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# 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, emergency 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 or 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 made 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