

Have You Considered DD Nursing?

Nurses who work with individuals with developmental disabilities are called DD Nurses. DD nursing is a unique form of nursing because nurses have the opportunity to know their patients for a long period of time. Some nurse-patient relationships last for many years – maybe even a lifetime. DD nurses can build strong bonds with family members as they become the primary source of information about their patients.

As the case managers of a core group of patients, DD Nurses are intimately involved in the lives of the people they support. They not only know about the medical status, medications, and health history of the people they provide services to, they are also an important participant in family events and life changes. It is not unusual to see a DD Nurse at a birthday party or holiday celebration, or meeting with a relative to discuss a family issue that may affect the patient.

As DD nurses assess and treat their patients clinically, they also have the benefit of knowing about the life experiences, living environment, and personal concerns and interests of the people they support. Care is broad and continuous.



"I am a DD nurse. That means that I have really gotten to know my patients – some for the fifteen years I have been working in this field. I have formed an attachment to so many people I serve, and love knowing that I have truly helped them. That's why I chose nursing in the first place."

Because DD nursing requires knowledge of a variety of clinical skills, it is sometimes misunderstood as being a "jack of all trades" or an "easier" form of nursing because it is not acute care. But DD nursing is comprehensive care, challenging DD nurses to manage the cases of individuals who may be on several medications, in constant need of monitoring and hands-on care, and connected with multiple doctors. In addition, individuals with developmental disabilities may have difficulty communicating, making quality care even more challenging.

DD nurses have to be masterful at managing multiple complex cases. This involves tracking everything related to a patient's physical and psychological well-being. It means building relationships with specialists and coordinating the scheduling of care. It may mean involving physical, occupational, and speech therapists; residential and day program staff; other clinicians; family members and physicians in decision-making and treatment of the people they provide services to, who often have challenging conditions and symptoms that are hard to diagnose.

"In DD Nursing, you have to use academic training, problem-solving strategies, and management skills to do the medical case management of patients. DD Nursing is less hands-on and more fast-on-your-feet coordinating."



An unusual aspect of this area of nursing is that DD nurses are responsible for training and supervising direct support staff, who are similar to nurse's aides or home health aides but with numerous additional responsibilities. Direct support staff may perform delegated duties under the supervision of the Registered Nurse's license based on the Nurse Practice Act of New York State, such as administering medications and oxygen, and performing wound care. In some settings DD nurses also delegate g-tube feedings, finger sticks for blood glucose measurement, and insulin administration.

The training provided to direct support staff is regulated, and needs to be frequent to maintain quality and orient new employees. Case management with individuals with developmental disabilities is much more efficient if the DD nurses can oversee all aspects of care. This includes the delegation of clinical tasks. DD nurses are always building their own knowledge base because they are responsible for training staff.

"The best part is that I am an educator. I teach the patients, direct care staff, and families. And every day I learn something new, so I'm being educated, as well. When one of my patients presents something new, we all make an effort to learn more about the problem and how to treat it."

Most nursing, regardless of the setting, requires a combination of teamwork and independent decision-making. DD nurses network with a variety of resources but must be able to work autonomously, especially in small facilities. DD nurses are usually located in residential homes, day programs, clinics, or special education facilities such as a school, and are often the only source of medical management of individuals with DD.

They are responsible for identifying needs, balancing multiple requests, educating themselves and others as new patient issues arise, supervising staff, and making arrangements for immediate and regular patient care.

"When I started in DD Nursing I felt like I was completely on my own and needed to be self-reliant. Then I discovered that I have a network of assistance and am part of a large team. But I'm the one who coordinates it all. I love that."

DD Nurses are problem-solvers. Individuals with developmental disabilities often have unique body function and architecture, syndromes, behavioral issues, and/or physical challenges that require DD nurses to be creative thinkers when arranging for assessment and treatment. Patients with conditions such as hypotonia, spasticity, scoliosis, low muscle strength, tactile defensiveness, or limited verbal skills may have difficulty during routine tests such as an EKG, mammogram, or audiometry. They may not be able to follow instructions or describe the source of their discomfort. In facilitating their care, DD nurses have to determine alternative approaches to helping patients, working closely with medical team members.

What are the characteristics of DD nurses? They tend to enjoy the independence and the freedom to gather the necessary resources to assist their patients. They like to juggle many things at once because they are organized, and relish the fact that the days are always different and they see the direct impact of their decisions. They need to be able to be flexible, accepting challenges as they come along. And most of all, they have to be able to manage their time. For many DD nurses, time management is the biggest challenge of all because the “to do” list seems to never get done. But DD nurses quickly learn to prioritize and tackle what needs to get accomplished as top priority.

“There’s never enough time. I have learned how to cope with the fact that there will always be more to do. I concentrate on what I know needs to get done so that my patients are safe and comfortable. And when I have those wonderful moments with residents I have come to know so well, I gather my direct care staff and gear up to tackle the list again.”

Every field of nursing is demanding, particularly in these days of staff shortages, reduced resources, and a growing number of patients with co-morbid conditions. A nurse’s job in any type of facility can be stressful. But nursing is a field where jobs are plentiful, salaries and benefits are strong, and nurses are needed. Facilities that employ DD nurses are especially welcoming to those who have chosen the field or would like to try a new approach to nursing. Orientations for new DD nurses are mandatory, and team support is standard practice. Professional development is constant, and networks such as the New York State MR/DD Nurses Association and the Talent Development and Training Office of the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) are ready to provide information and support. For nurses who would like a routine schedule with minimal on-call and overtime requirements, and the opportunity to connect with patients over a long period of time, DD nursing may be the perfect choice.



“I am the senior staff person, the highest ranking healthcare person in a residence or other facility. I do pretty much everything required to get a patient the help that they need – whether it be coordinating testing ordered by the physician, communicating with a pharmacist, learning a new procedure and training staff. DD nurses love the fact that they are the ones making the decisions about how to arrange for quality care.”

For many DD nurses it is very satisfying to have the opportunity to step out of acute care nursing and into an environment where they are helping people to make choices, grow and learn, and have a good quality of life. DD nurses usually work Monday through Friday, with the rare instance of being on-call or working on a weekend or nights. They form connections with day program and residential staff so that they can keep an eye of the daily experiences of the people they support. They may be clinically supervising, but they are also gathering puzzle pieces from all aspects of the patient’s life to create a picture that will result in the highest quality of care.

What is DD?

“Developmental disabilities” or “DD” refers to individuals with conditions that occur prior to, at birth, or during childhood (before the age of 22) that affect normal growth and development. The conditions may interfere with functioning in several life activity areas, such as learning, mobility, speech, caring for oneself, making life decisions and earning an income. These conditions include Down syndrome, cerebral palsy, epilepsy, Fragile X syndrome, autism, intellectual impairments, and sensory or neurological impairments.

Challenges and Solutions for DD Nurses:

Challenge:

Communication is required with multiple physicians.

Solution:

DD nurses build relationships with doctor’s offices and are often treated with respect by doctors and nurses because they know their patients and their patterns, trends, and needs. In many cases, the DD nurse is the key source of communication between caregivers and physicians.

Challenge:

Direct care staff have a wide range of skills and high levels of turnover.

Solution:

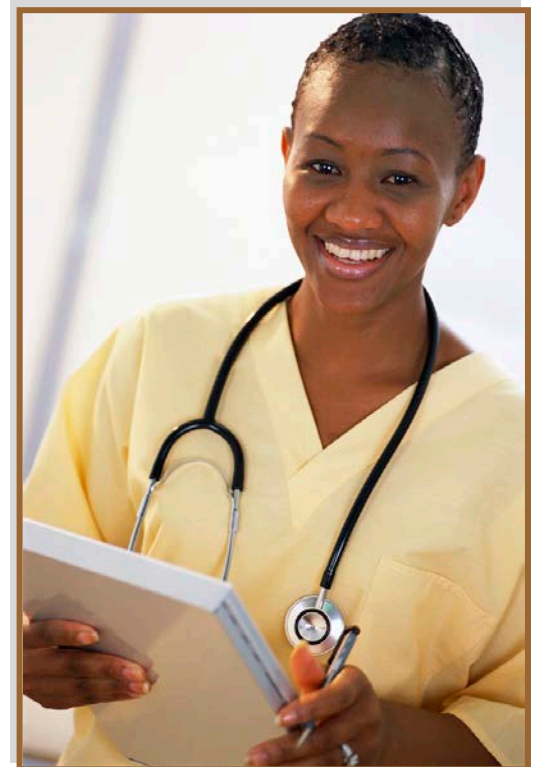
The turnover of direct care staff is a critical problem in all healthcare settings. DD nurses are involved in training and supervising their own direct care staff, so they have many opportunities to provide coaching and support. They create care plans that lay out step-by-step instructions that are specific to the patient, so that direct care staff can provide tailored quality care. DD nurses come to know their staff and skill levels, and can provide the guidance and training that they may need.

Challenge:

The medical, psychological, and even social needs of the patients need to be tracked.

Solution:

DD nurses are responsible for the well-being of a caseload of patients and have the opportunity to interact with them during times when they are well as well as when medical intervention is required. They are the “point of need” and often have to adapt to changes quickly. As they work with the same patient load continuously, they get to know the needs of the patients, and recognize when there are changes in behavior.



Challenge:

The pay rate for DD nurses is usually lower than the salaries of nurses in other fields.

Solution:

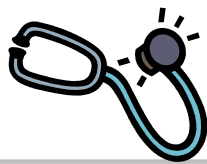
Compensation for full-time DD nurses can be considerably less comparatively. DD nurses who have opted to stay in the field have chosen it because of the rewards such as: structured work hours; independence; the opportunity to be the leader of a team; work that is less physically demanding; ongoing clinical support and training; and the chance to know the people they serve over a long period of time. Nurses who are considering the field of DD nursing should understand that remuneration and benefits may not be what they are accustomed to, but intangible benefits are significant.

Challenge:

Nurses who are unfamiliar with the field of DD nursing are concerned that they may not be using their skills and will become out-of-touch.

Solution:

Nursing skills required in DD nursing are broad and intense. DD nursing is a prime opportunity to develop skills in areas that most nurses do not get the chance to learn about, such as geriatrics and polypharmacology, changing g-tubes and suprapubic catheters, heparin objectives, or outpatient pic line therapy. Most DD nurses who are new in the field discover that they are not only utilizing their past experiences, but they develop new skills. Learning new clinical skills may be challenging at first, but DD nurses express that the learning process is personally and professionally rewarding. There are numerous conferences and training opportunities. DD Nurses also have the opportunity to achieve national certification as a disabilities nurse through the Developmental Disabilities Nurses Association (DDNA).



Special Note to DD Nurses:

People with developmental disabilities are like all other people who require medical attention at times of physical distress and medical maladies. The difference is they won't always be able to tell you and just when you thought you figured it out, the tried and true remedy does not work. To be a nurse working with patients with developmental disabilities means you have a keen eye for what is different. The norm is never "normal" for your patient! Your typical patient is prescribed several different medications that all must be dosed and monitored. But you are a great task manager and you thrive on details. Your closest colleague is probably not a trained RN but a dedicated direct support professional who believes that you can solve any problem that arises! You are asked to train staff to understand the nuances of the people in their charge and report all issues to you. Triage is mandatory and you excel. Your biggest challenge will be finding enough hours in a day to do what needs to get done, but since you are in charge of your caseload, you can decide what to prioritize, what to delegate, and what can wait until tomorrow. The best thing is that the patients that you have come to know so well (and their families and friends, too) will appreciate your dedication. Thank you for your hard work!

Patricia Dowse, COO

New York State Rehabilitation Association

For More Information:

New York State Office for People with Developmental Disabilities

<http://www.opwdd.ny.gov>

New York State MR/DD Nurses Association

<http://www.nysmrddna.org/>

Developmental Disabilities Nurses Association

<http://www.ddna.org/>

Acknowledgements:

Nurse participants in the HRSA Nurse Training Programs sponsored by RRTI

Kathy Keating, RN, MSN, CPNP-PC, CNS/DD, Former Director of Nursing and Health Services, Office for People with Developmental Disabilities

Anne Hanson, BS, RN, CDDN, Coordinator of Health Education, Lexington Center, President, MR/DD Nurses Association

Michelle Peryea, RN, Health Education Nurse, Lexington Center

Nancy DeSando, BS. RN, Director of Clinical and Family Services, Lexington Center



This project is supported by funds from the Division of Nursing (DN), Bureau of Health Professions (BHP), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS) under Grant No. D11HP14612, Nurse Education Practice and Retention, Nurse Training Program: Pharmacology and Developmental Disabilities for \$741,644.00. The information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any official endorsement be inferred by, the DN, BHP, HRSA, DHHS, or the US Government.

The Rehabilitation Research & Training Institute (RRTI)

New York State Rehabilitation Association (NYSRA)

155 Washington Ave - Suite 410

Albany, NY 12210

Phone: 518-449-2976

www.rrti.org

www.nyrehab.org

Check the RRTI website for information about free
HRSA-funded courses for nurses in New York State!