



# Special Care Dentistry

for the General Practice Resident:  
Practical Training Modules

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## ***Special Care Dentistry For the General Practice Resident Practical Training Modules***

- **This educational modular series consists of eight evidence based Power Point presentations designed to give the general practice resident a global view of dental treatment for people with special needs. Approximately 300 references are listed throughout this work. The eight modules address the most important aspects of clinical medicine and dentistry required for treating a patient with special needs. Discussion of access and barriers to dental care, the need for special care dentistry in the pre and post doctoral dental curricula, along with assessment of the competency of participants are included in the modules. Upon completion of the modules, the participant should have the knowledge to assess a patient with special needs.**
- **The educational package is a previously piloted pre and post test exam. The modules are accompanied by “teacher’s notes” which are visible in each Power Point presentation. This format alternately allows the instructor to assign the series as a self-study project.**

**continued**



## **Special Care Dentistry For the General Practice Resident Practical Training Modules**

- A description of each module follows below:
- **Introduction to Special Patient Care:** discusses the definition of disability, the prevalence and incidence of disability, aspects of “normalization”, and the barriers to care. A list of resources is provided for the individual and family.
- **Special Care Dentistry/Legal and Ethical Issues:** discusses informed consent and various other types of consent, comprehensive medical history documentation, appropriate use of desensitization and restraint, communication/human rights issues, case law and detailed literature review of restraint.
- **Treatment Modalities/Treatment Planning for Patients with Special Needs:** discusses reasons for sedation, hospitalization OR cases, general anesthesia, pharmacological techniques, IV and enteral drugs.
- **Learning Disabilities/Mental Retardation and Down Syndrome:** discusses the causes and risk factors, diagnosis and intervention, physical findings and medical concerns, dental and craniofacial characteristics of people with learning disabilities, mental retardation and Down syndrome.
- **Neuromuscular Disorders/Cerebral Palsy and Muscular Dystrophy:** discusses types of cerebral palsy, risk factors, oral and dental findings, various forms of muscular dystrophy and treatment planning considerations.
- **Autistic Spectrum Disorders:** defines and describes the spectrum of autistic disorders including Pervasive Developmental Disorder and Asperger’s. A recent review of the literature regarding proposed etiologies (i.e.: genetic links, vaccines) is presented, as well as suggestions for behavior management and treatment strategies.
- **Oral Manifestations/Genetic and Congenital Disorders:** discusses syndromology definitions, gene and chromosomal abnormalities, craniofacial disorders, dental and orthopedic conditions.
- **Seizure Disorders:** discusses definitions of seizures and epilepsy, risk, incidence and prevalence of seizures, classification and treatment of seizures, choice of medication therapies and practical considerations for dental treatment.
- Pre and post tests and the answer sheets are not included in the module series. Please contact Annette Shafer in the Office of Investigations and Internal Affairs at [annette.p.shafer@omr.state.ny.us](mailto:annette.p.shafer@omr.state.ny.us) to request a copy and we will forward it to you electronically.



# Introduction to Special Patient Care

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# Special Care Dentistry for the General Practice Resident (GPR)

- **Access to dental care is difficult for patients with special needs**
- **Dentists who have not received clinical education for patients with developmental disabilities are unlikely to opt to care for them in their practices**
- **The goal of these modules is to familiarize general practice residents with clinical dental treatment for persons with special needs**
- **Upon completion of these educational modules, the GPR resident could perhaps be more likely to feel competent in treating persons with developmental disabilities in the community**



# Introduction to Special Patient Care

- **Objectives of this module**
  - Define disability
  - Generalized etiologies, prevalence, incidence of disabilities in society
  - Normalization concepts
  - Barriers to care (patient/parent view)
    - Financial
    - Transportation
    - Fearfulness
- **National and community resources for persons with disabilities**



## It is estimated that...

- **One in five people has a disability**
- **One out of every seven people has an activity limitation.**
- **25% of the population over 15 years old has some functional limitation**
  - **One-third has a severe limitation.**
- **One in 25 people age 5 and over needs assistance in daily activities.<sup>1</sup>**



**A disability may impact only a small  
portion of a person's life;**

**But the disability is considered his/her  
defining characteristic by many  
others.**



# People with Disabilities

- **Are at higher risk for developing secondary health problems**
- **May encounter barriers in regard to health promotion, wellness and well-being**
- **May face barriers regarding access to care, annual medical check-up**
- **Are twice as likely to be physically inactive compared to people who have no disability<sup>2</sup>**



# Prevalence of Disability

- Establishing accurate numbers of individuals with disabilities is problematic
  - Varying approaches to defining disability
- In 2004, 51.2 million people (18.1 percent of the population) in the US had some level of disability and 32.5 million (11.5 percent of the population) had a severe disability <sup>3</sup>
- Increasing numbers
  - Enhanced survival
  - More sophisticated medical care
  - Increased longevity



# Who is Disabled?

- **No single, universally accepted definition of disability**
- **May be physical or cognitive**
- **May be readily observed or “hidden”**
- **May result from a variety of causes.**
- **Broadest term**
  - **“A condition which limits a person’s ability to function in major life activities and which is likely to continue indefinitely, resulting in the need for supportive services.”<sup>4</sup>**



# Major Life Activities<sup>5</sup>

- **Caring for oneself**
- **Performing manual tasks**
- **Walking**
- **Talking**
- **Seeing**
- **Hearing**
- **Speaking**
- **Breathing**
- **Learning**
- **Working**



# Americans with Disability Act (1990)

## Definition

- A physical or mental impairment that substantially limits one or more of the major life activities of the individual
- Having a record of such an impairment
- Being regarded as having such an impairment
- Does not distinguish between type, severity, or duration of the disability<sup>5,6,7</sup>



# Models of Disability

- **Four different historical and social models of disability**
  - Traditional or moral
  - Medical or rehabilitation
  - Social
  - Integrative or Disability <sup>8,9</sup>



# Traditional (Moral) Model of Disability

- **Oldest model**
- **Based on culturally and religiously-determined knowledge, views, and practices**
- **Places blame on the individual for having something wrong with him or her.**
- **Disability is shameful and something to hide<sup>8,9</sup>**



# Medical Model of Disability

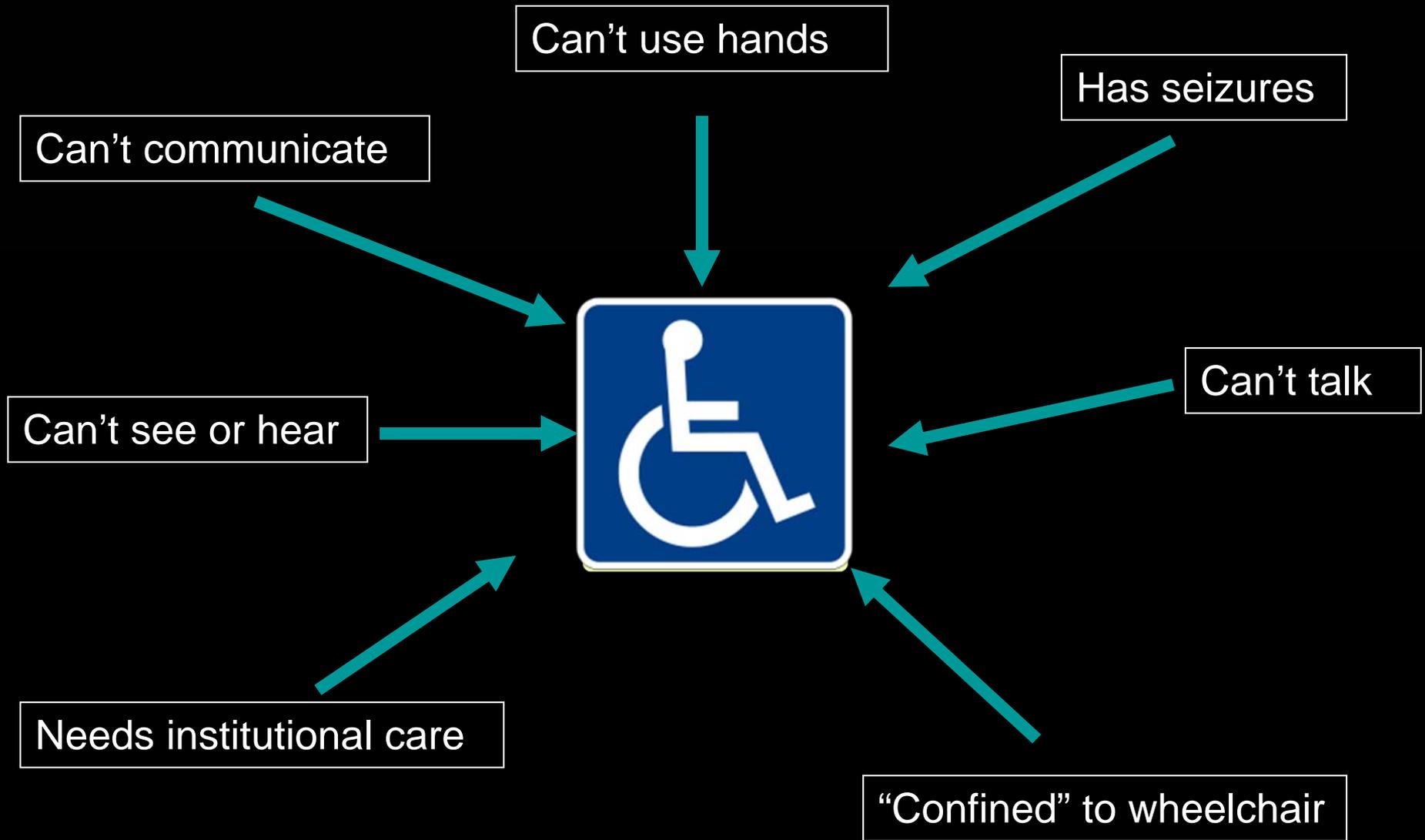
- **Disability as a defect or sickness which must be cured through medical intervention**
- **Rehabilitation model**
  - **An offshoot of the medical model**
  - **Regards the disability as a deficiency**
  - **Must be fixed by a rehabilitation professional or other helping professional<sup>9, 10, 11,12</sup>**



# Medical Model of Disability

## Definitions

- **Impairment**
  - **Abnormality, defect, condition of physiological or anatomical structure or function**
- **Disability**
  - **Restriction of activity because of impairment**
- **Handicap**
  - **Disadvantage suffered because of disability and impairment<sup>9,10,11,12</sup>**

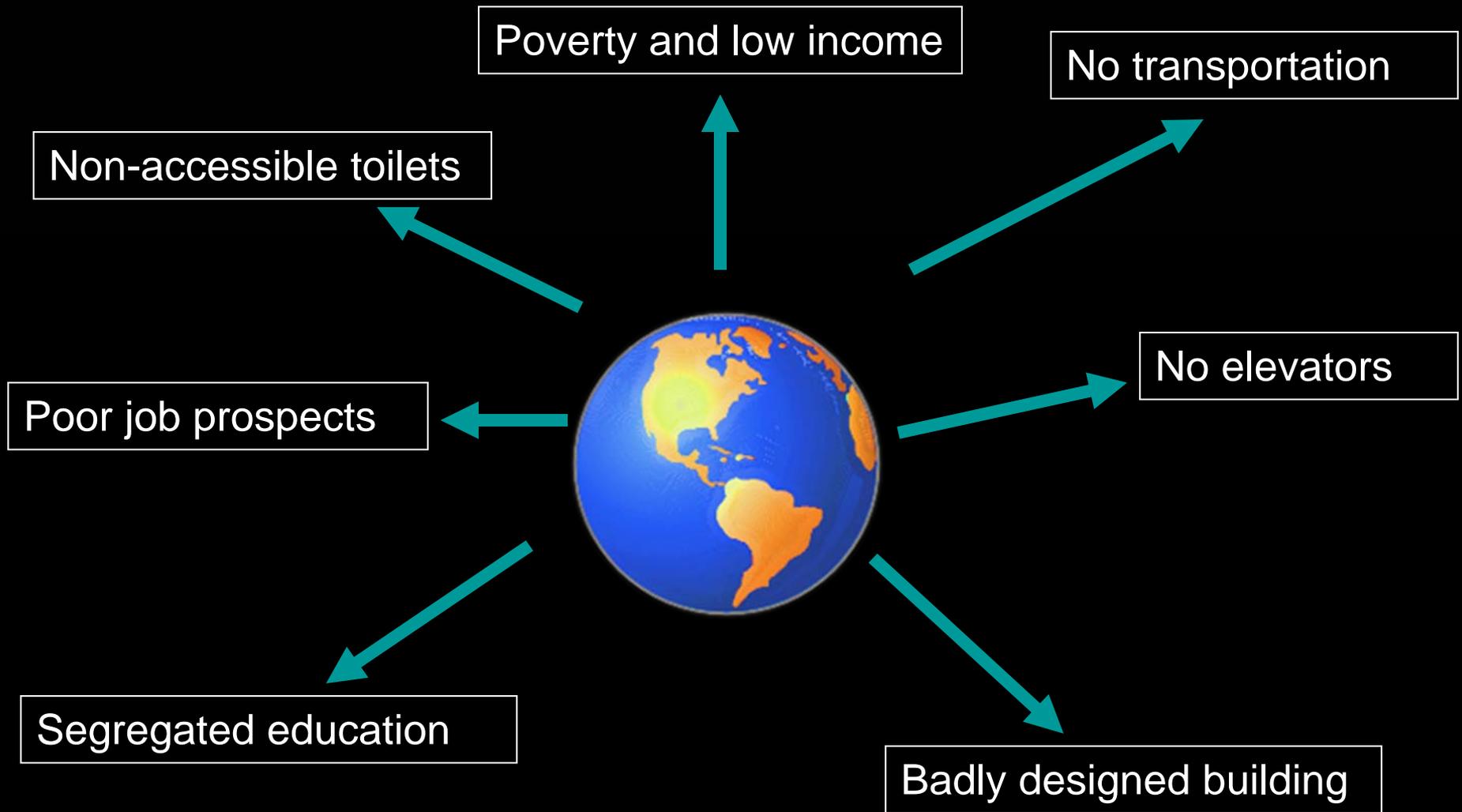


## Medical Model of Disability



# Social Model of Disability

- **Disability as a socially created problem**
  - **Not an attribute of an individual**
- **Looks at the strengths of a person with an impairment**
- **Problem is created by the unaccommodating physical environment**
- **Identifies the physical and social barriers that obstruct individuals with impairments**
- **Embraces disability as a diversity and civil rights issue**
- **Demands a political response<sup>11,13,14</sup>**



## Social Model of Disability



# Integrative/Bio-Psycho-Social Model

- **Prevailing model today**
- **Integration of medical and social models**
- **Functioning and disability**
  - **Complex phenomena with multiple factors**
    - **Health condition of the individual**
    - **Environmental factors**
    - **Personal factors<sup>10, 15</sup>**



# International Classification of Functioning, Disability & Health (ICF) <sup>15</sup>

- Developed by the World Health Organization (WHO, 2001) <sup>15</sup>
- Concept of **‘Functioning’**
  - An umbrella term for body functions, structures, activities and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors.
- Concept of **‘Disability’**
  - An umbrella term meaning negative experience in the interaction between impairments and activity limitations or restrictions in participation



# Disability<sup>15</sup>

## Definitions

- The presence of an impairment, an activity limitation and/or a participation restrictions
- Personal limitations that represent a substantial disadvantage when attempting to function in society
- Must be considered within the context of the environment, personal factors and the need for individualized supports
- Reduced participation due to society's failure to accommodate the needs of individuals
- Looks at impact on the domains of function



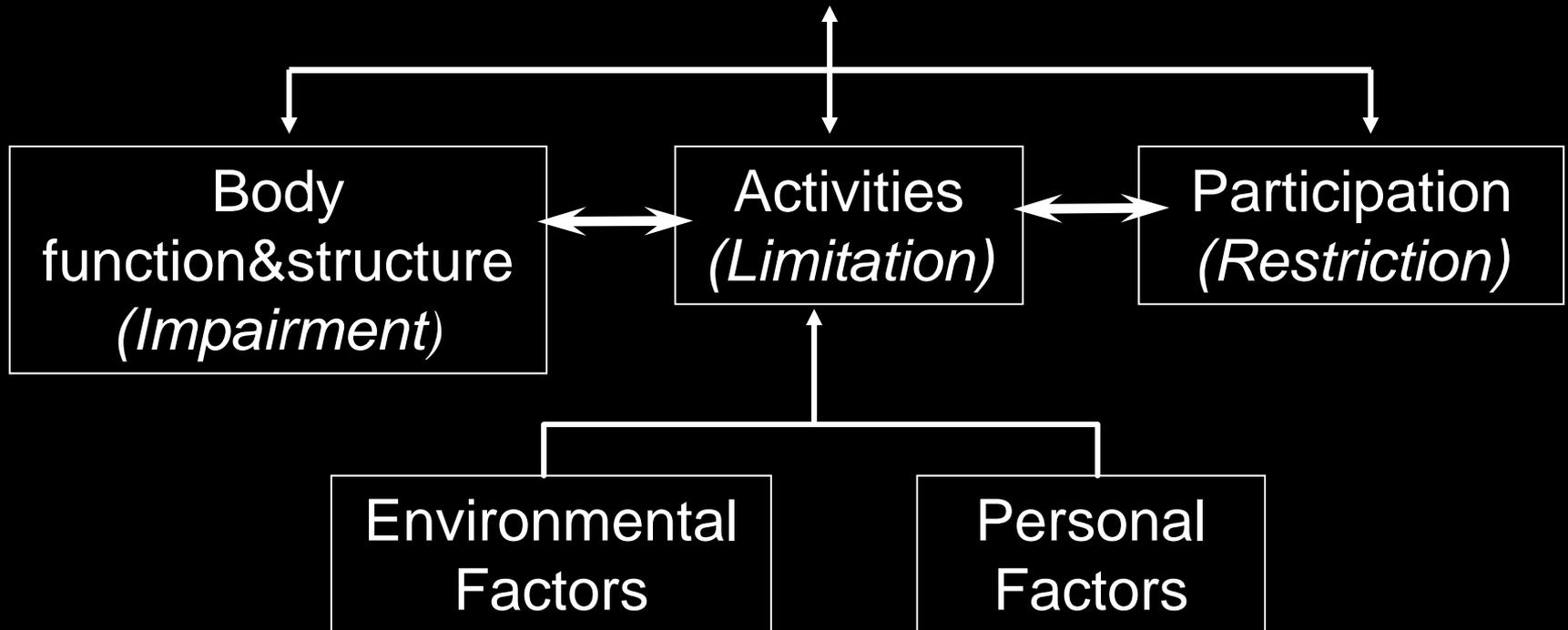
# Domains of functioning <sup>15</sup>

- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility
- Self-care
- Domestic life
- Interpersonal interactions and relationships
- Major life areas
- Community, social and civic life.



# Interaction of Concepts ICF 2001<sup>15</sup>

**Health Condition (disorder/disease)**





# Impairment

## Definitions

- **A loss or abnormality of body structure or of a physiological or psychological function.**
  - **E.g. the loss of sight or a limb may be classified as impairments.**
- **Long lasting health conditions that limit a person's ability to see or hear, limit a person's physical activity, or limit a person's mental capabilities.<sup>15, 16</sup>**



# Activity Limitation<sup>15,16</sup>

## Definitions

- **Difficulty in executing activities**
  - E.g. a person who experiences difficulty dressing, bathing or performing other activities of daily living due to a health condition
- **Activity limitations are identified based upon a standard set of activities of daily living questions (ADL's).**



# Activities of Daily Living (ADLs)

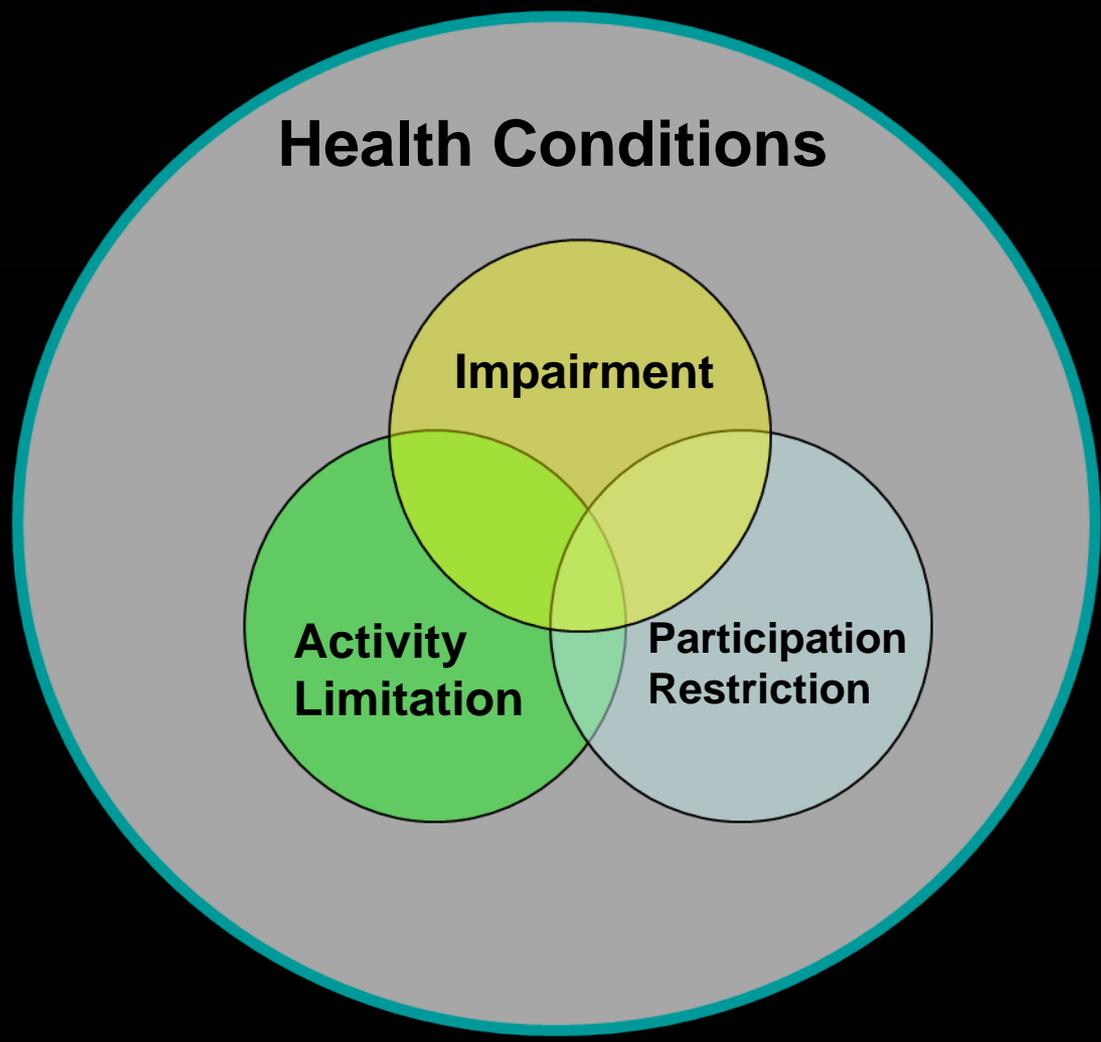
- **Getting around inside the house**
- **Getting in or out of bed**
- **Eating and toileting**
- **Going outside the house**
- **Preparing meals**
- **Using a telephone**



# Participation Restriction<sup>15, 16</sup>

## Definitions

- **A problem that an individual may experience in life situations in relationship to impairments, activities, health conditions and contextual factors (physical and social environmental factors).**
  - **E.g. Difficulty participating in employment as a result of the physical environment**





# Disabling Conditions

- A disease, disorder or event that produces a long-term effect resulting in disability<sup>2,15</sup>
- Common categories
  - Developmental
  - Sensory
  - Medical
  - Musculoskeletal
  - Neurologic
  - Communicative



# Developmental Disabilities

- **A term commonly used in the US to describe life-long disabilities**
- **Attributable to mental and/or physical or combination of mental and physical impairments**
- **Occurs during the developmental period**
  - **Manifests before age 22**
  - **Often present at birth**
- **Includes intellectual disability, cerebral palsy, epilepsy and autism.<sup>2, 17</sup>**



# Developmental Disability

- Refers to disabilities affecting daily functioning in three or more of the following areas<sup>17,18</sup>
  - Capacity for independent living
  - Economic self-sufficiency
  - Learning
  - Mobility
  - Receptive and expressive language
  - Self-care
  - Self-direction



# Causes of Developmental Disabilities

- **Brain injury or infection before, during or after birth**
- **Growth or nutrition problems**
- **Abnormalities of chromosomes and genes**
- **Extreme prematurity**
- **Poor diet and health care**
- **Drug misuse during pregnancy**
  - Including excessive alcohol intake and smoking
- **Child abuse<sup>17</sup>**



# Intellectual Disability

- **Current preferred term for mental retardation**
- **“A disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills that originates before the age of 18”<sup>19</sup>**
- **Most common developmental disability**
  - **6.2-7.5 million people**
- **87% of person with ID have mild impairment**
- **Cause of deficit is usually unknown**



# Cerebral Palsy

- **Non-progressive, non-inherited disorders caused by brain damage**
  - Prenatally or during birth
  - Hypoxic injury most common cause
- **Affects body movement, posture and muscle coordination.**
- **1.5-2.0 million children and adults in US**
  - 10,000 babies and infants diagnosed annually.
- **May or may not be accompanied by intellectual disability<sup>20</sup>**



# Epilepsy

- **Brain disorder characterized by recurrent seizures**
- **More than 2,000,000 people in US**
  - **100,000 new cases/year**
- **Trauma, infections, developmental disorders**
- **One of the most common secondary disabilities in people with intellectual disability**
  - **20-30% of patients with cerebral palsy**
  - **1/3 of persons with profound intellectual disability** <sup>21,22</sup>



# Autism

- **Neurologic lifelong developmental disability**
- **Number of people with autism increasing**
  - **In 5-15/10,000 births in 1990**
  - **In 2007, the Centers for Disease Control reported that 1 in 150 children is diagnosed with autism**
- **Disturbances**
  - **Developmental rates**
  - **Responses to sensory stimuli**
  - **Capacity to relate to people, events, objects**
  - **Speech and language patterns<sup>23</sup>**



# Sensory Disabilities

- Often co-exist with other developmental disabilities
- Interference with impulses from the external world
  - Visual impairment
    - 4.3 million people (17/1,000) in US
  - Hearing impairment
    - Most prevalent disability in the US
    - 20.3 million people
      - 550,000 deaf <sup>24</sup>



# Musculoskeletal Disabilities

- **1.5 million non-institutionalized people in US use wheelchairs<sup>1</sup>**
  - **Back or spine impairments**
  - **Very common among elderly**
    - **Lower extremities and hips**
- **Paralysis**
  - **Cerebrovascular accidents (strokes)**
  - **Spinal Cord Injury**
- **Missing Extremities**



# Concept of Normalization

- **Developed in Scandinavia during the sixties**
- **Based on concepts of citizenship and equality**
- **Rejection of the medical model of disability and institutions**
  - **Unacceptable living conditions and human rights violations**
- **Welfare provisions and human rights extended to all, including persons with disabilities**
- **Society and the environment can be educated for change**
  - **Allow full participation by people with disabilities**



# Independent Living Movement

- **The civil rights movement of Americans with disabilities.**
- **People with disabilities have the same civil rights, options, and control over choices in their own lives as do people without disabilities.**
- **Acceptance of people with disabilities**
  - **Offering them the same conditions as are offered to other citizens** <sup>25</sup>



# Objectives of Normalization

- **“Improving Quality of Life”**
- **Integration**
- **Equal opportunities and participation**
- **De-institutionalization**
- **The "environment", not the "person", is what is normalized**
- **It involves the normal conditions of life**
  - **housing, schooling, employment, exercise, recreation and freedom of choice**



# Normalization Principles

- **A normal daily rhythm**
  - Getting out of bed, getting dressed, eating, respecting an individual's need for personal rhythm
- **A normal routine of life**
  - Living in one place, working or receiving education in another
  - Leisure-time activities utilizing normal social facilities
- **The normal rhythm of the year**
  - Recognition and celebration of holidays, birthdays, anniversaries
- **An opportunity to undergo normal developmental experiences of the life cycle<sup>26</sup>**



# Normalization

- **Stresses what each person can do rather than can't do**
- **Places an emphasis on experiences in real life environments**
- **Supports people to follow their own interests**
- **Assumes that all people can learn and contribute to their community**
- **Supports people to live, work, and recreate in their local communities** <sup>27</sup>



# Normalization in US

- **Until the 1960s**
  - Children/adults with mental retardation and physical disabilities were routinely denied an education
  - Many were isolated in institutions
  - Those who were at home were kept out of public eye
- **Rehabilitation Act of 1973, Section 504**
  - Guarantees that no otherwise qualified person be discriminated against in the areas of education, employment or social services including health care by reason of a handicap<sup>28</sup>



# Americans with Disabilities Act (ADA)

- **Prohibits discrimination on the basis of disability**
  - **Employment, public services, public accommodations, commercial facilities and telecommunications**
- **Services to individuals with disabilities must be offered in the most integrated setting appropriate to the needs of the individual**
  - **Includes dental offices**



# Challenges

- **“Mainstreaming”** (in housing and education) many of the individuals with developmental disabilities
  - Lack of structured care systems
- **Altered the setting for dental services**
  - Placed demands for services on dental practitioners in the community
- **Possible decreased accessibility to care** <sup>2,29</sup>



# Challenges

- **Allowing people with intellectual impairment authority over their own lives, daily activities and choice of care services can lead to decrease utilization of dental services**
  - **Balance between individual freedom and the responsibility of the health care professional**
- **Has to be supported by care tailored to the individual need and oversight**
  - **Development of care plans with specific emphasis on preventive oral care<sup>30</sup>**



# Challenges

- **Empowerment of the person with impairment**
  - Loss of autonomy of care provider
- **Greater independence may lead to less rigorous daily oral care and less supervision of diet**
  - Potential for dental neglect
  - Poorer oral health and increase in dental disease
- **Lack of screening and health needs assessment**
- **Need to adapt client centered care**
  - Establishment of care plans
  - Identification of risk factors
    - Systemic diseases, medications, impairment<sup>2,29</sup>



# Reduction of Care

- **Lack of efficient recall systems**
- **Challenging behavior**
  - **Refusal to institute self care**
  - **Refusal to go to dentist**
- **Degree of intellectual impairment**
  - **Impaired physical coordination**
  - **Inability to independently complete tasks**
  - **Inability to apply preventive measures**
- **Living arrangements**
  - **May not have access to full time supervision<sup>2,27</sup>**



# Barriers to Care

## Attitudinal

- **Both the patient's and his/her family's approach to dental care**
  - **Unaware of consequences of dental neglect**
  - **Low priority on adequate dental treatment and oral hygiene**
    - **Overwhelmed by other care needs**
- **Dentist's perception of the dental patient with a disability**
  - **Lack of training/confidence**
  - **Fear that they may harm patient**
  - **Belief that there is someone else to do it.** <sup>31,32</sup>



# Barriers to Care

## Primary Health Care System

- **Assumption that the primary care provider will be the gatekeeper**
  - **Financial disincentives**
  - **Time constraints**
- **Lack of training regarding oral health**
  - **Oral care not included in overall health plan**
  - **Caregivers are not as likely to seek or provide oral care for the patient**



# Barriers to Care

## Fear

- Parental fear that competent dentists who can treat their child are unavailable.
- Parent/caregivers themselves fear going to the dentist
  - Don't want to put the patient in a situation that they avoid themselves.
- Parent/care giver wish to deny patient any distress or anxiety
- Fear of Prejudice
  - Parents/caregivers of individuals with behavior problems or who look significantly different may be apprehensive of reaction of other patients in waiting room <sup>33</sup>



# Barriers to Care

## Physical Access

- **Gaining entrance to practice premises**
  - Lack of wheelchair access to waiting areas, toilets or operatory
- **Under the ADA Act, existing barriers must be removed when such removal is “readily achievable”**
  - Remodeled areas must be made accessible
  - New construction must meet construction codes.
- **Often, older construction remains inaccessible** <sup>34</sup>



# Barriers to Care

## Transportation

- Majority of patients experience difficulties going outside home alone
- Reliance on public transport
  - Transportation system that may be inadequate or susceptible to many obstacles
- Public transportation may not be wheelchair accessible
- Patient may not be capable of using public transportation without accompaniment
- Arrangements may need to be made ahead of schedule appointments<sup>34</sup>



# Barriers to Care

## Financial

- **Biggest barrier to obtaining dental care**
  - Patients often unable to work
  - Cost of dental care is prohibitive
- **Low payment rates discourage many dentists from accepting Medicaid patients for treatment**
- **No increased payments to cover the additional time and staff required when treating challenging special care patients**
- **Medicaid may be extremely limited in the scope of procedures covered.** <sup>32, 33, 35</sup>



# Barriers to Care

## Motivational

- Many patients are unable to comply with oral hygiene instruction
- Difficulty in keeping scheduled appointments
  - General level of health may be fragile
    - Frequently too ill to keep scheduled appointment
  - May be dependent on someone to get them to care
- Combination of poor oral hygiene and a pattern of many broken/missed appointments may lead dentists to be more likely to extract teeth rather than restore<sup>31</sup>



# Summary

- **The demographics on persons with disabilities is dynamic**
  - **The number of persons with disabilities and dental needs will continue to increase**
- **Changes in perception of persons with disabilities has changed dramatically**
- **Normalization and the mainstreaming of persons with disabilities has created some challenges to access to dental care**
- **Barriers to access dental care for the person with disabilities is multi-factorial**



# Community Resources

- **The Arc**
  - **Community based organization of and for people with intellectual and other developmental disabilities.**
  - **Politically active**
  - **Provide information and referrals**
  - **Most cities have chapters**
    - **Associated with state organization**
  - **[www.thearc.org](http://www.thearc.org)**



# Resources

- **The National Disability Rights Network (NDRN)**
- **Largest provider of legally based advocacy services to people with disabilities in the United States.**
- <http://www.ndrn.org/>



# Resources

- **DisabilityInfo.gov is a comprehensive online resource**
  - **Disability-related information and programs**
    - **Civil rights, education, employment, housing, health, income support, technology, transportation and community life.**
- **[www.DisabilityInfo.gov](http://www.DisabilityInfo.gov)**



# Resources

- **Division of Vocational Rehabilitation**
- **State programs for individuals with disabilities**
- **Name varies state to state**
  - **Vocational and Educational Services for Individuals with Disabilities in NY**
- **Promote participation of persons with disabilities in work and community life**
- **Dental care may be covered if it relates to an individual's employability**
- **<http://www.vesid.nysed.gov/>**



# Resources

- **National Oral Health Information Clearinghouse**
- **Oral health information for special care patients**
- **Series of publications,**
  - **Practical Oral Care for People With Developmental Disabilities**
- **<http://www.nidcr.nih.gov>**



# Resources

- **United Cerebral Palsy (UCP)**
  - [www.ucp.org](http://www.ucp.org)
- **Autism Society of America**
  - [www.autism-society.org](http://www.autism-society.org)
- **Epilepsy Foundation of America**
  - [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)
- **The American Association on Intellectual and Developmental Disabilities**
  - [www.aaid.org](http://www.aaid.org) or [www.aamr.org/](http://www.aamr.org/)



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