

Health Promotion/Disparities for People with Developmental Disabilities

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Objectives

- 1. define developmental disability
- 2. recognize health disparities that affect this population
- 3. identify specific health promotion issues in the DD population
- 4. highlight resources & system changes needed for quality of care

Tell me what you see



Cultural humility

Definition: *incorporates a lifelong commitment to self-evaluation & self critique, to redressing the power imbalances in the patient-provider dynamic & to developing mutually beneficial and nonpaternalistic clinical & advocacy partnerships with communities on behalf of individuals and defined populations.*

Tervalon, M & Murray-garcia, J. (1998) Cultural Humility vs Cultural Competence: A Critical distinction in Defining Physician Training Outcomes in Multicultural Education. Journal of health care for the poor and Underserved, 9(2), 117-125.

Developmental Disability

- The disability must begin before the 18th birthday, be expected to continue indefinitely and present a significant disability. Also, the disability must be due to one of the following conditions:
- Mental retardation/Intellectual Disability
- Cerebral Palsy
- Epilepsy
- Autism
- A disabling condition closely related to mental retardation or requiring similar treatment.

Developmental Disability shall not include handicapping conditions that are:

Solely psychiatric disorders where there is impaired intellectual or social functioning which originated as a result of the psychiatric disorder or treatment given for such a disorder

Solely learning disabilities. A learning disability is a condition which manifests as a significant discrepancy between estimated cognitive potential and actual level of educational performance and which is not a result of generalized mental retardation, educational or psycho-social deprivation, psychiatric disorder, or sensory loss.

Solely physical in nature. Congenital anomalies or conditions acquired through disease, accident, or faulty development which are not associated with a neurological impairment that results in a need for treatment similar to that required for mental retardation.

Intellectual Disability (MR)

- defined in the *Diagnostic and Statistical Manual of Mental Disorders-IV* as:
 - *significantly subaverage intellectual functioning: an IQ of approximately 70 or below
 - *concurrent deficits or impairments in present adaptive functioning in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety; and
 - *onset before age 18 years.

Causes of ID/MR

- *Intrauterine Risk Factors (15%)* Asphyxia; Developmental defects; Malnutrition/ Intrauterine growth retardation Maternal infections or diseases; Maternal substance abuse
- *Genetic Causes (65%)* Chromosomal defects; Structural anomalies; Inborn errors of metabolism
- *Perinatal Risk Factors (10%)*: Anoxia; Birth trauma; Low birth weight; Prematurity
- *Neonatal and Postnatal Causes (10%)*: Childhood infections and diseases; Environmental toxins; Severe malnutrition, Trauma

Cerebral Palsy

- A group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development
 - *Congenital* cerebral palsy (90% of cases) may be caused by inadequate blood or oxygen supply to the fetus, illness during pregnancy, prematurity, birth trauma, etc.
 - *Acquired* cerebral palsy (10% of cases) may be caused in the first few months after birth by head trauma, infections (encephalitis, meningitis, herpes simplex), exposure to toxics, severe malnutrition, child abuse, etc.

Cerebral Palsy

- *Motor involvement always present*
- *Seizures often co-occur*
- *Spasticity almost always present*
- *Speech disorders common*

Epilepsy

a chronic condition that briefly interrupts the normal electrical activity of the brain

causes unpredictable and recurrent seizures, which alter a person's consciousness, movement or actions for a short time.

Epilepsy: Causes

- In over 70% of cases, no cause for epilepsy is identified; however, it may be caused by genetic conditions, head injury, stroke, brain tumor, toxic poisoning or severe infections like meningitis and encephalitis.
- These causes may occur during the prenatal, perinatal or postnatal period.

Autism

- Autism is a behavioral syndrome characterized by a defined group of behaviors and associated with many genetic and acquired conditions that affect brain development.
- Cause is unclear.
- Likely to be a heterogenous condition with different causal factors in different cases.
- Brains of individuals with autism are likely to demonstrate abnormal micro-architecture and disturbed metabolism of certain neurotransmitters.

Diagnosis of Autism: DSM-IV

- Three necessary diagnostic criteria:

1. Qualitative impairment in social interaction; qualitative impairments in communication; restricted repetitive & stereotyped patterns of behavior, interests and activities

2. Delays or abnormal functioning in at least one of the following areas (onset prior to 3 years): social interaction, language as used in social communication, or symbolic or imaginative play; and

3. The disturbance is not better accounted for by Rett Syndrome or Childhood Disintegrative Disorder

Neurodevelopmental Disorder

- Impairments start during developmental years
- Are expected to be permanent
- Affect some combination of
 - Cognition
 - Neuromuscular function
 - Seizure threshold
 - Mental health
 - Sensory processing

Prevalence & Aging Facts

U.S.: 1% to 3% of general population have intellectual disability

- * 1/3 of cases are of unknown etiology
- * 1.5:1 male-to-female ratio
- * 6 million individuals in U.S.
- * 315,000 > 65 years old
 - * Projected 526,000 by 2020
- * Current life expectancy 76.5 years

Health Disparities are glaring

- barriers to health care
- *4-6 fold increase in preventable mortality in people with DD when compared with individuals in the general population*
- *Transition from pediatrics to adulthood is an esp vulnerable time*



Barriers to Effective care

- ◆ Barriers to effective care for People with Developmental disabilities
 - ◆ Difficulty of cognitively impaired patients
 - ◆ Difficulty of physically impaired patients
 - ◆ Attitudes of healthcare professionals

Doostan, D. WJM 1999

Barriers to Effective Care

- ◆ Difficulty of cognitively impaired patients
 - ◆ May not be able to communicate history or symptoms.
 - ◆ May be unable to tolerate waiting room stay.
 - ◆ May be threatened by aspects of the office or hospital environment such as needles, physical examinations of private areas, unfamiliar clinicians.
 - ◆ May resist or fight when confronted with an examination
 - ◆ May require ancillary or family help for even the smallest procedures
 - ◆ **Overall, H&P typically require 3 times longer than average.**

Barriers to Effective Care

- ◆ Difficulty of physically impaired patients
 - ◆ May require ancillary help to gain position, because many patients are severely compromised in movement.
 - ◆ Similarly, many have severe communication difficulties.
 - ◆ Because of their appearance and/or “unintelligible” speech, are misperceived as cognitively impaired.

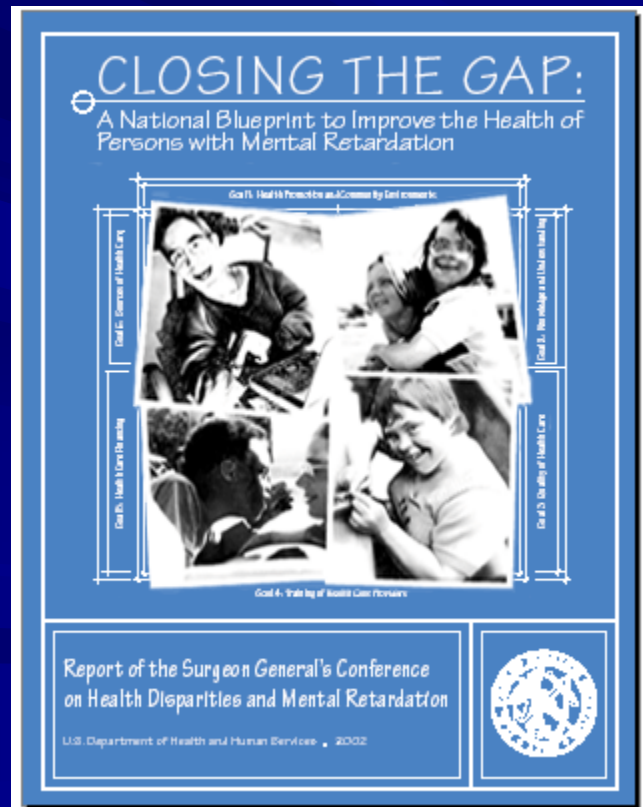
Barriers to Effective Care

- ◆ Attitudes of healthcare professionals
 - ◆ Providers of care
 - ◆ *lack proper training to see complex “difficult” patients*
 - ◆ Hold negative attitudes toward caring for patients with disabilities

Barriers to Effective Care

- ◆ The healthcare delivery system is:
 - ◆ ill-equipped to handle the de-institutionalized patient population.
 - ◆ inadequately reimbursed by Medicaid, Medicare, and / or private insurance agencies that do not recognize the greater time and effort required to provide adequate care for the developmentally disabled.

Closing the gap: a national blueprint for improving the health of persons with mental retardation (December 2001)



www.nichd.nih.gov/publications/pubs/closingthegap

6 Recommendations emerged

1. Integrate Health Promotion into community environments of people with mental retardation
2. Increase knowledge and understanding of health and mental retardation, ensuring that knowledge is made practical and easy to use
3. Improve the quality of health care for people with ID by identifying priority areas, adapting standards of care and rewarding excellence in care

Recommendations (continued)

4. Train Health care providers in the care of adults and children with ID
5. Ensure that health care financing produces good health outcomes for adults and children with ID
6. Increase sources of health care services for adults, adolescents, and children with MR, ensuring that health care is easily accessible for them

Goals for Health care providers caring for individuals with DD

- Follow the same general health care guidelines as for Non-DD patients
- Recognize where to find specific health risk profiles for DD
- Adopt strategies to overcome some of the obstacles that make providing health care to the DD population challenging

Standard Preventive Health care recommendations

- US Preventive Service Task Force recommendations
(can be downloaded to computer and/or PDA)
www.preventiveservices.ahrq.gov
- American Academy of Family Practice (based largely on the USPSTF recommendations) www.aafp.org
- American College of Physicians
www.acponline.org/clinical/guidelines

Specific Screening Recommendations for DD/MR

Guidelines

Consensus Guidelines for Primary Health Care of Adults with Developmental Disabilities (Sullivan, WF et al), *Canadian Family Physician*, Vol52, Nov 2006

Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs (American Academy of Pediatrics & American Academy of Family Physicians), *Pediatrics*, Vol 110 (6), Dec 2002

Health Care Guidelines for Individuals with Down Syndrome: 1999 Revision (Cohen, WI), *Down Syndrome Quarterly*, Vol 4 (3), Sept 1999

New York State Office of Mental Retardation & Developmental Disabilities. (2009). Preventative Health Care Screening Guidelines for People Aging with Intellectual and Other Developmental Disabilities. Available at:
http://www.omr.state.ny.us/document/image/hp_brochures_preventhealthfinal.pdf

Other resources:

Diagnostic Manual-Intellectual Disability: A textbook of diagnosis of Mental Disorders in Persons with Intellectual Disability (Fletcher, R) NADD Press, 2007

Prater C, Zylstra R. Medical care of adults with mental retardation. *Am Fam Physician*. 2006;73(12): 2175-2183.

Medical Co-morbidities assoc with DD

- Seizures
- GERD, constipation & other GI disorders
- Swallowing & feeding problems
- Orthopedic issues
- Asthma & other respiratory diseases
- Sleep apnea
- Obesity
- Dental disease
- Osteoporosis (50% of individuals with ID!)
- Women's health issues
- Depression, anxiety & other psychiatric disorders

Specific Screening issues

- Cardiovascular disease
- Metabolic syndrome
- Cancer (28% of women with DD over 50 never had a mammogram)*
- HIV & STD's
- Hepatitis
- TB
- Other ills of institutionalization

* Havercamp SM, Scandlin D, Roth M. Health disparities among adults with developmental disabilities, adults with other disabilities and adults not reporting disability in North Carolina. *Public Health Rep.* 2004;119(4):418-26.

Focus health promotion on

- Appropriate diagnostic screening (in patients whose history may be unreliable)
- Lifestyle modification
- Disease/syndrome specific risk
- *Cultural humility*
- *Involvement of family & caregivers*

Common Myths about Sexuality

■ People with DD

- Have little to no interest in sex
- Are hypersexual
- Are solely heterosexual
- Have inappropriate sexual behaviors
- Have no need for privacy

The Truth about people with DD

- very diverse sexually
- have varied levels of skill with language, literacy & communication
- with the right support, capable of having healthy sexual relationships

"Powerful. . . . Anyone involved with people with developmental disabilities will come away educated, inspired, and moved."
— Dan Woog, Author of *School's Out: The Impact of Gay and Lesbian Issues on America's Schools*
"A vital and compelling story of activism and grassroots organizing that can literally change lives."
— Michael Bronski, Author of *Culture Clash: The Making of Gay Sensibility*

GAY, LESBIAN, BISEXUAL, and TRANSGENDER PEOPLE



▶ with DEVELOPMENTAL
DISABILITIES
and
MENTAL RETARDATION

STORIES OF THE RAINBOW SUPPORT GROUP



JOHN D. ALLEN

Do It All! Swim Against the Tide!



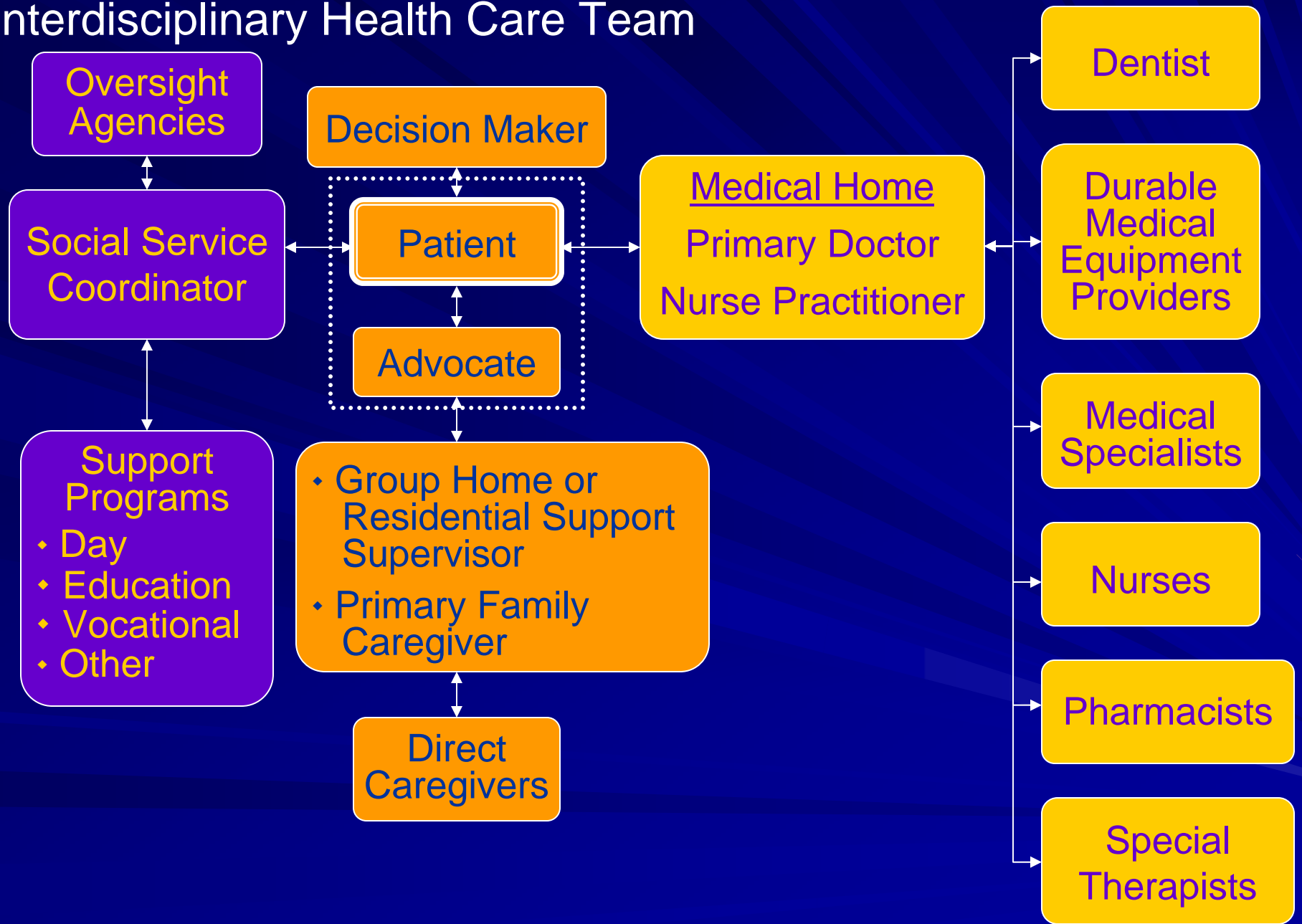
"LET ME WIN. BUT IF I CANNOT WIN,
LET ME BE BRAVE IN THE ATTEMPT."
- SPECIAL OLYMPICS OATH -



Local Community Resources

- ◆ Golden Gate Regional Center
- ◆ ARC
- ◆ Anchor Project- OMI mental health center
- ◆ Support for Families
- ◆ *Families, caregivers, health advocates*

Interdisciplinary Health Care Team



Recommendations for Eliminating Health Disparities for People with DD

- Health care provider competencies
- Caregiver competencies
- Developing appropriate models of care
- Creating system change

A Blind Spot in the System: Health care for People with Developmental Disabilities, 2008

Goals Frequently Identified by Adults with DD

- ◆ Self sufficiency
- ◆ Increased decision making
- ◆ Ability to work and make money
- ◆ To love and be loved
- ◆ Friends

Brown D.T., Counseling & Psychotherapy
with persons with Mental Retardation 1994

Resources

1. Department of Developmental Services website for specific issues: Developmental Disabilities Resources for Health Care Providers
www.ddhealthinfo.org
2. For info on genetic testing: www.genetests.com
3. UCSF Office of Developmental Primary Care (website under construction)

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*Improving outcomes for people
with developmental disabilities*

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