



# **HEALTH LITERACY ISSUES IN INDIVIDUALS WITH PHYSICAL DISABILITIES**

**SUZANNE C. SMELTZER, EDD, RN, ANEF,  
FAAN**

# IMPACT OF LITERACY ON HEALTH

Literacy affects

- health knowledge,
- health status
- access to and appropriate use of health services.

Library of Medicine, 2004

# HEALTH LITERACY

The degree to which individuals can *obtain, process, and understand* the basic health information and services they need to make appropriate *decisions* about one's own health (in the context of physical disability).

## Health literacy commonly affected in those with physical disability: Their ability to

- Obtain health information (not known or never studied, not readily accessible, or not shared because of paternalistic attitudes and bias of clinicians and society)
- Process health information (if not made relevant or considered by others to be important to persons with disability)

## Health literacy commonly affected in those with physical disability: Their ability to

- Understand health information (if not provided or made pertinent to the needs of person with physical disability).

# Consequences of inability to access, process and/or understand health-related information



- Lack of access to needed care and health-related services, *and*
- Inability to make informed decisions about own care

# EFFECTS OF INABILITY TO MAKE INFORMED DECISIONS ABOUT OWN HEALTH CARE

Bias of others and own low level of health literacy



Decisions are made **for** and not **by** or **with** persons with physical disability



May lead to increased dependence and passive acceptance of others' decisions

# ISSUES RELATED TO AVAILABILITY OF INFORMATION:

In those with physical disabilities from childhood or adolescence



Isolation or barriers to health-related education as children/adolescents



Low level of health literacy as adults

**Issues related to processing and understanding of information:**

SOME PHYSICAL DISABILITIES (E.G., MS, CEREBRAL PALSY, STROKE) MAY HAVE A COMPONENT OF COGNITIVE IMPAIRMENT



**Low level of health literacy**

**Issues related to lack of information on topics relevant to people with physical disabilities:**

INADEQUATE KNOWLEDGE ABOUT EVEN COMMON HEALTH ISSUES



LACK OF HEALTH PROMOTION ACTIVITIES (PREVENTIVE HEALTH SCREENING AND STRATEGIES TO REDUCE RISK)



INCREASED INCIDENCE OF PREVENTABLE SECONDARY HEALTH CONDITIONS

## SPECIFIC EXAMPLE OF LIMITED ACCESS TO NEEDED INFORMATION BY WOMEN WITH DISABILITIES DURING PREGNANCY

- Bias on part of clinicians who believe they know best what is needed by women with disabilities
- Beliefs of clinicians that they know what is best for women related to childbearing decisions
- Clinicians don't ask, don't explain, don't answer questions, and don't share information with women with disabilities.

# CONSEQUENCES OF LIMITED ACCESS TO INFORMATION OF WOMEN WITH DISABILITIES DURING PREGNANCY

- Fear of the unknown (effect of disability on pregnancy and of pregnancy on disability).
- Lack of preparation for labor and delivery, postpartum period, and childcare.
- Have to be innovative/self advocates in the absence of important information that all individuals with disabilities want, need and deserve.

# WHAT CAN WE DO TO IMPROVE THE SITUATION FOR INDIVIDUALS WITH PHYSICAL DISABILITIES?

- Ensure that persons with disabilities are included in health literacy research
- Query individuals with physical disabilities about their unmet needs related to health and health care
  - (They know better than anyone else and need to inform decisions made so that they are key to decisions and not merely on the receiving end of others' decisions)
- Ensure that the views of persons with physical disabilities are heard; their views must be primary in decisions made about their health and health care.

