

2010

Healthy Transitions for Children and Youth with Special Health Care Needs

Module 2 in a series of 5



North Dakota Center for Persons with Disabilities

Minot State University

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Healthy Transitions for Children and Youth with Special Health Care Needs

This training manual was developed by the North Dakota Center for Persons with Disabilities at Minot State University to be used by providers of coordinated medical care services for children and youth with developmental disabilities and special healthcare needs. Requests for use of this publication for any other purpose should be submitted to Minot State University, NDCPD, Attn: Executive Management, 500 University Avenue West, Minot, ND 58707.

SUGGESTED CITATION

Ressler, K. (2010). Healthy Transitions for Children and Youth with Special Health Care Needs. Minot, ND: North Dakota Center for Persons with Disabilities, a University Center of Excellence at Minot State University.

PRODUCTION OF THIS PUBLICATION SUPPORTED BY FUNDING FROM:

North Dakota Department of Human Services, North Dakota State Council for Developmental Disabilities

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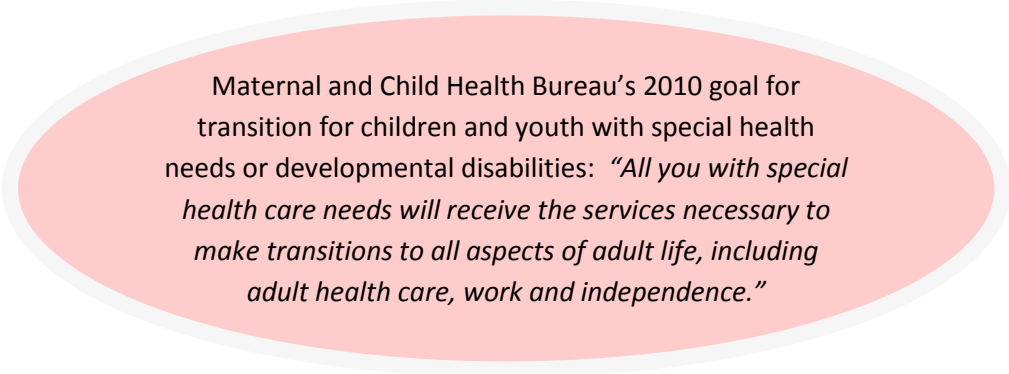
By NORTH DAKOTA CENTER FOR PERSONS WITH DISABILITIES, a center of excellence in disability research and education at Minot State University

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INTRODUCTION

The Healthy Transitions module is designed for care coordinators in the Medical home setting that work with children and youth with special health care needs or developmental disabilities. The content included in the module encompasses the major areas of consideration and does not imply that the module is all inclusive. The target audience includes professionals, families and advocates. The purpose of this learning module is to review transition from school age to post secondary education or into the workforce. A special thank-you to Family Voices of North Dakota, Department of Public Instruction, Children's Special Health Services, Family Voices of North Dakota, Federation of Families, North Dakota Protection and Advocacy, West Central Human Services, ND Department of Human Services and NDCPD for in the development of this module. Funding for the Healthy Transitions Module made possible by a grant from the North Dakota State Council on Developmental Disabilities (SCDD).



Maternal and Child Health Bureau's 2010 goal for transition for children and youth with special health needs or developmental disabilities: *"All you with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence."*

MODULE OBJECTIVES

1. Participant will be able to assist youth and young adult with finding a healthcare provider and how to access needed health care services including routine and preventive services.
2. Participant will be able to provide instruction and education on medication self management skills for CYSHCN/DD.
3. Participant will gain an understanding of the various lifestyle aspects of transitioning from youth to adulthood.
4. Participant will have an understanding of self-advocacy, guardianship and advanced directives.

ACCESS TO HEALTH CARE

Medical access is the ability of an individual to obtain medical and health care services. The provider and care coordinator can be instrumental in making referrals to adult providers and specialists as needed. The challenge in obtaining necessary health care can occur during the period of transition from youth to adulthood based on the change of insurance provider.

According to the North Dakota Century code, care cannot be denied based on the inability of the individual to pay for the services. Young people that leave their parents' home or is no longer covered on their parents' health insurance may be worried about what can happen if they are uninsured or underinsured. The law outlines emergency care situations as well as active labor. The uninsured or underinsured must be seen and treated even if the co-payment cannot be made at the time of the visit. Different criteria maybe followed if the medical situation is non-emergent. The request for a co-payment may then be asked for.

Co-Payment: *the fee insured persons pay, in addition to health insurance premiums and deductibles for medical services, emergency room visits, appointments with primary care provider, laboratory studies, prescriptions, or x-rays (Taber's, 2009).*

The newly enacted Affordable Care Act of 2010 will reduce the number of uninsured in several ways (beginning September 2010):

1. A young adult will be able to remain on their parent's health plan up to age 26
2. By instituting new insurance market regulations
3. Banning lifetime limits on insurance policies
4. Expanding Medicaid eligibility to cover adults with income below 133 percent of the federal poverty level (Collins et.al, 2010)

A clear description of how the Affordable Care Act of 2010 will be implemented on the payer side was not clear. It was stated by a Medicaid staffer that additional details will be outlined by the federal government beginning in September 2010.

Health Care Directives: *The North Dakota Century Code outlines the statement of purpose of the intent and law related to health care directives states that "Every competent adult has the right and responsibility to make the decisions relating to the adult's own health care including the decision to have health care provided, withheld, or withdrawn."*
(retrieved from www.legis.nd.gov/centurycode23-06.5-01)

HOW TO FIND ADULT HEALTH CARE PROVIDER

The current health care provider and care coordinator within the medical home would be a valuable resource for coordinating the referral to an adult health care provider if the patient has been seeing a pediatrician. According to AAP, pediatricians see patients from birth-21 years of age.

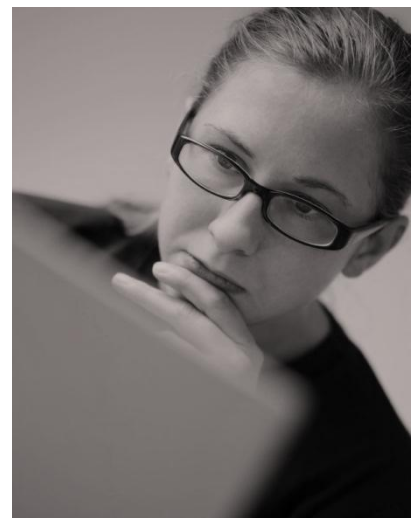
A family member may have a provider that has been very good to work with and might want to recommend having the individual with CYSHN/DD see the same provider. The individual with CYSHN/DD may have expectations or criteria in a primary care physician. By expressing the criteria, various members of the health care team would be able to make referrals to a suitable adult provider.

Family Voices of North Dakota maybe able to arrange for a visit with another family that has previously had experience with transitioning into adulthood. More information about Family Voices of North Dakota can be found at www.fvnd.org.

FINDING A HEALTH CARE PROVIDER: *Tips Care Coordinators Can Share with Patients*

If the current provider is a pediatrician, and will work with the young person until age 21 In the search for an adult provider, a mother of a young adult with special health care needs stated that “we looked for a doctor that would have more time at each clinic visit to answer all of our questions.” The impression many families have is the pediatric environment is more comforting than the more medicinal adult clinic settings. The care coordinator can be very instrumental in starting the conversation early. Some questions to ask:

- **How can I/we help in finding a new provider?** *The youth or family may have an idea of which physician would be best suited as an adult provider. In the event the youth or family wants the current provider or care coordinator to assist or find a new provider, re-enforce that collaboration that will occur between the providers.*
- **Tell me about your current health care needs?** *An assessment can be made at that time about additional teaching needs; if any as well as how involved the young person has been with his or her health care needs. By asking the question, information may be gained about therapies, adaptive equipment etc.*



Additional questions that could be asked at this time are as follow:

- **How health care needs might change with age?** *Ask questions about what may stay the same, get better or get worse. So a plan can be developed to stay on top of potential setbacks. It may not be possible to anticipate everything; however a proactive approach works better than reacting to situations that could have been treated earlier.*
- **Do you know what to do in case of an emergency?** *Encourage the youth and family to share their emergency medical plan medical. Reinforce the need for copies of health insurance cards, current medication lists etc. Examples of a portable medical record can be found at www.hrtw.org.*

If the young person understands how his or her health may change in the future or what to do in case of an emergency and can verbalize the changes or emergency steps, the care coordinator can then determine what added teaching is needed if any.

SELF ADVOCACY

Parents are the voices of their underage children. Once a child becomes a teenage or approach the age of 18, the young person is able to take on more responsibilities and eventually make their own decisions. With decision making comes responsibility and the need to advocate for one's self. When we advocate on our own behalf, it's necessary to express our wishes and be a vital part of all decision making. To be an effective self advocate, communication is the key. Knowing how to express your requests is vital. In addition to talking about our needs, it may also be necessary to put our requests in writing. If writing is not your strong suit, make sure you know who could assist with writing an effective letter that would get the message communicated.

As the care coordinator, it's important to make sure the young person understands that they are the star of the show. They have choices and should be encouraged to express themselves.

PROTECTION & ADVOCACY

There is a protection and advocacy system for people with disabilities in each state and territory. Legislation establishing this system was passed by Congress in 1975. In North Dakota, the organization designated by the Governor to serve as the protection and advocacy system is the Protection & Advocacy Project (P&A). P&A is an independent state agency established in 1977 to advance the human and legal rights of people with disabilities. P&A strives to create an inclusive society that values each individual.

One in every seven North Dakotans over the age of five has a disability (U.S. Census Bureau; 2006 Data Profiles).

People served include infants, children and adults of all ages. The majority of funds for program operations are from federal grants. Additional support is provided by the State of North Dakota. There is no cost for services, however, P&A does implement general eligibility requirements, including that the individual must reside within the State of North Dakota. P&A has seven different advocacy programs that serve individuals with disabilities:

1. Developmental Disabilities Advocacy Program;
2. Mental Health Advocacy Program;
3. Protection & Advocacy Project for Individual Rights;
4. Protection & Advocacy for Beneficiaries of Social Security;
5. Assistive Technology Advocacy Program;
6. Help America to Vote Program (HAVA);
7. Protection and Advocacy for Individuals with Traumatic Brain Injury (retrieved from <http://www.nndpanda.org>).

P&A has a governing board called *The Committee on Protection & Advocacy*. It consists of seven members whose terms are specified in State statute. Appointments are made by the Governor (2 members), Legislative Council (2 members), The Arc of North Dakota, Mental Health America of North Dakota, and a non-profit advocacy group for people with disabilities selected by the Committee. Currently this seat is filled by an appointee of the AMVETS. This is in recognition of the growing number of returning veterans with significant disabilities. P&A's staff comes from a wide variety of backgrounds. They are all trained to be knowledgeable about service delivery systems and the legal rights of people with disabilities.

GUARDIANSHIP

Persons authorized to provide informed consent for health care for incapacitated persons according to North Dakota Center Code 23-12-13 are outlined in priority order. The legal age of adulthood in the state of North Dakota is 18 yrs old.

Informed consent for healthcare for a minor patient or a patient who is determined by a physician to be an incapacitated person and unable to consent may be obtained from a person authorized to consent on behalf of the patient. Persons in the follow order of priority may consent to health care on behalf of the patient:

1. The individual, if any, to whom the patient has given a durable power of attorney that encompasses the authority to make health care decisions, unless a court of competent jurisdiction specifically authorizes a guardian to make medical decisions for the incapacitated person;
2. The appointed guardian or custodian of the patient, if any;
3. The patient's spouse who has maintained significant contacts with the incapacitated person;
4. Children of the patient who are at least eighteen years of age and who have maintained significant contacts with the incapacitated person;

5. Parents of the patient, including a stepparent who has maintained significant contacts with the incapacitated person;
6. Adult brothers and sisters of the patient who have maintained significant contacts with the incapacitated person;
7. Grandparents of the patient who have maintained significant contacts with the incapacitated person;
8. Grandchildren of the patient who are at least eighteen years of age and who have maintained significant contacts with the incapacitated person;
9. A close relative or friend of the patient who is at least eighteen years of age and who has maintained significant contacts with the incapacitated person.

Durable Power of Attorney, according to Tabers Cyclopedia Medical Dictionary (2005), designates another person to make healthcare decisions if the patient becomes incapacitated. Conservatorship is also an option for some individuals. A conservator is a person appointed by the courts to manage the affairs of another person. The conservator is responsible for preservation and protection of a dependent person's self and property. The term does not refer to imprisonment or confinement in a psychiatric facility. In some states conservatorship can also be guardianship (Tabers, 2009).

WHAT ARE ADVANCE DIRECTIVES?

- A living will allows you to document your wishes lawyer to fill out an advance directive, your advance directive becomes legally valid as soon as you sign them in front of the required witnesses. The laws governing advance directives vary from state to state, so it is important to complete and sign advance directives that comply with your state's law. Also, advance directives can have different titles in different states.
- ***Emergency medical technicians cannot honor living wills or medical powers of attorney. Once emergency personnel have been called, they must do what is necessary to stabilize a person for transfer to a hospital, both from accident sites and from a home or other facility.*** After a physician fully evaluates the person's condition and determines the underlying conditions, advance directives can be implemented.
- ***One state's advance directive does not always work in another state.*** Some states do honor advance directives from another state; others will honor out-of-state advance directives as long as they are similar to the state's own law; and some states do not have an answer to this question. The best solution is if you spend a significant amount of time in more than one state, you should complete the advance directives for all the states you spend a significant amount of time in.

A "guardian" is chosen or appointed to make legal decisions for a person who is unable to make those decisions on their own (usually a child or someone who has become incapacitated through age or disability (retrieved from <http://family.findlaw.com/guardianship>).

- **Advance directives do not expire.** An advance directive remains in effect until you change it. If you complete a new advance directive, it invalidates the previous one.

You should review your advance directives periodically to ensure that they still reflect your wishes. If you want to change anything in an advance directive once you have completed it, you should complete a whole new document (retrieved from www.caringinfo.org). concerning medical treatments at the end of life. Before your living will can guide medical decision-making two physicians must certify:

- You are unable to make medical decisions,
- You are in the medical condition specified in the state's living will law (such as "terminal illness" or "permanent unconsciousness"),
- Other requirements also may apply, depending upon the state.

A medical power of attorney (or healthcare proxy) allows you to appoint a person you trust as your healthcare agent (or surrogate decision maker), who is authorized to make medical decisions on your behalf.

Before a medical power of attorney goes into effect a person's physician must conclude that they are unable to make their own medical decisions. In addition, if a person regains the ability to make decisions, the agent cannot continue to act on the person's behalf.

- Many states have additional requirements that apply only to decisions about life-sustaining medical treatments.
- For example, before your agent can refuse a life-sustaining treatment on your behalf, a second physician may have to confirm your doctor's assessment that you are incapable of making treatment decisions.



WHAT ELSE DO I NEED TO KNOW?

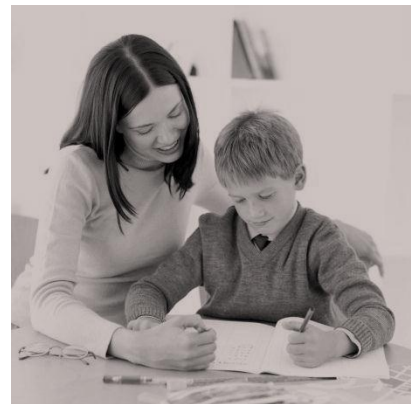
- ***Advance directives are legally valid throughout the United States.*** While you do not need a lawyer to fill out an advance directive, your advance directive becomes legally valid as soon as you sign them in front of the required witnesses. The laws governing advance directives vary from state to state, so it is important to complete and sign advance directives that comply with your state's law. Also, advance directives can have different titles in different states.
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TRANSITION IEP

Transition planning for the movement from high school to adult living is required for all students receiving special education services, according to federal legislation, Individuals with Disabilities Act (IDEA 2004). IEP teams must now include transition planning in the first IEP that will be in effect when the child is 16 years of age, or younger if deemed appropriate by the IEP team. Transition services are defined in IDEA 2004 as a coordinated set of activities for a student with a disability, designed within a result-oriented process, and focused on improving the academic and functional achievement of the student. This coordinated set of activities should facilitate the student's movement from school to post-school activities. These post-school activities may include postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, and/or community participation.



Transition services are based on the individual student's needs, taking into account the student's strengths, preferences, and interests. Students' success will depend on their active participation in the setting of postsecondary goals and planning a coordinated set of services to achieve those goals. The IEP team must develop an educational program plan designed to prepare the student for whatever he/she desires to do after high school. It must be updated annually thereafter, and include: *Measurable postsecondary goals* based upon age appropriate transition assessments related to education or training, employment, and if appropriate, independent living. If transition planning is to be effective, all of the discussion and decision making in the IEP must be based on the postsecondary goals of the student. In other words, all of the components of the IEP

must be reviewed – that is, the present levels of academic achievement and functional performance, transition services statements, annual goals, least restrictive environment, related services, and participation in regular education as interrelated components. The Transition IEP sequence is outlined on the department of public instruction website which is found by going to the www.nd.gov website and going to public instruction, department of.

POST SECONDARY GOALS

The team should begin its discussion surrounding a transition IEP by considering the student's long range plans after high school and to what extent supports will be necessary in the areas of education or training, employment and, independent living skills, when appropriate for the student. This section differs from the Present Levels of Academic Achievement and Functional Performance (PLAAFP). Measurable Postsecondary goals are defined as observable outcomes that a student wishes to attain after exiting high school or is no longer eligible for services. A measurable postsecondary goal is not the process of pursuing or moving toward a desired outcome. <http://www.dpi.state.nd.us/transitn/iep/apendixb.shtml>

MEDICATION SELF MANAGEMENT

Taking your medication on a scheduled basis according to provider's orders is an important part of living a healthy lifestyle. Many young people may have relied on their parents or care giver to make sure that the right medication was taken at the right time. The young person may have very little information about what the drug is for, side effects, best time to take the medication or even which pharmacy to pick up the medication.

Medication mismanagement can lead to illness, hospitalization or even death, so it is important to teach the young person about he or she needs to know about medication self administration. When the young person is ready to start learning how to take his or her own medications, teach him/her how to confirm the following:

Medication Self Administration (retrieved from <http://medscape.com>)

- Medication is stable
- Medication is not expired
- No known allergies or contraindications
- Medication administered at the right time

Routes of Medication

Administration

- PO- orally or by mouth
- IM- intramuscular
- SQ- subcutaneous
- IV- intravenous
- PRN- as needed
- Bid- 2 times per day
- qd- daily
- qod- every other day
- qid- 4 times per day
- tid- 3 times per day
- HS- at bedtime
- am- morning
- pm- evening
- mg- milligrams
- GM- gram
- Oz- ounce

- Medication administered by the correct route
- The correct dosage of medication is taken

Other important considerations include:

- Know why the medication is prescribed
- Be knowledgeable about the side effects
- Be aware of the possible drug interactions
- Know if the medication is to be taken with meals, before meals or other special considerations

Generic medication may be substituted for brand name if your physician has not specifically requested brand name drugs. The Federal Drug Administration (FDA) has approved the generic medications as a safe alternative to the brand name drugs. The pharmacist at your local pharmacy would be a great resource to assist with questions related to the prescriptions that have been ordered.

Care coordinators should encourage patients to keep an accurate medication list with them as well as record medication that has been taken and the times the medication has been taken. A resource for record keeping entitled care notes can be found at www.fvnd.org.

Durable Medical Equipment refers to any medical equipment that can be used in the home setting that improves quality of life. Some examples of durable medical equipment (DME) would be wheelchairs, walkers, oxygen, continuous positive airway pressure (CPAP) machines, and nebulizers. Many of the larger communities in North Dakota have DME companies. Your primary care physician or care coordinator could refer or recommend appropriate firms. Many insurance plans have benefits for DME however, the reimbursement criteria varies. It would be important to check with the insurance carrier, eligibility worker to confirm what benefits are included in the health plan. If coverage is denied for durable medical equipment, community organizations such as Easter Seals or Veterans of Foreign Wars (VRW) may have wheelchairs, walkers, or canes that can be rented or borrowed.

LIFESTYLE MANAGEMENT

The ability to manage one's day to day living is a vital part of getting older. Duties such as cooking, cleaning, grocery shopping, or transportation to medical appointments, leisure activities or employment are part of a daily living. The desire to manage all or some of the activities may come easy for some and others may want more assistance. No matter what the young person's individual needs maybe, resources are available throughout the state of North Dakota. Many of the resources available can be accessed by a simple phone call to get things going.

Personal care services may be the little extra that assists the young person with being successful in living more independently. "Personal care services" means services consisting of a range of human assistance, provided to an individual with disabilities or conditions, that will allow the individual to live as independently as possible while delaying or preventing the need for institutionalization. Assistance may be in the form of hands on assistance or cuing so that the individual can perform a task without direct assistance." (retrieved from <http://www.nd.gov/dhs/policymanuals>).

The **Interagency Program for Assistive Technology (IPAT)** increases access to assistive technology in North Dakota by engaging in activities that raise awareness, disseminate information, provide training and assessments, work with policy makers, loan equipment for trial-use, and demonstrate assistive technology (AT) devices to individuals of all ages with disabilities and those experiencing the effects of aging throughout the state. IPAT increases AT acquisition by making available a used equipment bulletin board and an alternative financial loan program specific to the purchase of AT devices and services. More information can be found at www.ndipat.org.

HOUSING

The care coordinator may want to approach the topic of living arrangements with the young person and family. The earlier the planning begins, the more prepared for transition the youth and family can be. Since it is impossible to know everything about all areas of transition, housing and living arrangements may not be an area of expertise. Providing information and referral to appropriate resources would be a good start. Centers for Independent Living (CILs) are located thru out North Dakota. In addition to independent living resources, apartment living or supported housing is also a consideration. Options for housing and living arrangements in North Dakota are as follows:

- **Individualized Supported Living Arrangement (ISLA)** - which provides support to individuals living in a home owned or leased by the individual. Services may include training and assistance in personal care, budgeting, shopping, laundry, etc. Levels and amounts of support may vary depending on the individuals needs. The individual is responsible to pay for room and board.

*The purpose of **Independent Living Services** is to eliminate barriers and to provide assistance to individuals with disabilities so they can live and work more independently in their homes and communities (www.nd.gov/dhs/services/disabilities/index.html).*

Centers for Independent Living

Independence Inc

Minot: (701) 839-4724

Williston: (701) 572-7373

Options Interstate Resource Center

East Grand Forks: (218) 773-6100 or
1-800-726-3692

Cavalier: (701) 265-4618

Freedom Resource Center

Fargo: (701) 478-0459

Jamestown: (701) 252-4693

Dakota Centers for Independent Living (DCI)

Bismarck: (701) 222-3636

Dickinson: (701) 483-4363

- **Minimally Supervised Living Arrangement (MSLA)**-community waiver group home or community complex setting which provides training in community integration, social, leisure, and daily living skills.
- **Supported Living Arrangement (SLA)**-residential service which provides support to individuals living in their own home or apartment setting. Services may include instruction in budgeting, shopping, laundry, etc. Support is provided on an intermittent basis and is generally less than 20 hours per month. Individuals receiving SLA services generally need less support and assistance than individuals receiving ISLA.
- **Transitional Community Living Facility (TCLF)**-community waiver group home which provides training for individuals in community integration, social, leisure, and daily living skills in a group environment. If the plan to move into supported housing, a case manager in one of the 8 regional human service centers, will do an assessment and assist with the process of moving into a supported housing unit. More information about living arrangements can be found at <http://www.nd.gov/dhs/services/disabilities/index>. The county social services office is also a great resource. In addition to assisting with the completion of eligibility paperwork for various programs, the eligibility worker can assist with contact information for the county housing authority. The rules and other resources for housing, including fair housing is included in the Appendix.

WORK LIFE

Finding a job or pursuing a career can be a very rewarding part of life. The process or pursuit of a job or career can also have challenges. As preparation is being made for the transition from youth to adulthood, keep in mind that resources and assistance is available. Job Services of North Dakota, Job Corp and Vocational Rehabilitation are several of the agencies that can be of assistance with job training. More information can be found on the state government website at www.nd.gov. In addition, transition planning from high school to adult living is required for all students receiving special education services, according to federal legislation, Individuals with Disabilities Act (IDEA 2004). (Information retrieved from <http://dpi.state.nd.us/transit/index>). If an individual is seeking a job and has a disability, being familiar with the Americans with Disabilities Act of 1990 (ADA) would be very beneficial. A primary principal under the ADA is that individuals with disabilities who want to work and are qualified to work must have equal opportunity (www.ada.gov/workta.htm).

How do I know if I am protected by the ADA? To be protected, you must be qualified individual with a disability. This means that you must have a disability as defined by the ADA. Under the ADA, you have a disability if you have a physical or mental impairment that substantially limits a major life activity such as hearing, seeing, speaking, thinking, walking, breathing, or performing manual tasks. You also must be able to do the job you want or were hired to do, with or without reasonable accommodation.

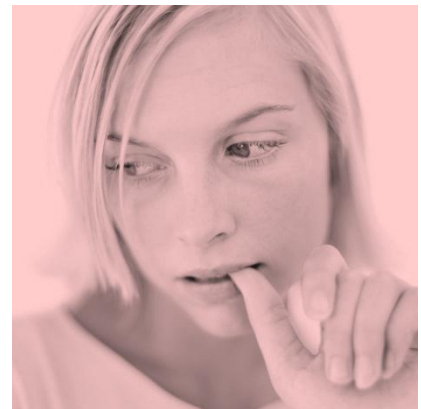
What are my rights under the ADA? The ADA protects you from discrimination in all employment practices, including: job application procedures, hiring, firing, training, pay, promotion, benefits, and leave. You also have a right to be free from harassment because of your disability, and an employer may not fire or discipline you for asserting your rights under the ADA.

What is a reasonable accommodation? A reasonable accommodation is any change or adjustment to a job, the work environment, or ways things usually are done that would allow you to apply for a job, perform job functions, or enjoy equal access to benefits available to other individuals in the workplace. There are many types of things that may help people with disabilities work successfully. Some of the most common types of accommodations are:

- Physical changes, such as installing a ramp or modifying a workspace or restroom;
- Sign language interpreters for people who are deaf or readers for people who are blind;
- Providing a quieter workspace or making other changes to reduce noisy distractions for someone with a mental disability;
- Training and other written materials in an accessible format, such as in Braille, on audio tape, or on computer disk;
- TTY's for use with telephones by people who are deaf, and hardware and software that make computers accessible to people with vision impairments or who have difficulty using their hands;
- Time off for someone who needs treatment for a disability

What should I do if I think I might need a reasonable accommodation? If you think you might need an accommodation for the application process or on the job, you have to request one. You may request a reasonable accommodation at any time during the application process or any time before or after you start working.

The Equal Employment Opportunity Commission (EEOC) can assist with alleged discrimination or rights violations. A complete listing of all of the ADA regulations can be found at www.ada.gov/workta.htm. In addition, the EEOC can be contacted at **1-800-669-4000 (voice) or 1-800-669-6829 (TTY)**. Or look in the telephone directory under U.S. Government.



RECREATION & LEISURE

People with disabilities should have access to the same social, cultural, and recreational activities enjoyed by all (<http://disability.gov>). The initiation of group or individual activities such as socializing with friends or working or learning a hobby can be facilitated by gathering some information from either the young person or parent by asking questions such as:

1. What do you (he/she) like to do outside of school?

2. Are there any activities you (he/she) would like to try or learn more about?
3. Are you aware of any activities you (he/she) have tried that have not been enjoyable?

TRANSPORTATION

Transportation can be a challenge for many people. Kids not old enough to drive depend on parents, siblings, neighbors or public transportation. The high school curriculum includes options to take drivers education if the young person is planning on getting a drivers license. In the event, a drivers license is not a goal, having transportation options can readily available will make life much easier. Some of the major cities have public transportation that is an economical means of transportation. Other areas have services for individuals with disabilities or senior citizens. This type of transportation has specific guidelines to ride but does also make accommodations for wheelchairs, adaptive equipment of even a personal guide. Check with your local social service office for details.

ROUTINE HEALTH CARE AND PREVENTIVE HEALTH CARE

When a person feels sick, it seems obvious that it would be necessary to see the doctor. However, when everything seems to be going well, doctor visits for routine or preventive health care maybe overlooked. Following up regularly for physicals or screenings are a great way to manage individuals over health and well being. The care coordinator should assists with reminders, referrals or scheduling of needed preventive or routine health care. For example, in the fall of each year getting a flu shot should be encouraged for everyone that does not have a contraindication as proactive step in maintaining good health. In addition, educational materials should be shared with each young person on healthy life style choices such as avoiding smoking, eating a balanced diet and getting as much exercise as her or she is able.

Routine Health Care

1. *Annual physical*
2. *Annual visit to the eye doctor; unless diabetic then every 3 months for dilated exam*
3. *Regular dental care*
4. *Keep immunizations up to date*

Many diseases can be treated when detected early. See your primary health care provider right away if:

- *A lump or persistent sore appears on your body*
- *Have unexplained weight loss*
- *Develop a chronic cough*
- *Continued body aches and pains (retrieved from www.preventivehealthcare.com MedlinePlusMedicalEncyclopedia.mht)*

Prevention health measures would include:

1. *Avoid alcohol use or use in moderation*
2. *Avoid smoking or drug use*
3. *Control blood pressure or high cholesterol*
4. *Maintain a healthy weight*
5. *Exercise daily*
6. *Eat healthy*

MENTAL AND EMOTIONAL HEALTH CARE

Mental health considerations are discussed when potential pathology or **problems** occur, however routine mental or emotional health care may not be discussed at a clinic visit when everything appears to be OK. Some of the activities that promote staying healthy should be included in the activities of daily living (ADL) and are as important as activities that correct or treat disease or illness.

Staying Healthy. To maintain good health, it's important to be aware of changes in your body. Having routine health screenings are also important. Routine screenings for adults could include: abdominal aortic ultrasound, blood pressure screening, blood sugar screening, cholesterol screening, colon screening, depression screening, genetic testing for ovarian or breast cancer for certain women, HIV testing, osteoporosis screening, pap smear, mammography and sexually transmitted disease screening. Your primary care physician would be able to recommend which screenings and when an appropriate time for such screenings to be done (information retrieved and adapted from www.preventivehealthcare.com/medlineplus/medical/encyclopedia/mht).

North Dakota has 8 human services centers located thru out the state. The primary objective of the human service centers are to provide services that help vulnerable North Dakotans of all ages to maintain or enhance their quality of life, which may be threatened by lack of financial resources, emotional crises, disabling conditions, or an inability to protect themselves. In addition the human service center, support the provision of services and care as close to home as possible to maximize each person's independence while preserving the dignity of all individuals and respecting their constitutional and civil rights.

The centers are located in Williston, Minot, Devils Lake, Grand Forks, Fargo, Jamestown, Bismarck and Dickinson. (Retrieved from <http://www.nd.gov/dhs/about>)

Psychosocial Rehabilitation Centers:

Mountainbrooke

Grand Forks: (701)746-4530

Myrt Amerstrong Center

Fargo: (701)293-7716

Progress Community Center

Jamestown: (701) 251-2964

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APPENDIX A: PLANNING FOR THE CARE OF A SPECIAL NEEDS CHILD

retrieved from *cnn.com* by Paul Keegan and Karen Cheney

(Money Magazine) -- Jason and Amanda Purnell met while getting their Ph.D.s in psychology at Ohio State, married in 2007, and were ecstatic when Amanda became pregnant shortly before they moved to St. Louis last July to be near family. Then they learned that their 22-week-old fetus had Down syndrome. They were shocked -- at 29, Amanda was well below the at-risk age to conceive a baby with this condition. "The first 24 hours, I was inconsolable," she says. But Amanda, a psychologist at a VA medical center, and Jason, an assistant professor at Washington University, didn't dwell for long on the difficulties they might face raising their coming child but instead kicked into high gear to do right by her. By the time Maya Elizabeth was born last December, her parents had found a day-care center that provides physical and speech therapy, drawn up wills and powers of attorney, and taken out \$1.6 million, 30-year term life insurance policies. They set up a trust as the beneficiary because if Maya has more than

\$1,000 in assets when she turns 18, she'll

lose eligibility for some government benefits. Maya is now 6 months old, healthy, and a sound sleeper. But the Purnells have plenty of worries to keep them up at night. Many children with Down syndrome eventually require surgery for heart or gastrointestinal problems or have developmental

delays. Jason and Amanda also worry about money. Even though they have a combined income of \$177,000, they're facing a rash of expenses: There's the usual (payments on their \$261,000 mortgage, \$37,000 in student loans, replacing their 10-year-old cars), plus Maya's special needs (medical bills not covered by insurance, possibly private school when state subsidies for her therapies end at age 3). "We know we'll be financially supporting Maya for the rest of our lives," Jason notes. The Purnells have made a great start by setting up wills and a trust for Maya, says St. Louis lawyer Martha Brown, part of a network of attorneys called the Special Needs Alliance. They should also write a memo, called a Letter of Intent that details instructions for her care from the food that she eats to the therapies that work best. "Think of it as a road map of Maya's life that will ensure she's well cared for," she says. As for the Purnells' finances, planner Michael Byrne of Cherry Hill, N.J., who has a daughter and two brothers with special needs, suggests the following:

1. Set up a second trust

The trust drawn up by the Purnells won't become operational until after they both pass away. So family and friends who want to

contribute to Maya's care should put money into a separate special-needs trust to fund nonessentials

(say, dental bills or trips to Disney World), says Brown. That way, Maya doesn't risk losing federal disability benefits.

2. Ramp up savings

Jason and Amanda need an emergency fund of \$42,000, vs. the measly \$4,000 they have now. Once that's taken care of, they should begin a "reserve fund" to pay for big-ticket nonemergency extras, including new cars and possible private-school tuition for Maya, says Byrne. The interest rate on their student loans is only 5%, so they can pay them off gradually.

3. Plan for three retirements

The Purnells must become hyper savers to cover their retirement as well as Maya's long-term care. Amanda's raises should go into her Federal Thrift Savings Plan, currently funded at 5% (just enough to get the match); Jason should do the same with his 403(b). An aggressive 80% stock/20% bond mix should maximize their returns over time and cover their retirement as well as Maya's long-term care. Amanda's raises should go into her Federal Thrift Savings Plan, currently funded at 5% (just enough to get the match); Jason should do the same with his 403(b). An aggressive 80% stock/20% bond mix should maximize their returns over time.

APPENDIX B: WEBSITES

www.ada.gov-The home page for the Americans with Disabilities which is part of the US Department of Justice.

www.brightfutures.org-Bright Futures is a national health promotion initiative dedicated to the principle that every child deserves to be healthy and that optimal health involves a trusting relationship between the health professional, the child, the family, and the community as partners in health practice.

www.cdc.gov-The Centers for Disease Control is a government website that is a great source for credible health information.

www.commonwealthfund.org-The Commonwealth Fund is a private foundation that aims to promote a high performing health care system that achieves better access, improved quality, and greater efficiency, particularly for society's most vulnerable, including low-income people, the uninsured, minority Americans, young children, and elderly adults.

www.disabilityinfo.gov-The disability information website includes detailed information on all aspects of life living with a disability. The site contains employment, civil rights, education, housing, transportation, funding sources and many other areas related to disability.

www.eeoc.gov-The U.S. Equal Employment Opportunity Commission (EEOC) is responsible for enforcing federal laws that make it illegal to discriminate against a job applicant or an employee because of the person's race, color, religion, sex (including pregnancy), national origin, age (40 or older), disability or genetic information. It is also illegal to discriminate against a person because the person complained about discrimination, filed a charge of discrimination, or participated in an employment discrimination investigation or lawsuit.

www.fvnd.org- Family Voices of North Dakota is a non-profit organization which assist families as they navigate public and private systems, including health systems and insurance plans as well as provide assistance to families in accessing services and resources for their children and how to partner with providers and caregivers.

www.healthytransitionsny.org-This website is for youth with developmental disabilities ages 14-25 years, family caregivers, service coordinators, and health care providers. The information is specific to youth in New York; however the examples and tools that are listed could be a guide for clients in North Dakota.

www.mymedschedule.com - A free website which assists with medication self management. print schedules that are easy to create, read and update ,receive reminders to take your medications by text or email, set refill reminders—reorder your prescriptions before they run out, keep track of your daily medications—strengths, dosage and purpose ,bring your pill schedule to all your doctor appointments Maintain medicine schedules for yourself and family members ,Print your schedule in English or Spanish, convenient wallet-size schedules to carry with you ,Pill box organizers and reminders

www.ndkids.count.org-The Annie E. Casey Foundation is a private charitable organization, dedicated to helping build better futures for disadvantaged children in the United States. It was established in 1948

by Jim Casey, one of the founders of UPS, and his siblings, who named the Foundation in honor of their mother.

www.nd.gov/dhs/policymanuals-This is a state website that has information about the Department of Human Services. The www.nd.gov has a directory with the agency names in alphabetical order.

www.ndpanda.org- A protection and advocacy system for people with disabilities in each state and territory. Legislation establishing this system was passed by Congress in 1975.

www.specialneedsalliance.com-The Special Needs Alliance (SNA) is a national, not for profit organization of attorneys dedicated to the practice of disability and public benefits law. Individuals with disabilities, their families and their advisors rely on the SNA to connect them with nearby attorneys who focus their practices in the disability law arena.

www.wrightslaw.org- Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law, education law, and advocacy for children with disabilities.

APPENDIX C: LIFE PLANNING CHECKLIST

<p>Life Planning Information for:</p> <p>_____</p> <p>(NAME)</p>

Life Planning Checklist	Completed Date	Reviewed Date	Date Updated	Date Updated
Letter of Intent (Insert)				
Notify relatives and friends that you have established a Trust, and if they want to leave money to your loved one, leave it to the Trust				
Copy of Birth Certificate				
Copy of Social Security Card				
Copy of all medical cards (Medicaid, Medicare, etc.)				
Information about/letters from the Social Security Administration (types of benefits received)				
Choose 3 people who have agreed to become a guardian or advocate				
Establish a Trust (Copy of Trust in folder)				
Notify the County Board of MR/DD or other appropriate agencies that you have established a Trust				
Signed my Last Will and Testament				
Change beneficiaries on all accounts/policies removing my loved one's name				
Made copies of this plan and have given it to family members				

Developed by the Center for Infants and Children with Special Needs: Children's Hospital Medical Center of Cincinnati and The Arc of Hamilton County

APPENDIX D: POWER POINT