Seniors and People with Disabilities

DHS Developmental disabilities nursing manual

DHS | Independent. Healthy. Safe.

Developmental Disabilities Nursing Manual
2nd Edition

Section I

Section II

Section III

Section IV

Section V

Section VI

Section VII

Appendix

SECTION I

Manual Overview
General Definitions
Insurance and Governmental Income Definitions
Overview of Human Services
Nursing Standards and Scope of Practice

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 l6, 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 polices 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 18th 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.

Section II

Values
Mandatory Reporting of Abuse
Rights and Risks
Individual Support Plan Process
Conflict Resolution
Medical Decision-maker Informed Consent
Do not Resuscitate Orders
Consent for Feeding Tubes
Life Sustaining Procedures
Admission to Nursing Homes
POLSTS
Transitions
Nutrition and Special Diets

Values

The underlying principle of all human service programs in Oregon is the belief in the worth, uniqueness and dignity of Oregon's citizens. The mission of Oregon's Seniors and People with Disabilities is to assist individuals with disabilities to achieve control of their lives, competence in dealing with community living and participation in satisfying lifestyles based on the same aspirations as all of Oregon's citizens. The following are values that govern and guide services funded, authorized and regulated through Seniors and People with Disabilities.

- All people, with or without disabilities, have the same inherent value and fundamental human rights. Community services should actively foster consideration and respect for the dignity and worth of people with developmental disabilities and their families.
- All community services should be "consumer-driven" and committed to the principle of local empowerment. Individuals, families and their advocates should have a decisive role in the planning, designing, funding, monitoring and operation of community services.
- Community services should assist persons with developmental disabilities to acquire and use practical skills in a manner that promotes their independence, productivity and integration into the community.
- Behavioral intervention strategies, when needed, must be based on positive approaches. Punitive approaches that inflict physical or emotional pain or suffering are prohibited.
- People with developmental disabilities need to live in a safe environment and receive adequate care for medical and physical needs.

Mandatory Reporting of Abuse

Oregon law requires that suspected or actual abuse of individuals with developmental disabilities be reported. All caregivers working with individuals with developmental disabilities are “mandatory reporters”. This means that a nurse who comes in contact with or has reasonable cause to believe that an individual has suffered abuse must report it immediately to your county developmental disability program or the Department of Human Services (DHS) by calling the Office of Investigations and Training 503-945-9495 or toll free at 1-866-406-4287. Nurses shall be familiar with the definitions of abuse and requirements of mandatory abuse reporting.

Abuse of adults with developmental disabilities is defined as:

- Any death caused by other than accidental or natural causes or under unusual circumstances;
- Any physical injury caused by other than accidental means, or that appears to be at variance with the explanation given of the injury;
- Willful infliction of physical pain and injury; or
- Sexual harassment or exploitation

Abuse may also include:

- 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, including but not limited to failure by a provider or staff to provide an adult with adequate food, clothing, shelter, medical care, supervision or condoning or permitting abuse of an adult by any other person. However, no person shall be deemed neglected and/or abused for the sole reason that he or she voluntarily relies on treatment through prayer alone in lieu of medical treatment.
- Verbal mistreatment by subjecting a person to the use of derogatory names, phrases, profanity, ridicule, harassment, coercion or intimidation and threatening injury or withholding services or supports, including implied or direct threat of termination of services.
- Placing restrictions on an individual’s freedom of movement by seclusion in a locked room under any condition, restriction to area of residence or from accessing ordinarily accessible areas of the residence, unless agreed upon in the ISP.
- Using physical restraints without a written physician’s order or unless an individual’s actions present an imminent danger to himself/herself or

others and in such circumstances until other appropriate action(s) is taken by medical, emergence or police personnel or unless arranged for and agreed to by the ISP team.

- Financial exploitation which may include, but is not limited to, unauthorized rate increases, staff borrowing from or loaning to persons, witnessing wills in which the staff is beneficiary, adding staff's name to person's bank accounts or personal property without legal authorization.
- Inappropriately expending an individual's personal funds or commingling a person's funds with program and/or another individual's funds.

Additionally, If you believe abuse of a child has occurred you must make an oral report by telephone or otherwise to a local Child Welfare Office of Department of Human Services, to the division's designee, or to a law enforcement agency within the county where the person making the report is at the time of contact.

Rights and Risks

The values of personal choice and independence may, at times, conflict with values of keeping people in the safest environment or optimizing their health. Our society allows individuals to make bad personal choices within certain limits. A well-known example is cigarette smoking. People are allowed to risk their health with tobacco, but smoking is limited to people over the age of eighteen years of age and is restricted in many environments.

People with disabilities also have the right to make their own decisions, as long as they have a reasonable understanding of the consequences. At times the ISP team will be required to consider whether a person has the capability to make an informed decision. In addition, the team may need to carefully weigh a person's preferences against an optimal plan to keep the person safe.

> For example, an individual who values his privacy but also experiences constipation may not wish to have caregivers flush the toilet for him and record his bowel movements. In order to protect his privacy, the team may decide that it is safe, although not optimal, to have the person self-report the frequency of bowel movements or to not record the bowel movements and use other criteria for determining when he may be constipated.

Individual Support Plan Process

All individuals who receive 24-hour residential services use Oregon's standardized ISP process. The process is "person centered" and "blended", meaning that the plan serves the hopes and dreams of the individual and that a single plan will include both residential and employment/community inclusion supports. The ISP plan provides written directives for support services that will enhance the person's quality of life and keep him/her safe and in optimum health. Caregivers from both sites (residential and employment/community inclusion programs) are expected to work closely together when preparing the plan. Although the plan reflects the value of family member's participation, the plan also recognizes the rights of an adult to make informed choices for which they are capable.

If the nurse has a holistic relationship with an individual, he/she is expected to participate in completing the health care segments of the ISP along with providing a Health Support Plan/Nursing Care Plan, which becomes a supporting document to the ISP. It is important to have representation from both residential and employment/community inclusion programs to complete the health section of the Risk Tracking Record. Nursing participation must also be included in the behavior section of the Risk Tracking Record as medical conditions often impact a person's behavior and visa versa.

Things to know and remember when participating in an ISP team:

- The caregiver(s) who knows about the person's health conditions and how those conditions affect the person should help complete the Risk Tracking Record and health sections of the ISP.

- The Risk Tracking Record may generate development of certain protocols or supports. ***Protocols that are indicated for the "Fatal Four" (aspiration, dehydration, constipation and seizures) risks must be on the State of Oregon's mandated forms.*** Protocols need to be developed by the nurse with input from caregivers who know the individual well. Protocols for health risks other than the "Fatal Four" can be in any format as long as they address the key elements of a standard protocol.

- There will need to be separate protocols for residential and employment/community inclusion supports. Each site has certain specifics that will result in differences in the protocols, such as bowel movements being recorded at both sites but on different records and forms. Another example is where the residential site is directed to notify the person's physician under specific circumstances and the employment site is directed to notify the residential site supervisor.

- The "what's most important to remember for the person" page of the personal focus worksheets is a good place to record medical/health concerns that are important to the person's well being and quality of life but are not otherwise addressed in the ISP as "risks".

  For example: the individual who will only allow a female gynecologist to perform her annual examination or an individual who should not wear incontinent garments at night because they will have skin breakdown.

  You may have another format for retaining this information over time, such as a medical problem list. Refer to your agency's policies and procedures.

- As a nurse, you will want to assure that all of the current health risks in the person's life are accurately reflected in the ISP and that the health issues that are not significant risks have a format for consistent, continued care. As new health issues arise or old ones reappear, the Risk Tracking Record and ISP will need updating to reflect those changes and supports.

Conflict Resolution

It is unrealistic to believe that all people involved in providing services for an individual with developmental disabilities will agree all of the time to all aspects of their care. Some individuals are able to advocate for themselves and make their wants and desires known or may have involved friends and family members who can advocate for them. Others may not be able to make their wishes known and have no family/friends or advocates. These individuals must depend on the nurse and other members of their team to make decisions in their best interest.

When conflicts occur within the team, they often involve health care issues or services. Often, it is just a degree of misunderstanding. All team members may not hear the same information or they may hear incomplete information leading to confusion and indecision. Bringing the team together again to review the issue frequently resolves the conflict. Team members should always place the person's needs first and foremost "if this person could communicate their wishes, what would they want"?

If unresolved issues continue, consider:

- Asking the agency's administrator or another case manager to review the information and broker a decision. This person may give a new perspective to the issue and allow all members to express their concerns. Once opinions are expressed, a consensus may be reached.

- Be aware that the individual may have a legal representative. If so, this person(s) is a member of the team and needs to be included in discussions. However, if the team feels that the legal representative is not acting in the person's best interest, they can file a court petition or help the person obtain an attorney.

Team Disagreement with a Professional Opinion

Team members may at times disagree with a health care professional's opinion. A negative or positive personal experience about a health concern may cloud a team member's ability to be objective about what is best for someone else. As a nurse, you are probably the most knowledgeable person on the team about health/medical issues. The team may look to you to sort through information and guide the team to a consensus. Sometimes the health decision may be definitive with everyone agreeing on the treatment plan. Infrequently, however, conflicts arise and members come to an impasse.

The following are helpful steps in resolving an impasse:

- Does the team have complete, accurate information? Information can change and be distorted when it flows through too many people. Evaluate the information given to and received from the health care professional. A health care professional's information is derived from input from the person, people who know him/her best and objective information derived from examination, tests and studies. He/she should be able to explain about the individual's health condition, management and the reason for choosing one treatment plan over another. If the information is not clear, ask to have the information presented in a more basic manner and/or in writing. There are many pamphlets or brochures on health care issues that are written for non-medical people.

- Ask for a second opinion. It is uncommon that a second health care professional's opinion will differ from the first; however, sometimes additional information is presented in a manner that is easier to understand. The additional information may help the individual and team make a more informed decision.

- The Internet provides a variety of health and medical information. However, while it is valuable to have this resource, be aware that not all of the information is correct or valid. With thousands of references on a condition such as colon cancer of cerebral palsy, the information can be overwhelming and confusing to caregivers. As the nurse, you may be asked to validate and clarify the information. The most reliable information comes from web sites by institutions or organizations, such as the American Cancer Institute or the American Epilepsy Society.

- ***The Health Support Unit Nurses from Oregon Seniors and People with Disabilities are also available to answer questions and to provide information.***

Medical Decision-Maker Informed Consent

All people should be allowed to make all decisions for which they are capable.

However, the capability to make a health care decision may be difficult to determine in persons with developmental disabilities. When working with the developmental disabilities service system, many will look to the nurse for guidance in difficult situations. Determining capability can require the input from numerous people and in depth discussions may ensue.

Informed consent involves the ability to understand the consequences of one's actions/decisions. When the consequences are serious, a person needs a deeper understanding of those consequences. A person may be able to give consent (or refuse) to take cold medication, but may not be able to understand the consequences of forgoing life-saving chemotherapy. A person who physically and vocally objects to going to a medical clinic and receiving treatment may simply be communicating that they are afraid of people in white coats, have been hurt in similar environments, etc. They are probably not communicating a true informed decision about rejecting medical care.

The values of personal choice and independence may, at times, conflict with the values of keeping people in the safest environment or optimizing their health. Our society allows us to make personal bad choices within certain limits. A well-known example is cigarette smoking. People are allowed to risk their health by smoking cigarettes, but smoking is limited to people over the age of 18 years and restricted to certain environments.

The following are helpful reminders that must be considered when determining if an individual is capable of making their own health care decision:

- Capacity/capability is not an "all or none" phenomena. A person may be capable of making a simple decision but not a complex one.
- A person's receptive language skills are frequently better than their expressive skills. Be sure to get input from others who know the individual's communication skills best.
- Use simple and concrete language. If possible, demonstrate by using pictures, manikins or showing a real situation, such as being introduced to a person with a tracheostomy.
- Do not ask leading questions. The person may be intimidated by your presence and not say what they truly want.
- Talk directly to the person with the developmental disability. Ask for help interpreting the person's communication style from a caregiver if necessary.

Remember: *Bad personal choices are allowed in our society within certain limits. People with developmental disabilities also have this right, but they need to have the capacity to understand the consequences of their decisions.*

Substitute Medical Decision Makers

When a person is not capable of making a health/medical decision, the team may look for a substitute decision-maker. The Oregon Administrative Rules and statutes govern the appointment and limit the authority of substitute decision-makers.

The following are the three different alternate decision- makers that you will encounter:

Guardians

- Courts appoint guardians
- Guardians can only make a decision for which the person is not capable of making for him or herself
- A child is considered emancipated at the age of 18 years. If parents want to remain their child's guardian, they must file a court petition for guardianship.
- Guardianship papers have different "powers". For example: the court may determine that a person needs a guardian over their finances only and not over medical decisions
- Guardianships may be time limited or for life
- Oregon may not recognize guardianships from other states

If unsure of a person's guardianship status, call the person's case manager or county probate court where the guardianship was issued.

Self-appointed Health Care Representatives

- The right to appoint a Health Care Representative (HCR) is available to anyone in any living situation.
    - A person with a developmental disability may not have the capability to make complex medical decisions but may be very capable of knowing whom they trust to make those decisions for them. The team must ensure that the person understands the process.
- The person and only the person can make the decision to appoint a HCR and who they appoint.
- Two witnesses are required who verify that the decision was make freely and without coercion.

- Employees or owners of any type of residential service (group home, foster home, etc.) are prohibited from becoming a HCR to any person they serve, unless related by blood, adoption or marriage.
- To be valid, a specific form must be filled out. Forms may be obtained from Oregon Health Decisions at 1-800-422-4805. Your local hospital or nursing facility may also give out forms.

ISP Appointed Health Care Representatives

ISP Team appointed HCRs are only available to persons with developmental disabilities who live in group homes and supported living sites. In foster homes, an ISP team appointed HCR can only be appointed with a variance from Seniors and People with Disabilities. The rule requires that:

- There must be a team consensus for the appointment of the HCR and for any significant medical decisions.
- The appointed HCR is prohibited from making certain decisions such as withholding or withdrawing life support or feeding tubes.
- Two members of the team, one of which must be the case manager, must have completed training by Seniors and People with Disabilities on health care representation.
- Appointment is limited to one year or less and must be renewed yearly.
- Two forms must be completed and sent to Seniors and People with Disabilities before the appointment is legal.
- The rule limits who can become an ISP team appointed HCR.

Family and Next of Kin

Often health care professionals will look to family to make health care decisions for a loved one when the person is incapable of making a medical decision. This practice is referred to as “common law” and is:

- Based on the premise that family knows what the person would have decided and they hold the person’s best interest at heart.
  - ***Nurses and ISP members should be cautious if family members give evidence otherwise.***
- Not authorized or prohibited by state or federal law.
- Has never been challenged in Oregon courts.

In rare cases, the definition of “family” may be stretched to include a friend(s) or a significant other.

Do Not Resuscitate Orders

Making judgements about "quality of life" issues for a person with developmental disabilities who we do not know is unwise. Usually their life is much richer than it appears at first meeting. A "Do Not Resuscitate (DNR)" order may be erroneously considered based on an acute health crisis, such as a broken leg or pneumonia and the fact that the person has developmental disabilities. This decision is based on the person's "poor quality of life" from the non-disabled health care professional's point of view and not based on the medical facts of the case. The nurse and other team members must come together and advocate for the person to get complete, aggressive treatment just as would be done for any other person under the same circumstances. "Do Not Resuscitate" orders may be appropriate if the person meets the criteria set forth by Oregon State Law (ORS 127.635).

Consent for Feeding Tubes

Oregon law ORS 127.580 states that it is presumed that every person who is deemed temporarily or permanently incapacitated has consented to a feeding tube for nutrition and hydration to sustain life. This law can be overcome in one or more of the following circumstances:

- The person, while a capable adult, clearly and specifically stated that they did not want a feeding tube.
- A feeding tube and administration of nutrition and hydration is not medically feasible or would cause severe, intractable and long lasting pain.
- The person has appointed a HCR and has given them the authority to refuse a feeding tube on their behalf.
- The person does not have a HCR or an advance directive nor did they make their wishes known about artificial hydration/nutrition and they are permanently unconscious.
- The person does not have an advance directive nor did they make their wishes known about artificial hydration/nutrition but they have a terminal medical condition.
- The person has an advanced, progressive, terminal illness and consistently cannot communicate by any means, swallow food/fluid safely, care for self and recognize family or friends.

Life Sustaining Procedures

The decision to withhold or withdraw life sustaining procedures is painful for all persons involved in the process. Weighing all of the information may be difficult even for health care professionals, let alone the Health Care Representative and members of the individual's team. Once life sustaining procedures are begun it is very difficult to know when and if they should be withdrawn.

Oregon State Law (ORS 127.635) gives the following guidelines on when withholding or withdrawal may be appropriate:

- The person has a medically confirmed terminal condition.
- The person is permanently unconscious.
- Administering life sustaining procedures would not be beneficial and cause permanent and severe pain.
- The person is in the advanced stage of a progressive, terminal illness and cannot communicate by any means, swallow food/fluids safely, care for self and recognize family or friends.

When a team is faced with life and death situation and the individual has immediate family members, an attempt should be made to contact them for their participation even though they may not be actively involved in the person's life. The family may still refuse input and contact but at least the team has made the effort on behalf of the individual.

The case manager should always be actively involved with the team process and decision making around life-sustaining procedures. You may also call your Health Support Unit Nurse at Seniors and People with Disabilities for additional information and guidance

Admission to Nursing Facilities

In 1989 a federal law determined that a person with mental retardation or mental illness must be screened for appropriateness of admission to nursing facilities (nursing homes). This law restricted persons from living in nursing facilities when an alternative community living arrangement would suit them better.

The law allows admissions to nursing facilities under the following conditions:

- For convalescence from an illness or surgery following acute hospitalization for 60 days or less while a community placement is being developed to support the person.
- When the person has a terminal illness and the physician expects him/her to live less than 30 days.
- When the person has a chronic or severe medical condition, such as being in a coma or dependent on a ventilator.
- For respite care for 30 days or less while community resources are being restructured.
- Under special, unique conditions to be determined on an individual basis by the health care provider, ISP team and personnel from Seniors and People with Disabilities.

For individuals with developmental disabilities who are over 21 year of age and who live in nursing facilities, “Specialized Services” may be provided. These services (DD 45) are provided through the county case management system and are individualized to meet each person’s community integration and socialization needs. These services should not duplicate services already provided by the nursing facility.

POLSTS

The routine use of ***Physician Orders for Life Sustaining Treatment (POLST)*** forms in the developmental disabilities 24-hour service system is discouraged. However, they may be appropriate under some conditions on a case by case basis.

When individuals are admitted to nursing facilities, a POLST form is usually filled out. This helps the facility staff anticipate what life sustaining interventions the resident would want if they should have an acute health crisis. Persons with developmental disabilities may not be able to comprehend the POLST decision making process and may not have a Health Care Representative or guardian. The nurse and other team members need to assure that the POLST form indicate that all aggressive life saving measures be implemented unless the person meets one of the criteria under OAR 127.635. POLST forms are not and should not be used as an advanced directive for medical services.

Transitions

Individuals with developmental disabilities may want or need to enter, exit or transfer to a home within the Oregon service system at some time during their lives. Individuals may also enter a program for the first time as an adult when leaving their parent’s home. There are rules covering the basic rights of the person to protect them from discrimination and denial of services. Even though the rules spell out many aspects that govern transitioning, health and safety issues may be overlooked. During times of transition, there is an increased risk that the person’s health status will be compromised. The following health and safety concerns need to be considered when a person moves from one setting to another:

Person’s communication abilities and style

- How do they express their preferences (verbally and non-verbally)?
- How do they express pain and discomfort?
- How do they appear when they are ill?
- How do they adapt to new situations?

Person’s activity level, physical management and equipment needs

- Do they need physical/occupational therapy?
- Do the caregivers need training on ambulation/transfers, positioning?
- Is there durable medical equipment (DME), such as a positioner that needs to be available upon transfer to avoid schedule interruptions?
- Have they had recent changes, repairs or evaluation of their positioning equipment, including wheelchair? Ensure that any written history on DME goes with the person.
- Do they need daytime rest periods and repositioning?
- Do they sleep through the night? When do they go to bed and awaken in the morning?

Nursing supports

- Does the person have delegated nursing tasks? If no registered nurse is available, could these tasks be trained by a physician?

Medications, treatments and health supports

- What are the person’s medical problems and health needs?
- Is there a health care provider willing to assume responsibility for the person’s care when they move?
- Has a health care provider signed the medication, treatment and diet orders?
- Do caregivers understand all the orders?

- Are medications being transferred with the individual?
- Has the pharmacy been notified of the transfer?
- How does the person take their medications?
- Do they have/need protocols, such as for aspiration, dehydration, constipation, seizures, etc.?
- What data is currently being tracked, such as intake and output or sleep data?

Nutritional supports

- What is the person's weight and how are they weighed? Has their weight changed lately?
- Are there special eating/feeding instructions?
- Are the instructions in writing and is a feeding specialist involved?
- Do caregivers understand instructions?
- Do they need special eating/feeding utensils?
- Does the person need assistance to access fluids?

Behavior supports

- Does the person have challenging behavior that may interfere with care, such as pulling on their gastrostomy tube?
- If so, do they have a behavior plan that addresses this issue or is one needed?

Last minute concerns

- When did the person last have their medications and meal and when did they void and have a bowel movement?
- Who will do the skin check upon entry into the program?
- Are all pertinent records available, such as protocols, seizure record, medication orders, etc.?
- Are there any scheduled appointments that need to be kept?
- Are there copies of all available medical records?

Nutrition and Special Diets

Many individuals with developmental disabilities are able to eat all foods and food textures. This type of diet is referred to as a “general diet”. However, some individuals need modified or special diets that must be ordered by a health care professional. A dietitian or feeding specialist may determine dietary requirements but the physician (health care professional) must sign the order. A diet order may specify calorie content, food restrictions and/or consistency requirements.

Caloric Level

The calorie level may be identified as a number or numerical range or may be described with words or phrases.

Examples: 3000 calorie general diet
1200 – 1400 calorie general diet
Reduced portion general diet

The terms “low calorie” and “reduced portions” should be defined, such as low calorie = 1800 calories. Otherwise, they are not measurable and are confusing for caregivers.

Food Texture and Consistency

The texture prescribed in a diet order should be based upon the individual’s chewing and/or swallowing ability. Foods offered to the individual must follow the texture ordered. Offering foods that are not allowed can result in choking, aspiration, pneumonia or even death.

Mechanical or Mechanical Soft Texture

Food is usually chopped, ground, grated or diced and is of a soft, easy to chew consistency. Size of bites and consistency of food pieces may vary slightly for each individual and should be identified, such as nickel size pieces, dime size pieces or coleslaw consistency. The term “bite size” is not recommended as it means different things to different caregivers. Items such as raw vegetables, peanuts, popcorn or hotdogs are not allowed on a mechanical soft diet.

Pureed Texture

Pureed foods are processed in a food blender to create a smooth consistency. The food is blended until soft and smooth, usually by adding liquids or by using food thickeners to create a specific consistency, such as mashed potato or pudding consistency. Pureed foods should be served separated on a plate so that the individual food flavors remain distinct. Some individuals need the consistency of pudding while others need a looser consistency. Caregivers need to have clear written instructions and demonstrations on how the food needs to be prepared.

Textures of Fluids

Fluids are most commonly thickened with a commercial thickener, such as Thick it or Thick n Easy. There are four common fluid consistencies:

- Thin = water, milk, juice, coffee, soft drinks, etc.
- Nectar thick = prune juice, apricot and peach nectars, etc.
- Honey thick
- Pudding thick

Section III

Role of the Developmental Disabilities Nurse
Delivering Nursing Services
Direct Nursing Services
Holistic Nursing
Limited Nursing
Agency Related Duties
Safe Practice Considerations
Coordination and Communication
Working with Consultants
Items to Discuss with Potential Employers
Billing for Visits (sample form)
RN Position Responsibilities (sample form)

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, othotics 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.

Section IV

Board of Nursing, Division 47 Rule
Nursing Delegation
Teaching for an Emergency
Sample Forms
    Delegation of Nursing Task to Unlicensed Staff
    Review of Delegated Task
    RN transfer of a Delegated Task
    Rescinding of a Delegated Task
    Teaching a Task for an Anticipated Emergency
    Review of Task for an Anticipated Emergency

Delegation and Teaching for Emergencies

Delegation (OAR 851- 47- 0000 through- 0040)

Nursing delegation means that a registered nurse authorizes an unlicensed caregiver to perform special tasks of nursing care under special circumstances and indicates that authorization in writing. "Special tasks" are those tasks, which require the education and training of a nurse to perform. Only registered nurses (RNs) are allowed to delegate nursing tasks.

Delegation Considerations:

Setting – Delegation applies only in settings where the site is not required by rule to have a regularly scheduled nurse. Delegation applies to community settings such as adult and child foster care, residential care facilities and schools. It does not apply to nursing care facilities or acute care facilities where nurses are regularly scheduled, nor does it apply to care given by immediate family members.

Tasks – A special task of nursing care can be delegated only after the RN has determined that the individual is stable and the unlicensed caregiver is competent and willing to perform the task. The RN must use his/her judgement to determine if the task can be performed accurately and safely.

Nursing Judgment – It is inappropriate for employers or others to require nurses to delegate a task when, in the nurse's professional judgement, delegation is unsafe and not in the individual's best interest.

Nursing Process – The decision to delegate should be consistent with the nursing process (assessment, planning, implementation and evaluation). The RN who assesses the individual's supports and plans nursing care should determine the tasks to be delegated and is accountable for that delegation.

Transferring Delegation – Nursing delegation may be transferred from one nurse to another, provided that there is documentation that the previous nurse has discussed the delegation(s) process with the new nurse. The new nurse must then document that he/she understands and accepts the delegations.

Rescinding Delegation – Delegation may be rescinded under the following conditions:

- The nurse feels that an individual’s condition is not longer stable and predictable
- The nurse feels a caregiver is no longer capable of performing a task safely
- The nurse leaves the employment of an agency and is unable to transfer delegation. Rescinding documentation should be on record. When a nurse gives notice to leave employment, the agency has an obligation to replace the nurse with another, so that there is no lapse in nursing care.

Sharing Delegation – Two (or more) nurses may choose to complete the delegation process together, such as having one nurse providing the initial delegation and another nurse providing ongoing supervision. If the process is shared, all involved nurses have the responsibility to ensure that all delegation steps were followed. Careful, detailed communication is vital to ensure that steps are not overlooked and that documentation is complete. The nurses need to document the reason for separation of delegation and supervision from the standpoint of delivering effective care.

Regulation:

The Board of Nursing’s authority is over the RN who delegates. The Board has no authority over the setting in which delegation occurs. If the setting is licensed, the authority over the setting belongs to the licensing agency.

Delegation Process Steps:

Assess

- Assess the situation and the person:
  - Identify the needs of the person
  - Consider the circumstances and setting
  - Assure the availability of adequate resources, including supervision
- Assess the person and determine that he/she is in a stable and predictable condition and requires minimal supervision. Individuals in hospice care are considered stable as the course of their illness is predictable.
- Consider and specify the nature of each task to be delegated, including the complexity of the task, risks involved in the performance of the task and the skill required to perform the task.
- Assure appropriate accountability:
  - As delegator, accept accountability for delegating each task
  - Verify that the caregiver accepts the delegation responsibility and accountability. If in the nurse’s judgement, the caregiver is

unable to understand or perform the task, no delegation should occur.

Teach:

- Teach caregivers and observe them in their performance of the task. The caregiver is taught what signs and symptoms to watch for and when to contact the RN or health care professional. It is not expected that the caregivers always understand the meaning of the symptoms, but they do need to know when to call a health care professional about their observation.
- Leave clear, written instructions regarding the task. The instructions are to be specific to the person and should be clear and concise. The entire nursing process cannot be delegated

Supervise:

- Supervise the performance of the task periodically. Monitor performance of the task to assure compliance with OAR Division 47 rule.

Reassess:

- Reassess and evaluate the entire delegation process. Adjust the overall plan of care as needed. Determine and document the need and timeframe for future nursing assessments and supervisory visits. After the initial delegation, a supervisory visit must be done within the first 60 days and then can be done every 180 days (refer to rule).

Document:

- The task to be delegated
- The stability of the person's condition based on assessment
- The ability of the unlicensed caregiver to understand and perform the task safely.
- How the task was taught
- Teaching instructions and the outcome
- Evidence that the caregiver accepts responsibility for the task, knows the risks involved in performing the task and a written plan for dealing with the consequences
- Evidence that the caregiver knows that they cannot teach the task to another caregiver
- The frequency of the assessment/supervisory visits

Teaching a Task for an Anticipated Emergency (OAR 851- 047- 0040)

Is a process in which a nurse teaches a task that may be used for an anticipated emergency. These are tasks that cannot be practiced routinely due to their emergent or infrequent nature and therefore, do not fall under delegation.

Process:

- The registered nurse must assess the probability that the caregiver will encounter an emergency situation with a given individual
- The RN teaches the emergency procedure
- The RN leaves step by step instructions
- The RN periodically evaluates the caregiver competence regarding the anticipated emergency situation
- The RN periodically reviews the client for changes in orders or condition

Documentation:

- Though the Board of Nursing does not spell out documentation requirements, they should include at a minimum:
    - The emergency task taught
    - Name of the unlicensed caregiver
    - Teaching methods and location of instruction material
    - Date and signature of unlicensed staff and nurse

Examples:

- Emergency injection to treat an acute allergic reaction
- Emergency injection to treat hypoglycemia
- Emergency rectal administration of diazepam (Diastat) to treat uncontrolled seizures

Teaching for an anticipated emergency can also be used in cases where an individual is mostly independent at performing a (usually delegated) task, such as blood glucose monitoring or insulin injections. The individual may need assistance from a caregiver with one step of the procedure, such as documentation or reading the meter correctly. The rest of the steps in the procedure the person can perform independently. However, caregivers need to know how to perform the task in its entirety in case the person becomes temporally incapacitated. If you have questions about an individual case, please call the Board of Nursing.

The following forms are samples only. They may be used as is or as templates for your own versions.

Section V

Nursing Documentation
Sample Forms
    Health Progress Notes
    Nursing Assessment
    Health Support Plan/Nursing Care Plan
    Review of Plan
    Health Needs Checklist

Nursing Documentation

Nurses working in community settings need to provide documentation that reflects the nursing process. A person's health record provides legal proof of the nature and quality of care the person receives.

Nursing documentation:

- ✓ Must adhere to standards, rules, regulations and laws of nursing practice.
- ✓ Should be written in language that is generally understood by caregivers. It is recommended that nurses not use abbreviations or technical medical terms.
- ✓ Needs to provide follow up on all health concerns/occurrences that are recorded/reported by caregivers and health care professionals. This should include interventions, monitoring of the person's response to interventions and eventual resolution of the problem(s).
- ✓ Should not be redundant. Double documentation should be avoided.
- ✓ Must remain at the person's residence so that it is accessible by caregivers at all times

When caring for an individual, the nurse is responsible for reviewing all documentation by caregivers and health care professionals. These include flow sheets (e.g. vital signs, intake/output, weight, menses, seizures, etc.), physician visit forms, consultation forms, medication administration records and any other documents that are pertinent to the person's care.

Documentation According to the 24-hour Rule

According to the 24-hour rule, the program must maintain records on each individual to aid others in understanding the person's health history.

Documentation must include:

- ✓ A list of known health conditions, medical diagnoses, allergies and immunizations
- ✓ A record of visits to licensed health care professionals that include documentation of the consultation and any therapy provided
- ✓ A record of known hospitalizations and surgeries

Document Organization

Because the 24-hour rule does not dictate how healthcare records are kept, organization will vary, depending on the setting and agency policy. The nurse is often the most knowledgeable person about health care record standards and may be the best person to evaluate and resolve documentation issues. However, the nurse is only one member of the team and needs to explore all points of view in a respectful manner.

Potential Issues:

- Documentation that is inconsistent with nursing regulations and/or the 24-hour licensing rule.
- Poor documentation practices that persist because “things have always been done this way” or practices that have become sloppy over time because no one is doing quality assurance reviews.

Health Progress Notes

Day to day nursing documentation is usually found in the progress notes, which are often done in a narrative format and in a chronological order. These notes also often include entries from caregivers, managers and health care professionals. Occasionally, nursing entries may be written in a different section of the individual’s file. There is no specific requirement for the frequency of entries. Entries are made as health issues arise. Most importantly, when someone identifies a health problem, the progress notes need to state the problem, what interventions are implemented and the eventual outcome. It is desirable that entries be kept in an individual’s current record for at least six months.

When a nurse follows up on health concerns documented in the progress notes or passed on verbally by care-givers documentation should include:

- ✓ An assessment
- ✓ Interventions used or planned
- ✓ Ongoing monitoring if necessary
- ✓ A resolution of the problem

Telephone Communication

When working in the community, nurses often give guidance to caregivers over the phone. It is important that the agency and caregivers understand the parameters around these calls.

The agency policy, nurse contract or job description should clearly state the hours that the nurse can be called. This can range from only during working hours to being available twenty-four hours a day, seven days a week. It is essential that caregivers have clear guidelines on when the nurse should be called and what to do if a health problem arises when the nurse is not available. These directions may be located in:

- ➢ Agency/program policy. The policy may have a specific list of circumstances under which the nurse is called
- ➢ ISP and/or Nursing Care Plan
- ➢ Nursing orders specific to an individual
- ➢ Protocols specific to an individual

Caregiver's instructions should be clear on how quickly the nurse must be notified, which can range from an immediate page or phone call to leaving a message for the nurse on the next business day.

When providing advice over the phone, the nurse needs to document the following:

- ✓ The contacting caregiver's name and title, the name of the person they are calling about, the date and time of call
- ✓ The reason for the call
- ✓ Additional information that is solicited
- ✓ Instructions given to the caller on how to intervene
- ✓ Instructions given to the caller regarding when and who to call if the suggested intervention fails
- ✓ The expected time for the nursing follow up
- ✓ The nurse's legal signature

We have included a sample telephone communication documentation form. Similar forms may also be purchased at an office supply store. The completed form should be filed in the person's health care record in a timely manner.

Nursing Orders

Within the scope of practice, as outlined by the Oregon Board of Nursing, is the ability of the registered nurse to write nursing orders, based upon the nurse's assessment and plan of care. These nursing interventions are written to maintain comfort, support human functions and responses, maintain an environment conducive to well being and to provide health teaching, counseling and advocacy of persons serviced.

This section is not intended to cover all examples of nursing orders. The Oregon State Board of Nursing can best answer questions regarding the appropriateness of a specific order. However, the following are some common interventions that can be addressed by a registered nurse *without physician direction:*

Examples that clarify a physician's order:

- ❖ **Physician's order:** 1 to 2 Advil up to q 4 hours PRN
    - ✓ **Nurse's order:** Give John 2 Advil when he complains of headache or pain in his ankle. If he still is complaining 1 hour later, call the nurse for further direction. Only give a maximum of 8 tablets in 24 hours.
- ❖ **Physician's order:** Ducolax suppository PRN for constipation
    - ✓ **Nurse's order:** If Amy has had no BM that is at least medium-sized for two days, at bedtime of the second day, insert 1 Ducolax suppository rectally. Monitor for results and call the nurse if no results within 12 hours.

- ❖ **Orders that change the times medications are given, if the physician's order allows flexibility**:
    - o **Physician's order:** Amoxicillin 250 mg every 8 hours t.i.d. for 10 days
    - o **Nurse's order:** Give Amoxicillin 250 mg at 7:00 AM, 3:00 PM and 10:00 PM for 10 days
    - o **Nurse's order:** Today, give Amoxicillin at 9:00 AM instead of 7:00 AM.

- ❖ **Preventive measures**:
    - o Offer fluids every two hours
    - o Minimal/maximum fluid requirements
    - o Sunscreen
    - o Barrier ointment (A & D, petroleum jelly, etc.)
    - o Dandruff shampoo
    - o Bran and prune juice
    - o Exercise
    - o Monitoring interventions with follow up instructions (vital signs, track fluid intake, etc.)

- ❖ **Physical management/comfort measures:**
    - o Repositioning schedule
    - o Keep home from work today
    - o Elevate foot
    - o Offer opportunity to go to the bathroom after breakfast for at least 15 minutes
    - o Clear fluids for next 24 hours

Under the Oregon Administrative Rule that licenses residential sites, a physician's order is required for the following:

- Over the counter medications, other than topicals
- Treatments for illness or injury
  - Ice for a sprained ankle (beyond immediate first aid)
  - Tar shampoo for mild psoriasis
  - Topical ointment for groin rash

- Special diets
  - Modified consistency, such as chopped, pureed, thickened liquids to honey consistency, etc.
  - Calorie content, such as 1200 calorie ADA or 3000 calorie general diet
  - Food restrictions, such as no added sugar or no milk products

Conflicts

When writing nursing orders, the nurse needs to consider the values of integration, inclusion and empowerment of the person being served. At times these values may conflict with nursing best practices. For example; a person with a nursing order to only be in a wheelchair for a total of two hours at a time may wish to go to a movie that lasts three hours.

In addition, scopes of practices of various health professionals overlap. For example, both registered nurses and physical therapists may write orders concerning physical management. Clear communication with other disciplines will avoid conflicts.

When conflicts arise, the nurse should discuss the issue with his/her employer or contractor. Does the employer/contractor want the RN to write nursing orders or have all orders come from the physician? Who should decide if someone needs to stay home from work because of illness? What should the nurse do when nursing orders are given and not followed? At times it may be necessary to seek the assistance of the case manager, especially when a person's health and safety are a concern.

Nursing Assessment

Prior to providing direct nursing services for an individual, the nurse must perform and document a nursing assessment. There is a sample form in this manual; however, it is not mandatory and the nurse may use any form that contains assessment information. A nursing assessment is a "snapshot in time"; that is, it documents the person's health issues at the time when it is written.

A holistic nursing assessment may contain the following information:

- ✓ Name, date of birth, other identifying data such address and contact person(s)
- ✓ Current medications
- ✓ Allergies/adverse drug reactions
- ✓ Weight and height
- ✓ Current and past medical diagnoses
- ✓ Immunizations
- ✓ Adaptive equipment needs
- ✓ Communication style
- ✓ Nutritional status
- ✓ Pertinent laboratory tests and diagnostic studies
- ✓ Also included, may be cultural/spiritual/social needs, family history, and any other health/safety concerns

From the assessment information, the nurse is able to construct a plan of care. Direct nursing services that are limited in scope may require a less detailed assessment. For example, a person who has a fractured arm may require a nurse to assess a new cast for comfort and fit and the person for pain control.

Occasionally, a nurse will be hired to provide direct nursing services and will need to provide guidance and training to caregivers immediately. In these cases, the nurse will need to document a brief assessment that will ensure that any training done will be safe and effective. For example, the nurse is called in to see a person who has returned from the hospital following a laparoscopic cholecystectomy. The nurse will need to assess the person’s medications, weight, diet, incisions, ability to communicate pain/discomfort, any behavioral issues that may affect healing and what happened during the person’s hospital stay. From this information the nurse can construct a safe plan to care for the person overnight until a full care plan can be constructed the following day.

Nursing Care Plans/Health Support Plans

The nursing care plan is an important part of the nursing process. The essential parts of the plan are:

- ➢ List of health problems
- ➢ Desired outcomes/goals; should be measurable goals
- ➢ Interventions
- ➢ Ongoing review/updates with changes in condition/ circumstances

It is important that the nurse use language that is easily understood by the caregivers. Avoid using medical terms and abbreviations. While we have included a sample care plan form in this manual, it is not mandatory that this particular one be used.

It is important to routinely review the plan and update when the person's health supports change. The nursing care plan is a work in progress and must remain current. The frequency with which you make updates will vary depending on the setting and the individual's condition. Best practice dictates that changes are made as the person's health condition changes; this is best accomplished when the plan is reviewed on a routine basis.

Health Maintenance Tracking/Health Needs Checklist

Routine examinations and certain laboratory tests will need to be tracked to ensure that they are done on a timely basis.

Commonly tracked items:

- Dental exams
- Dietary evaluations
- Eye exams
- Periodic laboratory tests, such as drug blood levels
- Mammograms
- PAP smears
- Specialist appointments (neurology, orthopedist, ENT, etc,)
- Primary care appointments
- Therapist evaluations

Other data may be tracked, depending on the person's needs. The nurse may not be the person who is responsible for maintaining this record. The agency may assign a house manager or health manager to track this data but the nurse needs to be aware of all appointments/exams as they arise.

Section VI

Psychotropic Medication Use
Monitoring Side Effects (sample forms)
    AIMS

Psychotropic Medication Use

The use of psychotropic medication in individuals with developmental disabilities has been the focus of legal debate and controversy for decades. A psychotropic medication is defined as a drug that has a prescribed intent to affect or alter thought processes, mood or behavior. This includes medications that are not typically classified as psychotropics, but may be used to affect or alter thought processes, mood or behavior.

> For example; Benadryl used at bedtime as a sleep aid or St. John's Wart used to improve mood.

A psychotropic medication is not considered a psychotropic medication when it is used to treat other health conditions or diagnoses.

> For example; Valium when used for spasticity or amitriptyline when used for migraine pain.

According to the 24-hour Rule:
When a person receives a psychotropic medication for a psychiatric diagnosis or behavior support, the medication must be:

- Prescribed by a physician or health care provider through a written order.
- Monitored by the prescribing physician, ISP team and program for desired responses and adverse consequences.
- When medication is first prescribed and annually thereafter, the provider must obtain a signed balancing test from the prescribing health care provider using the DHS Balancing Test Form.
- The provider must keep signed copies of these forms in the individual's medical records for seven years.
- ***Psychotropic medication cannot be prescribed on a PRN basis unless by variance.***

What is a Balancing Test?
The balancing test is a written statement from the prescribing health care provider stating that the risks of the psychiatric diagnosis or behavior outweigh the potential risks of the proposed psychotropic medication.

It is the responsibility of caregivers to:

- Collect a full and clear description of behavior or symptoms of the condition to be treated by the psychotropic medication.
- Collect data on frequency, intensity and circumstances around the targeted behavior(s) identified by the team and behavioral specialist through a functional analysis. You can expect short-term behavior fluctuations and should not react by favoring frequent medication changes.
- Define the expected goal(s) of treatment.
- Monitor and collect data on any medication side effects.
- Present all data to the prescribing health care professional in a understandable manner.
- Advocate for keeping drug regimes as simple as possible.

It is the responsibility of the health care provider to:

- Make a determination after reviewing the collected data that the harmful effects of the psychiatric illness or behavior outweigh the potentially harmful effects of the medication. ***The health care professional cannot make this determination without data collection and documentation from caregivers.***

Psychotropic medications cannot be used for:

- Punishment
- Convenience of caregivers
- As a substitute for a meaningful behavior plan
- In excessive amounts, thus interfering with the person's quality of life

Monitoring Forms:
If a psychotropic medication is used that has the potential of causing tardive dyskinesia (TD), a monitoring system may be put in place to track changes on a regular and systematic basis. If the drug is discontinued, monitor for withdrawal TD for approximately two months after the drug is stopped. The health care professional, the nurse, or a trained caregiver may complete the monitoring. See samples of MOSES and AIMS tools.

Abnormal Involuntary Movement Scale (AIMS)

An AIMS assessment is a useful tool when a person has involuntary movements that may be related to psychotropic medication use. These movements start insidiously and may go unrecognized by caregivers. If they do notice them, they may not understand the significance of what they observe. The following is a systematic process for evaluating involuntary movements with AIMS:

Examination Procedure:
Either before or after completing the examination procedure, observe the person unobtrusively, at rest (e.g. around the home). Having a caregiver present during the exam may be useful as the person may not be able to assist with the exam. If the person is unable to follow directions, information will come from caregiver and your observations.

The chair to be used in this exam should be a hard, firm one without arms.

- Have the person remove shoes and socks.
- Have the person remove any gum or candy from his/her mouth. Ask the person to open his/her mouth. Observe current condition of mouth. Do they wear dentures and if so do they fit properly? Have person open and close mouth twice. *Observe for tongue movement*.
- Observe if the person has any involuntary movements in mouth, face, hands or feet. If yes, do movements interfere with daily activities?
- Have the person sit in a chair with hands on knees, legs slightly apart and feet flat on floor.
  - ***Look for entire body for movements while in this position.***
- Have the person to sit with hands hanging unsupported. If male, between legs, if female and wearing a dress, hanging over knees.
  - ***Observe for hands and other body movements.***
- Have the person to tap thumb with each finger as rapidly as possible for 10 – 15 seconds; separately with right hand, then with left hand.
  - ***Observe for facial and leg movements.***
- Flex and extend the person's left and right arms one at a time.
  - ***Observe for rigidity.***
- Have the person stand up. Observe in profile all body areas again.
- Have the person extend both arms outstretched in front with palms down.
  - ***Observe trunk, legs and mouth.***
- Ask the person walk a few paces, turn and walk back to chair.
  - ***Observe hands and gait. Do this twice***

Section VII

- The Fatal Four: Special Risks
    - Aspiration
    - Constipation
    - Dehydration
    - Seizure Disorders
- Protocols: General Information
- Overview of Pica
- Overview of Self-injurious Behavior
- Protocol Forms
    - Generic
    - Aspiration
    - Constipation
    - Dehydration
    - Seizures

The “Fatal Four”

Aspiration, Dehydration, Constipation, Seizures

There are four major health issues that are more common in people with developmental disabilities than in the general population that can lead to severe morbidity and even death. They are frequently referred to as the “fatal four” risks: aspiration, dehydration, constipation and epileptic seizures.

Aspiration, dehydration and constipation may be insidious conditions that often go unrecognized. Many of the symptoms are subtle and persons with disabilities may not be able to express their discomfort or give indications that they are not feeling well.

If a person has epileptic seizures, it is the suddenness and the unpredictability of this disorder that places the person most at risk. Injury, aspiration, drowning accidents and seizures that continue without stopping may cause hospitalizations and/or even death.

For all of the “fatal four” risks, astuteness of the caregivers and careful monitoring can greatly minimize these hazards and ensure timely interventions should they occur. The following information will help nurses identify individuals with these risks and provide guidance on assessments, plans of care and protocols. The material is presented in a format that nurses can adapt to teach caregivers about the “fatal four” risks.

Aspiration

Aspiration is defined as the inhalation of food, fluid, saliva, medication or other foreign material into the trachea and lungs. Any material can be aspirated on the way to the stomach or as stomach contents are refluxed back into the throat. The following information will help identify risk factors and interventions that may be unique to persons with developmental disabilities.

Factors that place individuals at risk for aspiration:

- Being fed by others
- Inadequately trained caregivers assisting with eating/drinking
- Weak or absent coughing/gagging reflexes, commonly seen in persons who have cerebral palsy or muscular dystrophy
- Poor chewing or swallowing skills
- Gastroesophageal reflux disease (GERD, GER), which can cause aspiration of stomach contents
- Food stuffing, rapid eating/drinking and pooling of food in the mouth
- Inappropriate fluid consistency and/or food textures
- Medication side effects that cause drowsiness and/or relax muscles causing delayed swallowing and suppression of gag and cough reflexes
- Impaired mobility that may leave individuals unable to sit upright while eating
- Epileptic seizures that may occur during oral intake or failure to position a person on their side after a seizure, allowing oral secretions to enter the airway

Review the health history for aspiration risks:

- A diagnosis of risk for aspiration or past episodes of aspiration
- A diagnosis, such as cerebral palsy, muscular dystrophy, epilepsy, GERD, dysphagia or hiatal hernia
- History of aspiration pneumonia
- Needing to be fed by others
- History of choking, coughing, gagging while eating
- Needs modified food texture and fluid consistency
- Eating/swallowing evaluations and laboratory tests (barium swallow, pH study, etc.) that indicates dysphagia
- Has unexplained weight loss or chronic dehydration

- Takes medications that may decrease voluntary muscle coordination or cause drowsiness
- Has unsafe eating and drinking practices, such as eating/drinking rapidly and food stuffing
- Has chronic chest congestion, frequent pneumonia, moist respirations, persistent cough or chronically uses cough/asthma medications

Mealtime behaviors that may indicate aspiration:

- Eating slowly
- Fear or reluctance to eat
- Coughing or choking during meals
- Refusing food and/or fluids
- Food and fluid falling out the person’s mouth
- Eating in odd or unusual positions, such as throwing head back when swallowing or swallowing large amounts of food rapidly
- Refusing to eat except for “favorite caregiver”

Signs and symptoms that may indicate aspiration risks:

- Gagging/choking during meals
- Persistent coughing during or after meals
- Irregular breathing, turning blue, moist respirations, wheezing or rapid respirations
- Food or fluid falling out of the person’s mouth or drooling
- Intermittent fevers
- Chronic dehydration
- Unexplained weight loss
- Vomiting, regurgitation, rumination and/or odor of vomit or formula after meals

Aspiration interventions:

- Call 911 if the person stops breathing and start CPR
- Stop feeding/eating immediately (may restart meal if feeding/dining instructions, supervisor or health care professional give permission)
- Keep person in an upright position and encourage coughing
- If in doubt on what to do, call the health care professional or 911

Guidelines on how to prevent or minimize the risk of aspiration:

- Obtain a consultation by a swallowing specialist if symptoms occur
- Change diet consistency, texture or temperature (need a physician's order)
- Slow pace of eating and decrease size of bites
- Position to enhance swallowing during meal times
- Keep in an upright position after meals for 45 minutes or as ordered
- Elevate the head of the bed 30 to 45 degrees
- Avoid food/fluid 2-3 hours before bedtime
- Consider the use of medications to promote stomach emptying, reduce reflux and acidity
- Write an aspiration protocol and written instructions on how the person is to eat or be fed and provide caregiver training. Cover the following:
  - The assistance level needed
  - Correct positioning for all oral intake and tooth brushing
  - Eating/feeding equipment needed
  - Physical and verbal cueing needed
  - Location of meals. Some individuals may need to eat alone as they become distracted when eating with their peers
  - Recognition of aspiration symptoms, what to do about if noted and who to notify

Aspiration risks and feeding tubes:

Many individuals with developmental disabilities have permanent gastrostomy feeding tubes (or jejunostomy tubes). Having a feeding tube does not eliminate the risk of aspiration. Stomach contents can still enter the airway via regurgitation or oral secretions can be aspirated if the person has dysphgia. Occasionally anti reflux surgery will be performed to tighten the lower esophageal sphincter. Having this surgery will not conclusively eliminate the risk of aspiration, but should lessen the risk. Some standard aspiration precautions are:

- Administering tube feedings in an upright sitting position and keep upright for at least 45 minutes after.
- If the person must be fed in bed, keep the head of bed at a 45 degree angle while feeding and for 45 minutes to an hour after.
- Don't overfill the stomach.
- Formula given at room temperature is better tolerated.

- Don’t feed too rapidly; feedings should be administered over at least 30 minutes or as ordered.

After receiving a feeding tube, some individuals continue to eat small portions of their favorite foods orally. For these individuals, complete elimination of oral intake would take away a very valued activity - eating. To allow someone to eat after a feeding tube is placed is a difficult decision as even small infrequent amounts of food taken orally could be aspirated. The pros and cons of this decision should be discussed thoroughly by the team with good documentation on why the team reached its decision. If the team feels that the person should have some oral intake, guidelines should be written about what foods, how and when the person can be fed.

Constipation

Constipation is when an individual has difficulty passing stool; the stools are hard, dry and often look like marbles. The frequency of bowel movements varies greatly from person to person. Bowel movements are considered normal as long as the feces is soft, normal sized and is passed easily out of the bowel.

Factors that place individuals at risk for constipation:

- Neuromuscular degenerative disorders that impair the central nervous system's response for the need to elimination.
- Spinal cord injuries or birth defects that affect neural responses needed for elimination, such as spina bifida.
- Individuals with muscle weakness who lack the strength and tone needed for adequate bowel function.
- Diets that do not contain enough fiber and fluids.
- Poor swallowing skills with aspiration risk making it difficult to eat and drink adequate amounts of fiber and fluid.
- Inadequate or inconvenient access to the bathroom.
- Immobility and poor body alignment that does not allow for optimum positioning for bowel elimination.
- Poor toileting habits and routines or lack or privacy and time for toileting.
- Medications that slow down gastric motility or draw too much fluid from the GI tract.
- Hemorrhoids or other conditions that make bowel elimination painful.
- History of frequent bowel stimulant use leading to decreased bowel reactivity.
- Repression of the urge to defecate due to psychiatric issues.

Review of health history for risk of constipation:

- Has a current or previous diagnosis of constipation.
- Has a routine order for bowel medications and/or treatments.
- Uses PRN bowel medications.
- Hospitalizations or outpatient treatments for constipation (bowel impaction, obstruction or obstipation).
- Takes medications that affect the body's hydration status or have constipating side effects.
- Diet orders to increase dietary fiber (prunes, bran, psyllium, etc.) without adequate fluid intake.

- Individual has a constipation protocol.
- Caregiver’s documentation indicates that the individual complains of stomach discomfort, strains with elimination, has abdominal distention, makes frequent trips to the bathroom or engages in rectal digging.
- Bowel record shows that the individual is passing hard feces or bowel movements more that 2 – 3 days apart.
- Recent decrease or stopping of routine bowel medications.

Signs and symptoms of constipation:

- Spending a lot of time on the toilet
- Straining and grunting while passing stool
- Refusing to eat or drink
- Hard, small, dry feces
- Hard, protruding abdomen (usually an emergency)
- Vomiting digested food that smells like feces (is an emergency)
- Bloating and complaints of stomach discomfort

Constipation Interventions:

- Dietitian consultation regarding the type of food, texture, fiber content and fluid requirements to enhance elimination
- Implement an individual constipation protocol and train caregivers:
  - How to identify constipation symptoms, what to do if they occur and who to notify
  - Fluid requirements
  - When to give PRN bowel medications and how to document the results
  - When to toilet the individual
  - How and where to document bowel movements
  - To report observations and/or data to the health care professional routinely and as needed

Guidelines on how to prevent or minimize constipation:

- Encourage physical activity to increase muscle strength and tone.
- A positioning schedule for non-mobile individuals with time in an upright position. May need a physical therapist’s advise.
- Review of medications for side effects of constipation.
- Establish toileting routines and schedule, for example:
  - Drinking a warm beverage first thing in the morning
  - Teaching the person to take slow, deep breaths to increase abdominal pressure during toileting

    - Teaching the person to respond to the natural urge to defecate
    - Placing feet on a small step stool while sitting on toilet
    - Providing enough time and privacy for toileting

Observations that should prompt concern:

- No bowel movement for more than three days
- Last two bowel movements were hard and/or small
- In the last three days, only small bowel movements recorded

Observations that should prompt a review by a health professional:

- Abdomen firm to touch and/or looks distended and bloated
- Complaints of stomach pain
- Vomiting without any fever or flu-like symptoms and/or vomiting material that smells like fecal material (call 911)
- Runny liquid stools after several days of passing small hard stools, small liquid stools or no bowel movements

Dehydration

Dehydration occurs when an individual does not drink enough fluids. Fluids are needed for temperature control, chemical balance and for cells to make energy and get rid of waste products. Dehydration occurs when the body loses more fluid than is replaced.

Factors that place individuals at risk for dehydration:

- Unable to access fluids without assistance
- Needing assistance with drinking
- Dysphagia with coughing and choking during meals
- Food, fluid and saliva falling out of a person’s mouth
- Frequently refusing food and fluids
- Suppression of thirst mechanism that results in the inability to recognize thirst
- Unable to effectively communicate thirst to caregivers
- Medical conditions where fluid loss can potentially cause dehydration, such as kidney disease or diabetes
- Conditions where the individual loses body fluid, such as drooling, diarrhea, sweating and vomiting
- Taking medications that affect body fluid balance, such as diuretics

Review of health history for risk of dehydration:

- Physician has written a diagnosis of dehydration
- Physician has written an order for a minimum amount of fluid each day
- Has required intravenous fluids for dehydration either as an outpatient treatment or when in the hospital
- Takes a medication that affects body fluid balance, such as a diuretic
- Has a history of difficulty with drinking fluids, such as refusal or spillage
- Cannot independently access fluids or communicate thirst
- Has a protocol for dehydration
- Weight record reflects rapid weight loss
- History of frequent vomiting/diarrhea
- Has any type of stoma

Signs and symptoms that an individual may be dehydrated:

- Dry skin and poor skin elasticity
- Extreme thirst

- Dry sticky mucous
- Lethargy and decreased alertness
- Fever
- Increased heart rate and decreased blood pressure
- Decreased urination, dark colored urine and concentrated urine smell

Dehydration interventions:

- Offer fluid intake if the individual is alert and able to drink safely
- If unable to take fluid safely, call health care professional for administration of intravenous fluids

Guidelines for dehydration prevention:

- Individuals should be encouraged to drink 8 – 10 glasses of fluid/day (64 – 84 ounces/day or 2000 – 2400 cc/day).
  - Persons who weigh more must drink more; persons who weigh less need less.
  - If a person is reluctant to drink fluids, offer foods high in fluid content, such as gelatin, watermelon, puddings, yogurt or ice cream.
  - Persons who are very active, work hard, have a fever or perspire heavily need more fluids.
- Persons who have cardiac or kidney disease may need less fluid.
- A person with dysphagia needs a swallowing evaluation by a health care professional
- Implement a dehydration protocol and provide caregiver training:
  - Have clear instructions regarding fluid requirements
  - List acceptable minimal amount of fluid intake/day
  - Consider the need for monitoring of intake and output
  - List signs and symptoms of dehydration, what to do if seen and who to notify

Seizure Disorder (Epilepsy)

Epilepsy is a disorder of the brain that is characterized by recurring seizures. Individuals with developmental disabilities are more likely to have epilepsy because of an underlying brain dysfunction. Head injuries, brain tumors and brain congenital abnormalities are some causes of epilepsy. The clinical expression of an epileptic seizure varies according to where it starts in the brain.

Factors that place individuals at risk for epilepsy:

- Prenatal and postnatal brain injury, such as trauma, anoxia, infection
- Congenital brain malformations
- Brain tumors, clots, hemorrhage, aneurysms
- Traumatic brain injuries

Review of health history for risk of epilepsy:

- Has a diagnosis of seizures, seizure disorder or epilepsy
- Has a history of a seizure(s) within the last five years
- Has an epilepsy protocol
- Takes antiepileptic medications for epilepsy or has had other treatments, such as a vagal nerve stimulator or ketogenic diet

Guidelines for seizure prevention:

- Give antiepileptic medications on time as prescribed
  - provide a missed medication protocol
- Promote good relationships with health care professionals/specialists
  - Provide accurate documentation and record keeping
  - Keep appointments and be on time
- Encourage the person to live a moderate life style
  - Adequate sleep, low stress, good nutrition and discourage alcohol intake

Immediate interventions when an individual has a seizure:

- Stay with the person and guide gently away from or prevent access to dangerous areas
- Do not place anything in the person's mouth
- Move objects away from the person to prevent injury
- Only move the person if in an unsafe area such as a roadway or stairwell

- If in water, keep the person's head above the water
- Don't restrain the person's movements
- Pad under the person's head, arms and legs
- Keep track of how long the seizure lasts

After the seizure:

- Turn the individual on their side when relaxed
- Loosen clothing
- Check for injuries and treat appropriately
- Document the seizure on a seizure calendar or record
- Allow the person sufficient time to recover before returning to activities

Call 911 if:

- Two or more seizures occur without full recovery of responsiveness between seizures (unless the seizure protocol directs otherwise).
- When breathing does not resume after a seizure
  - Start rescue breathing
- When this is the person's first seizure
- When the person may have aspirated (seizure occurs during eating, swimming, bathing, etc.)
- When a seizure lasts for more than 5 minutes (unless the seizure protocol directs otherwise)
- When the person cannot be aroused two hours after the seizure (unless their protocol directs otherwise)
- When an injury has occurred that needs medical attention (follow your agency policy)

General interventions:

- Keep an accurate description of seizures and track all seizures in a consistent manner
- Monitor for medication side effects
- Keep the environment safe:
  - Water safety precautions, such as 1:1 continual observation in pool/tub, wearing a lifejacket, using shower only or no tub baths. Precautions much be considered when bathing/swimming if there has been a seizure in the past 12 months or antiepileptic medications have been changed with the last 6 months.

- Monitor for compliance with safety devices, such as wearing a helmet, elbow and/or kneepads and in keeping the devices in good repair
- Consider community safety precautions, such 1:1 observation in the community or bicycle safety
- Individualized seizure protocol with caregiver training
  - Description of person's normal seizure pattern(s)
  - Safety interventions
  - Degree of safety precautions in home and community
  - Caregiver interventions if person has a seizure and who to notify
    - When to call 911
    - Administration of PRN medications, if ordered

Observations that should prompt a review by a health professional:

- Increase in number and/or intensity or seizures
- New episodes or attacks that look like epileptic seizures
- Change in description of seizures
- Multiple seizure descriptions or poorly defined seizure descriptions
- Repeated minor injuries or suspected aspirations as a result of seizures
- Increased lethargy or cognitive decline
- Illness with vomiting/dehydration and/or not able to take medications
- Repeated refusal of medications and use of protective devices

Protocols – General Information

Protocols are written instructions for caregivers to follow when individuals have specific or frequent problems from a health concern that usually has a predictable outcome. Protocols give guidance to caregivers on sign and symptoms to look for, when and how to intervene and who to notify.

Protocols are sometimes confused with procedures

Procedures are task oriented.

They provide step-by-step instructions on how to do a task. For example: "how to administer a gastrostomy feeding" or "how to empty a Foley catheter bag"

Protocols are problem oriented.

They explain what to do about a health problem. They contain a description of the problem, when and how to intervene, when to call 911 and who to notify.

Protocols need to be specific to the setting and the individual

For instance, if three individuals living in the same home have seizure protocols, they should all read differently. There will be some similarities, such as basic safety guidelines and documentation requirements, but each should have a specific seizure description and may vary on when to call 911. Protocols need to be specific to the setting. An individual's seizure protocol for the home should read slightly differently than their protocol for the vocational site.

Protocols need to identify the author(s)

If an individual has a nurse involved in his/her care, the nurse will usually write protocols involving health concerns with input from caregivers. Occasionally, a physician may write directions on how to deal with a specific health issue, such as when to notify him/her if a person has a low or high blood glucose level. These directions should be included in the protocol, but are inadequate as a complete protocol. If the individual does not have a nurse involved in their care, someone knowledgeable about the individual and health issues should write the protocols. This is likely to be the health manager, house manager or program director. The author(s) of the protocol should be clearly identified.

Protocols need to be dated and reviewed periodically

As the individual's condition changes, the protocols should be updated. When physician orders are changed, protocols may need to reflect those changes. For example, if an individual's constipation protocol instructed the caregivers to start monitoring all bowel movements, the protocol would have to be revised. Any changes made to the protocol need to be initialed and dated. All caregivers need to be informed of the changes.

General Protocol Form

Mandatory protocol forms are required for the "fatal four" risks in all 24-hour residential setting and must be used in accordance with the Risk Record. When individuals have other health risks the team may elect to develop a protocol around each risk.

General Protocol Form addresses all elements of the protocol:

- When to call 911
- Brief description of the problem/contributing factors
- Preventative measures
- Signs and symptoms to look for
- Interventions

Pain Protocol

Evaluating pain is difficult when a person can't articulate if, how, when and where they hurt. Caregivers are left to interpret behaviors, gestures, vocalizations and facial expressions as indicators of pain. If there is frequent caregiver turnover, no one may know the person well enough to establish how the person communicates pain and discomfort. Even if a person can communicate with words, they may still not be able to communicate the nuances of their pain in a productive method. The following pain protocol has lists some generalized pain indicators but also leaves room for the nurse and caregivers to list signs and symptoms that are unique to the individual. This protocol is useful for the home and community inclusion program but should also accompany the person to other settings, such as a hospital where he/she will be cared for by strangers.

Overview of Pica

Pica is defined as the compulsive eating of non-food items. There are many theories about the cause of pica; however, within the field of developmental disabilities the cause often remains unknown.

Individuals who pica may seek out a wide variety of items to ingest. The behavior is very individualized. Some may seek out specific items to ingest while others may ingest any small item in their environment. Therefore a plan/protocol for safety must be developed specifically for the person, their pica behavior and health risks.

There are many risks associated with putting non-food items into the mouth and/or swallowing them include:

Bowel blockage – items that are swallowed may clump or stick together and eventually block the bowel

- Small stones
- Bark/mulch
- String, thread or fuzz
- Paper
- Disposable gloves (latex, plastic)

Ulceration and perforation

- Any object that stays in contact with one spot in the bowel can cause ulceration and eventually perforation. Coins are particularly dangerous.
- Any sharp object, such as a safety pin or screw can puncture the esophagus, stomach or intestines.

Poisoning/Toxicity/Parasitic Infection

- Furniture polish – damages the lungs
- Cleaning solvent
- Antifreeze – damages the kidneys
- Batteries
- Toilette freshener blocks
- Paint chips for lead based paints
- Cigarettes and butts
- Dirt from areas frequented by pets/animals
- Pet feces

Choking/Aspiration

- Non-food items large enough to block the airway

Dental and Mouth Injuries

- Items too hard to chew (rocks, buttons, etc.)

Nutritional Deprivation

- Eating enough non-food items to displace legitimate caloric intake

Pica Prevention – <u>prevention is the best strategy</u>

- Limited access to environments that are not rigorously monitored for small indigestible items.
- Ensure close supervision of the individual and that all caregivers understand the individual's risk of pica.
- Develop a protocol specific to the individual and their support needs; provide caregiver training in all locations where the person spends time.
- Consider the need to routine surveillance (pica sweeps) of the areas frequented by the individual to find and remove targeted pica items.
- Avoid clothing with buttons/bows that can be pulled off.
- Avoid toys/gifts with small pieces that can be chewed or broken off and swallowed.
- Avoid access to soaps, creams, shampoos, etc.

Protocol/Safety Plan

The plan should be developed with input from the people who know the individual and their environment best. The plan should give guidance for:

- When to call 911
- When to call poison control (the phone number of poison control should be posted by every phone).
- Reason why the individual is at risk (list favored items of pursuit and times/locations where pursuit is most likely, if known).
- Steps in prevention, such as pica sweeps, no buttons on shirt, etc.
- Signs and symptoms that the individual may display if a non-food item is swallowed.
- Non-emergency interventions and whom to notify. Example: a non-emergency intervention may be to monitor bowel movements for passage of objects for four days and then notify the physician if the object has not been noted to have passed.
- Who to notify if a pica incident occurs.

If a non-food item is suspected of having been ingested, the individual must be monitored for symptoms of obstruction, infection, poisoning or other adverse effect.

The following symptoms may indicate a need to notify the physician:

- Refusal of food or fluids or decreased intake
- Lack of bowel movements or small watery stools
- Abdominal pain and discomfort
- Vomiting
- Fever
- Hard or protruding abdomen
- Walking stooped or bent over as if in pain (if not usual for the individual)
- Complaining of not feeling well or not wanting to get out of bed, go to work or participate in favorite activities

If an individual displays pica behavior for the first time, it is essential to ensure that the physician is informed of the following facts:

- A clear description of the behavior, clarifying that it is new to the person
- Any data collected on frequency
- Specific items that the person is seeking out

This information will guide the physician on appropriate management. Further referrals may be needed to rule out depression, dietary deficiency or other possible causes.

Remember, pica presents a serious risk to a person's health and should not be disregarded or taken lightly. It can result in serious illness, surgery and even death. Knowledge of the condition and its specific manifestation in an individual and implementation of a well developed safety plan will give caregivers the information that they need to assist individuals to live safe, happy and healthy lives.

Overview of Self-injurious Behavior

One of the most difficult health issues to manage is injury prevention from repetitious self-injurious behavior (SIB). The prevalence of SIB among persons with developmental disabilities is anywhere from 10 to 40% and severity of injuries can vary from mild skin abrasions to life threatening head injuries. In persons with developmental disabilities the behavior occurs frequently and is directed at one part of the body, such as striking one ear with a fist or biting one hand. Suicide is uncommon in persons with developmental disabilities and SIB unlike persons with mental illness and SIB which is more common.

Theories of causation are:

- An attempt to reduce stress and maintain homeostasis by using SIB as a diversion from stressful internal feelings or external situations. Some experts view SIB as an extreme form of self-stimulating behavior.
- A way of blocking or controlling physical discomfort.
- An attention seeking behavior that elicits response from others.
- Results from boredom and the need for stimulation.
- A disruption or chemical deficiency in the brain's neurotransmitter system.

Injuries that occur can range from mild calluses on one hand or wrist from biting to skull fractures and retinal detachments from repeated head banging. The more at risk the person is from tissue and organ damage the more aggressive the intervention to stop or minimize the behavior.

Possible Interventions:

- Distraction and diversion
- Psychoactive medications alone or in combination. No one specific medication class lessens or eliminates SIB in all persons
- Removal of rewards contingent on SIB or ignoring the behavior
- Physical restraints when the behavior is intense. In some individuals, SIB occurs infrequently but is very intense when it occurs. Physical restraints such as mittens, wrist protectors and helmets can be worn during periods when SIB is intense.
- Combination of any or all of these methods.

Because of the complexity of SIB behavior, a behavior specialist is usually needed to help caregivers with interventions that may stop or minimize the behavior. If interventions are restrictive, the plan must be approved by the team and case manager.