



Caring for People with Disabilities

The Nurse Practitioner Tool Kit



Objectives

Describe and discuss types of disabilities likely to be encountered in primary care practice.

Identify and discuss similarities in people with and without disabilities and those with various types of disabilities.

Identify issues that healthcare providers (HCPs), including nurse practitioners (NPs), need to consider in practice.



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Key Terms and Issues

- Definitions of disability
- Models of disability
- Disabilities vs. disabling conditions



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ADA'S Definition of Disability

A physical or mental impairment that substantially limits one or more major life activities, a record or history of such an impairment, *or* is regarded/perceived by others as having such an impairment.

The American with Disabilities Act of 1990

www.ada.gov



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International Council of Nurses

A Disability:

Is a physical, mental, sensory, or social impairment that, in the long term, adversely affects one's ability to carry out normal day-to-day activities.

ICN supports programs designed to integrate PWD in all aspects of daily life—in the family, school, workplace and community.

ICN position statement: Prevention of disability and the care of people with disabilities (2000, revised 2010).



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ICN Position Statement

Ensure that nursing education addresses competencies needed for the prevention of disability AND the care and rehabilitation of PWD; promote fuller understanding of the particular problems faced by PWD and their families AND includes advocacy skills and a knowledge of programs and resources in the community.

Assist, support and advocate for PWD and their families to access education, information and support services that allow them to lead fulfilling lives.



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Another View of Disability

“Disability is a universal experience that affects nearly everyone without exception at some time in their lives.”

(Kirschner & Curry, 2009)



Significance of Definitions of Disability

- Determine who is eligible for services
- Determine what services are “allowed”
- Determine our views about perceptions of people with disabilities
- Determine how we interact with and treat people with disabilities in all education, clinical practice, and community sites and settings



Models of Disability

Medical Model

- Views disability as a problem of the individual.
- Goal of health care...medical management...is to cure (or “fix”) the individual or modify his/her behavior.
- Health care providers (HCPs) are the “experts”.
- Viewed by PWD as promoting dependency and passivity.



Models of Disability

Rehabilitation Model

- Based on medical model so characteristics are similar.
- PWD is seen as having a deficiency or defect.
- Failure to get better as seen as a failure of the PWD.



Models of Disability

Social Model

- Views disability as socially constructed and due to failure of able-bodied society to provide access and accommodations.
- Disability is a function of the social environment.
- Solution or “treatment” is social and/or political change.



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Models of Disability

Bio Psychological Model

- Integrates medical and social models.
- Addresses health from a biologic, individual, and social perspective.



Models of Disability

Interface Model

- Based on the life experience of the person with a disability.
- Views disability at the intersection (i.e. interface) of health issue and environmental barriers.
- Considers rather than ignores the health issue or medical problem.
- Only model of disability developed by a nurse (who had a disability).



Significance of Models of Disability

- Determine our views of and attitudes toward people with disabilities.
- Influence how we treat and interact with people with disabilities.
- Serve as a check on our attitudes and values about people with disabilities.
- Influence how we teach others about disability-related issues.



Disability vs. Disabling Conditions

Disability:

- Experience of difficulty performing daily activities and fulfilling social roles because of physical, sensory, psychiatric/mental health, emotional, intellectual, or cognitive impairment.
- Often compounded by environmental barriers.

Disabling Conditions:

- Underlying disorders that have the potential to lead to disability; typically include physiological or psychological causes of disability.



Disability vs. Disabling Conditions

Knowing details about disabling conditions is **NOT** the same as knowing about disability.



Prevalence of Disabilities

- ~60 million people in the U.S. and 1 billion worldwide live with one or more disabilities.
- One in every 4 people lives with 1 or more disabilities.
- Disabilities occur across the life span:
 - 13.9% of children
 - 11.0% of 18-44 year olds
 - 51.8% of those \geq 65 years



Characteristics of Disabilities

Disabilities Vary in Severity

- Very mild (inconvenience)
- Moderate (interfere with some activities)
- Severe (assistance needed for IADLs, ADLs)
- Very severe (technology needed for survival)



Characteristics of Disabilities

Disabilities Vary in Type

- Physical disabilities
- Sensory (vision and hearing) disabilities
- Psychiatric mental health disabilities
- Cognitive/intellectual disabilities
- Communication disabilities



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Characteristics of Disabilities

Disabilities Vary in Visibility

- Not at all visible to others
- Visible to informed others
- Visible to all



Characteristics of Disabilities

Population of people with disabilities is increasing in size

- Advances in health care and survival of people with disabilities across the lifespan (VLBW babies, adults who are chronically ill, etc.)
- Increase in number of people with chronic disease
- Increased survival of those with trauma
- Increased number of elderly and frail elderly



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Background

People with disabilities encounter serious barriers to receiving quality health care including preventive care and screening and reproductive care.



Barriers

- Lack of equipment and facilities to permit those with physical limitations to have complete physical exams.
- Lack of understanding interaction of disability and other aspects of health by some health care providers.
- Belief on part of many health care providers that all health problems are due to the disability.
- Negative attitudes and stereotyping of health care providers; belief that:
 - PWD don't need (or want) preventive screening
 - It would be a waste of resources.
 - PWD are asexual, uninterested & not at risk.
- Lack of attention to disability issues in health care professions' education/training programs.



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Background

Health care providers are often unable to address sexuality, pregnancy, childbearing and common health problems in people with disabilities.



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Background

People with disabilities have received lower quality of care, less aggressive treatment and are offered few choices.



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Background

People with disabilities have reported being refused care.



Consequences of Victimization and Lack of Health Care

- Negative encounters often result in people with disabilities avoiding health care providers unless and until *absolutely necessary*.



- Inadequate health care, including preventive screening.
- Delay in treatment or lack of treatment.
- Low level of participation in health promotion activities.



- Poor health status, isolation, psychological issues.



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Low Bone Density & Osteoporosis Risk in Women with Disabilities

- Earlier onset of age-related health conditions in women with disabilities.



- Low bone density/osteoporosis





Low Bone Density & Osteoporosis Risk in Women with Disabilities

Purposes:

- To examine bone density and osteoporosis risk factors in women with disabilities.
- To examine their use of osteoporosis prevention strategies and previous bone density screening.

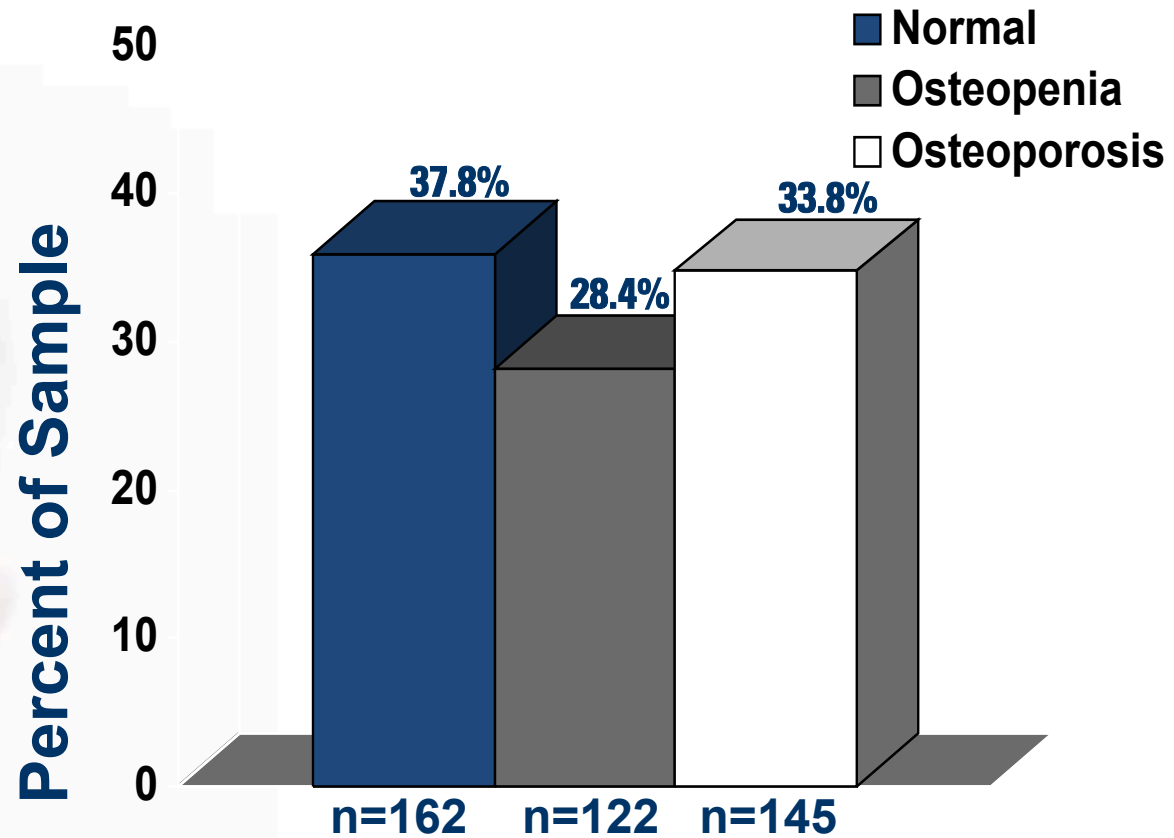
Methods:

- Bone density screening.
- Administration of a questionnaire.



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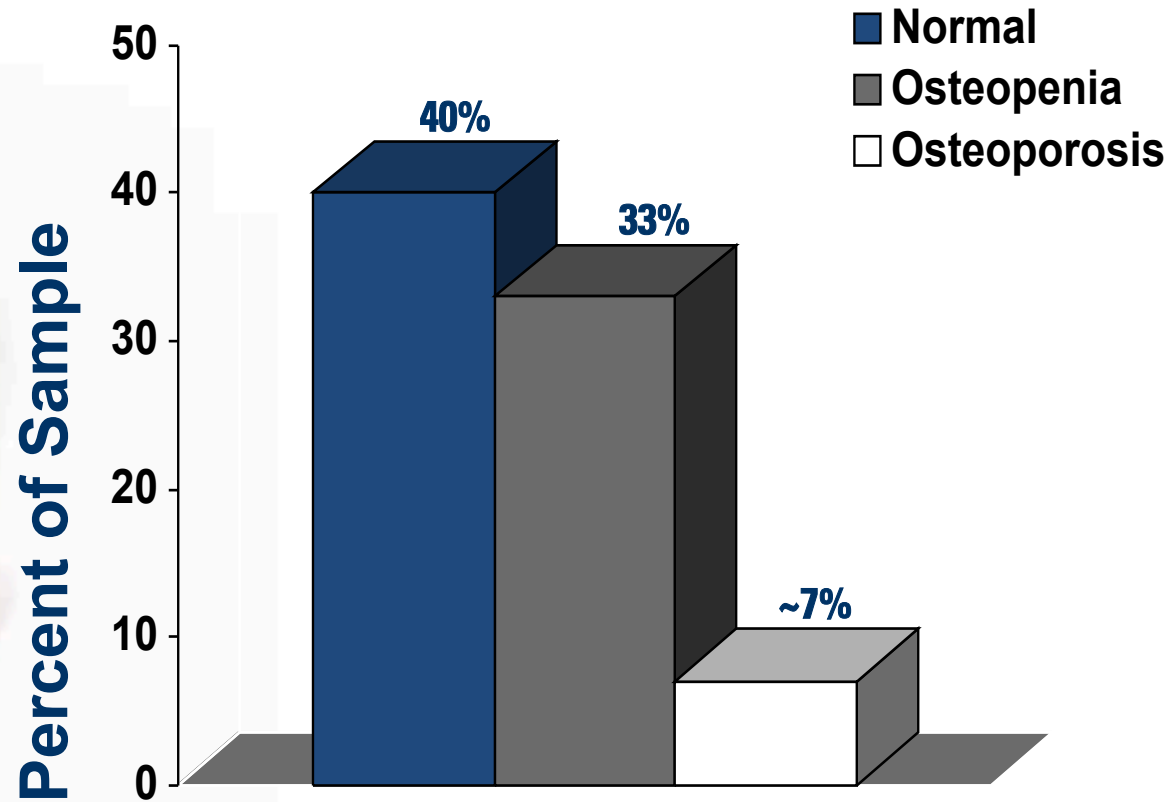


**WHO Classification of Bone Density
in Women with Disability (n = 429)
(Smeltzer, et al., 2005)**



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**WHO Classification of Bone Density
in Non-Disabled Postmenopausal Women
(n = > 200,000) Siris, et al., 2001)**



Low Bone Density & Osteoporosis Risk in Women with Disabilities

	Yes	No
Use of Prevention Strategies:		
• Weight-bearing exercise	13.3%	86.7%
History of BMD Testing:		
• Had previous testing	24.9%	75.1%
• Previously recommended	32.4%	67.6%



Implications

- Greater attention should be given to risks for osteoporosis among women with disabilities.
- Bone density testing should be considered in women with disabilities at risk for osteoporosis.
- Follow-up re compliance with testing is warranted.
- Discussion regarding strategies to prevent osteoporosis or reduce its severity is warranted.
- Risk for fracture is greatly increased compared to those without disabilities because of high incidence of falls.

NOTE: Osteoporosis is just ONE of many examples of early onset secondary conditions that occur in people with disabilities.



Findings Across Studies

- ☹️ Poor communication is a major barrier to care for people with disabilities.
- ☹️ Lack of awareness and knowledge about specific disabilities and of disability in general.
- ☹️ Lack of sensitivity to and knowledge about the effect of disability on health issues and, in turn, the effect of health issues on disability.
- ☹️ Lack of awareness and sensitivity to the need for “disability etiquette”.



Findings Across Studies

- ☹ General disregard of experience and expertise of people with disabilities about their disability (HCPs consider themselves the “experts”; they don’t know; don’t ask).
- ☹ Lack of accountability of HCPs for providing needed accommodations to enable people with disabilities receive health care.
- ☹ Lack of knowledge about the law or disregard for the legal mandates.
- ☹ All people with disabilities are assumed (in error) to be dependent on others and incapable of making their own decisions.



Myths re Similarities & Differences

- ☹ **Myth*:** The lives of people with disabilities are totally different than the lives of people without disabilities.
- 😊 **Fact:** People with disabilities go to school, get married, work, have families, do laundry, grocery shop, laugh, cry, pay taxes, get angry, have prejudices, vote, plan and dream like everyone else. (They have aspirations and want to attend school and go to work.)

***From Easter Seals “Myths about People with Disabilities”.**



Myths re Similarities & Differences

- ☹ **Myth:** People with disabilities do not have to worry about general health issues as they are less likely or unlikely to develop them on top of their disabilities.
- 😊 **Fact:** People with disabilities are at the same (and sometimes increased) risk for health problems that others experience.



Myths re Similarities & Differences

- ☹ **Myth:** People with disabilities do not need health screening and preventive care; their lives are going to be short anyway (it is a waste of resources to spend more money on them).
- 😊 **Fact:** People with disabilities may develop health issues at younger ages than people without disabilities so they sometimes need greater, not less, attention to primary health care and screening. Life span is not dramatically shortened in most.



Myths re Similarities & Differences

- ☹ **Myth:** People with disabilities do not want to participate in preventive health care and screening.
- 😊 **Fact:** No data indicates that PWDs do not want to participate in preventive health care and screening. What they do not want are unpleasant negative experiences when seeking and obtaining care.



Myths re Similarities & Differences

- ☹ **Myth:** Most people with disabilities have disabilities because of unhealthy behaviors and lifestyles.
- 😊 **Fact:** Many disabilities are related to factors that are not a result of unhealthy behaviors and lifestyles.



Facts re Similarities & Differences

- **Fact:** People with disabilities are at the same (and sometimes increased) risk for health problems that others experience.
- **Fact:** People with disabilities may develop health issues at younger ages than people with disabilities so they may need a greater, not less, attention to primary health care and screening.
- **Fact:** Most people with disabilities have a normal or near-normal life span.



Facts re Similarities & Differences

- **Fact:** Many people with disabilities have a smaller margin of safety than people without disabilities; thus, their need for health screening and preventive care is increased rather than decreased.
- **Fact:** People with disabilities do not differ in desire for preventive health care and screening from other people; it is, however, often more difficult and frequently an ordeal.
- **Fact:** People with disabilities are no more and no less responsible for their disabilities than those without disabilities.
- **Fact:** Disabilities is *not* illness; people with disabilities can be very healthy. Many of them are healthier than non-disabled populations.



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Recommendations to Improve Health of People with Disabilities

Two Surgeon General Reports (2002, 2005), one Institute of Medicine Report (2007), the National Council on Disability Report (2009), and the WHO World Report on Disability (2011) recommended several key actions to improve the health of people with disabilities:

- Improve public recognition that people with disabilities can live long, healthy and productive lives and reduce stigma and discrimination;
- Improve knowledge, skills and attitudes of health care providers to improve care;
- Improve accessibility of health care, including insurance, facilities, equipment, transportation;
- Improve opportunities for health promotion, safety and well-being;
- Improve data on disability populations, and research on disability-related health disparities and interventions.



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Strategies to Address Health-Related Disparities

- Increase our own awareness, sensitivity and knowledge about disability, health issues of this population, and disparities related to disability
 - Read, search Internet, read life stories of people with disabilities
 - Attend programs on disability in practice and education
 - Involve people with disabilities in teaching you and others
- Identify own attitudes, bias and prejudices
- Get to know someone with a severe disability
- Adopt “person-first language” (the person with a disability; NOT “the disabled” or “disabled person”)
- Use disability etiquette in interaction with people with disabilities
- Assume that people with disabilities are the experts on their own disabilities



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Strategies to Address Health-Related Disparities

- Put ourselves in the shoes of people with disabilities, but verify that we have it accurate
 - Example: obtain material on diabetes self-care for person with vision impairment
 - Example: consider having a mammogram or GYN exam from perspective of a woman who is a wheelchair user (try even finding an accessible office and scheduling an appointment!)
- Ask people with disabilities about their experiences and about how they learn best
- Provide accommodations (large print, Braille, pictures, tapes, etc.) to address their learning needs
- Learn from people with disabilities



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**Who are these people
with disabilities????**



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Stephen Hawking, PhD:

Holder of Isaac Newton's Chair, Oxford
ALS



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Margaret Nosek, PhD:

Founder of Center for Research on Women with Disabilities (CROWD)
Musculoskeletal Disorder



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Helen Keller:
Author and Advocate
Deaf & Blind



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Considering Disability...

“Disability is a universal experience that affects nearly everyone without exception at some time in their lives.”

(Kirschner & Curry, 2009)



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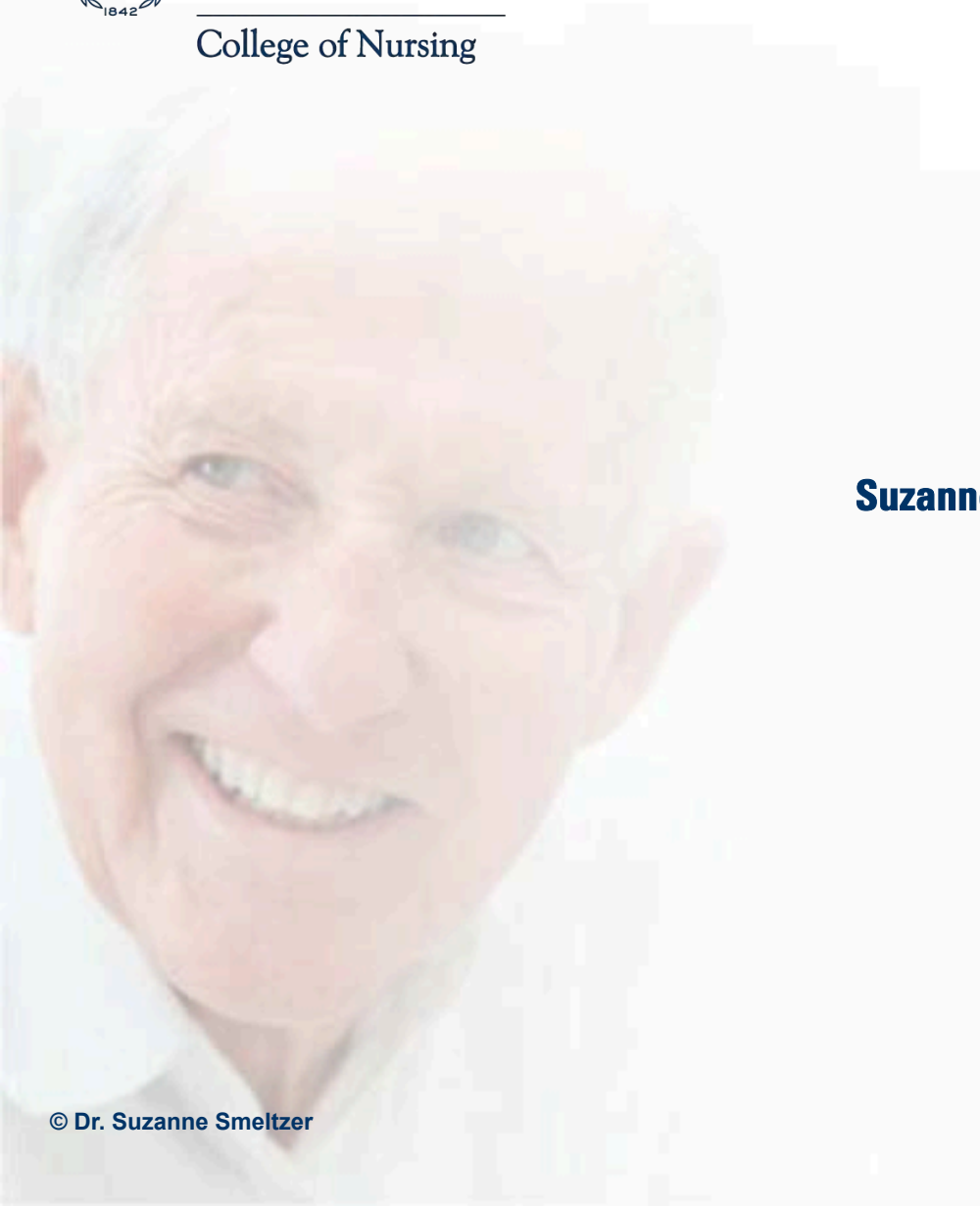
Rewards of Working with People with Disabilities

- Improves health and well-being of an underserved group: people with disabilities, including students
- Increases diversity and enriches the academic and health care environment
- Meets goal of nursing and education to be holistic and address health and needs of people with disabilities
- Improves nursing practice; retains students/nurses who otherwise would be excluded
- Provides opportunity to meet and learn from people with disabilities with incredible things to contribute to education, health care and the world



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