DRAFT Intellectual and Developmental Disabilities Nursing:

Scope and Standards of Practice, Third Edition

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For Public Comment

Contributors

The American Nurses Association (ANA) thanks those who contributed their valuable time and talents *to* development of *Intellectual and Developmental Disabilities Nursing: Scope and Standards of Practice, Third Edition*. This resource builds on and replaces previous editions entitled *Intellectual and Developmental Disabilities Nursing: Scope and Standards of Practice* and the original *Statement on the Scope and Standards for the Nurse Who Specializes in Developmental Disabilities and/or Mental Retardation* . The terminology has changed over the years and is reflected in each edition of the scope statement and standards of this specialty nursing practice.

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The American Nurses Association will approve the scope statement and acknowledge the standards of practice and professional performance of *Intellectual and Developmental Disabilities Nursing: Scope and Standards of Practice, Third Edition*, as defined herein. Approval is valid for five (5) years from the first date of publication of this document or until a new scope of practice has been approved, whichever occurs first.

About the American Nurses Association

The American Nurses Association (ANA) is the only full-service professional organization representing the interests of the nation's 4 million registered nurses through its constituent/state nurses associations and its organizational affiliates. The ANA advances the nursing profession by fostering high standards of

nursing practice, promoting the rights of nurses in the workplace, projecting a positive and realistic view of nursing, and lobbying the Congress and regulatory agencies on healthcare issues affecting nurses and the public.

About Nursesbooks.org, the Publishing Program of ANA

Nursesbooks.org publishes books on ANA core issues and programs, including ethics, leadership, quality, specialty practice, advanced practice, and the profession's enduring legacy. Best known for the foundational documents of the profession on nursing ethics, scope and standards of practice, and social policy, Nursesbooks.org is the publisher for the professional, career-oriented nurse, reaching and serving nurse educators, administrators, managers, and researchers as well as staff nurses in the course of their professional development.

Overview of the Content

Essential Documents of Professional Nursing

The American Nurses Association (ANA) has been the vanguard for nursing practice for more than a century. The *Code of Ethics for Nurses with Interpretive Statements* (ANA, 2015) and *Nursing: Scope and Standards of Practice* (3nd ed., ANA, 2015), are documents produced by ANA to inform the thinking and decision-making of registered nurses practicing in the United States and guide their practice. The *Code of Ethics for Nurses with Interpretive Statements* (ANA, 2015) lists the nine succinct provisions that establish the ethical framework for registered nurses across all roles, levels, and settings. *Nursing: Scope and Standards of Practice* (3nd ed., ANA, 2015) outlines the expectations of the professional role of the registered nurse. It includes the Scope of Nursing Practice Statement and presents the Standards of Professional Nursing Practice and their accompanying competencies. These documents are intended to help provide the public with assurances of safe and competent nursing care.

Along with these documents, specialty nursing organizations have worked with the ANA to publish specific standards of professional practice in their specialty. This document, concerning the care of individuals with intellectual and developmental disabilities (hereafter referred to as IDD), is a revision of the *Intellectual and Developmental Nursing: Scope and Standards of Practice*, 2nd Edition. This document has been revised to: (a) capture the changing practice of nursing in this specialty (i.e., encompassing all levels of education and all system levels of care from the individual to the system itself), (b) emphasize the unique health care needs and characteristics of individuals of all ages with IDD, (c) incorporate the ANA standards mentioned earlier (ANA, 2015a), (d) incorporate the provisions of the *Code of Ethics for Nurses with Interpretive Statements* (ANA, 2015b); (e) emphasize the importance of a family-centered and consumer-centered framework of care; and (f) incorporate the developments in the field since the last edition. The previous edition of these specialty standards and scope of practice is found in Appendix A.

Adolescents and adults with IDD and their families/legal guardian(s) collaborate with healthcare professionals to make person-centered decisions about their health care. This self-advocacy has arisen in tandem with an evolving healthcare system that may or may not optimize healthcare options for all people. Therefore, in response to these changes, individuals of all ages with IDD and their families/legal guardian(s) should be assured of safe and effective nursing care. This document addresses this care, the associated nursing standards, and the competencies expected of registered nurses who specialize in IDD practices.

Additional Content

This document should also be used in conjunction with other specialty nursing scope and standards of practice and professional performance such as but not limited to : *Pediatric Nursing: Scope and Standards of Practice*, *2nd Edition*, (Society of Pediatric Nurses [SPN], National Association of Pediatric Nurse Practitioners [NAPNAP], & ANA, 2015); *Genetics-Genomics Nursing: Scope and Standards of Practice, 2nd Edition*, (International Society of Nurses in Genetics, Inc. & ANA, 2016); *Public Health Nursing: Scope and Standards of Practice*, *2nd Edition*, (ANA, 2013); *Psychiatric-Mental Health Nursing: Scope and Standards of Practice, 2nd Edition,* (American Psychiatric Nurses Association, International Society of Psychiatric-Mental Health Nurses, & ANA, 2014); and *School Nursing: Scope and Standards of Practice, 3rd Edition*, (National Association of School Nurses & ANA, 2017). Additional important nursing documents that address the history and context of nursing standards include *Nursing: Scope and*

Standards of Practice, 3rd Edition, (ANA, 2015a); *Principles of Environmental Health for Nursing Practice* (ANA, 2007a); *Professional Role Competence: ANA Position Statement,* (ANA, 2014); and *Principles for Nursing Documentation for Registered Nurses and Professional Nursing* (ANA, 2015).

Audience for This Publication

Nurses, of any educational level and employed in any setting that serves individuals of any age with IDD, make up the primary audience for this book. Legislators, regulators, legal counsel, and the judiciary system will also want to reference it. Agencies, organizations, nurse administrators, other nurses not working in this specialty, and other interprofessional colleagues will find this publication an invaluable reference. In addition, healthcare consumers with IDD, their family/legal guardian(s), communities, and populations using healthcare and nursing services that cover the care of persons with IDD can use this document to better understand the role and responsibilities of registered nurses and advanced practice registered nurses who specialize in IDD.

Scope of Intellectual and Developmental Disabilities (IDD) Nursing Practice

Because the intellectual and developmental nursing specialty historically was primarily associated with an institutional setting and the stigma attached to this population until the late 1950s, many nurses are unfamiliar with this unique specialty nursing practice area. In fact, this nursing specialty was only recognized by the American Nurses Association in 1997 (Nehring, 1999). Unlike many nursing specialties, the scope of practice for nurses who specialize in IDD extends across all levels of care and all healthcare and many educational settings. Even though healthcare consumers with IDD are present today in all communities and healthcare settings, they remain a vulnerable and marginalized population because they often require assistance to advocate for their needs. Many healthcare professionals are not educated or prepared to care for specific condition and developmental needs of individuals with IDD. Such health disparities were highlighted in the Surgeon General's report, *Closing the Gap: A National Blueprint for Improving the Health of Persons with Mental Retardation* (U.S. Public Health Service, 2002). Working in an interdisciplinary context, nurses continue to strive to promote the importance of the nursing contribution in this specialty field and to provide healthcare at both the generalist and advanced practice level.

Definition of Nursing

Nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, facilitation of healing, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, groups, communities, and populations. (p. 1, ANA, 2015a)

This definition serves as the foundation for the following expanded description of the Scope of Nursing Practice and the Standards of Professional Nursing Practice for nurses who specialize in IDD.

Definition of Intellectual and Developmental Disability (IDD) Nursing

Consistent with the ANA (2015a) definition of nursing, IDD nursing focuses on protecting, promoting, and optimizing the health and functioning ability of persons with IDD; diagnosing and treating persons with IDD to alleviate discomfort and suffering; and advocating for and with persons with IDD and their families within and across groups, communities, and society.

Nurses who practice in the specialty field of intellectual and developmental disabilities (IDD) have clinical expertise and experience pertaining to the illness-health continuum of care of individuals across the lifespan whose conditions meets the diagnostic criteria identified in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (Box 1). IDD nursing practice is based upon a family-centered and in later years, an individual-centered philosophy of care wherein the family (and when appropriate, the individual) are considered full partners in the development of the comprehensive plan of care. IDD nursing is comprehensive in scope and is focused on all aspects of the biopsychosocial needs of the person with IDD, their family, and their community, and the resources that are available to the person, family, and community.

Major biopsychosocial issues impacting individuals with IDD and of ongoing concern for IDD nurses and their interprofessional colleagues include:

- Primary, secondary and tertiary prevention of developmental disability (DD) and intellectual disability (ID)

- Community inclusion
- Transition from pediatric to adult DD services
- Expansion of services that promote independence beyond their 22nd birthday
- Access to high quality, community-based health care including a health home
- Provision of culturally relevant care across the spectrum of IDD nursing
- Health equity
- Social determinants of health
- Non-discrimination in educational and work settings

BOX 1.
Definition of Developmental Disability
Developmental Disabilities Assistance and Bill of Rights Act of 2000

DEVELOPMENTAL DISABILITY

(A) IN GENERAL. The term ''developmental disability'' means a severe, chronic disability of an individual that
(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
(ii) is manifested before the individual attains age 22;
(iii) is likely to continue indefinitely;
(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.
(II) Receptive and expressive language.
(III) Learning.
(IV) Mobility.
(V) Self-direction.
(VI) Capacity for independent living.
(VII) Economic self-sufficiency;

and (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(B) INFANTS AND YOUNG CHILDREN. An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.

Description of the Scope of IDD Nursing Practice

Nurse members of the American Association on Intellectual and Developmental Disabilities (AAIDD), Developmental Disabilities Nurses Association (DDNA), American Academy of Developmental Medicine and Dentistry (AADMD), and other professional nursing associations have deemed it important that there be a scope and standards of practice for this specialty. This document serves as the contemporary template for the practice of nursing in IDD and the standards of practice portion of this document serves as a description of the practice of nurses who specialize in this field.

IDD nurses help comprehensively manage the biopsychosocial needs of children and adults with IDD in a wide array of health and community settings. IDD nursing is practiced in settings that may not be relevant for other nursing specialties, such as early intervention programs; special education programs in preschool, elementary, middle and high schools; postsecondary vocational programs; group homes; mental health programs; and senior residential and support programs. IDD nurses serve as care consultants for nursing specialties, nurse educators, nurse researchers, and interprofessional colleagues when they work with individuals with IDD. IDD consultation efforts include assistance with the provision of the care that addresses the unique care needs for patients with IDD who are hospitalized in tertiary and sub-acute settings. IDD nurses can be consulted about the provision of referrals to available resources and community services for those with IDD. IDD nurses can coordinate care and establish wrap-around support networks from a wide array of resources, including clinics, hospitals, rehabilitation facilities, schools, transportation, supported employment, mental and behavioral programs, and housing. The uniqueness of IDD nursing is that IDD nurses complete care coordination that is complex involving resources from a myriad of agencies and organizations that are not characteristically accessed in clinical settings. Furthermore, IDD nurses recognize resources that are available through local, state, regional, and national governing bodies.

The scope of IDD nursing practice is consistent with the 2015 ANA Scope and Standards of Practice (2015a) which describes the "who," "what," "where," "when," "why," and "how" of nursing practice. The answer to each of these questions helps to provide a complete picture of the dynamic and complex practice of IDD nursing. The definition of nursing answers the "what" of nursing practice question. IDD nurses are registered nurses and advanced practice registered nurses "who" have been educated, credentialed, and maintain active licensure to practice nursing. IDD nursing occurs "when" there is a need for nursing knowledge, wisdom, caring, leadership, practice, or education that is specific to persons with IDD and their families. IDD nursing occurs in any environment or setting "where" there is a person with IDD in need of care, information, or advocacy. The "how" of IDD nursing practice is the ways, means, methods, and manners that IDD nurses use to practice professionally. The "why" is characterized as IDD nursing's response to the changing needs of society to achieve positive healthcare outcomes for persons with IDD aligned with nursing's social contract with an obligation to society. The full spectrum of the IDD nurse's role in this specialty is described for both the registered nurse and advanced practice registered nurse. The depth and breadth with which individual registered nurses and advanced practice registered nurses engage in the total scope of IDD nursing practice for this specialty depend on each nurse's education, experience, role, and the population served.

Specialty Practice in IDD Nursing

All nurses will care for an individual with IDD sometime in their career. Each person with IDD is a person first and each person's healthcare needs are unique to that individual. It is also important that nurses recognize that a person with IDD (a) is not unwell based on the diagnosis of a IDD, (b) does not necessarily have all of the secondary conditions identified as common to the diagnosis (e.g., a person with spina bifida does not always have hydrocephaly), and (c) experiences many of the same life events (e.g., graduation, first job, etc.) and has the same feelings that all individuals have. It is important that diagnostic overshadowing does not occur. Diagnostic overshadowing refers to attributing a health problem to the person's diagnosis of IDD. For example, an adolescent with hydrocephalus who arrives in the emergency room with head banging behavior does not automatically have a shunt malfunction; he/she could be in pain or have constipation (Reiss, Levitan, & Szyszko, 1982).

Registered nurses must be able to provide care to individuals with IDD, but in most nursing education programs, the curricular content and clinical experiences related to the care of persons with IDD is minimal. Nursing education about IDD should be encouraged. Nurses practicing as registered nurses, both at the undergraduate and graduate level, must be able to provide holistic care to this population. Many books, articles, videos, and Internet sites are available to assist in this learning. Additionally, there are professional organizations such as the Developmental Disabilities Nurses Association (DDNA), American Association on Intellectual and Developmental Disabilities (AAIDD) and American Academy of Developmental Medicine and Dentistry (AADMD) that support continued development of the nurse caring for those with IDD.

The registered nurse who specializes in IDD provides care to individuals across the lifespan. Care of the persons with IDD should include families/legal guardian(s), particularly if youth are unable to make their own decisions or actively participate in their own care, based on an understanding of the concepts and strategies of nursing practice in this area. Decisions about healthcare plans for youth with IDD should be made with the healthcare consumer and/or parents/guardian(s) as partners in the plan (Institute of Medicine, 2001). IDD registered nurses, including APRNs, are included in an interprofessional team for healthcare consumers with IDD and are responsible for the coordination of care and support for those who have IDD. The IDD registered nurse participates in implementation of individual and family/legal guardian(s)' assessment and in the planning, implementation, and evaluation of their health and health services. along with the individual, family/legal guardian(s), and community support staff as partners Decisions about the healthcare plans for youth with IDD should be made with the healthcare consumer and/or parents/guardian(s) as partners in the plan's development and implementation (Betz, 2017; Betz, Krajieck, & Craft-Rosenberg, 2018; SPN, NAPNAP, & ANA, 2015).

Additionally, all IDD registered nurses, have roles in the preparation of youth as they transition to adult care. Recommendations for such preparations have been published by key organizations, including the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), the American College of Physicians (ACP) (AAP, AAFP, ACP-ASIM, 2002; Cooley, Sagerman, et al., 2011; White, Cooley, et al. 2018) the American Society of Internal Medicine (Talente & LeComte, 2013), the Society of Adolescent Medicine (Blum et al., 1993; Rosen, 2003), and position statements published by the Society of Pediatric Nursing (SPN) (Betz, 2017) and the National Association of School Nurses (2019a).

Development and Function of IDD Nursing Standards of Professional Practice

The Standards of Professional Nursing Practice in IDD Nursing are authoritative statements of the responsibilities that all registered nurses in this specialty are expected to perform competently (ANA, 2015a). These standards serve as evidence of the standard of care for IDD Nursing with the understanding that their application depends on context. The standards of professional practice in IDD nursing are subject to change as specific conditions and clinical circumstances change and new patterns of professional practice are developed and accepted by the nursing profession and the public. These standards will be formally and periodically reviewed and revised.

Standards of Professional Nursing Practice in IDD

The Standards of Professional Nursing Practice in IDD include the Standards of Practice and the Standards of Professional Performance in IDD.

Standards of Practice in IDD Nursing

A competent level of IDD nursing care is demonstrated by the nursing process which includes assessment, diagnosis, outcomes identification, planning, implementation, and evaluation. Consistent with the ANA scope and standards of practice for nurses (2015a), IDD registered nurses engage in the nursing process which is the foundation of the nurse's decision-making.

STANDARD 1. ASSESSMENT
The IDD registered nurse collects data related to the health and/or the situation of the person with IDD.

STANDARD 2. DIAGNOSIS
The IDD registered nurse analyzes the assessment data to determine the actual or potential diagnoses, problems and issues of the healthcare consumer with IDD.

STANDARD 3. OUTCOMES IDENTIFICATION
The IDD registered nurse identifies expected outcomes for a plan that is individualized to the healthcare consumer with IDD and/or the situation.

STANDARD 4. PLANNING
The IDD registered nurse develops a plan that prescribes strategies and alternatives to reach expected measurable outcomes.

STANDARD 5. IMPLEMENTATION
The IDD registered nurse implements the identified plan.

STANDARD 5A. COORDINATION OF CARE
The IDD registered nurse coordinates care delivery that requires the nurse to work closely with individuals with IDD, families, community resources and health systems.

STANDARD 5B. HEALTH TEACHING AND HEALTH PROMOTION
The IDD registered nurse uses strategies to promote health, prevention of secondary disability, and a safe environment of individuals with IDD.

STANDARD 6. EVALUATION
The IDD registered nurse evaluates progress toward attainment of goals and outcomes of individuals with IDD and their families.

Standards of Professional Performance in IDD Nursing

The Standards of Professional Performance which describe a competent level of behavior for all registered nurses in their role as a professional nurse apply equally to all IDD registered nurses in their professional role activities. IDD registered nurses are expected to engage in professional role activities that are appropriate to and consistent with their education and their position. As with all registered nurses IDD registered nurses are accountable for their professional behavior to themselves, healthcare consumers with IDD families/legal guardians of healthcare consumers with IDD, their professional peers, and society (ANA, 2015a).

STANDARD 7. ETHICS
The IDD registered nurse practices ethically.

STANDARD 8. CULTURALLY CONGRUENT PRACTICE
The IDD registered nurse engages in practice that is congruent with cultural diversity and inclusion principles, specifically as related to healthcare consumers with IDD and their families/legal guardians.

STANDARD 9. COMMUNICATION
The IDD registered nurse communicates effectively in a variety of formats in all areas of practice.

STANDARD 10. COLLABORATION
The IDD registered nurse collaborates with healthcare consumers with IDD, their families/legal guardians, and other key stakeholders while engaging in nursing practice.

STANDARD 11. LEADERSHIP
The IDD registered nurse demonstrates leadership in professional practice settings and the profession.

STANDARD 12. EDUCATION
The IDD registered nurse acquires knowledge and attains competence that reflect current nursing practice and promote futuristic thinking.

STANDARD 13. EVIDENCE-BASED PRACTICE AND RESEARCH
The IDD registered nurse IDD integrates relevant and current evidence and research findings into practice.

STANDARD 14. QUALITY OF PRACTICE
The IDD registered nurse contributes to quality nursing practice.

STANDARD 15. PROFESSIONAL PRACTICE EVALUATION
The IDD registered nurse evaluates one's own and others' nursing practice.

STANDARD 16. RESOURCE UTILIZATION
The IDD registered nurse utilizes appropriate resources to plan, provide, and sustain evidence-based nursing services that are safe, effective, and fiscally responsible.

STANDARD 17. ENVIRONMENTAL HEALTH
The IDD registered nurse practices in an environmentally safe and healthy manner that promotes environmentally safe settings that are beneficial to the health and well-being of individuals with IDD.

The Function of Competencies in IDD Nursing Standards

The competencies accompanying each standard may be evidence of the IDD nurse's demonstrated compliance with the corresponding standard; however, this list of competencies is not exhaustive. The application of a particular standard or competency depends on the circumstances (ANA, 2015a).

Integrating the Science and Art of IDD Nursing

Like the profession of nursing, the nursing specialty of IDD is built on a core body of knowledge that reflects its components of science and art. Nursing in IDD requires judgment and skill based on biological, physical, behavioral, and social sciences. Nurses use critical thinking to apply the best available evidence and research data when responding to the needs of individuals with IDD, evaluating

the quality and effectiveness of nursing practice and seeking to optimize outcomes for individuals with IDD and their families/legal guardian(s) (ANA, 2015a).

Consistent with the profession of nursing, IDD nursing promotes the delivery of holistic care that is centered on individuals with IDD and their families/legal guardians with the goals of optimal health outcomes through the lifespan and across the health–illness continuum. This occurs in an environmental context that acknowledges culture, ethics, law, politics, economics, access to healthcare resources, and competing priorities. Similarly, IDD nursing promotes the health of communities by using advocacy for social and environmental justice, community engagement, and access to high-quality and equitable health care to maximize population health outcomes and minimize health disparities. IDD nursing advocates for the well-being, comfort, dignity, and humanity of all individuals, families, groups, communities, and populations. IDD nursing focuses on healthcare consumer and interprofessional collaboration, sharing of knowledge, scientific discovery, and social welfare.

The What and How of IDD Nursing

What Is IDD Nursing?

IDD nursing is based on the definition of nursing which includes "…*the protection, promotion, and optimization of health and abilities, prevention of illness and injury, facilitation of healing, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, groups, communities, and populations"* (ANA, 2015, p.11). **IDD nursing is defined as protecting, promoting, and optimizing the health and functioning ability of persons with IDD; diagnosing and treating persons with IDD to alleviate discomfort and suffering; and advocating for and with persons with IDD and their families within and across groups, communities, and society.**

The integration of the art and science of nursing is described in the following detailed scope and standards of practice content. IDD nurses have a strong foundation of knowledge and skills related to the IDD diagnoses, treatments for IDD, and the provision of health care that is unique to persons with IDD across their lifetimes. Additionally, IDD nurses understand child and adult development (normal and delayed) as individuals with IDD have a condition that interferes with their ability to experience the typical patterns of human development that affect their ability to learn and process information. The person's developmental level may vary in terms of communication skills, ability to comprehend and reason, and their life experiences that contribute to their differing responses. Individuals with IDD learn differently than typically developing individuals. IDD nurses adapt healthcare procedures and processes to meet the needs of persons with IDD and their families. These individuals may have a broad range of cognitive and behavioral challenges that need to be understood and treated with respect by all healthcare providers. For example, the IDD nurse helps individuals with IDD feel comfortable when they are fearful during a medical examination or procedure. They may be fearful of being harmed that is a different reaction as compared to typically developing individuals. IDD nurses also understand behavioral challenges associated with IDD and know how to intervene appropriately so as not to escalate challenges behaviors. The IDD nurse knows when to refer to specialized services such as GYN and dental services needed.

IDD nurses are members of a healthcare team focused on the provision of interprofessional services that are comprehensive in scope, as individual healthcare providers alone cannot assess, manage or evaluate the full breadth of needs of the person with IDD. As a member of the IDD team, the nurse plans and coordinates care with the individual, family and interdisciplinary providers. These interprofessional providers include advocates, dieticians, occupational and physical therapists, primary and specialty care

physicians, social workers, special educators, speech and language specialists, who address the ongoing and long-term needs of the individual and family members. IDD nurses understand and value each profession's contribution to assessment, treatment and evaluation of the outcomes of a person with IDD, with the family and individual at the center of any interprofessional evaluation or treatment.

Advanced advocacy skills and greater knowledge of resources is needed to ensure that persons with IDD have their health needs identified, met, and move toward optimal health. Values such as respect of self and others, individual dignity, and having personal choices are critical for persons with IDD to promote their access to high quality health care. IDD nurses support individuals with the dignity of taking risk in making choices pertaining to their health and other lifestyle decisions.

The advocacy role in IDD nursing practice is essential, as individuals with IDD and their families can face extraordinary challenges in accessing health care and other services. IDD nurses advocate for the health and well-being of persons with IDD and encourage persons with IDD and their families to advocate in policy arenas for their health and a healthy environment. IDD nurses also advocate for policies that promote healthy environments for those with IDD.

IDD nurses assess, implement and evaluate plans that keep those with IDD safe and connected appropriately to medical care, health services (particularly specialty care as they transition to adult care), and resources in the community including transportation, accessible and affordable housing, and adequate food to live life to the fullest.

Five tenets characterize contemporary nursing practice **(ANA, 2015a),** and these are described here for the IDD nurse.

Tenets Characteristic of IDD Nursing Practice

1. Caring relationships and health promotion are central to the practice of the IDD registered nurse.

The key focus of IDD nursing is caring for healthcare consumers with IDD, their families/legal guardian(s), communities, and populations. A philosophy of family-centered care is the basis of IDD nursing practice and evolves to an individual-centered philosophy of care in which the family and individual with IDD (when appropriate) become full partners in health promotion.

2. IDD registered nursing practice is individualized.

IDD registered nurses individualize their care, respecting the diverse and unique needs of healthcare consumers with IDD. The healthcare consumers with IDD are broadly defined as patients, persons, clients, families/legal guardians, groups, communities, or populations with IDD who are the focus of the IDD registered nurse's attention and to whom they provide services as approved by the state regulatory bodies.

3. IDD registered nurses utilize the nursing process to plan and provide individualized care to healthcare consumers with IDD.

When assessing, diagnosing, identifying outcomes, planning, implementing, and evaluating care, IDD registered nurses use their knowledge of human experiences and responses, human development, and health conditions and diagnoses that result in IDD to collaborate with healthcare consumers with IDD

and their families. The intent of IDD nursing interventions is to produce beneficial effects, contribute to quality outcomes, and—above all—do no harm. IDD registered nurses evaluate the effectiveness of their care in relation to identified outcomes and use evidence-based practice to improve care.

4. IDD registered nurses coordinate care by establishing partnerships.

The IDD registered nurses establish partnerships with persons with IDD, their families/legal guardian(s) and support systems, and other providers to meet the health needs of persons with IDD and their families. IDD nurses use communication methods that facilitate delivery of health care and meeting health needs. IDD nurses recognize, understand, and respect the contributions and value of each discipline's contribution to the health outcomes of persons with IDD.

5. A strong link exists between the professional work environment and the IDD registered nurse's ability to provide persons with IDD quality health care and achieve optimal health outcomes.

IDD registered nurses have an ethical obligation to maintain and improve healthcare practice environments conducive to the provision of quality health care (ANA, 2015b**).** Healthcare practice environments should be safe, accessible, and facilitate participation by persons with IDD in their health care to the fullest extent possible. When work environments do not support the provision of quality health care and full participation by persons with IDD in their care, nurses will work to improve and advocate for improved healthcare practice environments.

The How of Nursing

The "how" of nursing practice is defined as the ways, means, methods, processes, and manner by which the registered nurse practices professionally. The ways in which registered nurses practice reflect integration of the five core practice competencies of all healthcare professionals: healthcare consumer-centered practice, evidence-based practice, interprofessional collaboration, use of informatics, and continuous quality improvement (ANA, 2015a; Institute of Medicine, 2003). Registered nurses recognize that using a holistic approach requires incorporation of all relevant data when implementing the nursing process. Such applies to the registered nurse specializing in IDD.

When incorporating a healthcare consumer and/or family-centered approach, the registered nurse who specializes in IDD collaborates with and treats all healthcare consumers with the utmost respect. The registered nurse demonstrates culturally congruent practice and advocates that healthcare consumers have sufficient information and questions answered, enabling them to exercise their autonomy to make the final decisions regarding their preferred care.

To achieve the best healthcare consumer outcomes, the "how" requires the registered nurse who specializes in IDD to employ evidence-based practice as a means to incorporate the best available evidence, healthcare consumer preferences, provider expertise, and contextual resources in which nursing is delivered. Closely linked to the best healthcare consumer outcomes is the need for effective interprofessional collaboration. Thus, an essential component of the "how" of registered nursing is care coordination (ANA, 2013a), requiring effective communications by all stakeholders.

Additionally, the "how" of registered nursing practice includes predictable and comprehensive communication using approaches such as informatics, electronic health records, and established system

processes to prevent errors. Methods may include SBAR or situation, background, assessment, and recommendation (The Joint Commission Enterprise, 2012) and evidence-based methods of teamwork and communication skill building such as TeamSTEPPS (Agency for Healthcare Research and Quality, n.d.; ANA, 2015a; Department of Defense, 2014).

Critical to the practice of professional nursing is ethical conduct of research to generate new knowledge and translate that knowledge to practice using theory-driven approaches (Estabrooks, Thompson, Lovely, & Hofmeyer, 2006). Finally, the "how" of registered nursing practice reflects the manner in which the registered nurse who specializes in IDD practices according to the *Code of Ethics for Nurses with Interpretive Statements*, standards for professional nursing practice, institutional review boards' protocols, and directives of other governing and regulatory bodies that guide the conduct of professional nursing practice (ANA, 2015a).

The ethical conduct of research that generates new knowledge and the translation of knowledge into practice using theory-driven approaches are critical to professional nursing practice (Estabrooks, Thompson, Lovely, & Hofmeyer, 2006). The *Code of Ethics for Nurses with Interpretive Statements*, standards for professional nursing practice, institutional review boards' protocols, and directives of governing and regulatory bodies guide the "how" of registered nursing practice (ANA, 2015a).

Nursing's *Social Policy Statement: The Essence of the Profession* identifies the following statements that undergird professional nursing's social contract with society and includes the registered nurse and advanced practice registered nurse who specializes in IDD (ANA, 2010, p. 6):

- Humans manifest an essential unity of mind, body, and spirit.
- Human experience is contextually and culturally defined.
- Health and illness are human experiences. The presence of illness does not preclude health, nor does optimal health preclude illness.
- The relationship between the nurse and patient occurs within the context of the values and beliefs of the patient and nurse.
- Public policy and the healthcare delivery system influence the health and well-being of society and professional nursing.
- Individual responsibility and interprofessional involvement are essential.

Consult Nursing's *Social Policy Statement* (ANA, 2010) for discussion of other content important to understanding the societal context related to the decision-making and conduct of professional nursing practice.

The Art of Nursing

Nurses who specialize in IDD value all persons and believe that everyone, regardless of their abilities or limitations, deserve access to care and the highest quality of care. Nurses provide compassionate and competent patient care to individuals of all ages with IDD in a variety of settings. Nurses collaborate with individuals with IDD and their families/legal guardian(s) along with interprofessional colleagues and other stakeholders as necessary to meet or help meet the needs of individuals with IDD using a patient-centered care model.

Optimal health for persons with IDD requires a holistic, caring, culturally sensitive, and interprofessional approach. IDD nurses possess unique skills in their comprehensive care of persons with IDD and their

families/legal guardian(s). These skills include sustaining long-term relationships based on trust, communicating through verbal and nonverbal avenues, handling unpredictable behavior and situations, developing plans of care that are both short- and long-term, and including a variety of individuals and disciplines in planning such care (Appelgren, Bahtsevani, Persson, & Borglin, 2018; Jaques, Lewis, O'Reilly, Wiese, & Wilson, 2018). Specifically, the nurse must be able to communicate effectively with individuals with IDD who may have difficulty communicating through usual written or verbal channels and understand and interpret the signs and cues sent by individuals with IDD to communicate their needs and desires.

Nursing in IDD aims to modify the relationships between individuals with IDD and their environments as needed to protect, promote, and optimize their health, healthy patterns of living, and quality of life**.** Nurses specializing in IDD employ practices that are promotive, supportive, and restorative in nature. Nurses are also involved in the facilitation of healing, alleviation of suffering; and transition to a dignified and peaceful death for a person with IDD.

Because nursing includes the diagnosis and treatment of human responses to actual or potential health problems and/or comorbid disabilities, nurses focus on modifying the impact of illness and/or disease on individuals with IDD and aim to prevent further disability. When individuals with IDD have a disease and illness, nurses should be careful to distinguish signs and symptoms of the disease and/or illness from characteristics of the disability. This is especially important when an individual's disability manifests in ways that are similar to a disease or illness. When planning and implementing care, nurses may have opportunities to develop innovative and creative approaches to assure optimal and positive outcomes for the individual with IDD and his or her family/legal guardian(s).

Care and Caring in IDD Nursing Practice

The relationship between the nurse, the person with IDD, and their family/legal guardian(s) builds on a bond that is usually long-term, based on verbal and non-verbal communication, and mutual respect recognizing strengths while helping to optimize limitations. Nurses support the right of individuals with IDD to self-determination. That is, individuals with IDD have opportunities and experiences that enable them to have control in their lives and to advocate for themselves [American Association on Intellectual and Developmental Disabilities (AAIDD) Board of Directors, The Arc of the United States (ARC) Board of Directors, & Chapters of the Arc, 2018]. Individuals with IDD learn skills and have experiences that facilitate personal control over their health and lead to healthy choices. As self-advocates, individuals with IDD should be heard, respected, and supported to fully participate in their own health care. Nurses work to assure that individuals with IDD and their families/legal guardian(s) have the knowledge and skills to engage in informed decision-making about health. Family members and substitute decision-makers may need assistance in understanding the importance of self-determination and the limits that self-determination can place on their own authority to make decisions, with and for the individual with IDD.

Nurses (a) believe in individuals with IDD and their abilities to meet developmental and lifespan milestones, (b) work to understand the meaning of health and health-related events from the perspective of individuals with IDD and their families/legal guardian(s), (c) are emotionally present for individuals with IDD and their families/legal guardians, (d) carry out health-related activities and tasks for individuals with IDD and their families/legal guardian(s) when these persons cannot carry out these activities and tasks themselves, and (e) support and facilitate transitions and unpredictable events experienced by individuals with IDD and their families/legal guardian(s). Although persons with IDD

experience symptoms and experiences unique to their diagnosis and require specialized care, nursing care often requires normal, age-related preventive care that is individualized for their special needs for adaptation and accommodations.

Nurses should be mindful that the experiences of individuals with IDD in society may be those of oppression and limitations on their ability to fully participate in their communities and be treated equally. Health services such as routine gynecological care, mammograms, and preventive and therapeutic dental services should be accessible to individuals with IDD. There should be a balance between under-treatment – the limitations of treatment based on IDD diagnosis – and overtreatment – the unwillingness to recognize when treatment is no longer beneficial. Nurses may have advocacy and educator roles in the decision-making process with the individual with IDD, if capable; the family, if appropriate; and others involved in the individual's care.

Advances in assistive and medical technology contribute to improved health, functioning ability, and quality of life in individuals with IDD. Assistive technology should benefit individuals with IDD by improving their independence, mobility, communication, and ability to control their environments (AAIDD, Arc, and Chapters of The Arc, 2018). Medical technology should be directed toward improving the quality of life and relieving pain, isolation, fear, and physical discomforts. Individuals with IDD should have the opportunity to accept or refuse services after they have been provided information and assisted to understand the risks and benefits of services. When information cannot be provided in a way that takes into account the communication and/or cognitive limitations of the individual with IDD to ensure informed consent, then the individual's advocate (i.e., legal guardian(s), health care power of attorney, or surrogate decision maker) should be involved to assure that the individual's demonstrations of acceptance or refusal are respected and followed (AAIDD, Arc, and Chapters of The Arc, 2018; Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, 2018). Nurses should advocate for a careful evaluation of the benefits and risks of a proposed treatment for an individual with or at risk for IDD and not accept a categorical denial or plan to institute treatment based on another's estimation of the quality of life of the individual with or at risk for IDD.

Genetic and genomic advances promise both gains for and threats to individuals with IDD. Sometime in the future, the basis for IDD may be identified and eventually "treated" with gene therapy. If this technology evolves, there may be social pressure to submit to the treatment to ameliorate or eliminate the disability, and even less tolerance for the spectrum of human difference. Some assume that if a prenatal disability is detected, the mother (or parents) will choose to terminate the pregnancy. Nurses respect the autonomous decisions of the mother but also grant that the mother's decision may be influenced by society's response to individuals with IDD and tolerance for difference.

The IDD nurse must have advanced assessment skills to correctly identify issues related to the individual with IDD's health, chronological and mental age development in all domains, social relationships, and activities of daily living. Such assessments are used for short- and long-term care planning and implementation, regular evaluations, and consequent adjustments. Creativity, adaptations, patience, and involvement from the individual with IDD, their family/legal guardian(s), and other disciplines are required for optimal outcomes.

It is also important to note that nurses who specialize in this population are often stigmatized themselves. Such misunderstanding comes from other nurses not involved in this specialty and even other professionals in the field. Having a network of nurses working in the field through formal and informal means is helpful for support and consultative input on difficult care situations.

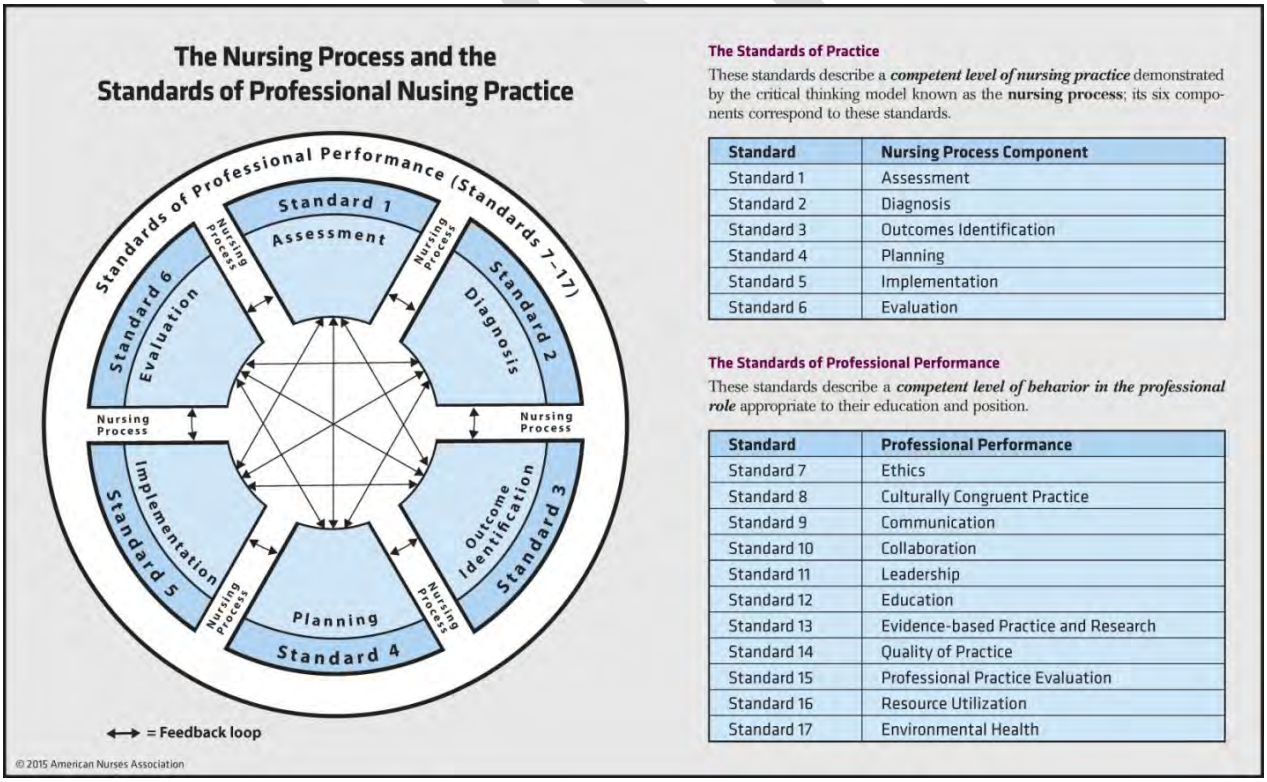
Cultural Components of Care

The nurse provides care to individuals with IDD and their families/legal guardian(s) in a manner that reflects sensitivity to culture and varied expressions of care among all forms and types of cultures (Leininger, 1988) and supports the implementation of caring processes built on Watson's framework (2012). Persons with IDD are a minority culture in which positive and negative behaviors and opinions are found by other persons and cultures, and these have existed across time. Our understanding of cultural literacy must go beyond race, and encompass all forms of culture, including persons with IDD.

The Science of Nursing

Both qualitative and quantitative research has been conducted to identify and describe conditions resulting in IDD, to detail best practices in the treatment of primary and comorbid conditions across the lifespan, and to develop policy and procedures for optimal care of persons with IDD. Nurses have been involved in such research over the years through their own original studies as well as the translation of research findings in their practice.

Nurses use the nursing process in their care of persons with IDD. The six stages of assessment, diagnosis, outcomes identification, planning, implementation, and evaluation are illustrated in Figure 1. As noted in the figure, this process is dynamic and cyclic.



The Standards of Practice

These standards describe a ***competent level of nursing practice*** demonstrated by the critical thinking model known as the **nursing process**; its six components correspond to these standards.

Standard	Nursing Process Component
Standard 1	Assessment
Standard 2	Diagnosis
Standard 3	Outcomes Identification
Standard 4	Planning
Standard 5	Implementation
Standard 6	Evaluation

The Standards of Professional Performance

These standards describe a ***competent level of behavior in the professional role*** appropriate to their education and position.

Standard	Professional Performance
Standard 7	Ethics
Standard 8	Culturally Congruent Practice
Standard 9	Communication
Standard 10	Collaboration
Standard 11	Leadership
Standard 12	Education
Standard 13	Evidence-based Practice and Research
Standard 14	Quality of Practice
Standard 15	Professional Practice Evaluation
Standard 16	Resource Utilization
Standard 17	Environmental Health

There are two sets of standards represented in this figure: Standards of Practice and Standards of Professional Performance. The Standards of Practice are aligned with the six steps of the nursing process. The Standards of Professional Performance are evident across the nursing process and the

nurse's practice. As both sets of standards are universal to nursing practice, they will be specified in this document for the nurse specializing in IDD.

When Nursing Occurs

The nursing care of persons with IDD takes place in all settings in which nurses are employed. The settings in which nurses often interact with persons with IDD are in various healthcare settings, school-based settings, community-based facilities, work sites, and large regional developmental centers. The relationships between the nurse and the person with IDD often last many years.

The health care needs of persons with IDD may not correlate with the normal population as far as typical developmental and physiological changes. Brown (2016) provides an excellent discussion of the nurse's role and knowledge base in IDD nursing. She focuses on the nurse's primary functions of prevention; continual assessment, care, and evaluation of health needs; and coordination of services and supports across the lifespan. Brown discusses the nurse's need to deliver care and education and always be an advocate for the individual with IDD and their family members/legal guardians. The roles and responsibilities of IDD nurses were discussed in two recent literature reviews (Appelgren, Bahtsevani, Persson, & Borglin, 2018; Jaques, Lewis, O'Reilly, Wiese, & Wilson, 2018). The major distinctions between the care of persons with IDD and those without concerned communication; person-centered comprehensive care; long-term relationships; caring for physical, intellectual, and behavioral issues; advocacy; and stigmatization.

The care of persons with IDD is retrospective, current, and prospective and should involve the person with IDD, their family/legal guardian(s), and an interprofessional team. The membership of the team will change as the person with IDD ages or moves. It is a commitment across the person's lifespan to anticipate needs and problems, reduce or eliminate problems in the present time, and regularly evaluate identified needs and problems retrospectively in order to better address such needs and problems in the future. Everyone is an individual and not all solutions are uniform. In this population, state and national legal and ethical ramifications for care, including education, work, and residential must be considered. It is important that anticipatory guidance is identified and described across the lifespan for conditions resulting in IDD. Much is known about these conditions during the pediatric years, but less is known and documented in the literature for the adult years and at end-of-life.

IDD Nursing Knowledge

IDD nursing knowledge is best described through a historical perspective. This section provides a summary of the history of education of nurses and nursing care in this specialty.

Early education for nurses who specialized in the care of persons of any age who had IDD occurred in general nursing hospital schools and in asylums and institutions; however, the term IDD was not used until the mid-20th century. Until the early 20th century, persons with IDD were diagnosed as having mental illness and their care took place in settings where persons with all forms of mental illness were housed. After WWI a better understanding of mental illness occurred, and the care of persons with IDD as we now know it was more specifically detailed. Terminology at that time included *idiot* and *imbecile.*

In the early 1960s, President Kennedy brought needed attention to the living conditions of persons of all ages with IDD, then called *mental retardation*. New legislation was introduced, and for the first time, funding became available for this population. Large institutional settings remained the primary place of

residence for persons of all ages with IDD until the late 1960s. It was the social norm to place newborns and children with known conditions resulting in IDD in institutions as soon as possible so as not to burden families, either financially or through social stigma.

After public attention to the custodial and often inhumane care of persons with IDD in the early 1970s, radical changes took place. Many individuals with IDD were moved back to their homes and to newly formed community settings, such as group homes, semi- independent living arrangements (SILAs), and smaller congregate settings (e.g.,16 beds). The transition from institutional to community living continues to vary, state by state.

Today, newborns with IDD are no longer placed in institutional settings. Most individuals with IDD live with their families in the community. Others live in small-group community settings. Only the most severely affected individuals who require substantial medical care remain in larger developmental centers (Nehring, 1999; Nehring & Lindsey, 2016).

IDD nursing care has also evolved through time. Early documentation about nursing care was written either by physicians or nurses who cared for both persons with IDD and mental illness. Literature by nurses about the nursing care of persons with IDD first appeared with any frequency in the 1950s. At that time, nurses in institutional settings did little more than give medications and record vital signs and occasional weights. Some public health nurses provided care for children with IDD who remained at home; however, parents were often encouraged to enroll their children in institutions by the time they reached school age.

The first national meeting for nurses specializing in the care of children with IDD was sponsored by the Children's Bureau in 1958 (Nehring, 2010). In the 1960s, nursing care in the institution resembled nursing care provided in hospitals. The role of the nurse expanded to include education and research. Advanced practice registered nurses were employed by some institutions, and post-baccalaureate and graduate programs emerged to provide education designed especially for the care of children and adolescents with IDD. Interdisciplinary faculty (including nurses) at university-affiliated programs and facilities (UAPs or UAFs) established by President Kennedy in universities across the country, offered interdisciplinary education to future specialists (including nurses) in the field; conducted research on topics related to mental retardation; and provided health and social services to individuals with IDD and their families.

In the 1960s, nurses began to write more prolifically about the care of children with IDD conditions. The increased numbers of articles and books, some of which are now considered classics, were especially useful for public health nurses. Developmental diagnostic clinics were established across the country to identify and refer children with IDD for developmental and health care when appropriate. Nursing consultants who specialized in this field were hired by the Children's Bureau; Division of Neurological Diseases and Stroke, U.S. Public Health Service; Mental Retardation Division, Department of Health, Education, and Welfare; Association of Retarded Children; and the United Cerebral Palsy Associations, Inc. National meetings were convened for these nursing specialists and the first standards of nursing practice for this specialty emerged in 1968, *The Guidelines for Nursing Standards in Residential Centers for the Mentally Retarded* (Haynes, 1968; Nehring,1999, 2010).

The 1970s saw the first national education legislation, mandating that all children with IDD receive a free and appropriate public education from the ages of 3 through 21 years. During that period, school nurses sought education and resources about IDD nursing, and IDD nursing was soon included in the Scope and

Standards of Practice for school nursing. Advanced practice roles for nurses in the IDD specialty continued to expand, including roles in schools and early intervention programs for the infant from birth to three years of age.

Publications and regular national and regional meetings about IDD nursing continued throughout the 1970s. Special IDD nursing courses also began to appear in nursing programs across the country (Hahn, 2003; Nehring, 1999, 2010). The term *developmental disabilities* were first introduced during the Nixon presidency to describe conditions similar to those defined as mental retardation but that differed slightly. Interdisciplinary care was the norm in the 1980s, when all disciplines worked together with individuals and family members of those with IDD to assess and plan care in a variety of settings (Nehring, 1999; Nehring & Lindsey, 2016). In 1980, the American Nurses Association published *School Nurses Working with Handicapped Children* (Igoe, Green, Heim, Licata, MacDonough, & McHugh, 1980). Later in the 1980s, two sets of standards of nursing practice for nurses specializing in this field emerged: *Standards of Nursing Practice in Mental Retardation/Developmental Disabilities* (Aggen & Moore, 1984) and *Standards for the Clinical Advanced Practice Registered Nurse in Developmental Disabilities/Handicapping Conditions* (Austin, Challela, Huber, Sciarillo, & Stade, 1987).

Emphasis on the adult with IDD emerged in the nursing literature in the 1990s. An examination of the individual with IDD across the lifespan was first highlighted in *A Life-Span Approach to Nursing Care for Individuals with Developmental Disabilities* (Roth & Morse,1994). Nursing standards for this field were also revised: *Standards of Developmental Disabilities Nursing Practice* (Aggen, DeGennaro, Fox, Hahn, Logan, & VonFumetti, 1995) and *Statement on the Scope and Standards for the Nurse Who Specializes in Developmental Disabilities and/or Mental Retardation* (Nursing Division of the American Association on Mental Retardation and American Nurses Association, 1998). Other related standards of nursing practice in early intervention (ANA Consensus Committee, 1993), care of children and adolescents with special health and developmental needs (ANA Consensus Committee, 1994), and genetics (ISONG & ANA, 1998) were issued as well.

In the first years of the 21st century, a greater effort was made to provide educational materials for nursing students and nurses in practice who care for persons of all ages with IDD (Betz & Sawin, 2018; Hahn, 2003; Nehring, 2005). However, IDD nursing remains an area where nursing students in general receive little information about or clinical experience with persons who have IDD. Concentrated efforts by nursing experts in the field and national organizations, such as the American Association on Intellectual and Developmental Disabilities and the Developmental Disabilities Nurses Association, to establish standards for IDD nursing education, should persist.

This specialty field of nursing has changed greatly from its early years. As the healthcare system continues to evolve, so will the nursing care of persons with IDD of all ages. Such care continues to occur in a variety of settings and at both the professional registered nurse and advanced practice registered nurse levels. Continued publication and research into such nursing care are needed, as are additional didactic and clinical content materials for nursing students.

Research in IDD Nursing

Nurses have faced a myriad of challenges in researching the IDD population over the years that include societal changes, laws affecting education, Institutional Review Board approval for this vulnerable population, and research expertise in those nurses working in the field. These factors have resulted in difficulty in obtaining data for the development of evidence-based IDD nursing interventions. There is

clearly a need for consistent nursing education, nursing management, and more research in the field of IDD nursing (Auberry, 2018).

There have been champions of IDD healthcare who have accomplished research in the field, which IDD nurses can use base future research. Dorothea Dix is thought to be the first leader in IDD nursing. Although Dix was not a nurse, she is viewed by many as being instrumental in the development of IDD, public health, and mental health nursing (Nehring, 1999). Using her careful observations of the living conditions of individuals with IDD, Dix made many appeals for more hygienic buildings for individuals with IDD and mental illness, and some of her efforts met with success (Dix, 1847). For example, she spoke to the Massachusetts legislature in 1843 about the conditions of jails, asylums, and almshouses in Massachusetts (Dix, 1976). Consistent with Florence Nightingale's call for nurses to use their observations to bring about change (Nightingale, 1859), Dix used her observations to inform and influence legislators to improve the living conditions of individuals with IDD (Nehring, 1999; 2010).

In the 1960s, nurses began conducting and publishing their research about individuals with IDD. These early nurse researchers relied on models, research findings, and/or research methods from the fields of education, medicine, physical therapy, cognitive and developmental psychology, psychiatry, public health, speech therapy, and sociology. Miller (1979) described a program that was implemented from 1962 through 1964 to teach personnel in the Central Wisconsin Colony and Training School to provide speech and physical therapy to residents. Pat McNelly (1966) conducted a study that "was a precursor to the development of the transdisciplinary model of care delivery" (Nehring,1999, p. 79). A cross-disciplinary project, the Mimosa Project, was funded to teach adolescent girls with IDD daily living skills (Devine,1983). Barclay, Goulet, Holtgrewe, and Sharp (1962) examined parents' evaluations of the clinic services provided to their children with IDD. By 1970, many studies related to IDD had been or were being carried out by nurses, and graduate students in nursing programs were focusing their dissertation research on IDD. Between 1970 and 2019, more than 200 nursing dissertations related to IDD were completed.

Nurses contribute to research and scholarly work related to IDD across the lifespan. Two nurses who are well recognized for their work in developmental disabilities focused their work on infants and children with or at risk for IDD. Una H. Haynes, a committed nurse who made many contributions to the field of developmental disabilities, was on the national staff team of the United Cerebral Palsy Associations, Inc. and is credited with developing the transdisciplinary approach to early intervention for infants with developmental disabilities (Haynes, 1974). Kathryn Barnard began her work with children with IDD (Barnard, 1966, 1968). She developed the Nursing Child Assessment Satellite Training (NCAST) and was an advocate for prevention in nursing and mental health. Scales that have been widely used to assess parent–infant interactions (Sumner & Spietz, 1994). A third nurse, Cecily Betz, has dedicated her life work to the conceptual understanding of transitions in care for persons with IDD (e.g., Betz. Nehring, & Lobo, 2015; Mahan, Betz, Okumura, & Ferris, 2017).

Evidence Based Practice in IDD Nursing

Just as nursing research has evolved and developed across the profession, nursing research in IDD has evolved and continues its development, including an emphasis on evidence-based practice. Quantitative, qualitative, and mixed-methods studies are conducted across the lifespan using nursing and non-nursing theories. Nurses working in the field of IDD have long recognized the importance of interprofessional collaboration in practice. Likewise, interprofessional collaboration is essential for many nursing research activities, including the identification and implementation of evidence-based practice

related to IDD.

Nurse researchers have focused their research on specific conditions that result in or are associated with IDD, roles and responsibilities of nurses working in this field, families/legal guardians and family-centered care, and education of nurses and others about IDD. Nehring (1999) called for research that (a) evaluates programs and services provided to individuals with IDD; (b) examines adult health care, adult development, and the educational needs of caregivers across the lifespan of individuals with IDD; (c) explores issues related to genetics; and (d) explores the perspectives of individuals with IDD and their families/legal guardians that need to be addressed by nurses. Such research remains relevant, as Betz and Sawin (2018) echoed these research needs and added better understanding and practice models for care coordination across the lifespan. In addition, new challenges related to the complexities of health care and demands for healthcare reform also require attention. For example, the National Association of School Nurses has published evidence-based position statements related to children with special healthcare needs (e.g., *Chronic Health Conditions (Students with): The Role of the School Nurse,* 2017; *The Role of the 21st Century School Nurse,* 2018; and *Transition Planning for Students with Chronic Health Conditions,* 2014). Nurse researchers should examine nursing practice in IDD to demonstrate that staffing is adequate to ensure quality care for individuals with IDD and their families/legal guardians. Consistent with the call for continual evaluation of nursing practice, as stated in Nursing's *The Code of Ethics for Nurses with Interpretive Statements* (ANA, 2015), ongoing evaluation of patient outcomes and learning needs of nurses working with individuals with IDD and their families/legal guardians, and dissemination of information to address these outcomes and needs, are critical.

The Where of Nursing Practice

Nurses care for persons of all ages with IDD in any environment or setting. A few salient examples follow to illustrate the breath of settings and environments. By the1950s, many infants born with an intellectual and/or developmental disability were institutionalized. Many times, the mother was told that her newborn had died since she was unconscious during birth and the father signed away the parental rights and kept the secret. With deinstitutionalization and federal and state law changes beginning in the 1960s and 1970s, infants and children with IDD stayed at home and were able to attend school. Today, home health care, school-based care, post-acute care, assisted living and long-term care facilities, and community-based living, faith communities, outpatient, and ambulatory settings are standard settings for care, yet developmental centers for individuals with severe IDD still exist. The care of persons with IDD in each of these settings require the services of nurses. This evolution has greater importance as transitions in care, cost reduction measures, financial penalties for adverse outcomes, and healthcare reform initiatives materialize.

Nurses specializing in IDD may be employed in colleges and universities as faculty or practicing nurses, nurse practitioners, or administrators of nurse-managed clinics or school health centers. There is a scarcity of nursing faculty and scholars with IDD as their area of expertise and scholarship focus**.** When present, they are often employed at universities that are designated as University Centers of Excellence in Developmental Disabilities (UCEDD).

Technological advances for persons with IDD have allowed them to live more integrated lives and provide another area where nurses can use entrepreneurial skills in new roles. Nurses will play active roles in accessing needed technology for their patients, adapting it for their optimal use, evaluating it for continued use, and developing their own ideas for use by persons with IDD.

The IDD nurse plays an active advocacy role in the facilitation of full integration of persons with IDD into all aspects of community and residential settings to their optimal level of functioning**.** Advocacy and a commitment to community integration with optimal individual functioning are key characteristics of nurses working on behalf of people with IDD and their families/legal guardians. From advocacy with legislatures at the state and national levels to individual advocacy supporting choice and self-determination for the individual with IDD, nurses in the specialty are passionate about the population and about achieving social justice for them. Assisting an individual with IDD to transition from an institutional setting into a less restrictive setting, such as their own home or a supervised apartment or group home; to obtain quality health care, identifying and responding to allegations of abuse; and aiding in healthcare decision-making by supporting the individual or identifying a surrogate are all crucial areas for advocacy intervention.

Though there are many challenges in the care of persons of all ages with IDD, such as communication difficulties, multiple comorbid conditions, public ignorance, and societal prejudice, there are also many rewards. Learning about and working with this population, for whom significant health disparities have only recently been identified, can enlighten and add meaning to nursing practice and personal life. Nurses learn to appreciate individual strengths and assist the individuals to cope and function in spite of their limitations while caring for preventive and specific health needs.

Healthy Work Environments for Nursing Practice

Characteristics of IDD Nursing Practice Tenet #5 explicitly states that "a strong link exists between professional work environment and the IDD registered nurse's ability to provide quality health care and achieve optimal outcomes" (Nehring et al. 2013). The ANA Scope and Standards of Practice 3rd Edition, states that "all must be mindful of the health and safety of both the healthcare consumer and the healthcare worker in any setting, providing a sense of safety, respect, and empowerment to and for all persons" (2015, p. 27). Several models of healthy work environments have been recognized and supported by the ANA. These models are universal and can be adapted to IDD nursing practice.

Safe Patient Handling and Mobility (SPHM)

Individuals with intellectual disability possess various levels of thinking, reasoning, planning, and problem solving placing them at greater risk for safety issues. IDD nurses must be equipped to identify and mange potential harmful situations for both the individual with IDD and the nursing staff. Safe patient handling begins with trust and communication appropriate to the level of the patient with IDD and/or the caregiver. This is especially crucial when individuals with IDD become even more vulnerable when hospitalized or removed from a familiar setting. A sample Toolkit for Primary Care Providers on communicating effectively with individual's with IDD is available at http://iddtoolkit.vkcsites.org/general-issues/communicating-effectively/. IDD nurses should also be trained in responding to and reporting abuse that so highly occurs among people with IDD, especially women and children (Byrne, 2018). Additionally, aggressive behavior toward staff is a concern.

In 2013, the ANA along with other professional organizations established eight Evidenced-based Standards for Safe Patient Handling and Mobility to be used in any health care setting, including

residential living where many individuals with IDD may reside. While these apply to the general population they can and should be adapted to nurses caring for those with IDD.

1. Establishing a culture of safety, which includes ensuring safe levels of staffing, creating a non-punitive environment, and developing a system for communication and collaboration. For patients with IDD, this may include the use of auxiliary aids/services such as;
    - Sign language interpreters
    - Braille materials
    - Simplified language documents
    - Computer Assisted Real Time text (CART)
    - Large print documents

2. Implementing and sustaining a safe patient handling and mobility program specific to the needs of the individual with IDD and their caregiver;

3. Incorporating ergonomic design principles to provide a safe environment of care;

4. Selecting, installing and maintaining safe patient handling technology;

5. Establishing a system for education, training and maintaining competence;

6. Integrating patient-centered assessment, care planning and technology;

7. Including safe patient handling in reasonable accommodations and post-injury return to work policies; and

8. Establishing a comprehensive evaluation system.

Fatigue in Nursing Practice

IDD nurses have a responsibility to maintain their own health and well-being in order to perform at their highest level of competence. In 2017, the ANA launched the Healthy Nurse Healthy Nation campaign that promotes nutrition, stress control, sleep health and fatigue prevention (ANA, 2017). In 2017, the American Academy of Nursing released a position statement entitled Reducing Fatigue Associated with Sleep Deficiency and Work Hours in Nurses that included the following recommended actions (Caruso, et al., 2017, p. 767):

- Urge nurses and employers of health care organizations to educate themselves about the health risks linked to shift work and long work hours and the evidence-based strategies to reduce those risks.
- Urge employers of health care organizations to incorporate evidence-based practices in the design of their employees' work schedules and establish policies, programs, practices, and systems at work that promote sleep health and an alert workforce.
- Urge employers to promote a workplace culture that promotes sleep health to achieve optimum functioning, health, safety, and sense of well-being of their workforce.
- Encourage employers to recognize the role of shift work, long shifts, and nurse fatigue on turnover, absenteeism, patient safety, and related costs.

- Urge experts to develop additional continuing education courses for nurses and nursing managers that relay evidence-based personal practices and workplace interventions to maximize sleep health and alertness in nurses.
- IDD nurses have an ethical responsibility to take these actions, as well as report to work alert, well-rested, and prepared to give safe, quality patient care (ANA, 2015b; ANA, 2014).

Workplace Violence and Incivility

Healthcare workers and healthcare support personnel experience a higher amount of serious workplace violence than other private industries averaging 7.8 cases per 10,000 full-time employees in 2013 (US Department of Labor, OSHA, 2015). This is almost 400 percent more cases than other sectors of industry including manufacturing, construction, and retail. Workplace violence, bullying, and incivility may come from clients, co-workers, administration, and support personnel, and it is believed to be vastly under-reported (OSHA, 2015). Risk factors include: a) working with people who have a history of violence; b) working alone; c) poor environmental design d) lack of means for communicating an incident or emergency; e) lack of training and policies, f) understaffing, high turnover rate g)working in high crime areas; h) lifting, moving, and transporting clients; i) lack of funding for mental health services; j) the perception that violence is tolerated; and, k) a fear of repercussions for reporting (OSHA, 2015).

Those who work with clients with IDD may also experience issues with role ambiguity, poor social support, and poor organization of work settings which may lead to workplace bullying and incivility (Figueiredo-Ferraz et. al, 2012). Additionally, many caregivers consider that violence may be a part of the job because injuries caused by clients are often unintentional (OSHA, 2015).

Prevention of workplace violence and incivility includes identifying the risk factors specific to the work environment and developing strategies to reduce the incidence of the violence. Nurses, including nurses who specialize in IDD, must advocate for safe work environments, training, and policies that address workplace violence, bullying, and incivility (ANA, 2015).

Optimal Staffing

Nurses working with clients with IDD practice in a variety of settings including community settings, homes (family, individual and group), long-term care facilities, outpatient and ambulatory settings, psychiatric and rehabilitation facilities, faith-based communities, home health, correctional facilities, assisted-living homes, schools, and hospitals. Optimal staffing should be based on client needs and should support individuals with IDD to function to their full potential in a safe, efficient, and meaningful way (Bigby & Beadle-Brown, 2018). Staffing should accommodate the client's physical, emotional, spiritual, and social needs and allow for self-determination, empowerment, and community. IDD nurses should advocate for safe staffing models that support team-based care and consider principles that improve work environments and improve outcomes of clinical care (ANA, 2015).

The ANA Principles of Nurse Staffing (2012)Need to reference new 2019 edition includes a framework to assist nurses to consider principles related to healthcare consumers, registered nurses and other staff, organization and workplace culture, the practice environment, and staffing evaluation in order to provide optimal staffing. Staff levels should reflect careful planning according to client complexity and acuity, professional nurse and staff expertise, the physical layout, and the availability of resources and technical support (Kane, Shamilyan, Mueller, Duvall, & Wilt, 2007; Needleman, 2015). IDD nurses must

advocate for a culture of safety. When work environments do not promote safety and health as a priority, employees will not be able to provide error-free care (OSHA, 2015). Unhealthy work environments also lead to higher rates of staff absenteeism, higher turnover rates, and burnout.

Supports for Healthy Work Environments

ANA supports the following models of healthy work environment design. These concepts apply to the healthy work environments of IDD nursing practice as well.

American Nurses Association

The initial ANA Healthy Nurse™ framework began in 2009. The definition and constructs are as follows: ANA defines the healthy nurse as

> …one who actively focuses on creating and maintaining a balance and synergy of physical, intellectual, emotional, social, spiritual, personal and professional well-being. Healthy nurses live life to the fullest capacity, across the wellness–illness continuum, as they become stronger role models, advocates, and educators, personally, for their families, their communities and work environments, and ultimately for their patients. (ANA, 2013b).

The five Healthy Nurse™ constructs include:

- Calling to Care: Caring is the interpersonal, compassionate offering of self by which the healthy IDD nurse builds relationships with IDD patients and their families, while helping them meet their physical, emotional, and spiritual goals, for all ages, in all healthcare settings, across the care continuum.

- Priority to Self-Care: Self-care and supportive environments enable the healthy IDD nurse to increase the ability to effectively manage the physical and emotional stressors of the work and home environments.

- Opportunity to Role Model: The healthy IDD nurse confidently recognizes and identifies personal health challenges in themselves and their IDD patients and families/legal guardians, thereby enabling them and their IDD patients to overcome the challenge in a collaborative, non-accusatory manner.

- Responsibility to Educate: Using non-judgmental approaches, considering adult learning patterns and readiness to change, the healthy IDD nurse empowers themselves and others by sharing health, safety, wellness knowledge, skills, resources, and attitudes.

- Authority to Advocate: The healthy IDD nurse is empowered to advocate on numerous levels, including personally, interpersonally, within the work environment and the community, and at the local, state, and national levels in IDD policy development and advocacy.

Characteristics of IDD Nursing Practice Tenet #5 explicitly states that “a strong link exists between professional work environment and the IDD registered nurse’s ability to provide quality health care and achieve optimal outcomes” (Nehring, Natvig, Betz, Savage, & Krajicek, 2013, p.20).

The ANA Scope and Standards of Practice 3rd Edition (2015a), states that “all must be mindful of the health and safety of both the healthcare consumer and the healthcare worker in any setting, providing

a sense of safety, respect, and empowerment to and for all persons" (p 27). Several models of healthy work environments have been recognized and supported by the ANA. These models are universal and can be adapted to IDD nursing practice.

American Association of Critical Care Nurses Standards

Seminal work by the American Association of Critical Care Nurses (AACN) has identified six standards that must be in place to establish and maintain healthy work environments (AACN, 2016):

- Skilled Communication: Nurses must be as proficient in communication skills as they are in clinical skills.
- True Collaboration: Nurses must be relentless in pursuing and fostering true collaboration.
- Effective Decision-Making: Nurses must be valued and committed partners in making policy, directing and evaluating clinical care, and leading organizational operations.
- Appropriate Staffing: Staffing must ensure the effective match between patient needs and nurse competencies.
- Meaningful Recognition: Nurses must be recognized and must recognize others for the value each brings to the work of the organization.
- Authentic Leadership: Nurse leaders must fully embrace the imperative of a healthy work environment, authentically live it, and engage others in its achievements.

The environments where IDD nurses' practice are varied and complex. Yet these six standards can be universally applied. A quality healthcare environment can be achieved by aligning IDD nurse competencies to patient needs within the context of these six standards.

High-Performing Interprofessional Teams

Individuals with IDD often have complex and chronic conditions requiring a team collaboration among healthcare professionals. IDD registered nurses are experts at person centered care, an approach that places the person with an IDD at the center of the team. IDD registered nurses are role models who consider the IDD individual's values, desires, family system, and goals of their clients while engaging with other members of the interprofessional team.

The Interprofessional Education Collaborative Expert Panel ([IECEP], 2011) introduced four core competencies of collaborative practice that can be applied to all settings where IDD registered nurses practice:

1. Values and Ethics: Work with Individuals of other professions to maintain a climate of mutual respect and shared values (IECEP, p. 19).
2. Roles and Responsibilities: Use the knowledge of one's own role and those of other professions to assess and address the health care needs of the patients and populations served (IECEP, p. 21).
3. Interprofessional Communication: Communicate with patients, families, communities, and other health professionals in a responsive and responsible manner that supports a team approach to health maintenance and the treatment of disease (IECEP, p.23).

4. Teams and Teamwork: Apply relationship-building values and the principles of team dynamics to perform effectively in different team roles to plan and deliver patient-/population-centered care that is safe, timely, efficient, effective, and equitable (IECEP, p.25).

Adherence to these competencies will not only improve health outcomes of persons with IDD but may alleviate professional burnout of IDD nurses.

Key Influences on the Quality and Environment of Nursing Practice

Auberry (2018) identified several distinct challenges in the field of IDD nursing that include: complexity of care, educational preparation specific to the field is lacking, role ambiguity exists across varied practice settings, and a scarcity of evidence based research to guide practice. IDD registered nurses not only need to be aware of these challenges but should take a lead in removing barriers that prevent a productive, high quality environment within which to practice.

Other major influences on the Quality and Environment of IDD Nursing Practice are:

- *The Future of Disability in America* IOM report (2007) which addressed issues related to monitoring healthcare trends and services and identifies gaps in disability science in order to strengthen evidenced based care.
- IDD nurses must utilize current resources such as *Healthy People 2020: Disability and Health* (2019) to discover specific objectives, interventions, resources, and data to:

"Maximize health, prevent chronic disease, improve social and environmental living conditions, and promote full community participation, choice, health equity, and quality of life among individuals with disabilities of all ages." (https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health)

The healthcare industry, legislation, and regulatory bodies are major external influences on the work environment of all nurses. IDD registered nurses must keep abreast of trends and changes to healthcare delivery; they must practice to the full extent of their education. IDD registered nurses can ensure that their consumers have access to high quality health care thus alleviating disparities among people with IDD (ANA, 2015; IOM, 2011).

Societal, Cultural, and Ethical Dimensions Describe the Why and How of Nursing

IDD nursing is responsive to the changing needs of society that include its changing diversity, the legislative changes and the expanding knowledge base of its theoretical and scientific domains. One objective of nurses who specialize in IDD is to achieve positive outcomes that maximize quality of life across the entire lifespan. Registered nurses specializing in IDD facilitate the interprofessional, comprehensive and cultural care provided by healthcare professionals, paraprofessionals, and volunteers. In other instances, IDD registered nurses consult with other colleagues to inform decision-making and planning to meet the healthcare needs of individuals with IDD. Registered nurses specializing in IDD participate in interprofessional teams in which the overlapping skills complement and enhance each member's individual efforts.

IDD nursing practice, like all nursing practice, is fundamentally an independent practice in that registered nurses are accountable for nursing judgments made and actions taken in the course of their nursing practice. Therefore, the registered nurse specializing in IDD is responsible for assessing individual competence and is committed to the process of life-long learning. Registered nurses specializing in IDD develop and maintain current knowledge and skills through formal and continuing

education and seek available certification. Advanced Practice Registered Nurses (APRNs) specializing in IDD require specialized knowledge and skills obtained through formal and continuing education (i.e., Leadership Education in Neurodevelopmental Disabilities-LEND, meeting presentations on IDD health issues) related to the health care and management of conditions that are general or unique to the IDD population and their families.

All registered nurses are bound by a professional code of ethics (ANA, 2015b) and practice with highest respect and advocacy for the persons with IDD and families. The registered nurse is charged by the nursing practice act and empowered to promote the optimal life and environment for themselves and persons with IDD and their family. High quality care will also be guided by research and evidence-based practice, in coordination through collaboration with the multidisciplinary team, to influence policy and practice. IDD registered nurses regulate themselves as individuals through a collegial process of peer review of practice. Peer evaluation fosters the refinement of knowledge, skills, and clinical decision-making at all levels and in IDD nursing practice. Self-regulation by the profession of nursing assures quality of performance, which is the heart of nursing's social contract (ANA, 2010). IDD registered nurses recognize the larger scope of nursing's concern relative to the health of not only individuals and families, but also groups, communities, and IDD nurse roles as members of this nursing specialty. Registered nurses in IDD are fundamentally committed to respect for the individual, family, group, community or population and their inherent dignity, worth and uniqueness through advocating and protecting the rights, health and safety of patients. The IDD registered nurse is accountable and responsible for decisions and actions that promote health and provide optimal patient care using such practices as shared decision making, self-determination, and interprofessional collaborations. Individually and collectively, the IDD registered nurse has the duty to maintain and promote *their own* health, safety, competence, personal and professional growth within an ethical work environment. The IDD registered nurse advances the profession beyond individual patient care through scientific and scholarly inquiry, professional standards development, and generation of policy reflecting social justice principles in collaboration with other professionals and communities, with the goal to reduce health disparities and protect human rights.

Registered nurses specializing in IDD nursing and members of various professions exchange knowledge and ideas about how to deliver high-quality health care, resulting in overlaps and constantly changing professional practice boundaries. This interprofessional team collaboration involves recognition of the expertise of others within and outside one's profession and referral to those providers when appropriate. Such collaboration also involves some shared functions and a common focus on one overall mission. By necessity, IDD nursing's scope of practice has flexible boundaries.

Registered nurses specializing in IDD regularly evaluate safety, effectiveness, and cost in the planning and delivery of nursing care to individuals with IDD. Nurses recognize that resources are limited and unequally distributed, and that the potential for improving access to care requires innovative approaches, such as treating individuals with IDD remotely. Advanced Practice Registered Nurses (APRNs) in IDD nursing are uniquely qualified to assess, diagnose and treat individuals with IDD locally and remotely in accordance with state-approved regulations. As members of a profession, registered nurses work toward equitable distribution and availability of healthcare services to individuals with IDD throughout the nation and the world.

Model of Professional Nursing Practice Regulation

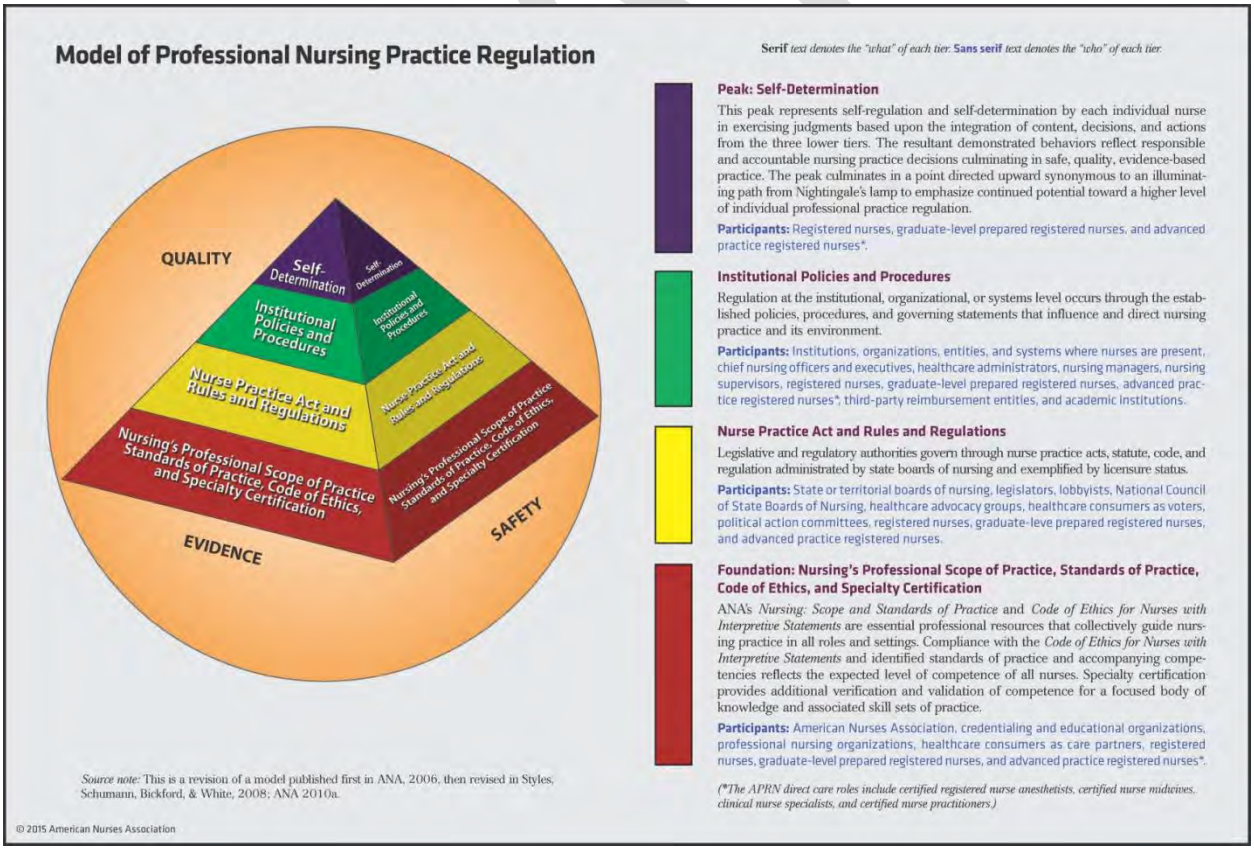
The Model of Professional Nursing Practice Regulation (Styles, Schumann, Bickford, & White, 2008) depicted in Figure 2 emerged from ANA work and informs the discussions of specialty nursing and advanced practice registered nurse practice. This Model of Professional Nursing Practice Regulation applies equally to IDD specialty nursing practice.

Each of the four levels of the Model of Professional Nursing Practice Regulation contributes to nursing evidence, quality, and safety. The lowest level in the model represents the responsibility of the IDD professional and specialty nursing organizations to their members and the public to define the scope and standards of practice for IDD nursing. The next level of the pyramid represents the regulation provided by the nurse practice acts, rules, and regulations in the pertinent licensing jurisdictions. APRN practice regulations, though defined by the Nurse Practice Act, are governed by Boards of Nursing so can vary across states (American Nurses Association, 2015a; 2015b).

The third level demonstrates how institutional policies and procedures provide further considerations in the regulation of nursing practice for the IDD registered nurse and IDD advanced practice registered nurse.

Note that the highest level is that of self-determination by the IDD nurse, after consideration of all the other levels of input about professional nursing practice regulation. The outcome is safe, quality, and evidence-based practice.

Figure 2. Model of Professional Nursing Practice Regulation



The Code of Ethics for Nurses

The *Code of Ethics for Nurses with Interpretive Statements* ("The Code"; ANA, 2015) serves as the ethical framework in nursing regardless of practice setting or role, and provides guidance for the future. The **provisions** explicate key ethical concepts and actions for all nurses in settings that care for the healthcare consumer with IDD. Detailed descriptive interpretive statements for each of the nine provisions of the Code are available at http://www.nursingworld.org/codeofethics.

> The *Code of Ethics for Nurses with Interpretive Statements* arises from the long, distinguished, and enduring moral tradition of modern nursing in the United States. It is foundational to nursing theory, practice, and praxis in its expression of the values, virtues, and obligations that shape, guide, and inform nursing as a profession. It establishes the ethical standard for the profession and provides a guide for nurses to use in ethical analysis and decision-making. (ANA, 2015, p. vii)

The Code also describes the ethical characteristics of the professional nurse:

> Individuals who become nurses, as well as the professional organizations that represent them, are expected not only to adhere to the values, moral norms, and ideals of the profession but also to embrace them as a part of what it means to be a nurse. The ethical tradition of nursing is self-reflective, enduring, and distinctive. A code of ethics for the nursing profession makes explicit the primary obligations, values, and ideals of the profession. It provides normative, applied moral guidance for nurses in terms of what they ought to do, be, and seek. The values and obligations in the *Code of Ethics for Nurses* apply to nurses in all roles, in all forms of practice, and in all settings. In fact, it informs every aspect of the nurse's life. (ANA, 2015, p. vii)

The IDD registered nurse uses the Code of Ethics for Nurses with Interpretive Statements (ANA, 2015) to guide practice. The IDD population-specific provisions are below. The nurse caring for the healthcare consumer with IDD will:

Provision 1 – practice compassion and respect for the dignity and uniqueness of the healthcare consumer with IDD.

- Deliver care in a manner that preserves and protects the autonomy, dignity, rights, values, beliefs, and practices of the healthcare consumer with IDD and their family.
- Support the expression of sexuality of the healthcare consumer with IDD in a manner that is consistent with the healthcare consumer's gender expression**,** native culture, religious upbringing, family values, level of maturity and offer counseling as appropriate.
- Facilitate the self-determined decisions of the healthcare consumer with IDD in all healthcare settings. The concept of "dignity of risk" means that the healthcare consumer with IDD should be empowered to make an informed decision that others might not have chosen. This reflects a shared balance in decision-making with the consumer, in which all the treatment options are presented and the benefits and risks of each discussed with respect for the consumer's self-determination.

- Advocate for life-sustaining treatment or refusal/withdrawal of life-sustaining treatment decisions by the healthcare consumer with IDD and the family
- Provide palliative care for serious and/or terminal illness when appropriate and agreed upon by the healthcare consumer with IDD and family; or works with a palliative care agency to provide appropriate, individualized care to the health care consume with IDD and family.
- Provide or arrange for effective and appropriate palliative care for healthcare consumers with IDD who undergo tests or treatments for illnesses, have chronic conditions, and/or are at the end of life.
- Provide support and resources for end-of-life care, grief, and bereavement when healthcare consumers with IDD experience loss.

Provision 2 – be committed to the healthcare consumer with IDD, their family, and their community.

- Recognize the centrality of the healthcare consumer with IDD and family/legal guardian(s) as core members of the healthcare team.
- Identify a surrogate for healthcare decisions in lieu of a formal guardian(s)hip process, when appropriate, and in accordance with local and/or state statutes.
- Advance the transitional care of the healthcare consumer with IDD and their family throughout the lifespan in healthcare and the community.

Provision 3 – protect, promote, and advocate for the health and safety of the healthcare consumer with IDD and their family.

- Serve as an advocate for the healthcare consumer with IDD and family/legal guardian(s) by developing their collective self-advocacy skills in areas of health and safety. For example, teaching the individual with IDD and family how to safely access transportation services that will facilitate their independence.
- Advocate for the healthcare consumer with IDD in self-determination decisions and engage the surrogate decision-maker for full discernment.
- Assist in assuring that the living arrangement for the healthcare consumer with IDD is the most appropriate and the least restrictive environment possible.

Provision 4 – be accountable and responsible to the nursing practice act; with decision and actions to promote health and provide optimal care of the healthcare consumer with IDD and their family.

- Maintain a therapeutic and professional relationship with the healthcare consumer with IDD and their family that promotes appropriate professional role boundaries.
- Advocate for the decisions and actions that promote optimal care of the individual with IDD and family/legal guardian(s) and when appropriate initiate referral to an organizationally recognized advocate.
- Assist in the referral process for local, state, regional, and federal assistance services and programs.

Provision 5 – promote health and safety for the IDD nurse; maintain competencies, as well as personal and professional development.

- Demonstrate a commitment to maintaining IDD nursing competencies and professional development, while practicing personal self-care, healthy interpersonal relationships and use of stress-reduction skills.

- Educate colleagues outside of the IDD specialty who provide healthcare **to individual** consumers with IDD and their family.

Provision 6 – work collaboratively to provide ethical, safe, and high-quality work environment for him/herself and for the healthcare consumer with IDD and their family.

- Uphold confidentiality of the healthcare consumer with IDD and families within legal and regulatory parameters.
- Take appropriate action regarding instances of illegal, unethical, or incompetent behavior that can endanger or jeopardize the best interests of the healthcare consumer with IDD and their family.
- Work to prevent abuse or exploitation of the healthcare consumer with IDD and promptly respond to suspicion or evidence by reporting to appropriate authorities.
- Contribute to an environment that protects the healthcare consumer with IDD from sexual exploitation at home, school, work, and community.

Provision 7 – advance the profession through scholarly inquiry, standards development, and influencing policy.

- Question healthcare practices and institutional policies that are not in alignment with the optimal safety of the individual with IDD and family to promote organizational quality improvements using improvement science or systematic research.
- Contribute to the educational and vocational program recommendations and advocate for the least restrictive environment to maximize the potential of the healthcare consumer with IDD.
- Serve as an advocate to ensure that the healthcare consumer with IDD receives coordinated, continuous, and accessible health care that is provided by a professional who is competent in managing health concerns of healthcare consumers with IDD.

Provision 8 – work as a team with other providers to protect the rights, promote the health, and reduce disparities for the healthcare consumer with IDD and their family.

- Participate on interdisciplinary teams to address ethical risks, benefits, and outcomes.
- Inform administrators or leaders of the risks, benefits, and outcomes of programs and decisions that affect inequitable healthcare delivery of the healthcare consumer with IDD and their family.
- Contribute to the life-course plan and advocate for the most appropriate employment situation for the healthcare consumer with IDD. The nurse assists in identifying reasonable accommodations to maximize the healthcare consumer's performance and satisfaction with chosen employment.

Provision 9 – will work with professional organizations to communicate values and incorporate social justice.

- Respect the right of the healthcare consumer with IDD to self-determination by engaging them and their family in shared decision-making, unless the healthcare consumer's incapacity to participate in a specific decision is demonstrated and a surrogate decision-maker is legally required.
- Advocate for equitable health care for consumers with IDD and families in organizations and the community.

- Contribute to resolving ethical issues involving the healthcare consumer with IDD, colleagues, community groups, systems, and other stakeholders as evidenced by activities such as participating on ethics committees and influencing policy makers.

Professional Registered Nurses Today: The Who of Nursing

Statistical Snapshot

The number of nurses identifying themselves as IDD nurses is unknown. The only national certification program for registered nurses specifically addressing individuals with IDD is through the Developmental Disabilities Nurses Association (DDNA), which claims about 1,300 members, including LPNs, associate's-degree registered nurses, and baccalaureate-prepared registered nurses, as well as APRNs and doctorally prepared nurses. Interdisciplinary organizations such as the American Association on Intellectual and Developmental Disabilities (AAIDD), American Academy for Cerebral Palsy and Developmental Medicine (AACPDM), and the International Association for the Scientific Study of Intellectual Disability (IASSID) count nurses among their membership. Additionally, of interest, is that the National Association of School Nurses' Special Needs Special School Nurses Special Interest Group numbering 3260 registered nurse members in May, 2019 (NASN, 2019b) Those school nurses are not necessarily certified as IDD registered nurses, but it is an indication of the large number of school nurses who want to keep up with education and issues related to students with IDD. The Special Needs School Nurses Special Interest Group has a discussion list-serve that facilitates communication among members.

Licensure and Education of IDD Registered Nurses

The IDD registered nurse is licensed and authorized by a state, commonwealth, or territory to practice nursing.

In the United States, the student who graduates from a basic nursing education program is eligible to be licensed as a registered nurse (RN). IDD registered nurses, like all registered nurses, can take several educational routes. Although most professional nursing organizations, such as ANA, emphasize that Baccalaureate preparation in nursing is the entry into practice, there are several pathways to obtaining the entry level education to become a registered nurse. These educational options include nursing diploma, associate and baccalaureate degrees. Many community colleges, private educational institutions and hospitals still offer the Associate Degree for registered nurses, particularly when there are local or national shortages of registered nurses. Three-year diploma programs are offered primarily through hospitals. Associate degree and diploma graduates take the same national licensing exam (NCLEX-RN) as Baccalaureate graduates as all must address the basic competencies needed for the NCLEX-RN exam (American Association of Colleges of Nursing [AACN], 2017). Entry-level registered nurses are prepared as generalists, and often specialize following graduation and licensure. More programs (777) now exist that offer a pathway from AD RN to BSN, and above from RN to MSN (219 programs) (AACN, 2019).

The licensed registered nurse, regardless of educational pathway, is not prepared to specialize in IDD. Continuing education programs and progressive work experience with individuals who have IDD enhance the IDD nurse's knowledge, skills, and abilities.

At the graduate level, a few nursing education programs across the country do offer specialization in IDD, and these programs are funded by the Maternal and Child Health Bureau. These training programs,

known as the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) are funded by the Maternal Child Health Bureau, Department of Health and Human Services in partnership with many of the UCEDDs. A listing of these programs can be found on the Maternal and Child Health Bureau web site (http://www.mchb.hrsa.gov/training/; from the home page, indicate "nursing" in the field asking for discipline).

IDD registered nurses with a Master's degree may continue their education toward the Doctor of Philosophy (PhD) degree or the Doctor of Nursing Practice (DNP) degree. The PhD graduate focuses on research and theory generation, as well as academic education. The DNP graduate focuses on clinical practice, quality assurance, and clinical outcome evaluation, as well as clinical education in academic and other settings.

It is projected that there will be opportunities for DNPs (i.e. nurse practitioners) to practice under full scope of practice (SOP) given the projected shortages of primary and specialty care physicians (Bauer & Bodenhimer, 2017; Kirch, & Petello, 2017; Xue, Kannan, Greener, et al. 2018). It is estimated by 2030, there could be a shortage of more than 100,000 physicians with the specialty fields of practice most significantly affected the field of intellectual and developmental disabilities (Kirch & Petello, 2017). Likewise, the number of NPs will rise and constitute as large percentage of the workforce, rising from 19% in 2010 to 29% by 2025. It is projected that there will be greater numbers of NPs practicing in rural and health professional shortage areas (HPSA), and those who are insured by Medicaid, particularly in states wherein there are full SOP regulations (Bauer & Bodenhimer, 2017). Since individuals with IDD are likely to be included among those who do not have access to primary physicians, DNPs might become primary caregivers to many of these individuals. This is another indication that IDD nursing education is needed.

Efforts to address underserved areas and populations are underway that can positively affect access to care for individuals with IDD. In January 2018 the Nurse Licensure Compact (eNLC) was implemented and adopted by 29 states. Although narrow in scope as it affects RNs and LVNs only (APRN not included), nurses with licensure in an eNLC state can migrate to other eNLC member states without having to take the licensing examination of that state ("Progress and Precision", 2018). The aim of this regulation is to redirect nursing resources in underserved areas and for vulnerable populations wherein there are fluctuations in nursing resources. It also provides for immediate reciprocity of licensure among compact states.

Definitions and Concepts Related to Competence in IDD Nursing

Competence in IDD nursing is based upon the standards of nursing practice generated by ANA, state boards of registered nursing and specialty organizations. The ANA Professional Role Competence Position Statement (2014) defines competence as "…performing successfully at an expected level and with "…an expected level of performance that integrates knowledge, skills, abilities, and judgment." (p.3). In, the ANA Code of Ethics for Nurses with Interpretive Statements (2015b), Provision 5.5 directly addresses the issue of competence and continuation of professional growth. Competence is referred to as "… a self-regarding duty" (p.22). That is, nurses have a responsibility to "…maintain competence and strive for excellence in their nursing practice, whatever the role or setting" (p.22).

The National Council of State Boards of Nursing defined competence as "the application of knowledge and the inter-personal, decision-making, and psychomotor skills expected for the practice role, within the context of public health" (NCSBN, 2005, p. 81). Competence is referred to as ". a measure of

performance that is the active, behavioral expression of expertise lying on a continuum from novice to expert (Bathisha, Wilson, Potempac, 2018). Competence has also been defined as the description of a behavior or act, while competency has been defined as the underlying behavior that leads to the competent performance (McMullan et al., 2003). Competence is composed of varied attributes, including judgment, critical thinking skills, and physical/behavioral skills. Competence is job-related, situation-related, and represents qualities that yield effective performance on the job. Competence is the capacity and potential to perform in a given setting (Cowan, Norman, & Coopamah, 2007). Competence is the application and demonstration of skills, knowledge, and judgment (Scott Tilley, 2008).

Attributes associated with nurse competence, including IDD nursing competence, are the ability to integrate knowledge into practice, caring attitude, communication skills, critical thinking, professional experience, motivation, organizational environment, professionalism, and skills proficiency (Smith, 2012). Benner (1984) proposed a developmental model of competence, with stages from novice to expert, which posits that competence is also dependent on length of experience. More recently, deliberate practice defined as activities undertaken "…aimed at improving one's competence and leading to expertise" is linked to competence (p. 106, Bathish, Wilson, Potempa, 2018). Lifelong learning serves as the basis of deliberate practice and essential for achieving and maintaining competence. Because nursing education generally lacks content and experience in care of individuals with IDD, nurses must continually seek learning opportunities on the job, through advanced educational preparation or combined with continuing education.

A variety of intrinsic and extrinsic factors influence competence in actual day-to-day nursing practice including IDD nursing practice. Quality care results from competence. Environmental factors may be supportive of competence or present challenges. For example, performing a physical exam on a cooperative patient may be a basic skill, but performing a physical exam on an individual with autism, a sensory disorder, and a communication disorder may requires a different set of knowledge, skills, and expertise.

There is little empirical data to inform care of individuals with IDD and to guide competence in nursing practice with this population. However, evidence for practice can be sought by accessing the interdisciplinary literature and serving as a member of interdisciplinary teams. The majority of nurses entering into practice have little or no experience with children or adults with IDD, and many believe they will never encounter persons in practice. However, as more individuals with IDD leave institutions and live in the community, nurses in all settings, including school nurses, will find themselves involved in providing services for the IDD population.

Lazarus and Lee (2006) studied healthcare consumers' identification of factors they believed influenced nursing competence. Education, number of patients, hours worked, education in procedures, salary, involvement in professional activities, attitude, and work conditions were among the factors listed. Excessive work hours and poor work conditions translated to poor quality of care. Behaviors such as lack of courtesy and caring, poor communication skills, discomfort with performing technical skills, and knowledge deficits negatively influenced competence (Lazarus & Lee, 2006). Behaviors such as these put all patients at risk, and are particularly risky for individuals with IDD, due to their vulnerabilities.

The registered nurse who specializes in IDD systematically enhances the quality and effectiveness of nursing practice by performing care according to quality standards and by meeting both generalist and specialist nursing competencies. These examples include the scope and standards of nursing practice

published by ANA, such as gerontological nursing, pediatric nursing, psychiatric/mental health, public health nursing, genetics/genomic nursing and school nursing practice. Other nursing subspecialty resources such as *Health Care Quality and Outcomes Guidelines for Nursing of Children, Adolescents and Families* that denotes excellence in pediatric nursing practice can be accessed for IDD nursing practice (Betz, Krajieck, & Craft-Rosenberg, 2018). Lifelong learning is a commitment to quality, requiring nurses to constantly reappraise their own practice and seek to upgrade knowledge and skills.

Evaluating Competence

Competence in nursing practice, including IDD nursing practice, must be evaluated by the individual nurse (self-assessment), nurse peers, and nurses in the roles of supervisor, coach, mentor, or preceptor. In addition, other aspects of nursing performance may be evaluated by professional colleagues and patients. Competence can be evaluated by using tools that capture objective and subjective data about the individual's knowledge base and actual performance and are appropriate for the specific situation and the desired outcome of the competence evaluation. However, no single evaluation tool or method can guarantee competence. (ANA, 2014).

Bachelor's and associate-level programs prepare nurses to meet general nursing competencies and to pass the NCLEX-RN licensing exams upon graduation (Kronk, Colbert, Smeltzer, & Blunt, 2019). Graduation from an accredited program and successful completion of the licensing exam represent to the public, consumers, and employers that the registered nurse is capable of general, competent, and safe nursing care. The IOM (IOM, 2011) recommends that all graduating RNs complete a nurse internship before entering into independent practice. Currently, this occurs mostly in the hospital setting, but nurse internships in community agencies serving individuals with IDD are needed. They would allow novice registered nurses to hone the basic skills they developed in training and apply them to the needs of the IDD population.

Continuing education and monitoring numbers of continuing education units has traditionally been the primary method for evaluating competence for practicing registered nurses, as well as many advanced practice registered nurses (APRNs). As noted previously, nursing organizations such as the Developmental Disabilities Nursing Association (DDNA) offer certification of registered nurses (separate from APRN certification) as one method of evaluating competence of professional nurses working in specialized settings. Certification in IDD nursing can be found on the DDNA website (https://ddna.org/certification/).

IDD registered nurses evaluate their own nursing practice in relation to professional practice standards and evidence-based guidelines, and relevant statutes, rules, and regulations, identifying strengths and areas in need of further development. As part of the self-evaluation of practice, the registered nurse solicits feedback from healthcare consumers, family members/legal guardian(s), colleagues, and others, including direct care support professionals. Use of practice portfolios places the responsibility of maintaining competence on the individual nurse, and can document experience in subspecialties (such as care of individuals with IDD), involvement in quality assurance efforts, and participation in professional interdisciplinary and nursing specialty organizations, as well as competencies not evaluated by other methods. The IDD nurse must also evaluate nursing care delegated to other professionals, direct care support professionals, unlicensed assistive personnel, or the family/legal guardian(s) and document the effect of delegation on health outcomes.

Professional Trends and Issues

Nurses practicing in the field of IDD continue to refine and improve their care through clinical practice and advocacy. As practice in this field continues to evolve and advance, several areas will remain essential to provision of quality care to this vulnerable population, including cultural sensitivity, early assessment and identification, inclusion in schools and community, chronic illness, transition from pediatric to adult healthcare services, self-advocacy and self-determination, accessing and securing equitable share of healthcare services, community living, and genomics.

The most significant societal shift that has emerged in the past several decades has been the increase in cultural diversity of the nation's population (ANA, 2015a; Campinha-Bacote, 2011a, b; Leininger, & McFarland, 2002; McFarland, & Wehbe-Alamah, 2015). This pattern of diversity is also observed in the IDD population (Butler et al., 2016). This trend demands increased efforts by nurses to expand their cultural competence in adapting care to cultural norms that foster communication and positive health outcomes for this population, their families and legal guardian(s).

Nurses also play a key role in the healthcare management of individuals with IDD throughout their lifetime. Technological medical advances have resulted in a longer lifespan for this population, resulting in a crucial need for nursing care that facilitates a smooth transition from pediatric to adult-oriented primary and specialty health services (Betz, O'Kane, Lobo, & Nehring, 2015). The shift to adulthood also requires individualized counseling and coaching strategies to develop key self-advocacy skills that ensure their healthcare needs are met. Advocacy efforts also guide and support efforts that include individuals with IDD in making, to the extent possible, decisions regarding their health and well-being, including their goals for care at the end of life. Further evidence needs to be discovered that focuses on effective assessment and intervention techniques that meet the unique needs of older persons with IDD, and particularly with those who develop dementia as a secondary diagnosis. (Jacques, 2018).

The continued aging of the IDD population requires nurses to prioritize care that is illness-focused to that which is increasingly oriented to health promotion and disease prevention. Specific nursing roles related to promotion of health and well-being of this population include creating environments conducive to health, involving stakeholders in planning health goals and promoting self-care. New discoveries in genetic and genomic health care continue to demand that nurses have essential competencies in this specialized clinical area. Such competence will promote appropriate utilization of genetic care resources for innovative diagnostic procedures, genetic evaluation, counseling or risk assessment and personalized, targeted drug and therapeutic interventions that might be indicated for the person with IDD and his/her family.

New advances in information technology (IT) have the potential to provide expanded professional nursing services to persons with IDD. In particular, telehealth services can connect nurses who work with those living in underserved and rural areas with a range of healthcare services and resources to facilitate virtual assessments and consultation about needed care. Telehealth services may also benefit the person with IDD whose mobility impairments or fragile health status impede safe and accessible transportation to other healthcare facilities.

There is also an ongoing nursing shortage in the specialty of IDD nursing. Efforts are being made by public and private institutions to increase salaries for IDD registered nurses. Although IDD nurses' expert knowledge and skills are necessary to meet the unique healthcare needs of the IDD population, their compensation is less than that of nurses in other specialty areas (Augury, 2018). The basis for this discrepancy is unclear, but may be related to "lack of recognition regarding this nursing specialty within

the profession, ambiguous nature of the IDD nursing role and significant gaps in research that clearly guide practice in this field" (Aubury, 2018, p.26). Integration of IDD content into pre-licensure and graduate nursing curriculum is limited, as well as opportunities for clinical experiences in settings that provide health services to this special population. Nursing curricular policy change is warranted to ensure that registered nurses have the basic knowledge and skills necessary to provide safe and competent care to this population. Curricular integration to include IDD nursing will provide opportunities for novice nurses to discover the benefits and contributions that a career in caring for this population can provide to individuals, families and society. Other opportunities for learning include membership in national professional organizations with subspecialty interest groups in IDD nursing. These are listed in the box below.

APRN Special Interest Groups for IDD Resources	
Nurse Practitioner Special Interest Group (SIG) in the Society of Developmental and Behavioral Pediatrics	This group advises APRNs and APRN students on ways to learn about IDD nursing and offers pre-conference workshops on topics in IDD that interest new and established APRNs in IDD nursing. The link for further details and contact information is http://www.sdbp.org/committees/sig-nurse-practitioners.cfm
NAPNAP SIG Developmental, Behavioral and Mental Health (DBMH)	This SIG would be of interest for new and established APRNs in the field of IDD nursing. The link to the DBMH website and contact information is found under the position statement for current officer names. https://www.napnap.org/developmental-behavioral-and-mental-health-sig
SDBP Nurse Practitioner SIG and NAPNAP DBMH SIG	These SIGs have partnered to provide a collaborative, innovative effort to establish an online asset management site for pediatric healthcare providers. Born out of a group of like-minded individuals with shared knowledge, experience, and practice, this effort is positioned as a go-to resource and catalogue for free, valuable, and vetted DBMH resources. The link below is available to all and a resource for nurses interested in IDD nursing: www.dbmhresource.org The DBMH site management team is also available for contact at mentalhealth@napnap.org

Creating a Sustainable Nursing Workforce

Scant empirical data are available on the number of nurses whose specialty area of practice is in the field of IDD and projected numbers of this specialty group of nurses to meet the ongoing and future comprehensive healthcare needs of individuals with IDD. Several reasons have been offered to account for the dearth of available data, which include lack of resources to conduct national surveys and the transformative changes resulting from the de-institutionalization movement begun decades ago have altered the practice of nurses who specialize in IDD nursing as care is no longer provided in easily identifiable institutional settings (S. Diane Moore, personal communication, October 15, 2018; O'Reilly, et al., 2018). As noted, "The specialized field of nursing has arguably been subjected to a greater amount of policy and professional delegitimization than any other specialty field of nursing" (O'Reilly, p. e12258).

It can be inferred, however, from the data reported on the projected trends with professional nursing and interprofessional practice, U.S. population health needs and predicted changes in the delivery of health services will have significant impact on the healthcare needs of individuals with IDD. These predicted changes will also alter the professional practice opportunities and challenges of IDD nurses to

respond to them (Auerbach, Staiger, & Buerhaus, 2018; Auerbach, Buerhaus, & Staiger, 2018; Bauer, & Bodenheimer, 2017; Xue, et al., 2018). Unfortunately, these challenges are not unique to the U.S. (Delahunty, 2017; Trollor, Eagleson, Turner, Salomon, Cashin et al., 2018).

The challenges facing professional nursing in the years to come are immense as significant societal trends are forecasted to effect changes in professional nursing practice, the delivery and organization of health care, and the population of Americans including individuals with IDD in the years to come. These projected trends include the aging United States (US) population, including seniors with IDD, shortages of the medical and nursing workforce, and the reform and retooling of the healthcare delivery system of care so that more care will be provided in the community, home and remotely (Buerhaus, Skinner, Auerback & Staiger, 2017; Robert Wood Johnson Foundation, 2013). All these projected changes will impact the access and quality of care provided to individuals with IDD.

Projections of the nursing workforce are predicted to vary according to the region in the U.S. These projections are based upon national workforce data collected from the Current Population Survey (CPS; N-70, 201) and the American Community Survey (ACS; N=366, 927) from 1979 to 2014 on the employment status of registered nurses. Based on these projections, nursing shortages are expected in New England (Maine, Massachusetts, New Hampshire, Rhode Island, Vermont) whereas the region of South Central (Arkansas, Louisiana, Oklahoma, Texas) are expected to have robust and ongoing growth workforce supply (Auerbach, Buerhaus, & Staiger, 2016; Ying, et al., 2018). The implications of projected workforce supply in regions nationwide suggest that access to health services for individuals with IDD will be affected by geographic region in the US, not only for those who live in rural areas and HPSA. For areas wherein projected nursing shortages are anticipated to occur, additional efforts with job recruitment and establishment of additional nursing education programs that include IDD content and specialization will be needed (Auerbach, Buerhaus, & Staiger, 2016).

The retirement of the generation of baby boomer nurses will shift generational focus to millennials who will become the largest segment of the nursing workforce (Auerback, et al., 2017). Of concern with the retirement of experienced nurses of the baby boomer generation amounting to approximately one million nurses is the loss of the valuable workforce asset of acquired knowledge and skills needed for the provision of nursing care, which is estimated at 1.7 million years of experience (Buerhaus, et al., 2017). This projected loss of expertise and experience will be felt for the care provided to individuals with IDD. This projected gap with the quality of care provided can result in adverse consequences associated with increases in the rates of hospitalizations and emergency room visits and higher rates of complications, secondary conditions and co-morbidities (Kleier, 2016; Buerhaus, et al. 2017).

Nursing Education

Healthcare consumer needs and the care environment are more complex in the 21st century. Nurses have to make more critical decisions; be adept at using a variety of sophisticated, life-saving technology and information management systems; coordinate care among a variety of professional and community agencies; help healthcare consumers manage their IDD and chronic illnesses; lead change from within their organizations; and affect national policy that has implications for individuals with IDD and their parents/guardian(s). Consequently, nursing students need to develop a broader range of competencies in the areas of health policy and healthcare financing (including understanding health insurance benefits), community and public health, leadership, quality improvement, information management, and systems thinking and their application to the IDD population, parents/guardian(s), as well as become excellent clinicians (IOM, 2011).

According to the IOM (2011), in order to meet this demand, nurses should achieve higher levels of education, while educational systems and other stakeholders should support seamless academic progression and include innovative ways for nursing students to achieve their degrees through online, using virtual, simulated, and competency-based learning. Curricula design should adequately prepare entry-level nurses and center on optimal patient outcomes. Schools of nursing must also build their capacities to prepare more graduate-level students to assume roles in advanced practice, leadership, teaching, and research in the field of IDD (IOM, 2011).

Nursing as a profession continues to face dilemmas in entry into practice, recognition of the autonomy of advanced practice, maintenance of competence, complexity of multistate licensure, and the appropriate educational credentials for licensure and professional certification. Registered nurses have a professional responsibility to maintain competence in their area of practice. Employers who provide opportunities for professional development and continuing education promote a positive practice environment in which nurses can maintain and enhance skills and competencies.

This is an exciting time of progress and evolution for interprofessional education, long acknowledged as the model of excellence for the provision of care to persons with IDD, their parents/legal guardian(s). According to the AACN (1995, para 1), "interdisciplinary education is when two or more disciplines collaborate in the learning process with the goal of fostering interprofessional interactions that enhance the practice of each discipline." Students from differing professions learn what each brings to the healthcare team and how each need to foster communication, collaboration, conflict resolution, and mutual respect before graduation and entry into practice pp. 48-49, (ANA, 2015a).

Technological Advances

Technology can drive effectiveness and efficiency, provide convenience, extend care to populations with little access to transportation, and serve as a major influence on how nurses practice (Huston, 2013; OECD, 2013). Technology can provide data transparency and offer a better work environment for nurses when designed and implemented in a manner that supports nurses' work and work flow. Work environments include conventional locations—hospitals, clinics, schools, and healthcare consumer homes—as well as virtual spaces such as online discussion groups, email, interactive video, and virtual interaction (Cipriano, 2009). Ideally, technology will eliminate redundancy and duplication of documentation; reduces errors; eliminates interruptions for missing supplies, equipment, and medications; and eases access to data, thereby allowing the nurse more time with the patient (Cipriano, 2009). Perhaps one of the most daunting challenges for nurses will be to retain the human element in practice. Other challenges include balancing cost with benefits, the daunting task of training the nursing workforce with a plan for sustainment, and assuring ethical use of technology (Huston, 2013).

The IDD nurse recognizes that these technologies are continuously emerging. While it is impossible to know them all, the IDD nurse should be aware of the proliferation and evolution of potential devices that serve to support patients with IDD and their families – some that have evidence to support use and some that may not be evidence-based. The nurse's technological role would be to inform patients and families, encouraging them to be informed by evidence rather than by commercials and social media outlets. Healthcare information technology (HT) is a mainstay in hospitals, clinic, community and home. Nurses are in a strategic position to tailor how to best use HT while balancing the human element in practice by actively participating in designing nursing workflow in and around HT.

Assistive technology (AT) refers to tools, equipment, or products that can help people with IDD successfully complete activities at school, home, work, and in the community. This can be as simple as a magnifying glass to improve vision or as complex as a digital communication system. Staying abreast with these AT treatment options require close collaboration with the rehabilitation professionals including physiatrist, physical therapist, occupational therapist, speech and language pathologist and vocational counselors. Collaboration with these team members allows the nurse to individualize AT that is appropriate for each client and family. Nurses who are knowledgeable and proficient with the use of AT are better equipped to assist in designing solutions that promote independence in the individual with IDD.

A wide assortment of assistive technologies exists to assist individuals with IDD to be more mobile such as wheelchairs, reverse walkers, crutches and orthotic devices. Individuals with sensory impairments now have access to a wide variety of AT devices that enhance and support vision and hearing abilities. Environmental modifications include the use of grab bars in showers, enlarged doorways and passages and ramps and modification of shelving and counters enabling residential access. Durable medical equipment includes transfer benches for bathing and toilet assist bars to facilitate independence with activities of daily living. Software programs are available to assist individuals with cognitive problems such as memory and learning challenges (American Foundation for the Blind, n.d., Center on Technology and Disability, 2018; U.S. Department of Health and Human Services. National Institutes of Health. Eunice Kennedy Shriver National Institute of Child Health and Human Development, 2018a).

Rehabilitative technologies (RT) and techniques, also referred to as assistive technology are designed to aid individuals, including those with IDD to restore or improve function following an injury or debilitating health condition. These disabling health challenges can occur at any time over the lifespan of an individual with IDD. These rehabilitation technologies include the use of robots and the use of virtual environments. Musculoskeletal modeling and simulations and motion analysis are used for the purposes to diagnostic analysis of movement problems. Technologies used for the recovery of movement through stimulation of the brain are transcranial direct current stimulation (tDCS) and transcranial magnetic stimulation (TMS) U.S. Department of Health and Human Services. National Institutes of Health. Eunice Kennedy Shriver National Institute of Child Health and Human Development (2018b).

The use of current and future technologies raises competence issues for IDD registered nurses in terms of understanding their appropriateness for delivery of services for individuals with IDD. Questions arise in terms of the practice expectations for IDD registered nurses and how to remain clinically competent with developments in the field of assistive and rehabilitative technologies. These questions involve not only the scope of practice expectations for IDD registered nurses, but also access to the educational options to be competent in this area of practice. Issues to consider include:

- Should AT and RT classes be offered in nursing curriculum across medical conditions as elective or required? Rationale: Nurses know it exists and need to be aware of its potential(s).
- Should AT/RT, as a testing section, be required to receive certification from Developmental Disabilities Nurses Association (DDNA)?
- What type of continuing AT/RT classes (CME) are offered to IDD-nurse specialists?
- What type of collaboration is available with the Rehabilitation Department to address AT/RT? Rationale: nursing cannot do AT/RT without the Rehabilitation team.

Population Focus: Redefining Health and Well-being for the Millennial Generation

The generation designated as Millennials is composed of individuals ages 22 to 37 years born between 1981 to 1996 (U.S. Bureau of the Census, 2017). In 2019, the number of millennials is projected to reach 73 million and will outnumber the baby boomer generation (72 million) for the first time (Fry, 2018). The Millennial generation is expected to peak in 2036 with 76.2 million (Fry, 2018). Relevant generational changes have been noted with the millennials in contrast to previous generations, which have implications for the provision of health services in the future for the population of individuals with IDD.

The current generation, referred to "digital natives" have been raised with exposure to and use of technology beginning early in their childhood. Technology is used by millennials, depending on their level of cognitive functioning, for entertainment and educational purposes, to access to personal and health-related resources, and for social communication. Nearly all millennials (97%) report that they access the Internet and 92% own smartphones (Fry, Igielnik, & Patten, 2018; Jiang, 2018). Additionally, access to technology is not relegated to higher income groups; a recent survey revealed that approximately two-thirds of low-income youth had a mobile phone and nearly 40% had a smart phone. Well known Internet social media used by millennials include Facebook, Twitter, Linkedin, and Instagram (Stephens & Gunther, 2016).

The use of technology for health teaching, health monitoring and communication have an important role in the provision of services to individuals with IDD and their families. Nurses specialists in the field of IDD will need to adapt and accommodate technology in the provision of services to remain current and in touch with the needs of the individuals and families served.

The implications for clinical practice are significant given that the demographic profile of the millennial generation is vastly different from the previous generations of the baby boomer and the Silent Generation. This generation of millennials are better educated than the men and women of previous generations. Women (36%) of the millennial generation with bachelor's degrees surpass men (29%), a trend that began with the Generation X in contrast to the previous generations of Baby Boomers and the Silent Generation. More young women of the Millennial generation (71%) are employed compared to women of past generations (Fry, Igielnik, & Patten 2018). The millennial generation marries later as compared to previous generations and is a more racially and diverse generation due in part to immigration from Latin America and Asia, increased interracial marriages, and high birth rates among ethnic and racial groups.

Nearly 90% of millennials live in metropolitan areas as contrasted with earlier generations wherein approximately two-thirds resided in metropolitan areas (Fry, Igielnik, & Patten, 2018). There are now 17 million millennial mothers. In 2016, 82% of all US births were to millennial mothers (Livingston, 2018). Given the aforementioned demographic characteristics, strategies in working with families will involve greater collaboration as this generation, unlike previous generations, has efficient and expedient access to information pertaining to health conditions, diagnostic issues, traditional and complementary treatments, other health services options and community-based resources. This ready access to information enables consumers to be health literate consumers of care and to engage in discussions that require providers to respond to questions and challenges to their expertise. It is also incumbent upon nurses to be informed about the sources of information parents and consumers access and respond with replies based upon the best evidence. Issues pertaining to the controversies pertaining to vaccination and autism are apt examples of access to erroneous information and misconceptions (American Academy of Pediatrics, 2013, Krishna, 2018).

Baby Boomers: Health and Chronic Illness

As the average lifespan of a person in the U.S. with IDD extends into the 60s (Janicki, Dalton, Henderson & Davidson, 1999). In a study of the life expectancy of Finnish adults with mild ID was comparable to the general population; the life expectancy of those with moderate, severe and profound ID was less than the general population (Patja, et al., 2000) This creates a growing population with a new set of needs in which nurses must integrate new care delivery knowledge and skills. According to testimony given by Heller (2017, October 25) on Service and Support Needs of Adults Aging with Intellectual/Developmental Disabilities (Testimony to the U.S. Senate Committee on Aging, 2017), individuals in this population have a higher risk of developing chronic health conditions at younger ages than other adults, due to the confluence of biological factors related to syndromes and associated disabilities. With poor access to adequate health care, as well as lifestyle and environmental issues, their physical health may be compromised. Furthermore, the report states that people with IDD are less likely to be employed and those that are employed or retired may need additional services and support as they reach middle and older ages. These new trajectories in the population of individuals with IDD point to the increased complexity of problems and the need for increased knowledge of providers and nurses about how to deal with complex issues of chronic illness and disability (Acharya, Schindler & Heller, 2016).

In addition to IDD health and nursing care needs, parenting takes on a new set of circumstances. Many parents are having children later in life, resulting in an increased age of parent caregivers (Prouty, Alba, & Lakin, 2008). Parents of adult children with IDD have special needs that are different from parents of young, growing children with IDD. Future planning becomes a large part of meeting the needs of their loved ones who are younger than they are, while at the same time considering their own age-related changes and needs. The information and support from the healthcare team in general and nurses who play a significant role in coordinating care in particular can increase a parent caregiver's ability to advocate for care, increase confidence in their parenting, and assist with navigating the complex array of services.

It is important for all nurses who work in the IDD communities, as the various generational groups enter the healthcare system – especially baby boomers who are quickly becoming aging parents with aging children who have IDD – to recognize the intergenerational differences and healthcare demands of aging parents along with their adult children. Just as aging people with IDD are likely to bring to their healthcare encounter a set of complex chronic illnesses that are associated with age, research on children with disabilities and other impairments has shown that parent caregivers also experience increased challenges to physical functioning, health status and level of stress (Anderson, Hewitt, Pettingell, Lulinski, Taylor, & Reagan, 2018; Carling-Jenkins, Torr, Iacono, & Bigby, 2012; Chou, Chiao, & Fu, 2011). Studies describe that families of children with ID/DD generally favor a lifetime assistance model – planning for the future and transfer of care (Hewitt et al., 2010). Families caring for an adult child with a disability can be viewed in context – that a family centered approach to integrating care, connecting aging parents with needed services for themselves and their child can be best implemented by nurses with advanced knowledge about disabilities, aging, chronic illness and psychosocial needs of families. Family Centered Care (FCC) is a philosophical and systematic approach of serving the family as a unit (Al-Motlaq et al., 2018), knowing that parent-caregivers and children are all stakeholders in meeting the needs of the individual with IDD.

A model that helps bring individuals, when able, and parents into the decision-making process is shared decision making (SDM) (Charles, Gafni, & Whelan, 1997) and informed shared decision-making (ISDM) (Towle, Godolphin, Grams, & La Marre, 2006), where information sharing is a prerequisite to treatment decisions made by all stakeholders who have reached consensus. Interdisciplinary teams need to work

with both caregivers and their children to support healthcare decisions, self-care independence, and in the event when current living arrangement is no longer safe or optimum, decision-making for alternative placement with greater supervision and medical oversight. Nurses with advance practice skills are key to guide the SDM process.

Parents approaching retirement age who have adult children with ID/DD who may also be baby boomers, have spent a lifetime of caring for the health and welfare of their children. These families often first come to the attention of the aging network through referrals from hospital discharge planners, friends, and neighbors, especially when the older parents need support due to age-related changes in health and function. One of the challenges of the aging population of baby boomers who have limited cognitive ability is that throughout their lives, healthcare decisions have not always been their own. Today, physicians – and other healthcare providers including nurses – are being taught to work toward accepting the patient as an equal partner and developing necessary skills to involve their patients as partners in care and decision making (Moulton & King, 2010; Nickel, Weinberger, Guze, et al., 2018). Nurses play an integral role in understanding how best to support families and individuals with IDD in the shared decision-making process.

Adults aging with IDD are more likely than adults in the general population to have received life-long services and supports. Based on 2015 data, an estimated 71% of individuals with IDD live with their family caregiver (s). Of those living with their family caregiver (s), 24% have caregivers aged 60 years and older, while another 35% have caregivers aged 41 to 59 years. Only 13 % of adults with IDD live in supervised residential settings (Braddock, Hemp, Tanis, Wu & Haffer, 2017). As of 2014, nationally, there were nearly 100,000 individuals on waiting lists for residential out-of- home services and over 216,000 estimated to be waiting for any type of long-term services and supports (Larson et al., 2017).

Services for adults and aging adults with IDD have transformed over the past decades from segregated services; to individualized and person-centered planning for older adults that provide training in different activities in the communities and goal setting within their circle of support; to more emphasis on the rights to full inclusion in the community, universal design and supported decision-making. The latter is described in the Medicaid Home and Community-Based Services Final Rule (Federal Register, 2014) where home and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings. These types of services are woefully in need of competent nurses and an array of providers who are aware of the connection of aging and disability.

As services in the US evolve, the demand for nursing leadership in caring for individuals with IDD grows, and especially the need for advance practice nurses with knowledge and skill that is required to meet the changing health needs of families. Increased supports for families are integral to helping the many adults with IDD who are living at home with family members. Challenges will occur as there is more pressure on community-based systems to supply a work force that can support people aging with and into disability. There is a growing recognition of family centered services, supportive decision-making and interdependence between people across generations. Finally, a need exists for research on better ways to bridge aging and disability (Trip, Whitehead, Crowe, Mirfin-Veitch, & Daffue, 2019).

Summary of the Scope of IDD Nursing Practice

The dynamic nature of the healthcare practice environment and the growing body of nursing research provide both the impetus and the opportunity for nursing in IDD to ensure competent

nursing practice in all settings for all individuals with IDD and to promote ongoing professional development that enhances the quality of nursing practice. *Intellectual and Developmental Disabilities Nursing: Scope and Standards of Practice, Third Edition*, assists that process by delineating the professional scope and standards of practice and responsibilities of all professional registered nurses engaged in IDD nursing practice, regardless of setting. As such, it can serve as a basis for:

- Quality improvement systems
- Regulatory systems
- Healthcare reimbursement and financing methodologies
- Development and evaluation of nursing service delivery systems and organizational structures
- Certification activities
- Nursing education guidance
- Research guidance
- Position descriptions and performance appraisals
- Agency policies, procedures, and protocols
- Educational offerings
- Establishing the legal standard of care

Standards of Professional Nursing Practice

Significance of Standards

The Standards of Professional Nursing Practice are authoritative statements of the duties that all registered nurses, regardless of role, population, or specialty, are expected to perform competently. The standards published herein may be utilized as evidence of the standard of care, with the understanding that application of the standards is context dependent. The standards are subject to change with the dynamics of the nursing profession, as new patterns of professional practice are developed and accepted by the nursing profession and the public. In addition, specific conditions and clinical circumstances may also affect the application of the standards at a given time (e.g., during a natural disaster). The standards are subject to formal, periodic review and revision.

The competencies that accompany each standard may be evidence of compliance with the corresponding standard. The list of competencies is not exhaustive. Whether a particular standard or competency applies depends upon the circumstances. The competencies are presented for the registered nurse level and are applicable for *all* nurses who specialize in IDD. Standards may include additional competencies delineated for the graduate-level prepared registered nurse, a category that also includes advanced practice registered nurses. In some instances, additional discrete competencies applicable only to advanced practice registered nurses may be included. These standards apply to the nursing care of individuals with IDD of all ages, cultures, socioeconomic backgrounds, and medical diagnoses. They further apply to any health care, education, residential, or community setting where healthcare consumers with IDD might be. The competencies have been developed to represent quality practice and performance in the nursing care of healthcare consumers with IDD.

Standards of Practice for IDD Nurses

Standard 1. Assessment

The registered nurse who specializes in IDD collects comprehensive data pertinent to the healthcare consumer's health and/or the situation.

Competencies

The IDD registered nurse:

- Collects pertinent data, including but not limited to demographics, social determinants of health, health disparities, and physical, functional, psychosocial, emotional, cognitive, sexual, cultural, age-related, environmental, spiritual/transpersonal, and economical assessments in a systematic, ongoing process with compassion and respect for the inherent dignity, worth, and unique attributes of every person. This may involve observation, interviewing, and the use of screening and assessment tools. Diagnostic tests may be used as part of the assessment process if the nurse has specific training in that area (e.g., developmental diagnostic testing).

- Uses analytical models and problem-solving tools that are appropriate for healthcare consumers with IDD.

- Recognizes the importance of the assessment parameters identified by WHO (World Health Organization), *Healthy People 2020*, or other organizations that influence nursing practice, in particular those for conditions that result in an IDD.

- Integrates knowledge from global and environmental factors into the assessment process.

- Elicits the healthcare consumer with IDD's values, preferences, expressed and unexpressed needs, and knowledge of the healthcare situation along with that of their family/legal guardian(s).

- Involves the healthcare consumer with IDD, family/legal guardian(s), other healthcare and interdisciplinary professionals and paraprofessionals, and the work and home environment, as appropriate, in holistic data collection.

- Recognizes the impact of one's own personal attitudes, values, and beliefs on the assessment process.

- Identifies barriers to effective communication based on psychosocial, literacy, financial, and cultural considerations.

- Assesses the impact of family dynamics on the healthcare consumer with IDD's health and wellness.

- Engages the healthcare consumer with IDD, their family/legal guardian(s) and other interprofessional team members in holistic, culturally sensitive data collection.

- Prioritizes data collection based on the healthcare consumer with IDD's immediate condition or the anticipated needs of the healthcare consumer with IDD or situation.

- Uses evidence-based assessment techniques, instruments, tools, available data, information, and knowledge relevant to the situation to identify patterns and variances, including, but not limited to, genetic studies, special serum screening (e.g., cystic fibrosis, Tay-Sachs, sickle cell disease), nutritional needs and metabolic functioning, and any other condition-specific data measures.

- Synthesizes all data, information, and knowledge from the healthcare consumer with IDD, family members/legal guardian(s), the interprofessional team, and individual's environment that is relevant to the situation to identify patterns and variances This may involve data and information from the school, work site, and/or residential setting.

- Applies ethical, legal, and privacy guidelines and policies to the collection, maintenance, use, and dissemination of data and information.

- Recognizes the healthcare consumers with IDD have authority over their own health by honoring their care preferences. As legally appropriate, a guardian may be involved in identifying and expressing those preferences.

- Documents relevant data accurately and in a manner accessible to the interprofessional team.

Additional competencies for the graduate-level prepared registered nurse who specializes in IDD

In addition to the registered nurse competencies, the graduate-level prepared registered nurse:

- Assesses the effect of interactions among individuals, family/legal guardian(s), community, and social systems on health and illness of the healthcare consumer with IDD.

- Synthesizes the results and information leading to clinical understanding.

Additional competencies for the advanced practice registered nurse who specializes in IDD

In addition to the competencies of the registered nurse and the graduate-level prepared registered nurse, the advanced practice registered nurse who specializes in IDD:

- Initiates diagnostic tests and procedures relevant to the healthcare consumer with IDD's current status.

- Uses advanced assessment, knowledge, and skills to maintain, enhance, or improve health conditions for the healthcare consumer with IDD.

Standard 2. Diagnosis

The registered nurse who specializes in IDD analyzes assessment data to determine diagnoses, problems, and issues.

Competencies

The IDD registered nurse:

- Identifies actual or potential risks to the healthcare consumer with IDD's health and safety or barriers to health, which may include but are not limited to interpersonal, systematic, cultural, or environmental circumstances.

- Uses assessment data, standardized classification systems, technology, and clinical decision support tools to articulate actual or potential diagnoses, problems, and issues.

- Verifies the diagnoses, problems, and issues with the individual with IDD, family/legal guardian(s), community, population, and interprofessional colleagues.

- Prioritizes diagnoses, problems, and issues based on mutually established goals to meet the needs of the healthcare consumer with IDD across the health-illness continuum.

- Documents diagnoses, problems, and issues in a manner that facilitates the determination of the expected outcomes and plan.

Additional competencies for the graduate-level prepared registered nurse who specializes in IDD

In addition to the competencies of the registered nurse, the graduate-level prepared registered nurse who specializes in IDD:

- Uses information and communication technologies to analyze diagnostic practice patterns of nurses and other members of the interprofessional healthcare team.

- Employs aggregate-level data to articulate diagnoses, problems, and issues of healthcare consumers with IDD and organizational systems.

Additional competencies for the advanced practice registered nurse who specializes in IDD

In addition to the competencies of the registered nurse and the graduate-level prepared registered nurse, the advanced practice registered nurse who specializes in IDD:

- Formulates a differential diagnosis based on the assessment (including developmental), history, physical examination, and diagnostic test results.
- Systematically compares the history and clinical findings with normal and abnormal variations and developmental events in formulating differential diagnoses, including specific values, ranges, and outcomes for a specific diagnosis (e.g., Down syndrome).
- Serves as a consultant to the registered nurse and other staff in developing and maintaining competence in the diagnostic process.
- Analyzes accessibility and availability of services, barriers to adequate health care, specific populations at high risk, health promotion needs for specific populations, and environmental hazards that may affect the health of healthcare consumers with IDD.

Standard 3. Outcomes identification

The registered nurse who specializes in IDD identifies expected outcomes for a plan individualized to the healthcare consumer with IDD and/or the situation.

Competencies

The IDD registered nurse:

- Engages the healthcare consumer with IDD, family/legal guardian(s), interprofessional team, and others in partnership to identity expected outcomes.

- Formulates culturally sensitive expected outcomes derived from assessments and diagnoses.

- Uses clinical expertise and current evidence-based practice to identity health risks, benefits, costs, and/or expected trajectory of the condition.

- Collaborates with the healthcare consumer with IDD and their family/legal guardian(s) to define expected outcomes integrating the healthcare consumer with IDD and their family members/legal guardian(s)' culture, values, and ethical considerations.

- Generates a time frame for the attainment of expected outcomes.

- Develops expected outcomes that facilitate coordination of care and person-centered care as appropriate.

- Modifies expected outcomes based on the evaluation of the status (i.e., health, social, living, economic, and/or legal) of the healthcare consumer with IDD and situation.

- Documents expected outcomes as measurable goals.

- Evaluates the actual outcomes in relation to expected outcomes, safety, and quality standards.

Additional competencies for the graduate-level prepared registered nurse who specializes in IDD, including the APRN who specializes in IDD

In addition to the competencies of the registered nurse, the graduate-level prepared registered nurse or advanced practice registered nurse who specializes in IDD:

- Defines expected outcomes that incorporated cost, clinical effectiveness, legal and ethical boundaries, among the individual with IDD, family/legal guardian(s), healthcare providers, and are aligned with the outcomes identified by members of the interprofessional team.

- Differentiates outcomes that require care process interventions from those that require system-level actions.

- Integrates scientific evidence and best practices to achieve expected outcomes.

- Advocates for outcomes that reflect the healthcare consumer's culture, values, and ethical concerns.

Standard 4. Planning

The registered nurse who specializes in IDD develops a plan that prescribes strategies and alternatives to attain expected, measurable outcomes.

Competencies

The IDD registered nurse:

- Develops an individualized, holistic, evidence-based plan in partnership with the healthcare consumer with IDD, their family/legal guardian(s), and interprofessional tea considering the person's characteristics or situation, including but not limited to values, beliefs, spiritual and

health practices, preferences, choices, chronological age and developmental level, coping style, culture, available technology, and the least restrictive environment.

- Establishes the plan priorities with the healthcare consumer with IDD, their family/legal guardian(s), and interprofessional team.

- Advocates for responsible and appropriate use of interventions to minimize unwarranted or unwanted treatment and/or healthcare consumer suffering.

- Prioritizes elements of the plan based on the assessment of the healthcare consumer with IDD's level of risk and safety needs.

- Includes evidence-based strategies in the plan to address each of the identified diagnoses, problems, or issues. These strategies may include but are not limited to:
    - Promotion and restoration of health,
    - Prevention of illness, injury, and disease,
    - Facilitation of healing,
    - Alleviation of suffering, and
    - Supportive care

- Incorporates an implementation pathway that describes steps and milestones.

- Identifies cost and economic implications of the plan on the healthcare consumer with IDD, family/legal guardian(s), caregivers, or other affected parties.

- Integrates current scientific evidence, trends, and research affecting comprehensive care of healthcare consumers of all ages with IDD into the planning process.

- Uses the plan to provide direction to family members/legal guardian(s) and other members of the healthcare and interprofessional team.

- Develops a plan that reflects compliance with current statutes, rules and regulations, and standards affecting comprehensive care of healthcare consumers of all ages with IDD into the planning process.

- Investigates practice settings and safe space and time for the nurse and the healthcare consumer with IDD to explore suggested, potential, and alternative options.

- Modifies the plan according to the ongoing assessment of the healthcare consumer with IDD's response and other outcome indicators.

- Documents the plan using standardized, person-first language or recognized terminology.

Additional competencies for the graduate-level prepared registered nurse who specializes in IDD

In addition to the competencies of the registered nurse, the graduate-level prepared registered nurse who specializes in IDD:

- Designs strategies and tactics to meet the multifaceted and complex needs of healthcare consumers with IDD or other.

- Leads the design and development of interprofessional processes to address the identified diagnoses, problems, or issues.

- Designs innovative nursing practices.

- Participates actively in the development and continuous improvement of systems that support the planning process.

Additional competencies for the advanced practice registered nurse who specializes in IDD

In addition to the competencies of the registered nurse and graduate-level prepared registered nurse, the advanced practice registered nurse who specializes in IDD:

- Integrates assessment strategies, screening and diagnostic strategies, and therapeutic interventions that reflect current evidence-based knowledge and practice.
- Selects or designs strategies to meet the multifaceted and complex needs of healthcare consumers with IDD.
- Includes in the plan a synthesis of the values and beliefs of the healthcare consumer with IDD regarding nursing, medical, social, and educational therapies.
- Leads the design and development of interprofessional processes to address the identified diagnosis, situation, or issue.
- Participates actively in the development and continuous improvement of organizational systems that support the planning process.
- Supports the integration of clinical, human, and financial resources to enhance and complete the decision-making and evaluation processes.
- Serves as a consultant to the registered nurse to plan development, priority setting, cost-benefit analysis, and identification of resources, as needed.
- Collaborates with the registered nurse and other members of the interprofessional team, and in partnership with the community, derives community-focused plans that are based on identified problems, conditions, or needs that build on the strengths of the community.
- Develops plans that ensure continuity of care and minimize or eliminate gaps and duplications of services.

Standard 5. Implementation

The registered nurse who specializes in IDD implements the identified plan.

Competencies

The IDD registered nurse:

- Partners with the healthcare consumer with IDD, their family/legal guardian(s), significant others, and caregivers as appropriate to implement the plan in a safe, effective, efficient, timely, patient-centered, and equitable manner (IOM, 2010).

- Integrates interprofessional team partners in implementation of the plan through collaboration and communication across the continuum of care.

- Demonstrates caring behaviors to develop therapeutic relationships with healthcare consumers with IDD, significant others, and groups of people receiving care.

- Provides culturally congruent, holistic, and person-centered care that focuses on the healthcare consumer with IDD and addresses and advocates for the needs of diverse populations across the lifespan.

- Uses evidence-based interventions and strategies to achieve the mutually identified goals and outcomes specific to the problem or needs.

- Integrates critical thinking and technology solutions to implement the nursing process to collect, measure, record, retrieve, trend, and analyze data and information to enhance nursing practice and healthcare consumer outcomes.

- Uses community resources and systems to implement the plan.

- Collaborates with nursing colleagues and other healthcare providers from diverse backgrounds to implement and integrate the plan.

- Accommodates different styles of communication used by healthcare consumers with IDD, families/legal guardian(s), members of the interprofessional team, and other healthcare providers.

- Delegates according to the health, safety, and welfare of the healthcare consumer with IDD and considering the circumstance, person, task, direction or communication, supervision, evaluation, as well as the state nurse practice act regulations, institution, and regulatory entities while maintaining accountability for the care.

- Promotes the capacity of the healthcare consumer with IDD to achieve the optimal level of participation and problem-solving.

- Documents implementation and any modifications, including accommodations and changes or omissions, of the identified plan.

Additional competencies for the graduate-level prepared registered nurse who specializes in IDD

In addition to the competencies of the registered nurse, the graduate-level prepared registered nurse who specializes in IDD:

- Uses systems, organizations, and community resources to lead effective changes and implement the plan.

- Applies quality principles while articulating methods, tools, performance measures, and standards as they relate to implementation of the plan.

- Translates evidence into practice.

- Leads interprofessional teams to communicate, collaborate, and consult effectively.

- Demonstrates leadership skills that emphasize ethical and critical decision-making, effective working relationships, and systems perspective.

- Serves as a consultant to provide additional insight and potential solutions.

- Uses theory-driven approaches to effect organizational or system change.

Additional competencies for the advanced practice registered nurse who specializes in IDD

In addition to the competencies of the registered nurse and graduate-level prepared nurse, the advanced practice registered nurse who specializes in IDD:

- Uses prescriptive authority, procedures, referrals, treatments, and therapies in accordance with state and federal laws and regulations.

- Facilitates use of systems, organizations, and community resources to implement the plan.

- Uses advanced communication skills to promote relationships between nurses and healthcare consumers with IDD, to provide a context for open communication about the healthcare consumer's experiences, and to improve healthcare consumer outcomes.

- Participates actively in the development and continuous improvement of systems that support implementation of the plan.

- Prescribes traditional and integrative evidence-based treatments, therapies, and procedures that are compatible with the healthcare consumer with IDDs' cultural preferences and norms.

- Prescribes evidence-based pharmacological agents and treatments according to clinical indicators and results of screening, diagnostic, and laboratory tests.

- Supports collaboration with nursing colleagues and other members of the interprofessional team to implement the plan.

- Provides clinical consultation for healthcare consumers with IDD and professionals related to complex clinical cases to improve care and patient outcomes.

- Implements the plan using principles of project or systems management.

Standard 5A. Coordination of Care

The registered nurse who specializes in IDD coordinates care delivery. Coordination of care requires that the nurse work closely with individuals with IDD, families, community resources and other health systems.

Competencies

The IDD registered nurse:

- Organizes the components of the plan.
- Collaborates with the consumer with IDD and the family/legal guardian(s), as appropriate, to help manage healthcare based on mutually agreed upon outcomes.
- Manages a healthcare consumer with IDD's care in order to reach mutually agreed upon outcomes.
- Engages healthcare consumers with IDD in self-care to achieve preferred goals for quality of life in partnership with family/legal guardian(s).
- Assists the healthcare consumer with IDD and the family/legal guardian(s), as appropriate, to identity options for care.
- Communicates with the healthcare consumer with IDD, family/legal guardian(s), interprofessional team, and community-based personnel to effect safe transitions in continuity of care.
- Advocates for the delivery of dignified and holistic care by the interprofessional team.
- Documents the coordination of care.
- Makes referrals to other disciplines as needed.
- Provides direction or supervision to ancillary and unlicensed personnel who provide health care to healthcare consumers with IDD and their families/legal guardian(s).
- Keeps the healthcare consumer with IDD and family/legal guardian(s) (and direct care support professionals when present) informed about the health status of the consumer.
- Keeps the healthcare consumer with IDD and the family/guardian(s) informed about healthcare resources that are available.

- Employs strategies to promote health in home and community settings that are safe and utilize the least restrictive alternatives.

Additional competencies for the graduate-level prepared registered nurse who specializes in IDD

In addition to the competencies of the registered nurse, the graduate-level prepared registered nurse who specializes in IDD:

- Provides leadership in the coordination of interprofessional healthcare for integrated delivery of healthcare consumer services to achieve safe, effective, efficient, timely, patient-centered, and equitable care (IOM, 2010).

Additional competencies for the advanced practice registered nurse who specializes in IDD

In additional to the competencies of the registered nurse and graduate-level prepared registered nurse, the advanced practice registered nurse who specialize in IDD:

- Manages identified consumer panels or populations.

- Serves as the healthcare consumer with IDD's primary care provider and coordinator of healthcare services in accordance with the state and federal laws and regulations.

- Provides leadership in the coordination of interprofessional health care for integrated delivery of healthcare services for the healthcare consumer with IDD.

- Synthesizes data and information to prescribe and provide necessary system and community support measures, including modifications of environments.

- Coordinates system and community resources that enhance delivery of care across continuums.

Standard 5B. Health Teaching and Health Promotion

The registered nurse who specializes in IDD employs strategies to promote health, prevention of secondary disability, and a safe environment.

Competencies

The IDD registered nurse:

- Provides opportunities for the healthcare consumer with IDD to identify needed healthcare promotion, disease prevention, and self-management topics.

- Provides health teaching that addresses such topics as healthy lifestyles, risk-reducing behaviors, developmental needs, activities of daily living, self-care concepts, and preventive self-care.

- Uses health promotion and health teaching methods in collaboration with the healthcare consumer with IDD's values, beliefs, health practices, developmental level, learning needs, readiness and ability to learn, language preference, spirituality, culture, and socioeconomic status.

- Uses feedback and evaluations from the healthcare consumer with IDD, family/legal guardian(s), and caregivers, as appropriate, to determine the effectiveness of the employed strategies.

- Uses technologies to communicate health promotion and disease prevention information to the healthcare consumer with IDD and their families/legal guardian(s) in a variety of settings.

- Provides healthcare consumers with IDD and their families/legal guardian(s) with information about intended effects and potential adverse effects of the plan of care.

- Engages consumer alliance and advocacy groups in health teaching and health promotion activities for healthcare consumers with IDD.

- Provides anticipatory guidance to healthcare consumers with IDD and their families/legal guardian(s) to promote health and prevent or reduce the risk of negative health outcomes.

Additional competencies for the graduate-level prepared registered nurse, including the APRN who specializes in IDD

In addition to the competencies of the registered nurse, the graduate-level prepared registered nurse or advanced practice registered nurse who specializes in IDD:

- Synthesizes empirical evidence on risk behaviors, gender roles, learning theories, behavioral change theories, motivational theories, translational theories for evidence-based practice, epidemiology, and other related theories and frameworks when designing health education information and programs.

- Evaluates health information resources for applicability, accuracy, readability, and comprehensibility to help healthcare consumers with IDD, family/legal guardian(s), and other members of the interprofessional team access quality health information.

- Conducts personalized health teaching and counseling considering comparative effectiveness research recommendations.

- Designs health information and healthcare consumer education appropriate to the developmental level, learning needs, readiness to learn, and cultural values and beliefs of the healthcare consumer with IDD.

- Provides anticipatory guidance to individuals with IDD, families/legal guardian(s), groups, and communities to promote health and prevent or reduce the risk of health problems.

Standard 6. Evaluation

The registered nurse who specializes in IDD evaluates progress toward attainment of goals and outcomes.

Competencies

The IDD registered nurse:

- Conducts a holistic, systematic, ongoing, and criterion-based evaluation of the goals and outcomes in a relation to the structure, processes, and timeline prescribed in the plan.
- Collaborates with the healthcare consumer with IDD, family/legal guardian(s), members of the interprofessional team, and others involved in the care or situation in the evaluation process.
- Determines, in partnership with the healthcare consumer with IDD and other stakeholders, the patient-centeredness, effectiveness, efficiency, safety, timeliness, and equitability (IOM, 2001) of the strategies in relation to the responses to the plan and attainment of outcomes. Other defined criteria (e.g., Quality and Safety Education for Nurses) may be used as well.
- Uses ongoing assessment data to revise the diagnosis, outcomes, plan, and implementation strategies.
- Shares evaluation data and conclusions with the healthcare consumer with IDD and other stakeholders in accordance with federal and state regulations.
- Participates in assessing and assuring the responsible and appropriate use of interventions in order to minimize unwarranted and unwanted treatment and healthcare consumer suffering.
- Documents the results of the evaluation.

Additional competencies for the graduate-level prepared registered nurse, including the APRN who specializes in IDD

In addition to the competencies of the registered nurse, the graduate-level prepared registered nurse or the advanced practice registered nurse who specializes in IDD:

- Evaluates the accuracy of the diagnosis and the effectiveness of the interventions and other variables in relation to the attainment of expected outcomes.
- Synthesizes evaluation data from the healthcare consumer with IDD, their family/legal guardian(s), caregivers, community, population and/or institution to determine the effectiveness of the plan.
- Engages in a systematic evaluation process to revise the plan to enhance its effectiveness.
- Uses results of the evaluation to make or recommend process, policy, procedure, or protocol revisions when warranted.

Standards of Professional Performance for IDD Nurses

Standard 7. Ethics

The registered nurse who specializes in IDD practices ethically.

Competencies

The IDD registered nurse:

- Uses the *Code of Ethics for Nurses with Interpretive Statements* (ANA, 2015) to guide practice.
- Practices compassion and respect for the inherent dignity, worth and unique attributes the healthcare consumer with IDD, family/legal guardian(s).
- Is committed to the healthcare consumer with IDD, their family/guardian(s), circle of support, community or populations.
- Recognizes the centrality of the healthcare consumer with IDD and family/legal guardian(s) as core members of any healthcare team.
- Upholds confidentiality of the healthcare consumer with IDD within legal and regulatory parameters.
- Serves as advocate for the healthcare consumer with IDD and family/legal guardian(s) by supporting the development of their advocacy and self-advocacy skills.
- Maintains a therapeutic and professional relationship with the healthcare consumer with IDD within appropriate professional role boundaries.
- Protects, promotes, and advocates for the health and safety of the healthcare consumer with IDD and their family/guardian(s).
- Has authority, accountability, and responsibility for the nursing practice act; makes decisions; and takes actions consistent with the obligation to promote health and provide optimal care of the healthcare consumer with IDD and their family/guardian(s).
- Owes the same duties to self as to others, including the responsibility to promote health and safety for consumers with IDD, their family/guardian(s); preserve wholeness of character and integrity, maintain competence, and continue personal and professional growth
- Establishes, maintains, and improves the ethical environment of the work setting and conditions of employment that are conducive to safe, quality health care for the consumer with IDD, family/guardian(s) and colleagues.
- Takes appropriate action regarding instances of illegal, unethical, or inappropriate behavior that can endanger or jeopardize the best interests of the healthcare consumer with IDD or situation.

- Questions healthcare practice when necessary for safety and quality improvement.
- Advocates for equitable healthcare consumer care.
- Informs administrators or others of the risks, benefits, and outcomes of programs and decisions that affect healthcare delivery.
- Respects the right of the healthcare consumer with IDD to self-determination and inclusion the healthcare consumer in decisions unless the healthcare consumer's incapacity to participate in a specific decision is demonstrated. Family or a legally designated guardian(s) is included in decision-making or makes the decision as a surrogate decision-maker if legally required.
- Identifies a surrogate for healthcare decisions in lieu of a formal guardianship process, when appropriate and in accordance with local and/or state statutes.
- Advocates for the healthcare consumer with IDD in self-determination decisions when in conflict with the surrogate decision-maker.
- Facilitates the self-determination decisions of the healthcare consumer with IDD in all healthcare settings.
- Acts as an advocate for the healthcare consumer with IDD and family/legal guardian(s) and initiates referral to a qualified advocate for healthcare consumers with IDD when appropriate.
- Works to prevent abuse or exploitation of the healthcare consumer with IDD and promptly responds to suspicion or evidence by reporting to appropriate authorities.
- Assists in assuring that the living arrangement for the healthcare consumer with IDD is the most appropriate and inclusive environment.
- Contributes to the educational program recommendations and advocates for inclusive environments to maximize the potential of the healthcare consumer with IDD.
- Contributes to the life plan via advocacy for the most appropriate employment situation for the healthcare consumer with IDD. The nurse assists in identifying reasonable accommodations to maximize the healthcare consumer's performance and satisfaction with chosen employment.
- Assists in the referral process for local, state, regional, and federal assistance programs.
- Supports the expression of sexuality of the healthcare consumer with IDD in a manner that is consistent with the healthcare consumer's native culture, gender preference, religious upbringing, family values, and level of maturity and provides counseling as appropriate.
- Contributes to an environment that protects the healthcare consumer with IDD from sexual exploitation at home, school, work, and community.

- Serves as an advocate to ensure that the healthcare consumer with IDD receives coordinated, continuous, and accessible health care that is provided by a professional who is competent in managing health concerns of healthcare consumers with IDD and family/guardian(s).
- Provides or arranges for effective and appropriate palliative care for healthcare consumers with IDD who undergo tests or treatments for illnesses, have chronic conditions, and/or are at the end of life.
- Advocates for life-sustaining treatment or refusal/withdrawal of life-sustaining treatment as the healthcare consumer with IDD and family or legal guardian(s) decide.
- Provides support and resources for end-of-life care, grief, and bereavement when healthcare consumers with IDD experience loss.
- Participates on interprofessional teams that address ethical risks, benefits, and outcomes.
- Advances the profession through research and scholarly inquiry, professional standards development, and influences the generation of both nursing and health policy.
- Collaborates with other health professionals and the public to protect human rights, promote health diplomacy, and reduce health disparities for the healthcare consumer with IDD and their family/legal guardian(s).
- Articulates nursing values in work with professional organizations
- Maintains the integrity of the profession
- Integrates principles of social justice into nursing and health policy on behalf of consumers with IDD, their families and legal guardian(s).

Additional competencies for the advanced practice registered nurse

The advanced practice registered nurse who specializes in IDD:

- Informs the healthcare consumer with IDD and family/legal guardian(s) of the risks, benefits, and outcomes of healthcare regimens to allow informed decision-making, including informed consent and informed refusal.

Standard 8. Culturally Congruent Practice

The registered nurse who specializes in IDD practices in a manner that is congruent with cultural diversity and inclusion principles, especially as it relates to individuals with IDD.

Competencies

The IDD registered nurse:

- Demonstrates respect, equity, and empathy in actions and interactions with all healthcare consumers with IDD and families/legal guardian(s).
- Participates in life-long learning to understand cultural preferences, worldview, choices, and decision-making processes of diverse consumers with IDD and their families/legal guardian(s).
- Creates an inventory of one's own values, beliefs, and cultural heritage.
- Applies knowledge of variations in health beliefs, practices, and communication patterns in all nursing practice activities.
- Identifies the stage of the consumer's acculturation and accompanying patterns of needs and engagement.
- Considers the effects and impact of discrimination and oppression on practice within and among vulnerable cultural groups.
- Uses skills and tools that are appropriately vetted for the culture, literacy, and language of the population with IDD and their families/legal guardian(s) served.
- Communicates with appropriate language and behaviors, including the use of medical interpreters and translators and assistive devices in accordance with consumer with IDD and family/legal guardian(s) preferences.
- Identifies the cultural-specific meaning of interactions, terms, and content.
- Respects consumer with IDD decisions based on age, tradition, belief and family influence, and stage of acculturation.
- Advocates for policies that promote health and prevent harm among culturally diverse, under-served, or under-represented consumers with IDD, their families/legal guardian(s).
- Promotes equal access for consumers with IDD, families/legal guardian(s) to services, tests, interventions, health promotion programs, enrollment in research, education, and other opportunities.
- Educates nurse colleagues and other professionals about cultural similarities and differences of healthcare consumers with IDD, families/legal guardian(s), groups, communities, and populations.

Additional competencies for the graduate-level prepared registered nurse

In addition to the competencies of the registered nurse, the graduate-level prepared registered nurse who specializes in IDD:

- Evaluates tools, instruments, and services provided to culturally diverse populations.
- Advances organizational policies, programs, services, and practice that reflect respect, equity, and values for diversity and inclusion of consumers with IDD and families/legal guardian(s).

- Engages consumers with IDD, families/legal guardian(s), key stakeholders, and others in designing and establishing internal and external cross-cultural partnerships.
- Conducts research to improve health care and healthcare outcomes for culturally diverse consumers with IDD and their families/legal guardian(s).
- Develops recruitment and retention strategies to achieve a multicultural workforce.

Additional competencies for the advanced practice registered nurse

In addition to the competencies of the registered nurse and graduate-level prepared registered nurse, the advanced practice registered nurse who specializes in IDD:

- Promotes shared decision-making solutions in planning, prescribing, and evaluating processes when the healthcare consumer's with IDD and their families/legal guardian(s) cultural preferences and norms may create incompatibility with evidence-based practice.
- Leads interprofessional teams to identify the cultural and language needs of the consumer with IDD and family/legal guardian(s).

Standard 9. Communication

The registered nurse who specializes in IDD communicates effectively in a variety of formats in all areas of practice.

Competencies

The IDD registered nurse:

- Conveys information to healthcare consumers, families/legal guardian(s), the interprofessional team, and others in communication formats that promote accuracy, health literacy and in the native language of non-English speakers.
- Discloses observations or concerns related to hazards and errors in care or the practice environment to the appropriate level of professional and/or institutional oversight and regulation.
- Establishes communication with other providers to minimize risks associated with forthcoming and actual transfers and transition in care delivery.
- Contributes her or his own professional perspectives in discussions pertaining to the care of individuals with IDD, their families/legal guardian(s) with the interprofessional team.
- Uses current knowledge of the adaptive, and communication skills of the healthcare consumer with IDD to communicate effectively with the healthcare consumer.

- Facilitates communication between the healthcare consumer with IDD, family/legal guardian(s), and members of the interprofessional team, building on the adaptive and communication strengths of the healthcare consumer with IDD.

- Confers with interdisciplinary team members including speech and language specialists and audiologists on the need of the individual with IDD to use assistive devices and hearing aids for communication.

Standard 10. Collaboration

The registered nurse who specializes in IDD collaborates with the healthcare consumer with IDD, family/legal guardian(s), and other key stakeholders in the conduct of nursing practice.

Competencies

The IDD registered nurse:

- Partners with others to effect change and produce positive person-centered and family-centered outcomes through the sharing of IDD knowledge of the healthcare consumer with IDD, the family/legal guardian(s) and/or situation.

- Communicates with the healthcare consumer with IDD, family/legal guardian(s), members of the interprofessional team, healthcare providers, and community providers regarding healthcare consumer care and the nurse's role in the provision of IDD care.

- Promotes conflict management and engagement within the professional scope of practice.

- Participates in building consensus or resolving conflict in the context of patient care for individuals with IDD, their families/legal guardian(s).

- Applies group process and negotiation techniques with the healthcare consumer with IDD, the family/legal guardian(s) and colleagues.

- Adheres to standards and applicable codes of conduct that govern behavior among peers and colleagues to create a work environment that promotes cooperation, respect, and trust.
- Cooperates in creating a documented person-centered and family-centered plan focused on outcomes and decisions related to care and delivery of services that indicates communication and involvement with healthcare consumers with IDD, families/legal guardian(s), and others.

- Engages in teamwork and team-building processes for the provision of person-centered and family-centered care for individuals with IDD, their families/legal guardian(s).

- Partners with other disciplines to enhance the outcomes of person-centered and family-centered care of healthcare consumers with IDD through interprofessional activities, such as

education, consultation, management, technological development, continuous quality improvement or research opportunities.

- Documents plans, communications, rationales for person-centered/family-centered plan changes, and collaborative discussions with the individual with IDD, the family/legal guardian(s) and interprofessional and nursing colleagues.

- Partners with the healthcare consumer with IDD and family/legal guardian(s) or significant others to support the efforts of healthcare consumers and family/legal guardian(s) to make appropriate decisions about utilization and allocation of resources.

Additional competencies for the advanced practice registered nurse

In addition to the competencies of the registered nurse, the advanced practice registered nurse who specializes in IDD:

- Partners with other disciplines to enhance the care of healthcare consumers with IDD through interprofessional activities, such as education, consultation, management, technological development, continuous quality improvement, or research opportunities.

- Invites the contribution of the healthcare consumer with IDD, family/legal guardian(s), and interprofessional and nursing team members in order to achieve optimal person-centered and family-centered outcomes.

- Leads in establishing, improving, and sustaining collaborative interprofessional and interagency relationships to achieve safe, quality evidence-based health care.

- Documents communications regarding the person-centered/family-centered plan of care, rationales for changes to the plan, and collaborative interprofessional and individual with IDD, family/legal guardian's discussions to improve the care of healthcare consumers with IDD.

- Partners with other interprofessional administrative team members in policy-making and in overall agency and community planning, implementation, and evaluation of services to and programs for healthcare consumers with IDD. Their families/legal guardian(s).

Standard 11. Leadership

The registered nurse who specializes in IDD leads in the professional practice setting and the profession.

Competencies

The IDD registered nurse:

- Oversees the nursing care given by others while retaining accountability for the quality of person-centered and family-centered care given to the healthcare consumer with IDD, the family/legal guardian.

- Abides by the vision, the associated goals, and the person-centered plan to implement and measure progress of a healthcare consumer with IDD or progress within the context of the healthcare organization.

- Demonstrates a commitment to continuous, lifelong learning and education for self and others in IDD and related fields.

- Mentors interprofessional and nursing colleagues for the advancement of IDD interprofessional and nursing practice, the profession, and quality health care for individuals with IDD, their families/guardian(s).

- Develops communication and conflict resolution skills.

- Participates in nursing and IDD professional organizations.

- Participates in efforts to influence healthcare policy involving healthcare consumers with IDD, their families/legal guardian(s) and the IDD and nursing profession.

- Influences institutional, professional and public decision-making bodies to improve the professional practice environment and healthcare outcomes of healthcare consumers with IDD and their families/legal guardian(s).

- Provides direction to enhance the effectiveness of the interprofessional team that provides services to individuals with IDD, their families/legal guardian(s) based upon a person-centered and family-centered framework of care that is evidence based.

- Interprets the role of IDD nursing for healthcare consumers with IDD, families/legal guardian(s), interprofessional colleagues and policymakers.

- Promotes communication of information and advancement of the profession as it relates to nursing and the field of IDD through writing, publishing, and presentations for interprofessional and nursing professional or lay audiences.

- Designs innovations to effect change in IDD nursing practice and outcomes of care for individuals with IDD, their families/guardian(s).

Additional competencies for the advanced practice registered nurse

In addition to the competencies of the registered nurse, the advanced practice registered nurse who specializes in IDD:

- Influences decision-making bodies to improve the professional practice environment and healthcare outcomes for healthcare consumers with IDD, their families/legal guardian(s).

- Promotes advanced practice nursing and role development by interpreting its role for healthcare consumers with IDD, families/legal guardian(s), interprofessional colleagues and policymakers.

- Models expert IDD nursing practice to interprofessional team members and healthcare consumers with IDD, their families/legal guardian(s).
- Mentors interprofessional and nursing colleagues in the acquisition of IDD clinical knowledge, skills, abilities, and judgment.

Standard 12. Education

The registered nurse who specializes in IDD attains knowledge and competence that reflect current nursing practice and promotes futuristic thinking.

Competencies

The IDD registered nurse:

- Identifies learning needs based on nursing knowledge, the various roles the IDD nurse may assume, and the changing needs of the IDD population.
- Participates in ongoing educational activities related to appropriate knowledge bases and professional issues needed to provide comprehensive, consumer and family-centered care to individuals with IDD across the lifespan, the family/guardian(s).
- Demonstrates a commitment to lifelong learning in the field of IDD and related areas of practice (i.e. psychology, occupational therapy, nutrition) through self-reflection and inquiry to address ongoing learning needs and personal growth needs.
- Seeks experiences that reflect current practice to maintain knowledge, skills, abilities, and judgment in clinical practice or role performance in the field of IDD and related areas of practice (i.e. psychology, occupational therapy, nutrition).
- Acquires knowledge and skills appropriate to the IDD role, population, specialty, setting, or situation.
- Seeks formal and independent learning experiences to develop and maintain clinical and professional skills and knowledge in the field of IDD and related areas of practice (i.e. psychology, occupational therapy, nutrition).
- Participates in formal or informal IDD consultations to address issues in IDD nursing practice as an application of education, knowledge base, and evidence-based practice.
- Shares educational findings, experiences, and ideas with peers in the field of IDD and related areas of practice (i.e. psychology, occupational therapy, nutrition).
- Contributes to a work environment conducive to the education of interdisciplinary healthcare professionals and paraprofessionals

- Maintains professional records that provide evidence of competence and lifelong learning in the field of IDD and related areas of practice (i.e. psychology, occupational therapy, nutrition) for licensure and certification purposes.

- Uses current healthcare research findings and other evidence related to the care of healthcare consumers with IDD to expand competencies pertaining to knowledge, skills, abilities, and judgment; to enhance role performance; and to increase knowledge of professional issues related to IDD nursing.

Standard 13. Evidence-Based Practice and Research

The registered nurse who specializes in IDD integrates evidence and research findings into practice.

Competencies

The IDD registered nurse:

- Utilizes current evidence-based nursing knowledge, including research findings generated in the IDD field and related fields, to guide practice.

- Incorporates evidence when initiating changes in IDD nursing practice.

- Participates, as appropriate to education level and position and IDD area of specialization, in the formulation of evidence-based practice through research and quality improvement.

- Shares personal or third-party IDD and related fields research findings with colleagues and peers.

- Participates, as appropriate to education level and position, in research, quality improvement and scholarly activities (i.e. systematic reviews) activities to improve the health and health care of healthcare consumers with IDD and their families/legal guardian(s).

- Engages healthcare consumers with IDD and their families/legal guardian(s) in research activities consistent with their informed consent, assent and informed refusal.

Additional competencies for the advanced practice registered nurse

In addition to the competencies of the registered nurse, the advanced practice registered nurse who specializes in IDD:

- Contributes to IDD nursing knowledge by conducting or synthesizing research, quality improvement, scholarly activities (i.e. systematic reviews) and other evidence that discovers, examines, and evaluates current practice, knowledge, theories, criteria, and creative approaches to improve healthcare outcomes of healthcare consumers with IDD, their families/legal guardian(s).

- Promotes a climate of research and clinical inquiry in the IDD field.

- Disseminates research findings through activities such as podium and poster presentations, publications, consultations, and journal clubs.

Standard 14. Quality of Practice

The registered nurse who specializes in IDD contributes to quality nursing practice.

Competencies

The IDD registered nurse:

- Demonstrates quality nursing care by documenting the application of the nursing process in a responsible, accountable, and ethical manner that are evidence-based.
- Uses creativity and innovation to enhance comprehensive nursing care that is person and family-centered of healthcare consumers with IDD and their families/legal guardian(s).
- Participates in quality improvement. Activities may include: examination of care practices in the hospital setting; implementation of intervention in community-based setting designed to prevent transmission of infections; and person-centered
- Provides leadership in the implementation of quality improvements for healthcare consumers with IDD and their families/legal guardian(s).
- Designs innovations to effect evidence-based change in practice and improve health and quality of life outcomes of healthcare consumers with IDD and their families.
- Participates in the programmatic evaluation of the practice environment and continuous quality improvement projects of nursing care provided to healthcare consumers with IDD and their families/legal guardian(s).
- Evaluates nursing care delegated to other professionals, direct care support professionals, unlicensed assistive personnel, or the family/legal guardian(s).
- Monitors health outcomes of the healthcare consumer with IDD in terms of measures of consumer satisfaction, measurable consumer outcomes and costs.
- Identifies opportunities for the generation, dissemination and use of research and evidence in IDD nursing.
- Participates in IDD and interprofessional organizations that strive to improve the quality of nursing and health care provided to healthcare consumers with IDD and their families/legal guardian(s).

Additional competencies for the advanced practice registered nurse

In addition to the competencies of the registered nurse, the advanced practice registered nurse who specializes in IDD nursing:

- Provides leadership in the design and implementation of continuous quality improvements projects.
- Evaluates on a continual basis, the practice environment and quality of nursing care rendered to individuals with IDD, families/legal guardian(s) in relation to existing evidence.
- Identifies opportunities for the generation, dissemination and use of IDD research and evidence in professional and consumer forums.
- Obtains and maintains IDD professional certification, as needed.
- Uses the results of continuous quality improvement to initiate changes in IDD nursing practice and the healthcare delivery system for individuals with IDD, their families/legal guardian(s).

Standard 15. Professional Practice Evaluation

The registered nurse who specializes in IDD evaluates one's own and others' nursing practice in relation to professional practice standards and guidelines, relevant statutes, rules, and regulations.

Competencies

The IDD registered nurse:

- Engages in self-evaluation of practice on a regular basis, identifying areas of strength, as well as areas in which professional development in IDD and related fields would be beneficial.
- Obtains informal feedback regarding her or his own practice from healthcare consumers with IDD, family/legal guardian(s), peers, professional nursing and interprofessional colleagues, and others, including direct care support professionals.
- Participates in systematic peer review as appropriate.
- Takes action to achieve goals identified during the evaluation process.
- Provides the evidence for practice decisions and actions as part of the informal and formal evaluation processes.
- Interacts with peers and colleagues to enhance her or his own professional IDD nursing practice or role performance.
- Provides peers with formal or informal constructive feedback regarding their IDD practice or role performance.

Additional competencies for the advanced practice registered nurse

In addition to the competencies of the registered nurse, the advanced practice registered nurse who specializes in IDD:

- Engages in a formal process seeking feedback regarding her or his own practice from healthcare consumers, peers, professional nursing and interprofessional colleagues, and others, including direct care support professionals.

Standard 16. Resource Utilization

The registered nurse specializing in IDD utilizes appropriate resources to plan, provide and sustain evidence-based nursing services that are safe, effective, and fiscally responsible to healthcare consumers with IDD.

Competencies

The IDD registered nurse:

- Assesses healthcare consumer care needs and the resources available to achieve desired outcomes for individuals with IDD, their families/legal guardian(s).
- Identifies resource allocation for the needs of the healthcare consumer with IDD, desired outcome, complexity of the strategy to meet their comprehensive needs, and the potential for harm if needs are not addressed.
- Delegates elements of person-centered/family-centered care to appropriate healthcare workers in accordance with any applicable legal or policy parameters or principles.
- Identifies the evidence when evaluating resources for individuals with IDD, their families/legal guardian(s).
- Advocates for resources, including technology, that enhance IDD nursing practice.
- Modifies IDD nursing practice when necessary to promote positive interaction between healthcare consumers with IDD, their families/parents, care providers, and technology.
- Assists the healthcare consumer with IDD and family/legal guardian(s) in identifying and securing appropriate services to address their needs across the healthcare continuum and lifespan.
- Assists the healthcare consumer with IDD and family/legal guardian(s) in factoring costs, risks, and benefits in decisions about treatment and care.
- Applies innovative solutions and strategies to obtain appropriate resources for individuals with IDD, their families/legal guardian(s).

- Utilizes organizational resources to ensure a work environment that is conducive to completing the identified person-centered/family-centered plan and outcomes for individuals with IDD, their families/legal guardian(s).

- Designs evaluation methods that measure safety and effectiveness of person-centered/family-centered interventions and outcomes for individuals with IDD, their families/legal guardian(s).

- Promotes activities that assist healthcare professionals and health care and community-based providers and policymakers, as appropriate, in becoming informed about costs, risks, and benefits of care, or of the plan and solution.

- Addresses discriminatory healthcare practices and the impact on resource allocation, especially for the IDD population and their caregivers.

Additional competencies for the advanced practice registered nurse

In addition to the competencies of the registered nurse, the advanced practice registered nurse who specializes in IDD:

- Utilizes organizational and community resources to formulate interprofessional person-centered/family centered plans of care for individuals with IDD, their families/legal guardian(s).

- Formulates innovative solutions for healthcare consumer care for individuals with IDD, their families/legal guardian(s) that utilize resources effectively and maintain quality of care.

- Designs evaluation strategies that demonstrate cost-effectiveness, cost benefit, and efficiency factors associated with IDD nursing practice.

Standard 17. Environmental Health

The registered nurse who specializes in IDD practices in an environmentally safe and healthy manner that promotes environmentally safe settings beneficial to the health and well-being of individuals with IDD.

Competencies

The IDD registered nurse:

- Attains knowledge of environmental health concepts, such as implementation of environmental health strategies.

- Promotes a practice environment that reduces environmental health risks for workers and healthcare consumers with IDD, their families/legal guardian(s).

- Assesses the practice environment for factors such as sound, odor, noise, and light that threaten health.

- Advocates for the safe, judicious and appropriate use of products in health care.
- Communicates information about environmental health risks and exposure reduction strategies to healthcare consumers with IDD, families/legal guardian(s), colleagues, and communities.
- Utilizes scientific evidence to determine if a product or treatment is an environmental threat.
- Participates in strategies to promote healthy communities for individuals with IDD, their families/legal guardian(s).
- Identifies developmental and behavioral characteristics that predispose healthcare consumers with IDD to increased risk of exposure to environmental hazards and risks.
- Carefully assesses the home, school, and/or work environments of healthcare consumers with IDD, their families/legal guardian(s) for potential threat of exposure to environ-mental hazards and risks.
- Uses knowledge of chronic health disorders and IDD to distinguish between signs and symptoms associated with disorders and disabilities and signs and symptoms associated with harmful environmental exposures.
- Develops strategies to prevent and/or minimize environmental health risks for healthcare consumers with IDD, their families and legal guardian(s).

Additional competencies for the advanced practice registered nurse

In addition to the competencies of the registered nurse, the advanced practice registered nurse who specializes in IDD:

- Creates interagency and interprofessional partnerships that promote sustainable environmental health policies and conditions for individuals with IDD, their families/legal guardian(s).
- Analyzes the impact of social, political, and economic influences on the environment and human health risk exposures for individuals with IDD across the lifespan, their families/legal guardian(s).
- Critically evaluates the manner in which environmental health issues related to the needs of individuals with IDD, their families/legal guardian(s) are presented by the popular media.
- Advocates for implementation of environmental principles for IDD nursing practice.
- Supports IDD nurses in advocating for and implementing environmental principles in IDD nursing practice.

Glossary

Advanced Practice Registered Nurses (APRNs). A nurse who completed an accredited graduate-level education program preparing her or him for the role of certified nurse practitioner, certified registered nurse anesthetist, certified nurse-midwife, or clinical nurse specialist; has passed a national certification examination that measures the APRN role and population-focused competencies; maintains continued competence as evidenced by recertification; and is licensed to practice as an APRN (adapted from APRN Joint Dialogue Group, 2008).

Advanced Practice Registered Nurses (APRNs) specializing in IDD. An APRN with IDD specialization requires specialized knowledge and skills obtained through formal and continuing education (i.e., Leadership Education in Neurodevelopmental Disabilities-LEND, meeting presentations on IDD health issues) related to the health care and management of conditions that are general or unique to the IDD population and their families.

Assessment. A systematic, dynamic process by which the registered nurse, through interaction with the patient, family/legal guardian(s), groups, communities, populations, and healthcare providers, collects pertinent data, including but not limited to demographics, social determinants of health, health disparities, and physical, functional, psychosocial, emotional, cognitive, sexual, cultural, age-related, environmental, spiritual/transpersonal, and economical assessments in a systematic, ongoing process with compassion and respect for the inherent dignity, worth, and unique attributes of every person. This may involve observation, interviewing, and the use of screening and assessment tools. Diagnostic tests may be used as part of the assessment process if the nurse has specific training in that area (e.g., developmental diagnostic testing).

Assistive Technology (AT). These adaptative devices can be used to assist individuals with IDD to improve and maintain level of functioning. They can be used to assist with all forms of activities such as the activities of daily living (ADL) that include bathing, dressing, grooming and eating. Examples of ADL assistive technologies include wheelchairs, walkers, bath bench, grab bars, ramps, adaptive utensils and long-handled devices for dressing, reaching. AT devices are used to support work-related activities and facilitate learning such as the use of computers, workstation adaptations, automated page turners, and hearing aids.

Autonomy. The capacity of a nurse to determine her or his own actions through independent choice, including demonstration of competence, within the full scope of nursing practice.

Caregiver. A person who provides direct care for another, such as a child, dependent adult, the individual with a disability or chronic illness.

Code of ethics (nursing). A list of provisions that makes explicit the primary goals, values, and obligations of the nursing profession and expresses its values, duties, and commitments to the society of which it is a part. In the United States, nurses abide by and adhere to *Code of Ethics for Nurses with Interpretive Statements* (ANA, 2015).

Collaboration. A professional healthcare partnership grounded in a reciprocal and respectful recognition and acceptance of: each partner's unique expertise, power, and sphere of influence and responsibilities; the commonality of goals; the mutual safeguarding of the legitimate interest of each party; and the advantages of such a relationship (ANA, 2015a).

Competency. An expected and measurable level of nursing performance that integrates knowledge, skills, abilities, and judgment, based on established scientific knowledge and expectations for nursing practice.

Comprehensive care. Care that integrates health (primary, secondary, and tertiary levels) and social/family/legal guardian support and service programs with educational or vocational services.

Continuity of care. An interprofessional process that includes healthcare consumers, families/legal guardian(s), and other stakeholders in the development of a coordinated plan of care. This process facilitates the healthcare consumer's transition between settings and healthcare providers, based on changing needs and available resources.

Coordinated care (also known as coordination of care). Care that facilitates access to needed resources and services and promotes continuity of care among multiple providers and diverse service systems. Work is done collaboratively with the healthcare consumer and/or family/legal guardian(s) to achieve mutually agreed-upon goals. Timeliness, appropriateness, and completeness of care are central to this concept.

Cultural competence. Care that respects, honors, and incorporates beliefs, norms, attitudes, and life practices of healthcare consumers and their families/legal guardian(s) congruent with their values and practices.

Cultural knowledge. The concepts and language of an ethnic or social group used to describe their health-related values, beliefs, and traditional practices, as well as the etiologies of their conditions, preferred treatments, and any contraindications for treatments or pharmacological interventions. Historical events, such as war-related migration, oppression, and structural discrimination are also included, when relevant (ANA, 2015a).

Cultural skills. The integration of cultural knowledge and expertise into practice when assessing, communicating with, and providing care for members of a racial, ethnic or social group (ANA, 2015a).

Delegation. The transfer of responsibility for the performance of a task from one individual to another while retaining accountability for the outcome. Example: The RN, in delegating a task to unlicensed assistive personnel, transfers the responsibility for performance of the task but retains professional accountability for the overall care.

Developmentally appropriate. Care focused on the unique needs of healthcare consumers across the lifespan to promote developmental skills and independence congruent with the healthcare consumer's present functional abilities rather than chronological age.

Developmental screening. Generally assessing a person's global or specific domains of development for evidence of developmental deviation. The results of screening are not diagnostic; if the results reveal a possibility of delay, they must be repeated within a short period of time. If developmental delay is suspected after the repeated screening, the person should be referred for diagnosis and appropriate treatment and intervention.

Diagnosis. A clinical judgment about the healthcare consumer's response to actual or potential health conditions or needs. The diagnosis provides the basis for development and determination of a plan to achieve expected outcomes. Registered nurses use nursing and medical diagnoses depending upon educational and clinical preparation and legal authority.

Diagnostic overshadowing. Assigning a mental health diagnosis to a person with IDD because the person has IDD. Example: An adolescent with Down syndrome is "feeling down" after a breakup with a boyfriend. The adolescent's provider diagnoses depression without any assessment other than the history.

Early intervention. The provision of health, social, and educational services in an interprofessional setting for children from birth to three years of age who are at risk for or who have IDD.

Environment. The surrounding habitat, context, milieu, conditions, and atmosphere in which all living systems participate and interact. It includes the physical habitat as well as cultural, psychological, social, and historical influences. It includes both the external physical space as well as an individual's internal physical, mental, emotional, social, and spiritual experience (ANA, 2015; AHNA & ANA, 2013)

Environmental health. Aspects of human health, including quality of life, that are determined by physical, chemical, biological, social, and psychological influences in the environment. It also refers to the theory and practice of assessing, correcting, controlling, and preventing those factors in the environment that can potentially adversely affect the health of present and future generations.

Evaluation. The process of determining the progress toward attainment of expected outcomes, including the effectiveness of care.

Evidence-based practice. A life-long problem-solving approach that integrates the best evidence from well-designed research studies and evidence-based theories; clinical expertise and evidence from assessment of the health consumer's history and condition, as well as healthcare resources; and patient, family, group, community, and population preferences and values. When EBP is delivered in a context of caring, as well as an ecosystem or environment that supports it, the best clinical decisions are made to yield positive healthcare consumer outcomes (ANA, 2015a; Melnyk, Gallagher-Ford, Long, & Fineout-Overholt, 2014).

Expected outcomes. End results that are measurable, desirable, and observable, and translate into observable behaviors or relate to policies, funding, and/or organizations.

Family. Family of origin or significant others, such as legal guardian(s), if identified by the healthcare consumer.

Family-centered care. Care to healthcare consumers in need of special services (e.g., therapies, rehabilitation, adaptive equipment) that is provided within the context of the healthcare consumer's family. The strengths, individuality, and diversity of each family/legal guardian is acknowledged and valued. The cornerstone of family-centered care is a partnership between the family/legal guardian(s) and the professionals.

Health. An experience that is often expressed in terms of wellness and illness, and may occur in

the presence or absence of disease or injury.

Healthcare consumer. The person, client, family, group, community, or population who is the focus of attention and to whom the registered nurse is providing services as sanctioned by the state regulatory bodies.

Health Home (Medical home). Care that uses primary care providers to ensure the delivery of coordinated, comprehensive care.

Healthcare providers. Individuals with special expertise who provide healthcare services or assistance to healthcare consumers with IDD. They may include nurses, physicians, psychologists, social workers, nutritionist/dietitians, and various therapists.

Illness. The subjective experience of discomfort, disharmony, or imbalance. Not synonymous with disease.

Implementation. Activities such as teaching, monitoring, providing, counseling, delegating, and coordinating.

Inclusion. Integration of all persons, regardless of special needs and disabilities and/or the environment (e.g., school, community, etc.), with typical peers in the least restrictive setting. Innovative programs geared to the healthcare consumer's strengths and capabilities must be provided.

Individualized education plan (IEP). An annual educational program plan and goals that are jointly determined by the school teachers, therapists, school nurse, and parents of the school-aged child with IDD and members of their support system. The IEP includes all developmental and academic testing results, the child's health status, and the child's strengths and weaknesses, as well as transition plans. This plan may include vocational goals beginning at age 14 and is known as the individualized transition plan (ITP).

Individualized family service plan (IFSP). An annual family service plan that includes goals and interventions for the entire family of a child, aged birth to three years, with or at risk for an IDD. The IFSP includes the child's strengths and weaknesses, the results of developmental testing in all areas of adaptive living, family needs, the identification of community resources, and transitional plans to the school setting. This plan is devised by the interprofessional team and the parents/legal guardian(s) of the child with IDD and members of their support system.

Individualized plan for employment (IPE). An annual work or habilitation plan, usually completed for adults with IDD that includes goals and interventions as determined by the healthcare consumer, his or her family/legal guardian(s), and the interprofessional team at the healthcare consumer's place of employment and/or residence. The IPE includes all developmental, adaptive skill levels, habilitative training and skill levels, and the healthcare consumer's strengths and weaknesses, which are summarized in the plan.

Individualized transition plan (ITP). An annual transition plan, to begin when the adolescent with IDD becomes 14 to 16 years of age. Includes goals and interventions as determined by the healthcare consumer, his or her family/legal guardian(s), and the interprofessional team for the

transition to adulthood. The ITP also includes the healthcare consumer's health, developmental, and adaptive skill levels, strengths and weaknesses, and goals for a successful transition into adulthood that incorporates all aspects of the healthcare consumer's life.

Information. Data that are interpreted, organized, or structured.

Interprofessional. Reliant on the overlapping knowledge, skills, and abilities of each professional team member, resulting in synergistic effects by which outcomes are enhanced and become more comprehensive than a simple aggregation of the individual efforts of the team members.

Interprofessional collaboration. Integrated enactment of knowledge, skills, and values and attitudes that define working together across the professions, with other healthcare workers, and with patients, along with families and communities, as appropriate to improve health outcomes (IECEP, 2011).

Interprofessional team. A group of professionals with varied and specialized backgrounds who work with the healthcare consumer and/or family/legal guardian(s) to make decisions about all aspects of the life of the healthcare consumer with IDD, including health, education, and vocational needs. This planning should be person-centered. The membership of the interprofessional team should be determined by the type of expertise needed to meet the healthcare consumer's needs.

Least restrictive environment. The environment that offers the person with IDD the least amount of restriction in carrying out activities of daily living.

Motion analysis. Motion analysis captures video of human motion with specialized computer software that analyzes the motion in detail. The technique gives health care providers a detailed picture of a person's specific movement challenges to guide proper therapy.

Musculoskeletal modeling and simulations. These computer simulations of the human body can pinpoint underlying mechanical problems in a person with a movement-related disability. This technique can help improve assistive aids or physical therapies.

Normalization. Providing a supportive environment for healthcare consumers with IDD to make decisions regarding activities of daily living and to live as close as possible to the norms and patterns in the mainstream of the society in which they reside. If this is not possible, then supporting the family/legal guardian(s) who care for the healthcare consumer with IDD.

Nursing. The protection, promotion, and optimization of health and abilities; prevention of illness and injury; facilitation of healing; alleviation of suffering through the diagnosis and treatment of human response; and advocacy in the care of individuals, families/legal guardian(s), communities, and populations.

Nursing practice. The collective professional activities of nurses, characterized by the interrelations of human responses, theory application, nursing actions, and outcomes.

Nursing process. A critical thinking model used by nurses that comprises the integration of the singular, concurrent actions of these six components: assessment, diagnosis, identification of outcomes, planning, implementation, and evaluation.

Patient. *See* Healthcare consumer.

Peer review. A collegial, systematic, and periodic process by which registered nurses are held accountable for practice and that fosters the refinement of a nurse's knowledge, skills, and decision-making at all levels and in all areas of practice.

Person-centered care. Care that is focused on the wishes of the healthcare consumer with IDD after the healthcare consumer (and the healthcare consumer's family/legal guardian(s)) is fully informed of the knowledge and options available regarding his or her care.

Plan. A comprehensive outline of the components that must be addressed to attain expected outcomes.

Quality. The degree to which health services for patients, families/legal guardian(s), groups, communities, or populations increase the likelihood of desired outcomes and are consistent with current professional knowledge.

Registered nurse (RN). An individual registered or licensed by a state, commonwealth, territory, government, or other regulatory body to practice as a registered nurse.

Robotics. Specialized robots help regain and improve function in arms or legs after a stroke.

Scope of Nursing Practice. The description of the *who, what, where, when, why,* and *how* of nursing practice that addresses the range of nursing practice activities common to all registered nurses. When considered in conjunction with *Standards of Professional Nursing Practice* (2015a) and *Code of Ethics for Nurses* (2015b), comprehensively describes the competent level of nursing common to all registered nurses.

Standards. Authoritative statements defined and promoted by the profession by which the quality of practice, service, or education can be evaluated.

Standards of Practice. Describe a competent level of nursing care as demonstrated by the nursing process. *See also* Nursing process.

Standards of Professional Nursing Practice. Authoritative statements of the duties that all registered nurses, regardless of role, population, or specialty, are expected to perform competently.

Standards of Professional Performance. Describe a competent level of behavior in the professional role.

Transcranial direct current stimulation (tDCS). In tDCS, a mild electrical current travels through the skull and stimulates the brain. This can help recover movement in patients recovering from stroke or other conditions.

Transcranial magnetic stimulation (TMS). TMS sends magnetic impulses through the skull to stimulate the brain. This system can help people who have had a stroke recover movement and brain function.

Transition. Refers to the passage from a stage of development, service system of care to another. The transition requires the individual to prepare for the change, learn new skills and knowledge needed to make the change and adapt to the new set of circumstances.

Virtual reality. People who are recovering from injury can retrain themselves to perform motions within a virtual environment.

Wellness. Integrated, congruent functioning aimed toward reaching one's highest potential (AHNA & ANA, 2013; ANA, 2015a).

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