships; bowel and bladder management; stress; and physical fitness. The book is written by researchers and women with disabilities.
<i>Why I Burned My Book and Other Essays on Disability</i> by Paul K. Longmore (2003). American Subjects. Temple University Press: Philadelphia.	<ul style="list-style-type: none"> This book sought to address the need of a history of disability.
<i>Nothing About Us Without Us: Disability Oppression and Empowerment</i> by James Charlton (2000). University of California Press.	<ul style="list-style-type: none"> Nothing About Us Without Us is the first book in the literature on disability to provide a theoretical overview of disability oppression that shows its similarities to, and differences from, racism, sexism, and colonialism.
<i>The Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of the Disability Rag</i> by edited by Barrett Shaw (1994). The Avocado Press, Inc.: Louisville, KY.	<ul style="list-style-type: none"> The Disability Rag is the voice of a mighty revolution, and this stunning collection from its first 15 years will become an invaluable primer for anyone who wants to understand the new thinking of the disability rights movement. Here are the urgent, spirited and provocative stories that have changed the way people -- disabled and nondisabled -- have come to view what it means to have a disability
<i>Planet of the Blind: A Memoir</i> by Steven Kuusisto (1998). Delta: New York.	<ul style="list-style-type: none"> A biography that recounts a struggle that leads to success and achievement.
<i>Understanding Disability: From Theory to Practice</i> by Michael Oliver (1996). Palgrave Macmillan: New York.	<ul style="list-style-type: none"> This wide-ranging collection of essays by Michael Oliver discusses recent

	and perennial issues- such as the fundamental principles of disability, citizenship and community care, social policy and welfare, education, rehabilitation, and the politics of new social movements and the international context.
<i>Beyond Ramps: Disability at the End of the Social Contract</i> by Marta Russell (1998). Common Courage Press: Monroe, ME.	<ul style="list-style-type: none"> In a tightly woven argument, Marta Russell shows how the onslaught of corporate power facing the disabled — from issues like genetic screening, to restricted access to health care, to welfare reform — will shortly be faced by a much broader segment of society. Freedom is reserved only for markets in a society increasingly strangled by corporate of power". Empowerment" is the new definition of destitution.
<i>The Facts of Life...and More</i> by Leslie Walker-Hirsch (Ed.) (2007). Brookes Publishing: Baltimore, MD.	<ul style="list-style-type: none"> This book gives social workers, teachers, and direct support professionals comprehensive instruction on how to educate people with disabilities about sexuality.
<i>Sexuality: Your Sons and Daughters with Intellectual Disabilities</i> by Karin Melberg Schwier & David Hingsburger (2000). Brookes Publishing: Baltimore, MD.	<ul style="list-style-type: none"> A book to help parents ensure their child develops healthy sexuality; that sense of self-confidence that helps make us all well-adjusted individuals.
<i>Just Say Know!</i> by David Hingsburger (1995). Diversity City Press Inc.: Newmarket, Ontario	<ul style="list-style-type: none"> This book explores the victimization of people with disabilities and helps reduce the risk of sexual abuse.
<i>The Relationship Series</i> by Young Adult Institute/ National Institute of People with Disabilities.	<ul style="list-style-type: none"> This is an innovative DVD series on relationships for people with intellectual and/or developmental disabilities. Includes #1 - The friendship Series, 3 parts; #2 - The Boyfriend/Girlfriend Series, 3 parts; #3 – The Sexuality Series, 3 parts.
<i>WE CAN Stop Abuse: A Sexual Abuse Prevention Curriculum for Persons with Developmental Disabilities</i> by Shirley Paceley (2004). Macon Resources, Inc.: Decatur, IL.	<ul style="list-style-type: none"> An 8-session, interactive curriculum to teach sexual abuse prevention skills to adolescents and adults with

	developmental disabilities. Includes objectives, pictures, activities, assessments, and much more!
<i>Moving Violations: War Zones, Wheelchairs, and Declarations of Independence</i> by John Hockenberry (1995). Hyperion: New York.	<ul style="list-style-type: none"> • A paraplegic since an auto accident at age 19, Hockenberry tells a story of obstacles- physical, emotional, and psychic- he overcomes again and again.

Health Advocacy

Education

Reference/Contact Information	Comments
Association on Higher Education and Disability Voice: (781) 788-0003 Fax: (781) 788-0033 www.ahead.org	<ul style="list-style-type: none"> • A resource addressing the need and concern for upgrading the quality of services and support available to persons with disabilities in higher education.
HEATH Resource Center Voice/TTY: (202) 973-0904 Toll Free (800) 544-3284 Fax: (202) 973-0908 www.heath.gwu.edu	<ul style="list-style-type: none"> • The national clearinghouse on postsecondary education for individuals with disabilities. • Participates in national conferences, training sessions and workshops • Develops training modules • Publishes resource papers, fact sheets, directories and website information • Fosters a network of professionals in the arena disability issues
Illinois State Board of Education Voice: (866) 262-6663 (312) 814-2220 www.isbe.net	<ul style="list-style-type: none"> • Provides leadership, advocacy and support for the work of school districts, policymakers and citizens. • Use the search function to find links to transition information. • TOTAL, Transition Outreach Training For Adult Living Project provides statewide training and technical assistance to transition

National Information Center for Children and Youth with Disabilities

Voice: (800) 695-0285 Fax: (202) 884-8441

www.nichcy.org

- Provides information on disabilities in children and youth; programs and services for infants, children, and youth with disabilities; IDEA, the nation's special education law; No Child Left Behind, the nation's general law; and research-based information on effective practices for children with disabilities.
- Web site information about specific disabilities; early intervention services for infants and toddlers; special education and related services for children in school; resources and connections in every state; individualized education programs; parent materials; disability organizations; professional associations; education rights and what the law requires; and transition to adult life.

Office of Special Education and Rehabilitative Services (OSERP)

Voice: (202) 245-7468

www.ed.gov/about/offices/list/osers/osep/index.html?src=mr

- The Office of Special Education and Rehabilitative Services (OSERS) is committed to improving results and outcomes for people with disabilities of all ages.
- OSERS provides a wide array of supports to parents and individuals, school districts and states in three main areas: special education, vocational rehabilitation and research.

Student Guides

www.nichcy.org/stuguid.asp

- Developed for older students.
 - Set 1 includes a booklet for students, another for families and also an audiotape to help students be more involved in the IEP process.
 - Set 2 helps students with cognitive disabilities find and keep a job.
-

Best Practices-Transition Services

Voice: (916) 443-8693

www.everhart.leon.k12.fl.us/bestprac.htm

- Local and National Resources
- Local and State Disability Resources
- Assistive Technology Resources
- E Newsletters and Disability Mailing Lists
- Support Groups and Disability News Groups
- Transition Guide and Services

Employment

Reference/Contact Information**Comments**

The Center for Self Determination

Voice: (734) 213-5220 Fax: (734) 213-5229

- Will offer assistance to individuals and organizations attempting to change their systems of support based upon self-determination principles.

Division of Rehabilitation

Voice: (800) 843-6154

www.dhs.state.il.us/ors/

- Offers evaluation and counseling, job training and placement, educational assistance, equipment, and follow up services.
- Funds supported employment programs.
- Links employers with potential applicants with disabilities

Illinois Career Resource Network

www.ilworkinfo.com/icrn.htm

- CIS (the Career Information System) Menu tells you about wages, education requirements and job duties for nearly 500 occupations.
 - Career Click Menu shows occupations by title, education level and wages.
 - Career Click Menu provides one-minute videos for some occupations showing people on the job: choose English, Spanish or open-captioned.
 - Countdown Menu helps younger students to learn how their interest
-

	fits with nearly 300 occupations. Identifies high school classes needed for each and how many job openings are expected.
Illinois Employment & Training Center Network Voice: (888) 367-4382 www.ides.state.il.us/ietc/network/index.asp	<ul style="list-style-type: none"> • Service centers designed to link Illinois employers with qualified job seekers. • Provide unemployment insurance, recruitment.
Job Accommodation Network www.jan.wvu.edu/media/ideas.html	<ul style="list-style-type: none"> • List several ideas for accommodating people with disabilities • Describes potential accommodation ideas by disability
Ticket to Work and Self-Sufficiency Program Voice: (866) 968-7842 TTY: (866) 833-2967 www.ssa.gov/work/ResourcesToolkit/FinalRegs2002.html	<ul style="list-style-type: none"> • A new program providing expanded access to employment services, vocational rehabilitation services, or other support services. • Information for youth with disabilities, employers, beneficiaries, service providers, and advocates.
Illinois Employment and Training Centers Voice: (847) 228-7744 www.agencyreferralnetwork.com/rg/network/network.asp	<ul style="list-style-type: none"> • Community organization designed to assist in identifying employment opportunities.
National Collaborative on Workforce and Disability (NCWD) for Youth Voice: (877) 871-0744 TTY (877) 871-0665 www.ncwd-youth.info/	<ul style="list-style-type: none"> • Website that provides information about employment and youth with disabilities.
Great Lakes Disability and Business Technical Assistance Center Voice/TTY: (312) 413-1407 www.adagreatlakes.org	<ul style="list-style-type: none"> • Provides technical assistance and training to businesses and people with disabilities • Provides information, problem solving assistance and referrals for implementing the Americans with Disabilities Act (ADA) and other related laws.

Division of Specialized Care for Children

Voice: (800) 322-3722 Fax: (217) 793-0773

www.uic.edu/hsc/dscc

- The Illinois Title V agency that provides care coordination for families and children with special health care needs.
- Focuses on public service, education and research as a basis to provide, promote and coordinate family-centered, community-based, culturally competent care for eligible children with special health care needs in Illinois.
- Core Program is the major focus and offers care coordination and cost-supported diagnosis and treatment for children with chronic health impairments determined eligible for program support.
- Other services and programs provided are: The Home Care Program, the Children's Habilitation Clinic, and the Supplemental Security Income – Disabled Children's Program.

All Kids

Voice: (866) 468-7543 TTY: (877) 204-1012

www.allkidscovered.com/

- State program that offers health care coverage or children, pregnant women and their babies or assistance in paying premiums.
- Services include doctor and nursing care, shots and preventive care, hospital, clinic care, prenatal care laboratory tests, x-rays, prescription drugs, medical equipment and supplies, medical transportation, dental care, eye care, psychiatric care, podiatry, chiropractic care, physical therapy, mental health, and substance abuse services.

Medicaid Waiver Program for Medically Fragile/Technology Dependent Children

Voice: (217) 557-1868

www.state.il.us/dpa/html/technology_dependent_medically.htm

- Program for medically fragile individuals, under the age of 21, who would otherwise require institutionalization in a skilled pediatric facility or a hospital.

	<ul style="list-style-type: none"> • Services provides are private duty shift nursing, home health aide services, special medical equipment, special medical supplies, environmental modifications, respite care in the child's home, respite care center services, medically supervised day care, placement maintenance counseling.
Medicaid Supportive Living Program www.state.il.us/dpa/html/slf_customer.htm	<ul style="list-style-type: none"> • Waiver Program to assist individuals with disabilities with personal care and other services allowing for more independent living arrangements and more opportunities take part in decision making.
Medicaid Home and Community Waivers www.state.il.us/dpa/home_and_community_based_servi.htm	<ul style="list-style-type: none"> • Waiver Programs for the disabled, persons with brain injuries, adults with developmental disabilities and for people with HIV or AIDS
Health Benefits for Workers with Disabilities Voice: (800) 226-0768 TTY: (866) 675-8440 www.hbwdillinois.com/abouthbwd.html	<ul style="list-style-type: none"> • Health Benefits for Workers with Disabilities (HBWD) is Illinois' Medicaid Buy-In program. • Allows individuals with income between 100% and 200% of the federal poverty level to pay a monthly premium based on their income to receive a Medical card.
Health Benefits for Workers with Disabilities Voice: (800) 226-0768 TTY: (866) 675-8440 www.hbwdillinois.com/abouthbwd.html	<ul style="list-style-type: none"> • Health Benefits for Workers with Disabilities (HBWD) is Illinois' Medicaid Buy-In program. • Allows individuals with income between 100% and 200% of the federal poverty level to pay a monthly premium based on their income to receive a Medical card.
Plan for Achieving Self-Support for PASS Voice: (800) 772-1213 TTY: (800) 325-0778 www.ssa.gov/work/ResourcesToolkit/pass.html	<ul style="list-style-type: none"> • PASS is a work incentive through the Social Security Administration that allows individuals to set aside income or resources to put towards a work goal.

	<ul style="list-style-type: none"> Information for youth with disabilities, employers, beneficiaries, service providers and advocates.
Benefits Planning Assistance and Outreach www.socialsecurity.gov/work/ServiceProviders/BPAODirectory.html	<ul style="list-style-type: none"> An initiative to educate and assist individuals with disabilities receiving SSI/SSDI and those who support them. Assist individuals to anticipate and plan for changes that may occur in their state and federal benefits as a result of employment
Disabilityworks http://www.disabilityworks.org/default.asp?contentID=57	<ul style="list-style-type: none"> Disabilityworks is dedicated to helping find a rewarding work experience in Illinois. People can look for a job, find job placement services, find job skills training, or learn about what Illinois community colleges and universities have to offer. Disabilityworks also has a section on Transition for Youth.

Health Care

Reference/Contact Information	Comments
CHOICES/Care Coordination www.shrinershq.org/choices/index.html	<ul style="list-style-type: none"> Links to resource guides care plans, survey results and the transition news page.
Healthy People 2010 www.healthypeople.gov	<ul style="list-style-type: none"> A set of national health objectives designed to identify the most significant preventable threats to health and to establish national goals to reduce these threats.
American Academy of Pediatrics Voice: (847) 434-4000 Fax: (847) 434-8000 www.aap.org	<ul style="list-style-type: none"> Policy Statements: <i>The Role of the Pediatrician in Transitioning Children and Adolescents with Developmental Disabilities and Chronic Illnesses From School to Work or College; Care Coordination Integrating Health and Related Systems of Care for CSHCN; Sexuality Education of Children and</i>

Adolescents With Developmental Disabilities.

- Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs.

Healthy & Ready to Work National Center

www.hrtw.org

- Provides information and connections to health and transition expertise nationwide.
- Focus on understanding systems, access to quality health care, increasing involvement of youth.
- Includes provider preparation plus tools and resources.

Family-to-Family Health Information Centers

www.familyVoice.org/pub/general/F2F%20Brochure.pdf

- A description of Family-to-Family Health Information Centers, including contact information for centers in the states

The North Carolina Office on Disability & Health Publications

www.fpg.unc.edu/~ncodh/Publications.cfm

- This link works to promote the health and wellness of persons with disabilities through an integrated program policy, practice, and evaluation.
- Goals include: increase awareness and understanding of the health related needs of individuals with disabilities and developing health promotion programs

Cultural Beliefs and Health Care Practices

erc.msh.org/mainpage.cfm?file=1.0.htm&module=provider&language=English

- Assist health organization throughout the U.S. in providing high quality, culturally competent services to multiethnic populations.
- Information on Patient Provider interactions.
- Specific information on different Cultural Groups' Health Care Beliefs.

Consortium for Children with Complex Medical Needs

- A community based coalition of medical professionals, government agencies, community activists and

www.childrensmemorial.org/newsroom/complexmedical.asp

parents designed to establish “gold standard” for how children with medical complexities and their families are empowered and cared for within their communities through networking.

- One of the goals for the consortium for Chicago-area children is to assure that youth with special health care needs receive transition services necessary for adult life. Some DSCC staff participate on the subcommittees.

Housing

Reference/Contact Information	Comments
Division of Developmental Disabilities www.dhs.state.il.us/mhdd/dd/	<ul style="list-style-type: none"> • The Illinois Department of Human Services, Division of Developmental Disabilities, provides delivery of quality outcome-based, person-centered services and supports for individuals who have developmental disabilities. • These services and supports will be appropriate to individual needs, gifts, talents and strengths; accessible; life-spanning; based on informed choice; • Services will be monitored to ensure individual progress, quality of life and safety.
Illinois Network of Centers for Independent Living www.incil.org/incil.asp	<ul style="list-style-type: none"> • The centers exist to empower individuals with disabilities to take charge of their lives and make their own choices and decisions in order to be as self-sufficient as possible. • Information available regarding services available in the community to help disabled persons live independently.

	<ul style="list-style-type: none"> • Peer relationship services serving as role models, mentors and advocates. • Individual and Systemic advocacy • Independent living skills training • Other services including community education and other public information services, equipment repair, recreational activities and home modifications.
Institute for Community Inclusion Voice: (617) 355-4664 TTY: (617) 355-6956 www.communityinclusion.org/transition/providerguide.html	<ul style="list-style-type: none"> • Resource guide for health care providers who care for children with special health care needs. • Information, resources and strategies needed to support adolescents and their families to meet the challenges of transition.
Presidents New Freedom Initiative Voice: (877) 696-6775 www.hhs.gov/newfreedom	<ul style="list-style-type: none"> • Provides information about eliminating barriers that prevent people with disabilities from participating fully in community life.
Transition Coalition Voice: (785) 864-0686 Fax: (785) 864-4149 www.transitioncoalition.org/index.html	<ul style="list-style-type: none"> • Information, support and linkages for all people interested and involved in transition. • Free publications including Planning for the Future: A Workbook to Help Young Adults with Disabilities, Their Families, and Professionals to Plan for Living, Working and Participating in the Community.
Disaster Preparedness for People with Disabilities Developed by the American Red Cross Disaster Services www.redcross.org/services/disaster/beprepared/disability.pdf	<ul style="list-style-type: none"> • Designed to help people who have physical, visual, auditory or cognitive disabilities to prepare for natural disasters and their consequences. • Contains information that can help you organize a personal disaster plan. • Includes checklist to help prepare for a disaster.

The National Center of Medical Home Initiatives for Children with Special Needs

Voice: (847) 434-4000 Fax: (847) 228-7035

www.medicalhomeinfo.org/index.html

- The mission of the National Center is to work in cooperation with federal agencies, particularly the Maternal and Child Health Bureau (MCHB), to ensure that children with special needs have access to a medical home.
- The National Center provides support to physicians, families, and other medical and non-medical providers who care for children and youth with special needs.
- The goal of the program is to ensure that children and youth with special needs have a medical home where health care services are accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-competent.
- Through the National Center, physicians, parents, administrators, and other health care professionals have access to educational, resource, and advocacy materials, guidelines for care, evaluation tools, and technical assistance.

Lawyers' Committee for Better Housing HomeSharing Program

Voice: (773) 627-8201 Fax: 347-7604

www.lcbh.org/homesharing.html

- HomeSharing describes a living arrangement in which two or more unrelated people share a home to their mutual benefit.
- Who Participates? HomeSharing arrangements involve partnerships between home providers and home seekers. Home providers are people who own a home and wish to share it. Home seekers are people who would like to share the home of another and are looking for a new housing arrangement. Adults from all walks of life are involved in HomeSharing. College students, older adults, single parents, persons

with disabilities, recently divorced or widowed individuals, persons of low-income, new immigrants and recently unemployed people are examples of HomeSharing Program participants.

- How Does it Work? 1) The first step is a call to our office. Once someone expresses interest in HomeSharing, an application and assessment process begins. 2) Next, applicants are ‘matched’ based on interest and compatibility. After a match is recommended by staff, the home provider and home seeker are introduced. 3) If applicants decide to enter a HomeSharing living arrangement, LCBH staff assist them in writing the terms of an agreement. Many HomeSharing agreements involve an exchange of reduced rent and services such as house cleaning, shopping, yard work, child care or cooking. LCBH staff also provide ongoing support throughout the HomeSharing arrangement.
- What are the Benefits? Companionship, Increased Housing Options, Reduced Housing Costs, Security, and Independence.

Adaptive Environments

Voice/TTY: (617) 695-1225

www.adaptiveenvironments.org

- Adaptive Environments (AE) is a 28 year old international non-profit organization, based in Boston, committed to advancing the role of design in expanding opportunity and enhancing experience for people of all ages and abilities. AE’s work balances expertise in legally required accessibility with promotion of best practices in human-centered or universal design.
-

Mentoring

Reference/Contact Information	Comments
Mentoring and Peer Support for People with Disabilities www.washington.edu/doit/Resources/mentor.html	<ul style="list-style-type: none">• This link provides resources to encourage young people to reach their highest potential in school, in careers, and in other life experiences via mentorship.
The Virtual Volunteering Project www.serviceleader.org/old/vv/direct/	<ul style="list-style-type: none">• This program provides direct contact online volunteers, online mentors, tutors, and advisors.• Direct contact online volunteers work directly with a client or recipient of your service. For example, a volunteer, via e-mail or a chat room can: electronically "visit" with someone who is home bound, in a hospital or a rest home, support group members providing advice to each other via a chat room or private e-mail discussion group or newsgroup, or advance "welcoming" of people about who are about to enter the hospital.
Partners for Youth with Disabilities Voice: (617) 556-4075 TTY: (617) 314-2989 Fax: (617) 556-4074 www.pyd.org/index.htm	<ul style="list-style-type: none">• Partners for Youth with Disabilities, Inc. (PYD) is committed to empowering young people with disabilities to reach their full potential for personal development. We do this by providing high quality one-to-one and group mentoring programs where adult mentors with disabilities act as positive role models and provide support, understanding and guidance for youth as they strive to reach their personal, educational and career goals.

Personal Assistance

Reference/Contact Information	Comments
Ability Hub Voice: (802) 775-1993 Fax: (802) 773-1604 www.abilityhub.com/	<ul style="list-style-type: none">• Assistive Technology for people with a disability who find operating a computer difficult, maybe even impossible.• This web site will direct you to adaptive equipment and alternative methods available for accessing computers.
National Center for Family Support Health Services Research Institute Voice: (503) 924-3783 Fax: (503) 927-3789 www.familysupporthsri.org/index.html	<ul style="list-style-type: none">• The National Center for Family Support of NCFS is a collaborative effort that combines the resources of HSRI and a diverse group of individual consultants, including family members and professionals who bring unique experiences and expertise to the Center.• The training and technical assistance we offer is designed to share knowledge, promote understanding, encourage family self-determination and control, build skills, and facilitate collaborative problem-solving related to family support policy and practice.
Infinitec.org Infinite Potential Through Assistive Technology Voice: (312) 464-1608 Fax: (312) 464-1646 TDD (312) 321-1233 Infitec.org	<ul style="list-style-type: none">• The Mission of Infinitec is to advance independence and promote inclusive opportunities for children and adults with disabilities through technology.• The Infinitec staff helps people with disabilities find and get access to information, technology services, training, assistive equipment and specialists by creating partnerships that maximize resources.• Assistive technology is any type of device that accomplishes a task for someone who cannot achieve it

	naturally. Examples include synthetic Voice: for speech, reading programs for those with learning disabilities or blindness, or a wheelchair for one who cannot walk on their own.
Self Advocated Becoming Empowered www.sabeusa.org/	<ul style="list-style-type: none"> • Makes self-advocacy available in every state including institutions, high schools, rural areas and people living with families with local support and advisors to help. • Works with the criminal justice system and people with disabilities about their rights within the criminal justice system. • Closes institutions for people with developmental disabilities labels nationwide, and build community supports.

Respite

Reference/Contact Information	Comments
Ray Graham Association for People with Disabilities Phone: (630) 620-2222 www.ray-graham.org/	<ul style="list-style-type: none"> • Family Support Service includes Respite and Children's Group Home.
Countryside Association for People with Disabilities Phone: (847) 438-8944 Fax: (847) 438-8892 www.countrysideassn.org/index.php	<ul style="list-style-type: none"> • Countryside Association for People with Disabilities is a private, non-profit organization serving children and adults with developmental and other disabilities. Based in Palatine, Illinois, Countryside offers a variety of support services including vocational training, in-home respite and family support.

Chapel Hill Training-Outreach Project, Inc.

Phone: (919) 490-5577 Fax: (919) 490-4905

www.chtop.org/

- Our Mission is to develop, demonstrate and deliver programs and strategies that will enhance the lives of children, youth and families. Of principal concern to project staff are families in poverty, families caring for the elderly, children with disabilities or chronic illness, and children at risk of abuse and neglect.

Illinois Crisis Nursery Coalition

Phone: (217) 337-2731

www.crisisnursery.net

- Respite Care: When pressures build up, family violence can occur. Families are encouraged to bring child(ren) before things blow up, allowing family to resolve problems. Addresses specific situations and can be up to three days if needed. Planned respite is scheduled to accomplish specific goals.
- Children's Crisis Care Program: Provides short term, nurturing care 24 hours a day, 365 days a year to children birth through five, when no other resources are available to help.

**Illinois Lifespan Project
The Arc of Illinois**

Phone toll-free: (800) 588-7002 or (708) 206-3993

Fax: (708) 206-1171

www.illinoislifespan.org/toolbox/respite/index.asp

- Statewide Information Resource & Referral for Advocacy & Services for People with Developmental Disabilities.

Recreation

Reference/Contact Information	Comments
National Center on Accessibility Voice: (812) 856-4422 TTY: (812) 856-4421 Fax: (812) 856-4480 www.ncaonline.org/index.shtml	<ul style="list-style-type: none">• A collaborative program of Indiana University and the National Park Service, the National Center on Accessibility is the nation's premiere resource promoting access for people with disabilities in recreation. Over the last decade, NCA has played a critical role in increasing awareness of inclusion of people with disabilities in parks, recreation and tourism while advancing the spirit and intent of the Americans with Disabilities Act, Rehabilitation Act and other disability legislation.
Disabled Sports USA www.dsusa.org/	<ul style="list-style-type: none">• A national nonprofit organization established in 1967 by disabled Vietnam veterans to serve the war injured. DS/USA now offers nationwide sports rehabilitation programs to anyone with a permanent disability.• Activities include winter skiing, water sports, summer and winter competitions, fitness and special sports events. Participants include those with visual impairments, amputations, spinal cord injury, dwarfism, multiple sclerosis, head injury, cerebral palsy, and other neuromuscular and orthopedic conditions.
National Disability Sports Alliance www.ndsaonline.org/index.shtml	<ul style="list-style-type: none">• The National Disability Sports Alliance (NDSA) is the National Coordinating Body for competitive sports for individuals with cerebral palsy, traumatic brain injuries and survivors of stroke. NDSA was originally formed as the United States Cerebral Palsy Athletic Association (USCPAA) in 1987. NDSA also provides programming for other physically disabling conditions such as muscular dystrophy and multiple sclerosis.

-
- As the National Coordinating Body for cerebral palsy sports, NDSA is responsible for conduct and administration of approved sports in the United States. NDSA formulates the rules, implements policies and procedures, conducts national championships in ten sports, disseminates safety and sports medicine information and selects the athletes to represent the United States in international competition.
-

The League for People with Disabilities

www.leagueforpeople.org/index.htm

- The League's year round Camping & Therapeutic Recreation program provides joyful, life-changing experiences in a safe environment and builds meaningful relationships in the lives of youth and adults. Camping & Therapeutic Recreation is proud to offer the following programs and services: Summer Camp Programs, Year Round Camping, Assisted Travel, and Community Recreation.

Self-Determination

Reference/Contact Information

Comments

The Center for Self Determination

Voice: (734) 213-5220 Fax: (734) 213-5229

- Will offer assistance to individuals and organizations attempting to change their systems of support based upon self-determination principles.
-

Disability Disclosure

www.ncwd-youth.info/resources_&_Publications/411.html

- A workbook for youth with disabilities designed to help youth make informed decisions about whether or not to disclose their disability and to understand the impact of disclosure on education, work and social life.
- Many activities to help you with communicating and defining their disability and related needs, knowing your rights, knowing when, to whom and how to disclose information.
- Enhancing self-determination and assisting with goal setting.

American Association on Intellectual and Developmental Disabilities

Voice: (800) 424-3688 Fax: (202) 387-2193

www.aamr.org/Policies/faq_advocacy.shtml

- Fact Sheet: Self-Advocacy

Self-determination across the life span: Independence and choice for people with disabilities

www.beachcenter.org/resource_library/beach_resource_detail_page.aspx?Type=Book&intResourceID=720

- This book is available electronically to help you frame the issues and act more responsibly to facilitate self-determined behavior.

Transportation

Reference/Contact Information

Comments

Department of Transportation

airconsumer.ost.dot.gov/publications/horizons.htm

- This is the complete guide describing what a person with a disability can expect under the Air Carriers Access Act, put out by the Department of Justice.

Easter Seals Project ACTION

Phone: (202) 347-3066 Toll-free: (800) 659-6428

Fax: (202) 737-7914 TDD: (202) 347-7385

projectaction.easterseals.com

- Funded through a cooperative agreement with the U.S. Department of Transportation, Federal Transit Administration, Easter Seals Project ACTION promotes cooperation between the transportation industry and the disability community to
-

increase mobility for people with disabilities under the ADA and beyond. We offer numerous resources, as well as training and technical assistance, in an effort to make the ADA work for everyone, everyday. Almost two decades after our creation, our goal - and our name - remains unchanged: Accessible Community Transportation In Our Nation (ACTION).

Wheelchair Gateways

Toll-Free: (800) 536-5518 or (888) 376-1500

Phone: (425) 712-3946

www.wheelchair-getaways.com/

- From the beginning, Wheelchair Getaways has emphasized quality service in transportation. Wheelchair Getaways continues to respond with undivided commitment to the needs of persons in wheelchairs and scooters. Wheelchair Getaways is a proven leader in accessible van rental and will lead the industry for many years to come.

Travel

Reference/Contact Information	Comments
Access-Able Travel Source www.access-able.com/	<ul style="list-style-type: none">• We provide information about: disabled travel, wheelchair travel, disabled holidays, disability travel, handicapped travel, accessible travel, accessible travel, vacations for disabled, mature travel.

Health Literacy and Communication

Articles/Resources

Reference/Contact Information	Comments
<p>Illinoisparents.org</p> <p>Voice: (217) 333-1386 Toll-free (Voice:/TTY) (877) 275-3227 Fax: (217) 244-7732</p> <p>Illinoisparents.org</p>	<ul style="list-style-type: none">• IllinoisParents.org—the information link for Illinois families—helps link parents directly to local programs, services, and community agencies to support them in their roles as primary caregivers of their children and as major contributors to their children's growth, development, and learning.• This link also provides research-based information about child development, care, and education in response to queries from Illinois parents and those who work with parents.• Collects and disseminates information about parenting classes and other services for parents statewide through a frequently updated World Wide Web site and public awareness materials in libraries, schools, and other agencies.
<p>The Role of the Pediatrician in Transitioning Children and Adolescents With Developmental Disabilities and Chronic Illnesses From School to Work or College. (2000). <i>Pediatrics</i> 106(4), 854-856.</p> <p>http://aappolicy.aappublications.org/cgi/content/full/pediatrics;106/4/854</p>	<ul style="list-style-type: none">• This article investigates the role of the pediatrician in transitioning children with disabilities and chronic illnesses from school to work or college and aims to provide anticipatory guidance and to promote self-advocacy and self-determination. Knowledge of the provisions of the key federal laws affecting vocational education is essential for the pediatrician's successful advocacy for patients.

Health Promotion

Articles/Resources

Reference/Contact Information	Comments
<p>Health promotion for people with disabilities: development and evaluation of the Living Well with a Disability program</p> <p>her.oxfordjournals.org/cgi/content/full/22/4/522</p>	<ul style="list-style-type: none">• This paper describes participatory action research (PAR) methods the authors used to develop, implement and evaluate the Living Well with a Disability program- a Community-based agencies that provide information and referral services to people with disabilities.
<p>Help-seeking behavior among people with disabilities: results from a national survey</p> <p>findarticles.com/p/articles/mi_m0825/is_1_71/ai_n13592431/pg_1</p>	<ul style="list-style-type: none">• Article that investigates health promotion by people with disabilities.
<p>Including young people with disabilities: Assessment challenges in higher education</p> <p>www.springerlink.com/content/1041x0353305866t/</p>	<ul style="list-style-type: none">• This articles looks at how schools and society can adequately promote the needs of adolescents with disabilities.
<p>National Center on Physical Activity and Disability</p> <p>Voice/TTY: (800)900-8086</p> <p>Fax: (312) 355-4058</p> <p>www.ncpad.org/index.php</p>	<ul style="list-style-type: none">• We have information and resources for everyone, from guidelines to consider before starting any kind of exercise program to factsheets on many popular activities, games, recreational pursuits, and sports that have been adapted to allow people with disabilities to participate as fully as they wish, become as active as they wish.• Our goal is to provide you with options and information to help you pursue whatever kind of activity you think you would enjoy. Indoor or outdoor, recreational or competitive, solo or team, easy or intensive, NCPAD has the resources, contacts, and assistance you need. Look through our site.

Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD)

Department of Disability and Human Development
University of Illinois at Chicago
1640 West Roosevelt Road
Chicago, Illinois 60608
312-413-4097 (phone)

www.rrtcadd.org

- The RRTCADD is a national resource for researchers, people with intellectual and developmental disabilities, their families, service providers, policy makers, advocacy groups, students, and the general community.
- The RRTCADD promotes the successful aging of adults with intellectual and developmental disabilities (I/DD) in response to physical, cognitive, and environmental changes. Its coordinated research, training, and dissemination activities promote progressive policies and supports to maintain health and function, self-determination, independence, and active engagement in life.

RERC on Accessible Medical Instrumentation

Marquette University

<http://www.rerc-ami.org/ami/>

- The RERC on Accessible Medical Instrumentation (RERC-AMI) is guided by the vision that all persons should have access to healthcare instrumentation and services and to employment in healthcare professions regardless of disability.
- RERC-AMI are to:
 - Increase knowledge of, access to, and utilization of healthcare instrumentation and services by individuals with disabilities.
 - Increase awareness of and access to employment in the healthcare professions by individuals with disabilities.
 - Serve as a national center of excellence for this priority area.

Final Words...

- ❑ Children and adolescents with disabilities want to interact with the world.
- ❑ They do grow up.
- ❑ Words matter!

Career Dreams: For Once in My Life



Beyond Media Education

For More Information:

Beyond Media Education (www.beyondmedia.org)

BEYOND DISABILITY: THE FE FE STORIES The Empowered Fe Fes (slang for female), a group of young women with disabilities, hit the streets of Chicago on a quest to discover the difference between how they see themselves and how others see them. Their revelations are humorous, thought provoking and surprising. As the young women grapple with issues as diverse as access, education, employment, sexuality and growing up with disabilities, they address their audience with a sense of urgency, as if to say, "I need to tell you so you'll see me differently." (Video, 26 minutes)

Instructors and Collaborators

- ❑ Beth Marks, RN, PhD
- ❑ Jasmina Sisirak, MPH
- ❑ Ann Cutler, MD
- ❑ Tamar Heller, PhD
- ❑ Darcy Contri, RN, MPH
- ❑ Orlando Torres
- ❑ Barbara Cole, BS

Rehabilitation Research and Training Center on Aging with Developmental Disabilities
Department of Disability and Human Development
University of Illinois at Chicago (M/C 626)
1640 West Roosevelt Road
Chicago, Illinois 60608
312-413-4097 (phone)
312-996-6942 (fax)
312-413-0453 (TTY)
www.rrtcadd.org