Please note that wherever Division of Developmental Services is referenced, the new name is the Division of Disability and Aging Services.

For additional information, or to obtain copies of this report in this or other formats, contact:

Developmental Disabilities Services Division  
Vermont Agency of Human Services  
280 State Drive, HC2 South  
Waterbury, VT 05671-2030  
Phone: 802-241-0304  
Fax: 802-241-0410  
http://www.ddsd.vt.gov
# Health and Wellness Guidelines

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Introduction

The Division of Developmental Services is responsible to insure the health and safety of people who receive Medicaid-funded developmental services.

One of the key purposes of the *Health and Wellness Guidelines* is to provide the tools necessary to advocate for the best possible medical care for people with developmental disabilities. The *Guidelines* will not address all possible health conditions and individual circumstances vary. Therefore, the role of the individual and those that support him/her to advocate for good health care is important. It is also important that those who help the individual be knowledgeable about health issues and receive the necessary training to gain this knowledge.

Each designated agency, specialized service agency and person or family who manages their supports has the responsibility to insure that health services are provided and documented as appropriate. These responsibilities apply to all individuals who receive home supports in group living (3-6 people), shared living or developmental homes (1-2 people); staffed living (1-2 people), and any other Division-funded residential living situation. The applicability of these Guidelines to individuals who live in their own home or with their families is dependent upon the degree of support a person receives to do so. *For most individuals receiving a small amount of support to live in their own home or to be employed, the person and his or her support team will determine the appropriate roles for members of the team. Most standards do not apply to individuals receiving only Flexible Family Funding and/or Transition grant funded employment services.*

Health and wellness services and the roles of various individuals must be specifically noted within the person’s Individual Support Agreement (ISA).
Variances

Circumstances may occur for which application of a standard may not be indicated or may not be in the best interest of an individual. When this occurs, there should be discussion(s) between the individual, the health care provider, support team and guardian (if there is one). Variances cannot be for the convenience of the support team or physician.

If a variance occurs secondary to difficulties such as fear of blood drawing, Pap test, etc., then there must be information in the file that indicates attempts have been made to desensitize the individual as well as the effectiveness and plans for review. Documentation of any decisions concerning variances to these guidelines must be documented in the person's file.

The right of an individual to refuse treatment is respected. However, the DA/SSA is responsible to insure the individual's decision is based on an informed choice.

Examples of situations where a variance might make sense are:

- A healthy person may need less frequent physical exams than on an annual basis
- Contractures or other physical difficulties may prevent certain testing.
Standard 1

Emergency Fact Sheet:
A current emergency fact sheet, following the standardized State format, is accessible and available in all files (e.g., home, agency, etc.) and to all individuals involved in a person’s supports.

Applies to:
All individuals receiving DDS-funded services, except Flexible Family Funding (see note)

Note: For this, and all other references, “individual or person” includes people who are self- or family-managing their services.

Emergency Fact Sheet

All relevant individuals, including “on-call” people and respite workers, need to have access to emergency information. The information required on an Emergency Fact Sheet includes:

1. Individual’s name, address, phone number, date of birth and marital status.
2. Guardian’s name (if there is one) and court-appointed powers, address and phone number; when there isn’t a guardian, the next-of-kin’s name, address and phone number. Parents are considered the next-of-kin/guardian for minor children, unless otherwise determined by a court.
3. Social Security number/Medicaid number; health insurance information.
4. Health care providers’ names (e.g., physician, therapist, dentist, etc.), phone numbers, and the specialty (e.g., primary physician, cardiologist, neurologist, etc.).
5. Medical problems list, any known allergies and a list of current medications with dosages, purpose and times of administration.
   - The medical problems list is complete when all current and past medical problems, surgeries, treatments, etc., are included and up-to-date. The information should be specific (e.g., history of seizures, status post, etc.) and include relevant dates.
   - The list should also include any significant family history such as diabetes or heart condition.
   - Food, drug or environmental allergies and any adverse reactions are also listed. Any specific emergency treatment that may be required as a result of an allergy should be indicated.
   - Medication information for people receiving home supports is obtained from prescriptions in the file. For people receiving other types of supports, the information is obtained from the person himself/herself, parent or other knowledgeable individuals.
The diagnosis and/or symptoms for which a medication is prescribed must be documented (i.e., each medication must have a corresponding medical problem identified on the Medical Problem List). Some medications have multiple uses (e.g., Valproic Acid and Tegretol could be given for seizures and/or as a mood stabilizer); therefore, it is important that this information is accurate.

PRN over-the-counter medications do not need to be listed.

6. Protocols for any emergency treatment and advance directives
   - Prior consent for emergency treatment on the fact sheet is optional; therefore, if an individual or guardian (if there is one) does not wish to sign, insure that proper emergency contact information is available.

7. Date of last annual physical exam and tetanus immunization.
   - Listing immunization information on the emergency fact sheet does not replace the need for an immunization record in the file for people receiving home supports.

8. Other interested individuals (friends, relatives, providers, etc.)
   - The service coordinator and shared living/developmental home provider need to be listed; the individual may wish to include the names of people whom she/he wants contacted in an emergency.

9. Other individual pertinent information (e.g., preferred communication method, ambulating needs, special dietary needs, etc.)
   - This information could include behavioral information; directions to a person’s home; physical description of the person; advance directives; method of communicating, etc. Remember to ask the individual what he/she would like included.

10. Date the Emergency Fact Sheet was completed or updated. Emergency Fact Sheets need to be updated as changes occur and at least annually.

It may be helpful to condense the Emergency Fact Sheet information and enter it on a small laminated wallet-type card.
Medical Consent

Some people have medical guardians appointed by a court. Some people are their own guardians. If a person has a medical guardian, he/she is an important part of an individual’s team. Except in emergency cases, the guardian is notified of appointments with the primary physician and other health care providers (e.g., psychiatrist, neurologist, etc.) prior to the visit. Consent from the individual or his/her guardian (if there is one) to administer prescribed medications must be obtained prior to starting the medications. The following information is shared or explained to the person or his/her medical guardian (if there is one):

- When medications may have significant side effects or are new or controversial, a plan to track or monitor the medication and its effects needs to be implemented.
- Information regarding the dangers of psychiatric medications should come from the prescribing psychiatrist. The person or guardian needs to know how the physician will monitor for side effects. The service coordinator may need to facilitate communication between the person/guardian and the physician.
- The service coordinator needs to inform the guardian when tests (other than routine) are ordered, especially if a problem is suspected. If the individual is their own guardian, the reasons for the tests need to be explained.
Incident Reporting

**Critical incident reports** note unusual and/or significant medical events. Examples of these are death, hospitalization, medication errors that result in hospitalization or other medical treatment, significant injuries, chemical restraints (see Guidelines for Critical Incident Reporting).

- The definition of chemical restraint is found in the Behavior Support Guidelines.

**Other medical incident reports** are used in cases where the DA/SSA reviews the circumstances around incidents to establish patterns, identify unsafe practices or environmental problems. Examples of these situations are medications that are used for pre-sedation for medical appointments, medication errors not resulting in emergency treatment, medication errors involving a pharmacy incorrectly filling a prescription, PRN medications prescribed as part of behavior support plan, injuries and/or emergency department visits not requiring medical intervention. This does not include a physician’s consultation done in the emergency department for convenience or time limitation.
Restraint Procedures for Medical Purposes

Restraints used for medical purposes must be time-limited in nature. (For a full definition of restraints, refer to the Behavior Support Guidelines.) When time-limited restraints are used, a physician’s or dentist’s order documenting the medical reason for the restraint must be present in the file. Any such order must be renewed at least weekly.

Physical, mechanical (e.g., mittens, straps, arm splints and restraint chairs, bed rails and bed netting) or chemical restraints may be used for medical purposes for the following reasons:

- To assist an individual during a time-sensitive, necessary medical or dental procedure.
- To promote healing following a medical procedure or injury.

Mechanical supports are not mechanical restraints. Some individuals may require the use of mechanical supports for daily life (e.g., devices used for body positioning, seat belts, etc.). For a full description of mechanical supports please refer to the Behavior Support Guidelines.
Universal Precautions

All agencies must comply with Occupational, Safety, and Health Administration (OSHA) training requirements related to blood borne pathogens and universal precautions. A record of the training and annual retraining for all workers is required.

In accordance with OSHA regulations, the Hepatitis B vaccine is offered to all DA/SSA employees. Individuals who are not employees of a DA/SSA (e.g., shared living/developmental home providers, contracted community support workers, respite workers, etc.) must be given information about the Hepatitis B vaccine. Responsibility for payment for non-agency employees is determined by the employer or the individual/organization contracting for services.

Hepatitis B Vaccine

For individuals receiving services, each person’s personal physician should evaluate his/her risk for contracting Hepatitis B. Hepatitis B can have life-long consequences such as cirrhosis of the liver, cancer, etc.

If someone living in a group home is a Hepatitis B carrier, other people who live in group homes are at an increased risk of contracting Hepatitis B. Therefore, all people who live in group homes must be offered the vaccine, without cost to the individual, because the Hepatitis status of other individuals who live in the home may not be known.
**Annual Physical Exam**

An annual physical exam is required for all individuals receiving home supports, unless otherwise documented, in writing, by the primary care physician. A copy of the exam results is required for the DA/SSA file and the home file that should include the following:

1. Physician’s name and signature
2. Complete medical problems list
3. Body systems review with blood pressure and weight; including review of ideal weight range
4. Complete list of prescribed medications, including over-the-counter medication and any other alternative therapy used by the individual
5. A list of lab, diagnostic or cancer screening tests ordered
6. Any recommendations made by the physician

For individuals receiving home supports, monitoring and follow-up to the physician’s recommendations is the responsibility of the service coordinator.

For all other individuals receiving Medicaid waiver services, only a notation of the date of the annual physical exam is required. If the person’s primary physician determines an annual physical is unnecessary, it must be documented in writing in the person’s file.
Suggestions to Prepare for the Annual Physical Exam:
1. Let the physician’s office know that the appointment is for an annual exam so that sufficient time is allowed.
2. Make a list of all known medical problems on the annual exam form before going to the appointment. The information is obtained from the Emergency Fact Sheet.
3. List all current medications. This includes over-the-counter medications and any other alternative therapy used by the person.
4. Review Standard 17 for testing that might be indicated. All testing that has been completed in the last year should be available to the primary physician. For example, anticonvulsant or psychiatric medication levels, complete blood count, liver function tests, etc., which the neurologist or psychiatrist may have ordered.
5. Review the immunization information and discuss the need for updates with the physician (see Standard 10).
6. Discuss the need for any cancer screening tests and indicate the need on the examination form (see Standard 17).
7. Discuss the need for vision or hearing screening (see Standards 12 and 16).
8. Ask the physician for an oral examination if the individual is edentulous.
9. Copies of all reports from other physicians such as specialists, emergency room episodes, etc., should be sent to the primary physician.
10. Medicaid reimbursement is available for vitamins or nutritional supplements prescribed by a physician. A medical justification form completed by the physician is required for payment.
**Dental Exam**

The American Dental Association recommends semi-annual dental cleanings and exams. In certain situations, an individual's dentist may specify a different frequency (i.e., either more or less frequently). A copy of the exam report is obtained for the person's file. The service coordinator is responsible to insure that all follow-ups and recommendations are completed.

- For individuals with diagnosed cardiac conditions (e.g., congenital cardiac malformations, rheumatic and other valve dysfunction, mitral valve prolapse, etc.) the person's physician or dentist will prescribe a prophylactic antibiotic to prevent infections of the heart tissues (endocarditis) (see Standard 9 regarding medications).
- The person's primary care physician or dentist may prescribe an anti-anxiety medication to be administered prior to exams. A medical incident report is required when this medication is given (see Standard 3 regarding medical incident reports and Standard 9 regarding medications).
Medication Prescription & Administration

In order for individuals with developmental disabilities to receive medication safely in home and community settings, a variety of procedural protections and trainings are necessary.

Medication Prescription

1. All prescription medications are reviewed and renewed annually at the time of the annual physical exam or as indicated by the physician or other authorized medical professional. A change in medication dosage requires a new prescription. A written order by the physician or other authorized medical professional, or a copy from the pharmacist indicating the medication prescribed and its side effects, is required for the person's file.

2. For individuals taking prescription medications, all other medications, including over-the-counter medication, must also be approved by the appropriate medical professional. The pharmacist should be informed of any over-the-counter medications because they may interact with prescription medications. The actual medication and dosages should be checked for accuracy at the time of purchase.

3. The diagnosis and/or symptoms for which medications are prescribed must be documented.

4. PRN medications (medications which are given as the circumstance arises) are specifically prescribed by a physician or other authorized medical professional. The prescription must include specific parameters and reason for use (e.g., Penicillin for strep throat; daily, 3 times/day until finished).

Written Procedures

1. The DA/SSA must have written procedures that address all components of medication administration. Procedures include the following subjects:
   - Medication refusal
Standard 9

Medication Prescription & Administration

- Recording medications
- Reporting medication errors
- Disposal of medications (outdated, unused or contaminated)
- Administering PRN medications
- Administering medications during different times of the day and week (e.g., during community supports, work, respite, etc.)
- Proper storage of medications
- Telephone orders
- Self-medication

Medication Administration

1. All medications must be administered as defined. Medication administration sheets are required for all people who are not self-medicating. Sheets include a clear record of medication name, dosage, time of administration and signature of person(s) who administered the medication.

2. If medication errors occur, the nature of the error or reason for the omission is documented with a medical or critical incident report (see Standard 3).

3. PRN medications must be documented on the medication administration sheets, and include the name and dosage, the time administered, the reason for use and effectiveness of the medication.

4. Prescription PRN medications require medical assessment. For example, medication given to address symptoms of a psychiatric condition will need assessment by a nurse or the prescribing physician prior to its administration by an agency employee.

5. The name and dosages of PRN medications given for the purpose of addressing a psychiatric illness as defined in a behavior support plan must be documented with a medical incident report or critical incident report (see Standards 3 and 11). The incident report shall include a description of the person’s behaviors as well as documentation of less intrusive interventions tried prior to medication administration. Follow-up by supervisory staff must occur.
Training and Monitoring
The provider shall have a training plan as required in the Regulations Implementing the DD Act of 1996 that insures verification that all workers paid with DDS funds (including contractors, subcontractors, employees of contractors and consumer-directed workers) have necessary training.

1. Shared living/developmental home providers who administer medications must be provided with initial training and information regarding safe and correct administration of medications, as well as handling and storage of medications. This training includes the following:
   - Correct recording of medication on the medication administration sheets
   - Notifying the physician of a change in the person’s condition
   - Medication side effect information
   - The five rights of administering medications
   - Safe storage of medications in original containers as labeled by the pharmacist
   - Medication refusal
   - Abbreviations and measurements
   - Reason for the medication

2. All DA/SSA employees who are paid with DS funds and who administer medications during their employment must receive training as determined by an appropriate medical professional. Only a registered nurse, a licensed practical nurse working under the supervision of a registered nurse, or a physician may determine if workers have the skills and knowledge to administer medications. Documentation of this training is required.

3. Ongoing monitoring of all people who administer medications is required to insure safe medication administration practices. Documentation of this monitoring is required. Monitoring includes:
   - Tracking of medication errors
   - Review of physician’s orders
   - Regular (monthly is recommended) check of medication administration sheets
Monitoring an individual's medication plan is a significant responsibility. Therefore, it is recommended that the service coordinator who has this responsibility also receive training in medication administration, even though he/she may not personally administer medications.

**Self-medication**
Individuals, who indicate the desire and possess the capabilities, may administer their own medications. An assessment based on recognized standards for self-medication should be used, with any accommodations needed by the individual specifically noted. A nurse or physician must assess knowledge and skills and determine the frequency of review/reassessment. Documentation of this assessment is required if the agency has a role in health services. Review of the person's knowledge and skill by the nurse or physician should occur periodically.
Immunizations

Immunizations are maintained in the individual’s file with current dates of relevant immunizations:

- Tetanus - every ten years
- Measles/mumps/rubella - for anyone born after 1957
- Influenza vaccine - annually for recommended individuals
- Pneumoccal - for recommended individuals, usually once, but sometimes repeated at six year intervals

If available, information about hepatitis immunizations should be included in the record.

Childhood immunization records are maintained for children aged two months through sixteen years. The childhood immunization schedule is based on the Vermont standard set by the Department of Health. Any parental approved variances to the standard must be documented in the child’s file.
Psychiatric Services

General Considerations for Treatment
The prevalence of co-occurring mental illness with developmental disability is estimated to be 30% - 40%. The principles of psychiatric assessment and treatment are the same for both people with developmental disabilities and those without developmental disabilities. People with developmental disabilities may experience all types of mental illness.

Many health conditions can result in changes in a person's behavior. Examples of these include untreated thyroid condition, pain, and brain lesions. Medication can have unintended side effects such as akathisia, disinhibition, aggression and self-injurious behavior. Other changes in a person's life (e.g., home provider changes, death of someone close, post surgery depression or a traumatic incident, etc.) can also trigger changes in behavior. It is likely that an individual may need active assistance and psychiatric intervention to cope with these changes.

All behavior is a form of communication; understanding what is being communicated is important when developing a support plan. The psychiatrist and the person's team should use a comprehensive biological-psychological-social approach to assessment and treatment. Often a comprehensive approach is required to effectively support a person with complex needs. This may include psychiatric medications, counseling or therapy, environmental considerations, social supports and teaching improved emotional regulation and communication skills. The goal of these supports is not only a reduction of symptoms, but improvement in the person's quality of life.

Psychopharmacologic Medications
Psychopharmacologic medications can be valuable tools in the treatment of psychiatric disorders and emotional distress. Psychopharmacologic medications are drugs...
prescribed to stabilize or improve mood, mental status, or behavior. These medications are sometimes called "psychiatric medications" or "psychoactive medications". The following protocols must be applied when treating both short-term and long-term symptoms of a person's mental illness that affect his/her life.

1. A working diagnosis for a prescribed medication is needed. The diagnosis needs to be clearly supported by findings outlined in a comprehensive assessment.
   - Physical health reasons for changes in behavior must be ruled out. Psychosocial reasons for acute behavior changes likewise need to be investigated. However, some persistent and significant behaviors may lead to a nonspecific diagnosis (e.g., aggression, self-injurious behavior).

2. Medical guardians and individuals who have no guardian are informed of any proposed psychiatric medication or changes to existing prescriptions prior to administration of the medication(s). Medical guardians and individuals who have no guardian must give consent to any medications or medication changes.
   - The prescribing psychiatrist should inform the individual or guardian (if there is one) of the medication's expected effects and side effects.

3. Active monitoring of medication effectiveness and side effects is required.
   - Critical incident reports or medical incident reports, medication sheets, as well as other relevant data need to be reviewed.
   - Risks/benefits of medications and side effects (e.g., adverse effects on cognition, sedation, weight changes, etc.) should be continuously assessed during treatment.

4. Medication checks require direct contact with the prescribing psychiatrist at least quarterly.
   - The psychiatrist may indicate that an individual's circumstances are stable and less frequent checks are appropriate.
5. Tardive dyskinesia checks are needed for individuals who are prescribed medications that have the potential for this side effect. Checks are performed and documented at regular intervals, preferably at medication reviews, by the prescribing psychiatrist or a nurse. Insuring that the checks are documented may require service coordinator intervention.
   - Tardive dyskinesia symptoms may not be apparent until the medication is decreased.
   - There are medications other than psychiatric medications that may cause tardive dyskinesia symptoms (e.g., Reglan).

6. A Psychiatric Medication Support Plan is required when psychopharmacologic medications are prescribed to treat psychiatric disorders, emotional distress, etc. Please see the Behavior Support Guidelines for further information on the Plan.

7. A psychiatrist may order medication to be administered as part of a support plan. The plan must include a medication order that specifically states when and under what conditions it is to be used. The need for the medication must not require an assessment of the individual’s behavior by a nurse or doctor prior to agency employees administering the medication. In other words, in this case it must not be a PRN.
   - A medical incident report is needed (refer to Standard 3 regarding medical incident reports).
   - Record the giving of medication on the medication administration sheet. The effectiveness of the medication must be documented. Medication used in a dosage that causes disorientation, confusion or an impairment of mobility is considered a chemical restraint (see Guidelines for Behavior Support).
8. A psychiatrist may order medication to be administered on a PRN basis, either as part of a support plan or not. In both cases, since this is a PRN medication, the psychiatrist or other physician is requiring a nurse’s or physician’s assessment of the individual prior to the medication being administered. A critical incident report is needed if the PRN medication meets the definition of a chemical restraint. Otherwise, a medical incident report is needed. (Additional information is found in the Behavior Support Guidelines; see also Standard 9 and Standard 13.)

- The team should evaluate the circumstances to determine if the situation is a one-time incident or if a behavior support plan is needed.

Medications used for pre-sedation for medical or dental appointments are not included in the requirements above, and do not require a critical incident report (see Standard 3).

The decision to use psychiatric medication must take into consideration the anticipated benefits of the medication in light of potential risks and side effects of the medication.

- The potentially observable benefits of the medication should clearly outweigh the risks.
- Medication dosages must be reasonable and within acceptable dosage parameters.
- Duration of treatment must be long enough to assess effectiveness. The psychiatrist and primary care physician need to work together to insure the medications are not contraindicated due to medical conditions. Only in rare cases, may it be appropriate for the primary care physician to prescribe the psychiatric medications.
Vision/Eye Health Care

At the initiation of home support services an initial comprehensive eye examination must be obtained. Documentation of the exam and any prescription(s) are kept in the person's file. Eyeglasses are provided as prescribed. The service coordinator is responsible for monitoring and insuring that follow-ups and recommendations are completed as required.

- Children need to have an initial exam as noted above, and only need to be reexamined if ocular symptoms, visual changes or injury occur.
- Individuals from the age of puberty to age 40 only need to be reexamined if ocular symptoms, visual changes or injury occur. The exception to this is for those individuals who are at risk of developing significant eye disease because of other risk factors (e.g., chronic disease such as diabetes, family history, race, etc.).
- Eye/vision exams are required for individuals from ages 40-64; the optometrist or ophthalmologist determines the frequency of follow-up.
- Individuals 65 years of age and older must have an examination every one-two years.
- Individuals with diabetes must be examined annually.

Individuals may need assistance or support to use eyeglasses as prescribed. They may also need assistance to keep their eyeglasses in good repair.
Neurological Services & Seizures

A diagnostic evaluation by a neurologist is obtained for individuals who are initially prescribed medications for seizures. Documentation of the evaluation is kept in the person's file. If an individual has a seizure for the first time, a neurology exam is required.

- The neurologist may prescribe an electroencephalogram (EEG) to identify the type of seizure; a computed tomography (CT) scan or a magnetic resonance image (MRI) to rule out lesion, tumor or structural problems; and lab work to rule out errors of metabolism, poisoning, infection, etc. Documentation of these diagnostic tests is needed in the person's file.
- An individual whose anti-epileptic medication has been stopped and who resumes having seizures should be seen by a neurologist as soon as possible and treated as if a new seizure disorder has developed.
- A primary physician may decide to follow a person with a stable seizure disorder.
- If an individual has been seizure free for five years, the physician may consider a medication reduction or discontinuance. The usual timeline is five years, but this may be a consideration anywhere from three to seven years. An EEG should be obtained prior to the attempt to withdraw medications. Medications should be gradually tapered.
- The discontinuance or tapering of seizure medication requires the consent of the individual or the guardian (if there is one). The physician should explain the possible risks associated with a change in seizure medication. Documentation of the effort and the results is needed in the person's file.
- Blood levels are required for specific medications at least annually and as determined by the physician. Most medications are metabolized in the liver. Liver function testing is indicated for most seizure medications, as well as complete blood count.
Neurological Services & Seizures

Documentation of lab results must be maintained in the person’s file (see Standard 17).

For all individuals receiving DDS-funded supports, except Flexible Family Funding, a seizure record must be maintained for individuals with seizure disorders. Seizure records are kept to assist the physician to more accurately treat seizures and to note trends of increased or decreased seizure activity. The services coordinator should review seizure frequency monthly. All individuals involved in providing support, including respite workers, must be informed about how and to whom seizures should be reported.

A complete seizure record consists of the following information:

- Date of seizure
- Time of seizure
- Antecedent to the seizure
- Description of the seizure
- Duration of the seizure
- Post seizure status

For individuals receiving community supports or employment supports the team needs to determine how the seizure information is communicated to others on the team. If a person lives with his or her family, where are copies of the seizure reports filed? What information does the physician need? These questions are worth discussing at the annual ISA meeting.
Orthopedic Services

An initial orthopedic evaluation is required for individuals with musculo-skeletal disorders, neurological dysfunctions and other related types of disease, injury or illness (e.g., cerebral palsy, spinal disorders, spastic paralysis, etc.)

Documentation of the orthopedic evaluation and any subsequent examinations is maintained in the person’s file.

After the initial evaluation the specialist and/or the primary care physician determine further exams. The service coordinator is responsible for insuring any necessary follow-up and monitoring.

Applies to:
Individuals receiving home supports and other individuals receiving DDS-funded services, except Flexible Family Funding, when indicated in the ISA

Occupational Therapy/Physical Therapy Services

A physician may prescribe occupational or physical therapy or these services may be requested through the physician by the individual or any member of the support team.

Training for workers by qualified individuals (e.g., physical therapist, occupational therapist, nurse, etc.) must be provided, especially if an individual has health issues such as osteoporosis or has extensive therapy programs.

Documentation of the consultation is maintained in the person’s file. The service coordinator is responsible for ensuring any necessary follow-up and monitoring.

Information regarding the therapy program must be included in the person’s ISA.

- Impairments that limit mobility can reduce the opportunities for people to participate in work, school, recreation, communication and leisure.

Maximizing mobility through position, range of
motion, exercise, adaptive equipment, etc., may be ways to treat or prevent certain conditions.

- Adaptive equipment requires care and upkeep. Details regarding correct and safe use, cleaning and maintenance, and trouble-shooting problems accompany the owner’s manual and need to be available for reference (see Standard 21).
- Routine and regular safety checks of equipment need to be done (see Standard 21).

Hearing & Hearing Aids

For children, hearing loss can show up at any age, but is often difficult to detect. An exam is indicated if there are concerns that a child cannot hear normally. This may include not achieving language-related milestones.

For adults, sudden and profound hearing loss is a medical emergency, and a physician must be called immediately. Exams are indicated for older adults if:

- Hearing loss interferes with quality of life.
- If work is done in a high-noise environment and there is difficulty hearing.
- If there is hearing loss accompanied by an earache, a discharge from the ears, or tinnitus (a ringing in the ears, dizziness or balance problems).

Individuals may need support to use hearing aids as prescribed. Hearing aids also require care. Details regarding correct and safe wearing, cleaning and maintenance, and trouble-shooting problems accompany the owner’s manual and need to be available for reference. Regular and routine checks of the hearing aids, including battery checks and changes, are needed.

Documentation of any hearing exam must be maintained in the person’s file, along with any prescriptions for hearing aids. The service coordinator is responsible for ensuring any follow-up and monitoring.
Lab & Other Diagnostic Tests

The decision of what tests and how often testing is needed is a dialogue between the physician and the individual and/or guardian (if there is one), and/or the person who is responsible for assuring that the health needs are being met. In some cases the physician, with the individual’s and/or team’s input, may decide that testing is too stressful for an individual and that the trauma outweighs the benefits. The physician and the individual and/or the support team may also decide that there may be trauma due to an existing condition (e.g., osteoporosis, contractures, etc.) that precludes testing.

Lab Testing

1. Baseline lab testing must be obtained, unless otherwise documented by the primary physician. Documentation from the physician is required for any reason for which testing is contra-indicated. Discussion within the support team, including the individual, if possible, regarding a desensitization program with the goal of allowing future testing needs to take place as necessary. Documentation of the desensitization program as well as the results of testing must be kept in the person’s file. The service coordinator is responsible for insuring follow-up, monitoring and completion of recommendations.

   ▪ Baseline testing needs to include a complete blood count (CBC), liver function test(s) (LFT). Other testing may include blood chemistry such as glucose level, cholesterol screening, urinalysis, etc.
   ▪ Testing is often used as part of a routine check-up to identify possible changes in a person’s health before any symptoms occur.
   ▪ The results of blood tests are printed in columns headed “In Range” and “Out of Range”. Next to that is a column called the “Reference Range”, which means the numbers in that column are the normal results. The reference range can vary from lab to
lab, so always compare the current results with the reference range on the current report only.

- When an “Out of Range” result is noted on the blood work, this indicates the need to follow up. Further information is available by calling the physician’s office, through lab interpretation test books, the DA/SSA nurse or the Internet. Although information may be researched, the interpretation of the findings must be sought through the prescribing physician.

2. Other lab testing as indicated by medication (e.g., various seizure, cardiac, psychiatric medications, etc.), age or risk factors (e.g., family history of heart disease, etc.), and certain diagnoses (e.g., diabetes, etc.) must be obtained as necessary. Documentation of all testing must be maintained in the person’s file. The service coordinator is responsible for insuring that follow-up and recommendations are completed.

- Blood work for commonly prescribed medications may include:
  a. **Seizure medications** (e.g., Dilantin, Neurontin, Depakote, etc.). Blood levels are needed for most seizure medications and should be ordered at prescribed intervals for therapeutic level monitoring when initially ordered and at least annually when the medication level is stable. Blood tests (liver function tests) for side effects of these medications, which may affect the liver, are indicated. Testing should be at least annually, and for certain individuals, this testing may be indicated more frequently.

  b. **Psychiatric medications** (e.g., Lithium, Clozaril, etc.). Lab studies are indicated for these medications and others due to side effects that can only be detected through blood work, which includes levels of the medication(s). It is necessary to discuss with the prescribing physician when and how often studies are indicated.
c. Monitoring of the therapeutic blood levels for certain medications such as cardiac antiarrhythmias (e.g., Digoxin); bronchodilators to ease breathing (e.g., Theophylline, Theo Dur); and thyroid replacement therapy (e.g., Synthroid) is required.

Check pharmacy print-outs of medication side effects; consulting with the prescribing physician; requesting information from the pharmacist; and, checking web sites such as www.labtestsonline.org are ways of finding out if lab studies for medications are required.

**Cancer Screening**

The American Cancer Society's (ACS) recommendations regarding baseline and continuing testing are the standards that must be followed for cancer screening. Documentation of all testing is kept in the person’s file. The service coordinator is responsible to insure that follow-up and recommendations are completed.

1. Colon cancer screening is obtained for men and women 50 years and older. The ACS recommends that both men and women follow one of five screening options:
   - Yearly fecal occult blood test.
   - Flexible sigmoidoscopy every five years.
   - Yearly fecal blood test plus flexible sigmoidoscopy every five years.
   - Barium enema with air contrast every five years.
   - Colonoscopy every ten years.

2. Every man 40 years and over has a digital rectal examination (DRE) as part of his regular annual physical exam. In addition to the DRE, the ACS recommends that men 50 years and over have an annual prostate specific antigen (PSA) blood test.

3. The ACS recommends that asymptomatic women have a screening mammogram by age 40; women aged 40-49 should have a mammogram every one-two years; women age 50 and over should have a mammogram every year. In addition, a clinical physical examination of the breast
is recommended every three years for women 20-40 years of age and every year for those over 40.

4. A Pap test is performed annually with a pelvic examination in women who are, or have been, sexually active or who have reached age 18 years. After three or more consecutive annual examinations with normal findings, the Pap test may be performed less frequently at the discretion of the physician.

5. Risks for skin cancer (e.g., excessive exposure to the sun, fair complexion, age, etc.) should be reviewed. The primary care physician should look at the person's skin at the annual physical exam and individuals who provide direct care should be aware of growths or changes in the skin.

For further information regarding cancer, treatments and support there are several web sites to access. Some of these are:

- [www.cancer.org](http://www.cancer.org) (the American Cancer Society)
- [www.nci.nih.gov](http://www.nci.nih.gov) (the National Cancer Institute Cancer Information Service)
- [www.cansearch.org](http://www.cansearch.org) (the National Coalition for Cancer Survivorship)

There is also a cancer information and counseling hotline at (800) 525-3777 and cancer response system at (800) 227-2345.

**Bone Density Testing**

Osteoporosis is a silent disease and testing for bone mineral density (BMD) should occur if indicated - often the first sign is a fracture of the wrist, hip or vertebra. One in three women and one in eight men 50 years of age and older will break a bone due to osteoporosis. Some risk factors are: age; heredity; body type; estrogen deficiency; inactivity, etc. Medicare covers BMD testing for beneficiaries who are estrogen-deficient, on long-term steroid therapy, currently taking drugs for osteoporosis, have spinal abnormalities suggesting low bone mass, or have an overactive parathyroid gland.
Down Syndrome

Individuals with Down Syndrome need the usual health care screening procedures recommended for the general population. Children with Down Syndrome need the usual immunizations and well-child health care, and adults with Down Syndrome should have health evaluations using the standard accepted practices (refer to Standard 7). Because individuals with Down Syndrome may develop certain medical problems at a higher frequency than other individuals, an initial evaluation at a Down Syndrome clinic or with a physician who specializes in the treatment of people with Down Syndrome is needed.

Specific health care issues that need to be monitored for individuals with Down Syndrome include:

- The incidence of thyroid disease is significantly increased; thyroid testing is needed yearly.
- Atlanto-axial instability, a congenital orthopedic problem at the cervical vertebra occurs in about 10%-20% of individuals. Most individuals are asymptomatic; signs and symptoms of spinal cord compression may be torticollis (twisting of neck into unusual position), change in gait, sensory disturbance, and change in bowel/bladder function. Initial X-ray screening should occur with repeat screening every ten years. Screening needs to occur before participation in any contact sport, horseback riding, diving, etc.
- Congenital heart disease is reported to occur in 30%-60% of individuals. Diagnosis of the specific cardiac problem and treatment and/or monitoring is indicated.
- Vision exams are needed every two years, especially to monitor for cataracts and keratoconus.
Obstructive airway disease (sleep apnea) has been recognized as a significant problem; symptoms include snoring, unusual sleeping positions, fatigue during the day and behavior changes. Further evaluation is needed if any symptoms are noted.

Psychiatric disorders in adults occur frequently. A decline in functioning in an adult should alert the primary care physician or provider to the possibility of a psychiatric disorder – after medical problems such as infection or thyroid disease have been ruled out. Alzheimer disease may cause a functional decline, but disorders such as major depression, bipolar disorder or complicated bereavement should be considered.

The National Down Syndrome Society maintains an extensive website which has comprehensive information, resources and health care guidelines and other links. Their address is www.ndss.org.
Prescribed Nutritional Diets

A therapeutic diet to address weight loss, allergies, cholesterol, phenylketonuria (PKU), etc., must be prescribed by a physician or registered dietician. All support team members must be aware of the dietary requirements and the effectiveness of the diet should be tracked. A copy of the diet prescription is required for the person's file.

- A referral to a registered dietician may be requested from the primary care physician if an individual or members of his or her support team think this may be beneficial.
- Monitoring of the individual's condition being treated, especially at the beginning of a diet, may be indicated.

Weight & Menses Charts

Regular weight records are kept for an individual if a need is determined (e.g., to track chronic weight maintenance; for medications and/or treatments which may affect weight changes, etc.). Individuals who receive gastric tube feedings with prescribed nutritional input from a physician or dietician need weight tracking to insure maintenance of adequate weight range. For some individuals who have a chronic weight maintenance problem and who are seen daily, weight changes may be subtle and not noticed expeditiously. It is important to keep accurate weight records; the readings should be obtained on a regular basis, in the same setting and under the same circumstances to insure accuracy.

A record of menses is kept for women if a need is determined (e.g., an existing condition; medications or treatments which warrant monitoring of menses).
Adaptive Equipment

The need for adaptive equipment should be evaluated as the circumstances arise. This need may change throughout the course of an individual’s life. Adaptive equipment (e.g., wheelchairs, braces, communication devices, etc.) is obtained as needed and is kept clean and in good repair. Regular monitoring of proper fit, usage and safety is also provided.

Individuals and their support workers may need training to use, or assist the individual to use, adaptive equipment. Details regarding correct usage, cleaning and maintenance, and trouble-shooting problems accompany the owner’s manual and need to be available for reference.

Special Care Procedures

The Regulations implementing the Developmental Disabilities Act of 1996 state “…people with developmental disabilities who have specialized health care needs will receive safe and competent care while living in home and community settings funded … by the Division.” The service coordinator is responsible for recognizing that the health care needs of an individual are above the level of care typically provided by support workers. If in doubt about this level of care, the DA/SSA nurse, DDS nurse or the individual’s primary care nurse should be called.

Service Coordinator Role

1. The service coordinator is responsible for notifying the registered nurse if they believe an individual needs a special care procedure. The registered nurse, however, is responsible for determining when a procedure is a special care procedure.

2. A copy of the current State of Vermont nursing license must be obtained and kept on record for any nurse whom
the DA/SSA uses to do special care procedures. If the DA/SSA uses a professional nursing organization to provide training, then the DA/SSA does not need a copy of the license.

**Information about nurse licensure is available on the Secretary of State’s website, www.sec.state.vt.us or by calling the Board of Nursing directly at (802) 828-2453.**

3. The service coordinator is responsible for including, with the individual’s ISA, a special care procedure plan. In the case of Flexible Family Funding, the plan must be available in the person’s file (because no ISA is required for Flexible Family Funding recipients).

4. The special care procedure plan must include:
   - The name(s) of the procedure(s)
   - The nurse providing the training and monitoring
   - The frequency of review

5. The person’s file at the DA/SSA and at the home must contain:
   - The training record
   - The procedure which was taught

**Nurse’s Role**

1. The nurse must evaluate the individual and decide if it is safe for a layperson to perform the procedure. The decision to determine something is a special care procedure is the registered nurse’s based on the criteria outlined below and in the *Regulations Governing the DD Act of 1996*:
   - The procedure requires specialized nursing skill or training not typically possessed by a layperson;
   - The procedure can be performed safely by a layperson with appropriate training and supervision; and,
   - The individual needing the procedure is stable and outcomes are predictable.

2. If the need for a procedure is determined to be a special care procedure, the nurse must complete the special care procedure plan.
3. The nurse will write the procedure(s) the support person(s) will be trained to perform:
   - Training must conform to best practice taking into consideration individualized accommodations.
   - The plan should include information about when training should occur.

4. The nurse must provide a record of who has been trained and found competent to perform the special care procedure, including:
   - Who did the training;
   - When it occurred;
   - Who was trained; and,
   - When retraining should occur.

**Other Information**

1. In the event of an emergency, the DA/SSA is responsible for insuring that a trained person or a nurse is performing the procedure.

2. The DA/SSA must notify the nurse of changes in the individual’s health or living situation.

3. If a person is discharged from the hospital with a caregiver who has been trained by hospital personnel, that caregiver may continue to perform care until the DA/SSA arranges for special care procedures. This should occur within seven to ten (7-10) days.

4. Medicaid will pay for special care procedures if the community home health nursing agency is providing the services, but not if the nursing overview is paid for by the DA/SSA.
Advance Care Directives & Planning

As an individual’s life progresses or if there is a change in a person’s health condition, opportunities for discussions with the person about advance care planning should occur. This enables documentation of these conversations and records the person’s preferences and values regarding end-of-life treatments and other types of medical care.

In order to be legally binding, advance care directives such as a do not resuscitate (DNR) or do not intubate (DNI) must be in writing and include specific information:

1. If the person does not have a guardian, the advance directive must be signed by the person in the presence of two witnesses.
2. If the person has a private guardian appointed by the Probate Court, the advance directive must have the approval of the Probate Court.
3. If the person has a State Guardianship Services Specialist, the advance directive must be submitted for review to the DDS Ethics Committee and approved by the Guardianship Services Specialist.

All documentation pertaining to the advance care directive (the directive itself, as well as any authorization or review required above) must be maintained in the person’s file.

Ethics committees in hospitals, the Division of Developmental Services and health care agencies may be accessed as resources in providing guidance about complex end-of-life decisions. For additional information concerning the ethics of medical decisions, the Vermont Ethics Network is a good resource; their web site is located at www.vtethicsnetwork.org.
Training for Support Workers

Training for people who are responsible for the special health needs of individuals must be provided in accordance with the Regulations Implementing the DD Act of 1996, Part 10. This includes shared living/developmental home providers, direct support staff employed by agencies, home providers, individuals or families, temporary and substitute workers, respite providers, etc. A knowledgeable and qualified person must provide specific training, as indicated by the particular health needs of individuals.

Alternative/Complementary Therapies

All alternative and complementary therapies need the input of the primary care physician prior to implementation. Any medications (e.g., herbal or homeopathic) need a written order by the primary care physician. Documentation must be kept in the person's file. The services coordinator is responsible to insure any follow-up or recommendations are completed as needed.

- Alternative and complementary healthcare and medical practices are those that are not currently an integral part of conventional healthcare.
- Conventional healthcare refers to medicine as practiced by individuals who hold a medical doctor (MD) or doctor of osteopathy (DO) degree.
- Alternative and complementary healthcare and practices may include, but are not limited to, chiropractic therapy, homeopathic and herbal medicines, acupuncture, naturopathy, mind/body therapy, etc.
**Tobacco Use**

There is well-documented information concerning the risks of tobacco use and exposure to second-hand smoke. Given that, the following information applies to the use of tobacco or tobacco products:

1. Individuals will receive services in smoke-free environments. Any exception to this must be documented in writing with the approval of the individual and/or guardian (if there is one) and the team. Input from the primary care physician needs to be obtained prior to making an exception when individuals have health concerns that may be further exacerbated by smoke.

2. Individuals who choose to use tobacco will receive information regarding the dangers of using tobacco. If an individual needs assistance with stopping the use of tobacco, it will be initiated. Discussion with the primary care physician regarding products developed to help people quit smoking, such as nicotine patches, gum, or prescription medications should be considered as part of a smoking cessation program.

3. Individuals who smoke will not have their opportunity to smoke restricted, except for the restrictions that are set by State and Federal law and consistent with DA/SSA policies.

4. Each DA/SSA must have a written smoking policy that is implemented and enforced.