

# **SECTION I**

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# Manual Overview

The goal of this manual is to assist Registered Nurses and Licensed Practical Nurses to attain the knowledge and skills necessary to deal with the profound impact that developmental disabilities have on individuals, their families and community.

## **Developmental Disabilities (DD) Nursing is Characterized by**

- ❖ Adherence to the civil rights and the values of respect and inclusion for people with development disabilities.
- ❖ A focus on long-term, holistic health.
- ❖ Participation in a team process that supports and enhances the lives of people with developmental disabilities.
- ❖ Specialized knowledge and understanding of developmental disabilities and its impact upon people, families and communities.

No single source of information will provide you with all that you will need to know about caring for individuals with developmental disabilities. Questions regarding nursing practice should be referred to the Oregon State Board of Nursing. Other questions can be referred to the Health Support Unit Nurses with Seniors and People with Disabilities, Oregon Department of Human Services.

# General Definitions

**“Abuse”** of an individual with a developmental disability includes, but is not limited to:

- Any death caused by other than accidental or natural means or occurring in unusual circumstances;
- Any physical injury caused by other than accidental means or that appears to be in variance with the explanation given of the injury;
- Willful infliction of physical pain or injury;
- Sexual harassment or exploitation;
- Failure to act/neglect that leads to or is in imminent danger of causing physical injury, through negligent omission, treatment or maltreatment of an adult;
- Verbal mistreatment;
- Placing restrictions on an individual’s freedom of movement by seclusion or restricted access unless agreed on with the individual support plan team and documented with the Individual Support Plan (ISP);
- Using restraints without a written physician’s order unless this poses imminent danger to self or others or is approved in the individual’s ISP; **or**
- Financial exploitation.

**“Agency”** is a term used when identifying or referring to a not-for-profit or for profit organization that provides residential and/or employment services to the person with developmental disabilities. An agency may also be referred to as a provider.

**“Americans with Disabilities Act” (ADA)** was signed into law on July 16, 1990. The ADA prohibits discrimination on the basis of disability in employment, programs and services provided by state and local governments, goods and services provided by private companies, and in commercial facilities. It contains requirements for new construction, for alterations or renovations to buildings and facilities and for improving access to existing facilities of governments to provide access to programs offered to the public. The ADA also covers effective communication with people with disabilities, eligibility criteria that may restrict or prevent access, require reasonable modifications or policies and practices that may be discriminatory.

**“Brokerage”** means an entity or distinct operating unit within an existing entity, that helps plan and implement support services for adults with developmental disabilities, using the principles of self-determination. A Brokerage is also known as Support Brokerage Services or Brokerage Support Services.

**“Case Manager”** is an employee of a community health program that contracts with the Oregon Department of Human Services to plan, procure, coordinate, and monitor Individual Support Plan services for an individual and to act as an advocate. Case Manager is also known as a Service or Case Coordinator.

**“Community Inclusion Program”** also known as Alternative to Employment (ATE) includes services for individuals whose age or condition precludes employment situations. The overall purpose is to provide opportunities for integration, independence and productivity, which are based on the individual’s needs.

**“Core Competencies” (Oregon Core Competencies)** is a list of skills and knowledge for newly hired group home staff in the areas of health, safety, rights, values and the service provider’s mission. There are associated timelines in which newly hired staff must demonstrate competency.

**“Crisis Services”** is a service provided to persons with developmental disabilities to prevent loss of his/her home.

**“Delegation”** means that a Registered Nurse authorizes an unlicensed person to perform special tasks of client/nursing care, such as gastrostomy tube feedings or complex wound care in selected situations and indicates that authorization in writing and leaves written instructions. The delegation process includes nursing assessment of a person in a specific situation, evaluation of the ability of the unlicensed person, teaching the task and ongoing supervision by the RN.

**“Developmental Disability” (DD)** for an adult means a disability attributable to mental retardation, autism, cerebral palsy, epilepsy or other neurological handicapping conditions which require training and support similar to that required by individuals with mental retardation and the disability:

- Originates before the person attains the age of 22 years, except in the case of mental retardation the condition must be manifested before 18 years of age; and
- Has continued, or can be expected to continue indefinitely; and
- Constitutes a substantial handicap to the ability of the individual to function in society; or
- Results in significant sub-average general intellectual functions with concurrent deficits in adaptive behavior which are manifested during the developmental period. Individuals of borderline intelligence may be considered to have mental retardation if there is also serious impairment of adaptive behavior. In children the definition is always provisional and slightly different than the adult definition.

**“Durable Medical Equipment” (DME)** refers to medical equipment that can stand repeated use and is primarily and customarily used to serve medical purpose; examples include: wheelchairs, crutches and custom built orthopedic braces. Medical supplies are non-reusable items used in the treatment of illness or injury. Some examples are syringes, gauze, bandages, incontinent supplies, etc.

**“Exceptional Needs Care Coordinator” (ENCC)** see Insurance and Governmental Income Definitions.

**“Grievance”** is a formal complaint by individuals with developmental disabilities or persons acting on their behalf about any aspect of the program or an employee of the program.

**“Incident Report” (IR)** is a written report of any injury, accident, act of physical aggression, medication irregularities or unusual incident involving an individual with a developmental disability.

**“Individual Support Plan” (ISP)** means a written plan of support and training services for an individual, revised at least annually, which addresses an individual’s support needs. All plans are based on person centered planning.

**“Individual Support Plan Team” (ISP Team)** is a team composed of the individual, case manager, the person’s legal guardian or health care representative, representatives of all current service providers, and advocates or others determined appropriate by the person receiving services.

**“Integration”** means that people with developmental disabilities live in the community, use the same community resources that are used by other members of the community, participate in community activities and have contact with other community members.

**“Mental Retardation” (MR)** means significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period (considered by the 18<sup>th</sup> birthday). Persons of borderline intelligence may be considered mentally retarded if there is also serious impairment of adaptive behavior.

**“Oregon Administrative Rule” (OAR)** is a group of laws that prescribe the standards and procedures for the delivery of care and services. There are numerous sets of rules, including those for 24 hour residential,

supported living, adult and child foster homes, employment and community inclusion programs, case management and Individual Support Plans.

**“Oregon Health Plan” (OHP)** see Insurance and Government Income Definitions.

**“Oregon Intervention System” (OIS)** is a continuum of behavior management services designed to support individuals who may present challenging behaviors. OIS emphasizes a philosophy of individualized positive behavior supports, functional behavioral assessment, adaptations of the environment and the structure of daily life.

**“Division of Medical Assistance Programs” (DMAP)** see Insurance and Government Income Definitions

**“Oregon Revised Statutes (ORS)”** are laws passed by the Oregon Legislature. The Oregon administrative rules are based upon these laws.

**“Oregon State Board of Nursing” (OSBN)** is an agency of the State of Oregon whose mission is to govern and regulate nursing practice and education for the purpose of protecting the public’s health, safety and well being. The board exists to protect the public from unsafe, incompetent or unauthorized practice of nursing.

**“Oregon Technical Assistance Corporation” (OTAC)** is a private, not-for-profit agency that provides a range of technical assistance in the areas of human services. Its mission is to promote full participation in community life for individuals with disabilities and their families through delivery of training, technical assistance and related services.

**“Physical Restraint”** means restricting the movement of an individual or restricting the movement or normal function of a portion of the individual’s body.

**“Pica”** is the eating of non-food items.

**“Protective Services Investigation” (PSI)** is an investigation required by administrative rule when there is reasonable cause to believe that abuse to an adult individual with developmental disabilities has occurred.

**“Psychotropic Medications” (behavior medications)** are defined as medications whose prescribed intent is to affect or alter thought processes, mood or behavior. This includes, but is not limited to, anti-psychotic, antidepressant and anti-anxiety medications and may also include herbal

supplements. Because a medication may have many different effects, the classification depends upon the stated, intended effect when prescribed.

**“Self-injurious Behavior” (SIB)** is repeated non-accidental behaviors initiated by an individual that directly result in physical injury to the person.

**“Serious Event Review Team” (SERT)** is a quality improvement system at the county and state level that reviews, monitors and responds to serious events that occur with the developmental disability service system.

**“Support Services”** means assisting an individual with developmental disabilities to maintain or increase independence, achieve community presence and participation and improve productivity. This assistance is flexible and subject to change with time and circumstances.

**“Support Service Brokerage” or “Brokerage”** means an entity or distinct operating unit within an existing entity, that helps plan and implement support services for adults with developmental disabilities, using the principles of self-determination.

**“Supported Living”** is a service that provides supports for persons with developmental disabilities living in a residence of their own choice within the community. Supported living provides the opportunity for individuals to live where they want and with whom they want.

**“Twenty-four Hour Residential Services”** are supports provided for individuals with developmental disabilities in a 24-hour residential setting.

**“Variance”** is an approved exception granted by the licensing or certification body.

# Insurance & Government Income Definitions

**“Exceptional Needs Care Coordinator” (ENCC)** is a resource person provided by each managed care plan of the Oregon Health Plan for members who are elderly or disabled. Services that an ENCC can provide clients:

- ❖ Accessing medical care and services;
- ❖ Obtain approvals for medicines and medical services;
- ❖ Resolving conflicts between individuals and health professionals;
- ❖ Hospital discharges planning;
- ❖ Skilled nursing facilities arrangements; and
- ❖ Locate community services.

**“Health Maintenance Organization” (HMO)** is an organization developed to deliver managed health care. This organization accepts a capitated payment (an amount per month per member) and agrees to provide all health services needed during the month by the member (within certain contract limits). The organization may be a not-for-profit organization or a for profit business. The organization develops a network of providers to give services and provides a level of quality assurance and member services, such as patient education, customer services, etc. The basic concept is that being responsible for the total costs and total care, the organization will “manage” the health care efficiently and effectively. There is frequently a stronger emphasis on prevention. HMOs may also be called Managed Care Organizations.

**“Medicaid – Title XIX”** is a funding source from the federal government that was originally intended to provide health care for people with low incomes. Currently in Oregon, the health care provided by Medicaid is called the Oregon Health Plan. Waivers allow the Oregon Department of Human Services to provide home and community-based services instead of providing services in an ICF/MR (nursing facility for people with mental retardation) or nursing home. Under Medicaid, the state is required to provide a significant portion of the funds. In Oregon, about \$60 of every \$100 spent must come from State funds. For most people with a developmental disability, eligibility for Medicaid is completed at local Seniors and People with Disabilities Office.

**“Medicare”** is a health insurance program funded through the federal government for people who have worked (or their dependents) and is now elderly or disabled. It is funded through federal payroll deductions. The benefits are more limited than Medicaid.



**“Division of Medical Assistance Programs” (DMAP)** is an office of the Department of Human Services responsible for coordinating Medicaid medical services through the Oregon Health Plan. DMAP writes and administers the state Medicaid rules for medical services, contracts with providers, maintains records of client eligibility and processes and pays Medicaid providers.

**“Oregon Health Plan” (OHP)** is an insurance or payment mechanism for health care of people with low incomes in the State of Oregon. Health care services are ranked in order of benefit and some services are not funded. Some individuals in the plan are enrolled in managed care plans.

**“Pre-Admission Screening Resident Review” (PASRR)** is a federally mandated screening program conducted prior to admission of any individual in to a Medicaid certified nursing care facility. The goal is to prevent inappropriate placement of individuals with mental illness and/or mental retardation and/or developmental disabilities diagnosis into nursing care facilities and to assure any special services related to those diagnoses are being provided.

**“Primary Care Case Manager”** is a person who agrees to manage the health care of OHP members for a small monthly fee. These health practitioners are available to OHP members who live in areas without HMOs or whose health needs can't be met by a HMO.

**“Social Security Benefit” (SSB)** is a form of federal government income for workers who are older or are disabled and their dependents (adult child with disabilities or the spouse) if the worker also qualifies for SSB. Eligibility for SSB entitles a person for eligibility in Medicare, but their income may be too high to retain eligibility in Medicaid.

**“Social Security Disability Income” (SSDI)** is a disability insurance plan from the federal government for workers who become disabled or for dependents who are disabled if the worker/parent is also disabled or elderly. Eligibility for SSDI entitles a person for eligibility in Medicare, but the income may be too high to retain eligibility in Medicaid.

**“Supplemental Security Income” (SSI)** is a social benefit payment by the federal government to people with significant disabilities and very low income. Eligibility for SSI entitles a person to eligibility for Medicaid. The payment is meant to assist with those routine costs that are greater because of the disability.

**“Temporary Aid to Needy Families” (TANF)** used to be known as “Aid for Families with Dependent Children (AFDC)” or more commonly “welfare”. It provides income assistance with numerous restrictions to families with

children. This is usually accessed through the local Department of Human Services Office in each county.

**“Waivered Services”** is permission by the federal government to deviate from their rules. The Seniors and People with Disabilities waivers include permission to serve people outside of the traditional Medicaid setting, such as nursing homes and ICF/MRs.

# Overview of Human Services

Human services are delivered in the State of Oregon under the direction of the governor and are funded and regulated by the Legislature. Most of the funded human services are organized under the Department of Human Services (DHS). The policy for the Department's services is organized into three major areas:

## **Seniors and People with Disabilities (SPD)**

This unit has responsibility for the policies that impact seniors and people with disabilities (both physical and developmental) and for the regulation, monitoring and funding of the long term case services, including nursing homes, foster homes, and DD group homes and employment services.

## **Children, Adults and Families (CAF)**

This unit includes those services that were formerly delivered through the Adult and Family Division (AFS) and the Office of Services for Children and Families (SCF). It is responsible for JOBS programs, income assistance and child protection.

## **Health Services**

This unit's responsibilities include public health, alcohol and drug services, mental health services and the Oregon Health Plan.

## **Local DHS Offices**

Services are available in a variety of places that include state offices and local government partners, depending on the community. Local DHS offices may include:

- ❖ Disability Services Office (DSO)
- ❖ Area Agency on Aging (AAA or Triple A)
- ❖ Health Department
- ❖ Mental Health Service Provider
- ❖ Developmental Disability Services (frequently housed with local health or mental health offices)
- ❖ Vocational Rehabilitation Office

## **Developmental Disabilities Services**

In general, Seniors and People with Disabilities deliver services through their local partners, the county-based office of DD services. These offices

may be situated in the local Health Department or Mental Health Office. In turn, the county contracts with local providers to actually provide the services to the individuals. The services that are available to adults and children with developmental disabilities and their families include:

- ❖ Case Management – usually provided by the County Mental Health provider.
- ❖ Residential Services – ranges from Supported Living, where the person lives in his/her own apartment and may receive minimal support to group homes providing complete support and 24 hour caregivers.
- ❖ Employment or Community Integration Services.
- ❖ Family Support Services for families of children with developmental disabilities who live with their families.
- ❖ Support Brokerage Services for adults with developmental disabilities who do not receive comprehensive services (residential and expensive in-home services).

## **Other Services**

Other services that people with disabilities and their families can access include:

- ❖ **“Early Intervention” (EI) and “Early Childhood Special Education” (ECSE)** – services are delivered in the home or at centers that address the educational needs of the preschool child, delivered through educational contractors and may include therapy services.
- ❖ **CaCOON** – is a case management service for children with physical and nursing needs, delivered by nurses, usually through the local health department.
- ❖ **“Oregon Health Plan” (OHP)** – is a health insurance program for people with low income. The identification is sometimes called the “medical card”.
- ❖ **“Food Stamps” (Oregon Trail Card)** – is accessed through the local county Human Services Offices.
- ❖ **“Medical Transportation”** – Medical transportation may be available if the person has no other way to access medical appointments. This service is usually accessed through the office where the person receives services. Transportation may also be paid through DD services, depending upon the needs of the person and the plan developed through the county.

- ❖ **“ARC” (The ARC of the United States)** – is a not-for-profit organization that was founded by parents of children with developmental disabilities. There is a state chapter and some local county chapters. Some local ARCs provide respite, day programs, staff training and other services.
- ❖ **“GAPS” (Guardianship Advocacy Protection Services)** – is a program that is run by ARC to provide advocacy and guardianship services for people with developmental disabilities. They accept only a limited number of people, generally those with highest/most urgent need.

# Nursing Standards and Scope of Practice

It is expected that the registered nurse and licensed practical nurse who provide professional nursing services to people within the developmental disabilities service system, do so in accordance with Oregon Administrative Rules (OARs) and the Oregon State Board of Nursing (OSBN) Rules.

These rules include:

- Division 45 Standards and Scope of Practice for the licensed practical nurse and registered nurse
- Division 47 Standards for registered nurse delegation of nursing care tasks to unlicensed persons.

The Purpose of Standards and Scope of Practice are:

- ❖ Interpret standards and the scope of practice for nurses;
- ❖ Establish acceptable levels of safe practice for nurses; and
- ❖ Serve as a guide for the OSBN to evaluate safe and effective nursing care as well as to determine when nursing practice is below the expected standard of care.

## Nursing Process as Related to Developmental Disabilities

It is expected that nurses use and document the steps in the nursing process as described by the OSBN. The nursing process for registered nurses who work with individuals with developmental disabilities is described as follows:

### Assessment

- Objective and subjective data should be collected via observations, physical examination, interviews and written record review. Caregivers and family members are good sources of information.
- The written assessment should be easily understandable by all caregivers.
- A comprehensive nursing assessment should be done annually, prior to a person's annual Individual Support Plan (ISP) and as the person's health status changes.
- The assessment must be documented and a copy placed in the person's record.

## Outcome Identification

- The nurse identifies expected individualized outcomes from the assessment
- Expected outcomes should be documented, reasonable and measurable. For example:

Measurable	Non-measurable
“Will have no more than 5 seizures per month.”	“Seizures will be well controlled.”
“Will use less than 2 enemas per month.”	“Will be free on constipation.”

## Planning

- The nurse develops a Plan of Care that outlines interventions to attain expected outcomes. It is helpful to identify the person(s) or title of the person(s) responsible for the interventions.
- The nurse-authored Plan, which addresses health supports, may be called a Nursing Care Plan (NCP), a Medical Support Plan (MSP), or a Health Care Plan (HCP).
- The Plan is written prior the person’s annual ISP and presented to the entire team for their review and consensus. The Plan, once approved, becomes a supporting document to the ISP.
- The team members will decide on how, when and what changes the nurse can make to the Plan without ISP team notification.
- The Plan should be written so that it is easily understood by all.

## Implementation

- Interventions to be implemented should be contained within the established Plan and should be implemented in a safe, timely and appropriate manner.
- All caregivers expected to implement the Plan need to be trained on its content.

## Evaluation

- The nurse evaluates the person’s progress toward attainment of outcomes/goals. The evaluation process looks at the effectiveness of the interventions in relation to the outcomes.
- New assessment data generated from the evaluation process should be documented and used to revise the Plan and implementation as needed.
- Evaluation or review of the Plan should occur at least monthly in most cases, but a person’s changing health status may warrant more frequent evaluations.
- Evaluation of the Plan must be documented.