



## Preface

# Intellectual and developmental disabilities

Unprecedented politico-legal activity has significantly altered the rights and welfare of persons with intellectual and developmental disabilities (I/DD) since *The Nursing Clinics of North America* last dedicated an issue to nursing care for children with I/DD. Following the 1975 issue (entitled “Symposium on the Child with Developmental Disabilities”), principles such as normalization, the least restrictive alternative, and mainstreaming have reshaped standards of treatment and broadened the spectrum of available services for children and adults with I/DD. Individuals with I/DD can now expect to live longer with improved living standards and have more opportunities to be active participants in their communities. Furthermore, as a result of the sociodemographic, legal, and philosophical changes, persons with I/DD today have health care needs and concerns that differ from their previous counterparts, who were segregated from mainstream society.

Nurses have a long history of providing care to persons with I/DD, from a time when care was provided primarily in institutional settings to today, when care is provided in a variety of settings including school, worksite, and primary care settings in the community. Although the American Nurses Association now recognizes the nursing specialty practice with persons with I/DD, most nurses report receiving little education in basic nursing programs that address I/DD or other disabilities. This issue expands Elizabeth Worthy’s initiative that was published 28 years ago by presenting a series of articles designed to improve nurses’ knowledge about the issues impacting the health and lives of persons with I/DD throughout the lifespan. These articles also present strategies that can be used to provide nursing care for individuals with I/DD throughout the lifespan.

Persons with I/DD are individuals who have disabilities that are “attributed to a mental [ie, intellectual] or physical impairment or combination of mental and physical impairment” (Public Law 103-230) that manifests before the age of 22. By federal definition, a developmental disability is likely to continue throughout a person’s life and results in limitations in functioning in at least three major life activities such as

self-care, language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. Although adults with I/DD represent a significant proportion of individuals with lifelong disabilities in the United States, they continue to experience a broad range of health issues and under-recognized and unmet health-related needs that are gaining increasing attention.

Several legislative changes have resulted in the greater attention to basic health care needs for individuals with I/DD. The passage of the Education for All Handicapped Children Act of 1975 (Public Law 94-142) afforded children with I/DD the right to a free public education in the least restrictive environment; and the Rehabilitation Act of 1973 prohibited discrimination in agencies receiving public funds. As the number of children with I/DD attending public schools increased, health care concerns were increasingly recognized, due to the necessity of a health assessment component required for school placement. Another legislative change supporting the concept of least restrictive alternative beyond the educational system was the passage of the Americans with Disabilities Act (ADA), Public Law 101-336, in 1990, which extended protection in private sector among agencies who did not receive federal funds. The ADA also reinforced the civil rights of individuals with I/DD to have equal access to all aspects of society's services, including health care services.

Although many of the legislative and philosophical changes that affect persons with I/DD have been evolving since the 1960s, the community-based health care system is still realizing the impact of these changes. Progress in the health care service delivery has been conspicuously slower than most other areas of human service that have shown steady and substantial advances in providing integrated services for individuals with I/DD in the areas of education, residential, recreation, training, and employment services. Health care research, clinical services, and education have also largely ignored subpopulations with specialized needs, such as persons with I/DD. The recent 2002 publication *Report of the Surgeon General's Conference on Health Disparities and Mental Retardation* attempts to address the health disparities among persons with I/DD. This report highlights the significant need for health promotion, health education, and the increased training among health care providers about the needs of persons with I/DD. Although many Americans face barriers to the access of health care, people with I/DD are especially vulnerable to the inadequacies of the existing health care system and disproportionately represent the poor and unemployed as a result of their disability. Although the health care system is usually responsive to acute care needs (eg, infections and emergency care), health care services for chronic conditions and lifestyle-related conditions are quite problematic.

The topics in this issue mirror some of the social and historical changes in the care of persons with I/DD. Shifts encompass changing and evolving definitions of disability; a growing body of knowledge about the

importance of early brain development; acknowledging rights and advancing ways to promote sexuality and sexual identity among individuals with I/DD; a greater attention to issues throughout the lifespan, including aging for persons with I/DD; a greater focus on the human rights of persons with I/DD; and growing advocacy among persons with I/DD and other disabilities.

Newer definitions of disability emphasize the social and environmental factors that impact upon a person's ability to fully participate in his or her life. The term *intellectual disability*, a more internationally accepted term, is replacing the term *mental retardation*, except when the latter is used as a diagnostic term. The term *mental retardation* is being rejected by persons who have been given this label for several decades. Rather than focusing on specific etiologies or syndromes associated with I/DD, except to illustrate unique health needs of persons with I/DD, this issue addresses health-related concerns that all individuals face across the life course. These include addressing developmentally supportive relationship-based interventions for families and infants, fostering healthcare transitions from adolescence to adulthood, engaging in health promotion, assessing and treating mental health issues, encouraging expression of sexuality and building healthy relationships, using technologies, and growing older.

Assisting all individuals with I/DD to engage in health promotion practices, calls for a look at the barriers to health promotion. Access barriers may include programmatic, attitudinal, physical, and communication barriers and inadequate professional education. Other disability issues frequently not addressed by policy makers include the marginalization, poverty, abuse, and lack of support, which reduce access to health education, preventive health screenings, and health promotion activities. The barriers to promoting good health care as well as implications for nurses to overcome these barriers are presented. This issue includes a compilation of published or Internet-accessible materials for use by nurses to support individuals with I/DD across the lifespan and in a variety of settings. Knowledge of resources is critical to provide the needed support to persons with I/DD and their families.

Today, nurses have an opportunity to promote the rights of persons with I/DD and engage in strategies to promote health for all persons with I/DD in all health care settings. Of importance will be nurses who take the time to listen to persons with I/DD; facilitate their involvement; enable them to access the needed health care interventions and supports; assist in monitoring and making supports pertinent over time; identify what resources are needed; and facilitate changes in policy. By fostering access to healthcare and providing assistance, nurses can support persons with I/DD in making choices and gaining a sense of control in their lives and personal health care. With an awareness of some unique, yet similar health issues, nurses can

assist persons with I/DD to bridge the gaps in their health care and receive equitable services within their community.

Joan Earle Hahn, DNSc, RN, CDDN, CS  
*University of California Los Angeles School of Nursing  
Factor Building Room 5–145  
700 Tiverton, Box 956919  
Los Angeles, CA 90095–6919*

*E-mail address: [jhahn@sonnet.ucla.edu](mailto:jhahn@sonnet.ucla.edu)*

Beth A. Marks, PhD, RN  
*University of Illinois at Chicago  
Department of Disability and Human Development  
Rehabilitation Research and Training Center on Aging  
with Developmental Disabilities  
1640 West Roosevelt Rd.  
Chicago, IL 60608, USA*

*E-mail address: [bmarks1@uic.edu](mailto:bmarks1@uic.edu)*