

Section III

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The Role of the Developmental Disabilities Nurse

Nurses who work in the field of developmental disabilities develop special knowledge and clinical skills to deal with the profound impact of how disabilities affect individuals, their families and communities. The practice of developmental disabilities nursing is characterized by those aspects of care that focus on the maintenance of health, development of skills, communication, socialization and participation in community life. There are two levels of nursing licenses in Oregon:

- **Registered Nurse (RN)** is able to perform all nursing tasks. A RN is able of doing an nursing assessment, write a nursing/health care plan, provide caregiver training and provide delegation of certain nursing tasks to unlicensed caregivers
- **Licensed Practical Nurse (LPN)** is able to perform limited nursing tasks and provide caregiver training under the RN's supervision.

Community nurses may work in variety of settings. Providers are usually not familiar with the Oregon State Board of Nursing (OSBN) rules and may ask the nurse to risk his or her nursing license by performing tasks beyond duties defined by their license. On the other hand, the nurse is hired as a nurse and needs to have accountability in his/her practice. Having a clear and detailed job description will help define expectations so that both parties have the same goal.

The employer should expect that the RN possess the following knowledge, understanding and/or skills:

- ❖ Practice the nursing process as set forth by the OSBN
- ❖ Function as an advocate
- ❖ Understand and support the community-based care philosophy
- ❖ Understand Oregon Administrative Rules that govern the setting
- ❖ Approach individual care needs in a holistic manner and with sound nursing judgement
- ❖ Understand the limitations of their role
- ❖ Function independently and as part of a team
- ❖ Provide teaching to individuals and caregivers
- ❖ Possess understanding of long-term care needs as well as knowledge about acute medical conditions
- ❖ Possess understanding of the needs of persons with developmental disabilities

- ❖ Possess problem solving skills and knowledge of community resources
- ❖ Possess skills in planning, teaching, listening, communication, organization and documentation

Supportive Health Care Personnel

The two levels of supportive health care personnel, who are sometimes confused as being “nurses” by the general public, are Certified Nursing Assistants (CNAs) and Certified Medication Aides (CMAs). Persons carrying these two certifications cannot practice under these certifications unless they are regularly supervised by a nurse or function under the nursing delegation rules. The differences between the two levels are:

- ❖ A Certified Nursing Assistant is someone who has completed a short course (150 hrs) in basic daily care duties and is tested and certified under the Oregon State Board of Nursing.
- ❖ A Certified Medication Aide is a CNA who has completed a short course on how to administer oral and topical medications and is tested and certified under the Oregon State Board of Nursing.

Delivering Nursing Services

Direct Nursing Services

For the purpose of this manual, “direct nursing services” will be the term used to describe the provision of nursing care or “duty of care”. A nurse may provide direct nursing services to one or more individuals living in a community setting.

Holistic Nursing Services

Long-term, complex health problems are often prevalent in persons with developmental disabilities. To complicate matters, many individuals may be unable to provide an oral health history and a written health history may be nonexistent or fragmented. In addition, the person may not be able to coordinate their own health care and may have to depend on caregivers who frequently change. It is extremely important, therefore, for nurses to provide a holistic approach to their services.

There are certain expectations set forth by the Oregon Board of Nursing “Standard of Practice” that the nurse is expected to adhere to. The RN is expected to complete a nursing assessment, using the nursing process, prior to providing direct care and/or caregiver training. From the nursing assessment, he/she will construct a complete health/nursing care plan. The nurse is also expected to review the Risk Tracking Record used in 24-hour residential settings and write the necessary protocols, procedures and other instructions as needed with input from caregivers. All information should be in a format that caregivers can easily understand and follow. The duties of a nurse who provides direct, holistic services include the following:

- ❖ Providing an annual nursing assessment and ongoing assessments as needed.
- ❖ Determining caregiver-training needs around health care issues.
- ❖ Writing a health care plan/nursing care plan annually and reviewing and updating it routinely or as the person’s health changes. The plan becomes a supporting document to the ISP. If both a health care plan and a nursing care plan are used, they should compliment each other and have no conflicting information or instructions.
- ❖ Attending the person’s ISP meetings and other pertinent meetings regarding the individual.
- ❖ Ensuring that the caregivers understand and are able to perform the interventions stated in the health/nursing care plan.

- ❖ Providing appropriate health data tracking records
- ❖ Providing delegation and teaching according to OAR 851-047-0030 and 0040.
- ❖ Communicating with team members and health care professionals in order to coordinate care.
- ❖ Coordinating care with other nurses, who have a short term, limited role in caring for the person, such as a hospice or home health nurse.

When assuming responsibility for direct nursing services after another nurse has left employment, assess the person and determine if his/her existing Plan is appropriate. This must be done prior to delivering nursing services and must be documented. A new assessment and Plan may be needed or the existing documents may still be valid with only minor changes.

Remember to Sign and date all entries!

Limited Nursing Services

Occasionally, a RN may be involved in an individual's care for only a short period of time while the person has an acute, transient health problem, such as wound care or ostomy care. The nurse would not necessarily respond to all of the health issues that the person has, but would only address the care of the wound or ostomy. The RN would be expected to follow the same standard of nursing practice as a RN providing holistic care. An assessment would be expected prior to providing care and training, but it would be limited in focus, depending on what nursing services are needed. The nurse would be expected to develop a care plan specific to the health concern being addressed.

The residential program should address all other health care issues not covered by the RN. All health care should be coordinated and all caregivers and the RN should understand their roles.

Example: A person who needs a RN to treat a leg ulcer may also have migraine headaches. The nurse would be expected to do an assessment around the management of the leg ulcer, but would not be expected to address the management of the person's migraine headaches. The person's ISP team would address that and any other health issue that the individual has that is unrelated to the leg ulcer. However, the RN should be aware of all of the person's health concerns and how they may impact the treatment and healing of the leg ulcer.

It is extremely important that when a program arranges for nursing services that it is clear to all parties whether the services are holistic or limited.

Agency Related Duties

Occasionally a nurse may be employed to help an agency with issues that are neither person specific nor prescribed by a health care provider.

Some duties that a nurse may do under this role are:

- ❖ Writing general health policies, procedures and protocols that are not individual specific.
- ❖ Reviewing health records to ensure compliance with the OARs.
- ❖ Training caregivers per in-service schedules and as requested (not individual specific).
- ❖ Performing quality assurance tasks.
- ❖ Participating on agency committees.
- ❖ Assisting the agency in determining if they can safely care for an individual when there is a change in health condition. Example: assessing a person's health supports prior to their discharge from the hospital.

Safe Practice Considerations

Nurses will frequently be asked to give health care advice on people for whom they do not provide direct nursing services. When asked about an individual for whom you do not have a nursing relationship, you will need to elicit enough information so that you can safely guide the caregiver as to what to do and/or who to call for further assistance. Mistakes can be made when the RN has only partial knowledge, leading to an incomplete understanding of the problem. Another step that may be appropriate is to refer the caregiver to an appropriate agency policy that will answer their question. Make sure to document the facts surrounding the call.

Caregivers should always be empowered to use their own judgement regarding when to call 911 if they believe someone is gravely ill. Not calling 911 and deferring to others in the agency to make that decision via phone calls will waste valuable time in getting the person help. What you cannot do, under the nursing practice law, is to leave the situation without ascertaining that the caregivers either have an answer, or are referred to someone who can answer their question and/or deal with the situation. If you are aware of a risk to the person's health, you must take action.

An agency may want a RN to be exclusively a "phone advice nurse", where he/she would only consult via phone. This can be dangerous practice as the RN is removed from the day to day workings of the home, does not have understanding of the caregiver competence or the person's history and current health status.

Coordination and Communication

Nurses who care for people with developmental disabilities often are faced with a variety of problems that they are expected to solve. The solutions will frequently involve communication and collaboration with others about coordination of appointments, reports, treatments, etc.

The nurse is just one member of a team whose collective goal is to provide supports for persons who may not be able to advocate for themselves or have involved family members. All team members can give useful input and are expected to help in the interdisciplinary team process. Each member in the home or household has something valuable to contribute. Showing respect and listening to each person's opinion can enhance the quality of nursing care and ultimately the quality of life for the individual.

The nurse may have more knowledge about health issues than other team members and should be prepared to educate caregivers. Other team members usually do not understand all of a person's health concerns and associated supports. However, they are able to give valuable information from which the nurse can base his/her assessment and plan.

Working with Consultants

Community nurses may need to work closely with consultants. Often the initial determination of the need to see a consultant comes from the nurse's assessment and care plan.

Consultants may have a private contract with the provider or services may be purchased through the Oregon Health Plan or other health care plan. Occasionally, a county may contract with a specific consultant who then sees all individuals in the county when the need arises.

Once the need for a consultant has been established, the agency's designated person contacts the consultant and an appointment is made. If the services are paid for through the medical card/insurance, a physician's order is necessary. It is important that the appointment be set at a time when the nurse and/or key caregiver(s) are available to attend. This will save numerous phone calls for clarifications.

Any recommendation from a consultant that involves active treatment, therapy or a change in diet texture/order will require a physician's order before it is implemented. The following consultants frequently provide services for people with developmental disabilities:

Behavior Specialist

Behavior specialists are persons who have special knowledge and understanding in dealing with challenging behaviors. They analyze the behavior and what the behavior communicates (functional analysis), write the behavior plan and train caregivers in the application of the plan. The analysis depends heavily on information from the caregivers.

The behavior specialist may be an employee of the agency, county or an independent consultant. After the initial consult, they may continue to follow the person's progress and make plan revisions as needed. The team needs to approve all plans and revisions.

The following is useful information to remember when working with a behavior specialist:

- Provide information from a variety of caregivers, who work directly with the person. Caregivers working different shifts and settings may have different opinions.

- A behavior plan needs to be understood by all. If portions do not make sense or are not practical, ask the specialist to clarify items and even rewrite it if necessary.
- Data tracking about the challenging behavior should be useful and pertinent. Often the specialist will assist with designing a data collection system that will provide the information he/she needs for review to keep the plan effective.

Use of Physical Restraints

Although the nurse may not be involved in implementing a behavior plan, it is important that he/she understand the OARs around the use of physical restraints. The rules state that physical restraints may be used only as part of the ISP plan that is intended to lead to a less restrictive means of intervening in and altering the challenging behavior for which the restraint was applied.

The following steps must be followed:

- The ISP team must approve the use of physical restraints.
- All caregivers need to be trained in the use of restraints according to the OARs if they care for someone who has restraint use in their plan.
- All physical restraints that are part of a plan are based on the Oregon Intervention system. This system teaches caregivers how to intervene with challenging behaviors in the least restrict manner.
- Physical restraints may also be used in an emergency situation to keep the person safe if they or someone else is in imminent danger of being injured.

Case Manager

All individuals with developmental disabilities who are served in the Oregon system have a case manager or service coordinator. Case management is a key element in the delivery of care. It is the case manager's job to identify access, coordinate and ensure the delivery of services and supports. They ensure that the care given to the individual is in compliance with the OARs.

Case managers are usually county employees who ensure that support services are locally based, offer a flexible array of services and are funded in a manner that can adapt to individual's needs and choices to enhance their quality of life.

The case manager monitors the supports that the individual receives by:

- Being a member of the ISP team and attending ISP meetings.
- Being an advocate for the person.
- Making visits to the home and/or work site.
- Reviewing incident reports in a timely manner
- Maintaining a case management file with pertinent information.
- Evaluating and advocating for supports as the individual's needs change. They have the right to review health care documents.

Orthotist

Orthotists are skilled individuals who are concerned with managing body function with the use of splints, braces, orthotics and wheelchairs as directed by a health care specialist. They will also modify equipment to ensure a therapeutic and comfortable fit. Orthotists may come to the home to see individuals in their own setting or they may evaluate them in a clinic or hospital.

Splints, braces, wheelchairs, etc. are called “durable medical equipment” (DME) and are usually paid for by insurance plans. The need for DME should be assessed by occupational or physical therapists and constructed or modified according to the therapists' specifications. If revisions are needed, the therapist may need to reassess the situation or entrust the Orthotist to make the adjustments.

Physical and Occupational Therapists

Individuals with developmental disabilities often have physical management problems and may need the services of these therapists. They may be contracted to give only an initial assessment and train caregivers to do maintenance activities, such as range of motion exercises. At other times, they may be contracted to follow the person at intervals and perform direct therapy. There are times when the skills of the physical and occupational therapist overlap. The therapists are expected to leave a written report or progress notes in the home for each visit.

The physical therapist's duties may include:

- Assessing body movement and posture
- Providing direct therapy
- Determining the need for adaptive and protective equipment. They may also assist in the design and repair of such equipment

- Assisting in training the individual and others in:
 - Proper positioning
 - Range of motion
 - Body mechanics to maximize mobility and flexibility

The occupational therapist's duties may include:

- Assessing motor skills needed to carry out activities of daily living
- Assessing hand-to-mouth and grasp/release patterns necessary for eating.
- Determining adaptive equipment needs and functional arm positioning to facilitate eating and other fine motor skills.
- Assessing body positioning and physical endurance during feeding.
- Depending on education and experience, they may also assess swallowing skills and train caregivers on feeding techniques.

Speech-Language Therapist/Specialist

Persons who have developmental disabilities often have swallowing difficulties that worsen as they age. Recognizing subtle changes that puts them at risk for aspiration is essential in keeping them safe. Speech-Language pathologists are often the specialists who assess speech, language development, and swallowing skills.

Speech-Language Therapist/Specialist duties include:

- Oral-Motor Function:
 - Assessing oral-motor function and swallowing status
 - Recommending, assisting and interpreting results of video fluoroscopy studies
 - Developing and managing exercises for swallowing
 - Recommending aspiration precautions, diet consistency and the degree of supervision required when eating. A physician's order is needed to permanently change food textures
 - Assisting the individual and training caregivers in safe swallowing techniques
- Language and Communication
 - Evaluating language and communication skills
 - Assessing language comprehension and overall responsiveness
 - Developing and teaching exercises for speech and communication
 - Recommending, developing, implementing and maintaining alternative communication devices, such as visual communication systems

School Services

When a nurse is providing services to a school aged individual (21 years or younger) it is important to know if therapies are being offered at school. Children with developmental disabilities frequently receive therapy services while attending school, such as physical and/or speech therapy. The school therapists may be willing to provide training to home caregivers in order to keep the therapeutic effects ongoing. This service provides continuity especially over holiday breaks and vacations.

Items to Discuss with Potential Employers

- ✓ Number of hours the nurse is to work per/week/month/quarter/year.
- ✓ Is there a provision for adding or subtracting hours as the need arises?
- ✓ Is the nurse expected to provide services at a specific time of day, such as from 8:00 AM to 12:00 PM on weekdays?
- ✓ How is the billing process done?
- ✓ Who is the nurse's supervisor and how should they be contacted?
- ✓ Does the nurse have any supervising role over caregivers?
- ✓ If conflicts arise concerning how care is delivered, what are the expectations of the employer?
- ✓ Who pays for liability insurance?
- ✓ The amount of money to be paid per hour or monthly. Does this include expected travel time, travel mileage, being on-call, weekend and holiday duty?
- ✓ The length of time the contract is valid, how is the contract renewed and how is employment terminated?
- ✓ Any documentation expectations in addition to what is expected and required by the Board of Nursing.
- ✓ Orientation training as dictated by the OARs and agency policy.
- ✓ Does employer pay for continuing education or State of Oregon trainings? If so, what is covered, i.e. driving time, training fee, nursing wages while in training?

Billing for Visits (Sample Form)

The following sample billing form can be used when a nurse is contracted to perform nursing services. The form provides a picture of the RN's workload, concerns, recommendations and documentation of when the nurse plans to visit again. Note that there is a place for the signature of the caregiver who was present in the home when the nurse visited.

RN Position Responsibilities (Sample Form)

Nurses should always know what nursing services their employer expects. If a nurse is hired for 5 hours a month to provide caregiver trainings, he/she will not have time to do quality assurance reviews on charts. If duties and hours are not specifically defined, an employer may have unrealistic expectations that a nurse can provide multiple nursing duties in a very limited amount of time. The following form helps define what nursing services the nurse is contracted to provide and the amount of time that is needed for each task. Ideally, this form should be reviewed after three months of employment as the time devoted to each nursing task may have been exaggerated or minimized.