

Health



This is your new doctor do not be afraid

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Health

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Health Advocate

A family member or friend who will interact with health care providers on behalf of the person with severe disabilities who may need assistance or be unable to communicate clearly for himself or herself.

Responsibilities of a Health Advocate

- Organize information before a visit.
- Keep appointments or cancel far in advance, if possible.
- Facilitate communication between health care provider and patient.
- Share all relevant information with health care provider.
- Clarify information and/or medication or treatment described by provider.
- Write down all information and directions.
- Follow advice or report information accurately to caregivers.

*Source: PACER Center, Inc.
Date: 1993*

Health Care Skills

Skill	Performs Independently	Performs part of skill independently	Needs practice	Plan to start	Skill accomplished	Comments
Describes chronic illness or disability						
Understands implications of chronic illness/ disability on daily life						
Accesses medical records, diagnosis information, etc.						
Prepares and asks questions for doctors, nurses, therapists						
Knows medication and what they're for, or carries information in wallet						
Is responsible for taking own medication						
Is responsible for doing own treatments						
Gets a prescription filled/refilled						
Calls to schedule own medical/dental appointments						
Keeps a calendar of medical appointments						
Knows transportation systems to medical office						
Knows height, weight, birth date, or carries information in wallet.						
Knows how to use and read a thermometer						

Skill	Performs Independently	Performs part of skill independently	Needs practice	Plan to start	Skill accomplished	Comments
Knows health emergency telephone numbers, or carries information in wallet						
Knows medical coverage numbers, or carries information in wallet						
Knows about medical insurance coverage						
Obtains sex education materials/birth control/family planning information as needed						
Discusses role of general health maintenance						
Has considered genetic counseling if appropriate						
Knows about how drugs/alcohol affect illness/disability						
Makes contact with appropriate community advocacy organizations						
Takes care of own menstrual needs and keeps a record of monthly periods						
Has considered the need for a health advocate						
Has identified a physician for adult care						
Knows how to hire and manage a personal care attendant.						

*Source: PACER Center, Inc.
Date: 1993*

The Comprehensive Care Plan:

Medical Summary, Emergency Treatment Plan and Working Care Plan for Children with Special Health Care Needs

Children with special health care needs, their families, physicians, practice teams and community providers will benefit from having a clear, written medical summary, emergency treatment plan and plan of care. These components can be combined or developed separately. When combined the Medical Summary, Emergency Treatment Plan and Working Care Plan are the components of a Comprehensive Care Plan. The medical summaries, emergency treatment and care plans can be on paper, disk or if possible web-based. There are multiple purposes of the medical summary/care plans. These include:

- An available source of information for parents to provide to the medical, educational and other care teams,
- A quick reference with child-specific information in a medical emergency,
- An action plan that the entire care team, including the family and patient develop, use to prioritize, assign tasks, implement and assess care.

In the beginning remember that your practice team will decide who needs a medical summary or an emergency care plan depending on the complexity of the condition. The summary and/or emergency care plan will take some time to develop in the beginning, but the family, the clinicians and the community providers will find them very helpful. Your parent partners will be a great resource here with family friendly language.

The working care plan is a written framework combining the goals of the patient/family/team with the treatment plan. It is best to keep it simple at the start. Remember to start small with little steps. The Center for Medical Home Improvement Action Care Plan (working care plan) is a practical tool to get you started.

The major components of the comprehensive care plan include a medical summary with an emergency treatment plan and a working care plan:

1. **The Medical Summary:** The child's medical summary contains a short synopsis of the child's current diagnosis, problem list, treatment including medications and recurrent problems, past medical history and community based care. The specific components of the medical summary include:
 - Identifying and family contact (including emergency contact) information

- Allergies and Medications
 - Diagnosis and Active Problem List (including critical equipment)
 - Consultants – Specialist and their contact information
 - Transport/Equipment Needs
 - Past History (Summary)
 - Review of System (Degree of current involvement)
 - Coverage Concerns/Recurrent Problems
 - Community Providers/Agencies
 - Hospitalizations
 - Assets and challenges unique to the individual child
 - Other information the family want caregivers to know about their child
2. **The Emergency Treatment Plan:** The medical summary can include information for emergency treatment and in many instances can serve as both the summary and the emergency plan. However, some parents and practices may want a separate Emergency Treatment Plan. The child with multiple, complex conditions and/or recurrent life threatening events may need an emergency treatment plan in addition to or in place of the medical summary. The AAP/ACEP emergency treatment plans are very similar to the medical summary and it would be duplicative to fill out both. The Emergency Treatment Plan do have more baseline physical/lab data. The AAP and the ACEP have approved them. The form is available on the AAP web site with links from the NICHQ website and others. (Some teams have found it helpful to use a medical summary and check of a box indicating an attached emergency plan).
3. **The Working Care Plan:** A care plan for a child with special health care needs can be as simple as a written, organized note developed during a visit, a more detailed plan of care developed during a meeting of the family, care coordinator and clinician or a comprehensive, integrated care plan developed by the child/family’s multidisciplinary team. This plan helps direct the role/focus of the practice-based care coordinator. The critical components of the care plan include:
- A prioritized list of main concerns/goals with
 - The current clinical/educational/social information pertinent to the concern/goal.
 - The current plan/intervention for that concern/goal
 - The person(s) responsible for that intervention

- The due date for the intervention

The working or action care plans are available on the NICHQ Medical Home website, the AAP Medical Home website and others.

How to Use the Health History Summary

Young adults with special needs are often unsure about which health information of an often lengthy health history they need to share with a new health care provider. The **Health History Summary** form for teens and their parents distills the most important facts in the teenager's medical record. In addition to the general health history, the information covered includes medications taken, names of providers, surgeries and other significant health events, as well as family health history.

Youths and their families who have used this health history summary needed about 30-45 minutes to complete the information. It can be completed by the teen and his/her parents together. If completed yearly, teens learn more about their general health and specific special health need. It helps teens with special needs learn what is most important about their health and provides opportunities to ask parents and health providers for more information.

Parents find they better understand how much their child knows about their condition and are guided in what to teach their teen. Teens learn how to access information and how to articulate their knowledge of their condition. In addition, the collaboration on the health history summary helps parents to deprogram themselves from filling out all the paperwork!

Our suggestions for successful use of the Health History Summary:

1. Begin in early teen years to complete a summary at least annually
2. Modify the health history summary whenever you experience a major health event or a change in medication type or dosage.
3. Complete the form as a parent-child team, moving more responsibility to the teen for completion whenever reasonable.
4. Ask questions of your health care provider and research library and/or reliable web resources for any further information you might need.
5. Take this form with you whenever you will be meeting with a new health provider.

*More information about the Health History Summary and testing its usefulness for teens with special health care needs and disabilities is described in the article "Promoting Successful Transition from Pediatric to Adult-Oriented Health Care" in the March 2004 edition of Exceptional Parent magazine.

*Source: Adolescent Health Transition Project
Date: 2004*

Health History Summary

As you make the transition from pediatric to adult health care, you will be assuming more responsibility for your health care. When you go to your new adult doctor (or other health care provider), you will be asked about major health events in your life. **Have a parent help you fill out this form** and take it with you when you go to your new adult care doctor (or other health care provider) and you will be prepared for the questions that you will be asked.



How would you describe your overall general health? (Please circle one and add comments if you want to)

Fair Good Excellent

What are your special health care needs? Is there anything in particular that your doctor needs to know about your special needs?

As a child and teenager, what were your major health problems?

What medications are you **currently** taking?

Medications:	What is it taken for?	How Much? (Dose)	How Often? (Schedule)

Allergies or adverse reactions to medications: _____

Are there any medications that you have taken that have caused you problems?

Medication	Reasons no longer taking medication

Food or other allergies: (include bee stings)

Food or substance	Reaction and Treatment

Past Medical History:

Your birth weight: _____ Were you born early? _____ If so, how many weeks early? _____

Did your mother have any problems with her pregnancy or delivery of you?

Were you hospitalized at the time of your birth? _____ If yes, how many days? _____ or weeks? _____

What problems did you have at birth?

Please list any serious illnesses you have had and any injuries that included loss of consciousness.

Please list hospitalizations and surgeries you have had and include the dates and places.

Personal health history:

Have YOU ever had the following:

Condition:	Yes	Age
Anemia		
Asthma		
Blood Transfusion		
Cancer		
Constipation		
Diabetes		
Ear Infections		
Eating Problems		
Heart Disease		
Hepatitis		
Seizures (Epilepsy)		
Tuberculosis		
Attention Deficit Disorder		

Condition:	Yes	Age
Depression		
Suicide attempt		
Conduct Disorder		
Anxiety		
Learning Disability		
Developmental Delay		
Eating Disorder		
Other Conditions not Listed:		

If the answer is yes to any of the above conditions please use this space to make any additional comments about the conditions. **For individuals with seizures,** describe the seizures and include how often the seizures occur, how long they last, and when was your last one?

What tests have previously been done for these conditions, what were the results, and where were they done? (MRI? CT? EEG? EKG? Genetic Testing? Blood Tests? Psychological Testing?)

What treatments have been tried for these conditions and what was the most successful?

Are the conditions the (please circle one): (same) (improving) (getting worse)

Resource Information:

School: _____ Grade in School: _____

Do you have an Individual Education Plan (IEP)? _____

Do you have a 504 plan? _____

Name of contact person at school _____ Telephone: _____

Do you use Vocational Rehabilitation services? _____ Contact person at
VR _____

Recent medical records:

List the name, address, and telephone number of any doctors or other health care provider who have the latest medical records about your health conditions.

Name	Specialty	Address	Telephone #

Other resources:

List the name, address, & telephone number of any other person that has worked with you in regard to your health condition in the past two years (such as a physical therapist, pharmacist, medical supply house, caseworker, school nurse, etc.).

Name	What They Do	Address	Telephone #

Your immunization dates:

(Or attach a copy of your immunization record)

DPT/DT	1.	2.	3.	4.	5.
TD	1.	2.	3.	4.	5.
OPV	1.	2.	3.	4.	5.
MMR	1.	2.			
HIB	1.	2.	3.	4.	
Hep B	1.	2.	3.	4.	
Varicella	1.	2.			

Family Health History

Have any of your blood relatives had the following:

Condition:	Relation	Condition:	Relation
Anemia		ADD/ADHD	
Breast Cancer		Alcoholism	
Cancer (Other)		Depression	
Diabetes		Drug Abuse	
Heart attack		Learning Disability	
High Blood Pressure		Manic Depressive	
High Cholesterol		Suicide	
Seizures		Schizophrenia	
Sickle Cell Anemia		Other Conditions?	
Stroke			
Thyroid Problems			
Tuberculosis			

Comments:

Insurance Coverage Information:

Insurance	Policy number	Telephone number

Do you receive social security income (SSI)?	YES	NO
Do you receive medical benefits through the SSI program?	YES	NO

Emergency Contacts:

Name	Relationship	Telephone numbers	
		(W)	(H)
		(W)	(H)

Activities of Daily Living

	YES	NO
Are you visually impaired?		
Do you wear glasses or contacts?		
Are you deaf or hard of hearing?		
Do you use a hearing aid?		
Do you have any speech problems?		
Do you use sign language?		
Is English your preferred language? If no, what language do you speak?		
Can you walk?		
Do you use a walker?		
Do you use a wheelchair?		
Do you routinely wear medic alert identification?		

What other aids do you use to accomplish daily activities?

Are there any restrictions to your daily activities? (Can you drive an automobile?
Do you need a computer to communicate? Etc.)

Your adult doctor will ask you questions in private about your sexuality, about
drug and alcohol and cigarette use.

Source: Adolescent Health Transition Project
Date: 2004

Transition Summary

Name _____ DOB _____ SS# _____

Address _____
Street City State Zip

Phone _____
Home Work Cell

Emergency Contact _____
Relationship Phone

Guardian/Medical Surrogate _____
Relationship Phone

Primary Insurance: _____
Policy # Case Manager Phone #

Secondary Insurance: _____
Policy # Case Manager Phone #

Unique Communication/Cultural Needs: _____

Strengths/Assets: _____

Assistive Technology: _____

Allergies: _(meds & food) _____

Height: ____ Weight: ____ Dietary/Nutritional Needs: _____

Bowel Program: _____ Bladder Program: _____

Head/Neurology	GI
EENT	GU
Heart/Lungs	MS

Diagnosis	Managing Provider	Address	Phone
1.			
2.			
3.			
4.			
5.			

Current Medications	Current Medications
1.	5.
2.	6.
3.	7.
4.	8.

Current Therapies	Frequency	Provider	Contact Information
1.			
2.			
3.			

Recent Labs/ X-Rays	Date	Where on File	Findings

Medical Equipment	Medical Supplies	Provider	Contact Information
1.			
2.			
3.			
4.			

Orthotics & Prosthetics	Provider	Contact Information
1.		
2.		

Past Hospitalizations (including surgeries)			
Date	Hospital Name	Reason	Physician

Functional Capabilities	Brief Summary
Upper Extremities	
Lower Extremities	
Speech/Language	
Cognitive/ Problem Solving	
Vision/Hearing	

Future Plans (including agencies involved, referral, appointments made)
Health Care
Health Care Insurance
School & Work
Independent Living (housing, transportation, attendant care)

Services Currently Receiving	Provider Contact Information
1.	
2.	
3.	
4.	

Signature Youth/Guardian: _____ Date Completed: _____

Signature Care Coordinator: _____ Phone #: _____

*Source: Shriners's Hospital for Children
Date: Accessed 10/05*

Finding and Using Adult Health Care

As young people grow from childhood into adulthood, many will move from care by pediatricians into adult medicine. Moving to a different town due to school or a change of employment will also create a need to find a new doctor, especially if you happened to grow up with chronic health issues. So, how do you find a doctor who will meet your medical needs, that will be covered by your health plan, and who will give you the care you are looking for?

Before you start looking for a new doctor, think about what you want:

- Is where the office is located important? Will you need help with transportation? Do you need an office that is wheelchair accessible or do you need other special assistance in the doctor's office? Are office hours convenient? How do you contact the doctor at other times? What hospital do you want to use, and is this doctor on the staff there?
- Do you want someone who will take time with you during an office visit or are you comfortable being seen by someone who is "good" in his or her field but perhaps does not have the best bedside manner?
- Is it important that this new doctor is knowledgeable about your special health care needs or do you think you can provide that information or connect the new doctor with those who could provide medical insight?

Ways to look for a new doctor include:

- Ask your current doctor
- Check out the doctor your parents or other family members see
- Call a family support group or adult disability agency and check around
- Ask adults who have health needs similar to yours for recommendations
- Refer to your health insurance company booklet of approved providers
- Ask a Vocational Rehabilitation or Independent Living Center counselor
- Find a university health center (sometimes there are research studies going on which offer free care)
- Contact your local Medical Society, American Academy of Family Practitioners, or Internal Medicine Society either through the Yellow Pages or on their national websites

Since your wellness depends on the medical services you receive, it is important that you are comfortable talking with your new doctor and feel that he or she understands your concerns. Consider scheduling a "get-acquainted" interview

before you make a final choice of a new doctor. You will have to pay for this visit, as it is NOT covered by insurance benefits. An ideal time is about 15 to 30 minutes and should not waste your time or the doctor's. The best time to see a new physician is when your health condition is stable so you aren't asking for crisis care while seeing if you can develop a working relationship.

Think about (and write down) questions that are important to you:

- Is the doctor knowledgeable about your health issues and/or willing to learn from you and from previous doctors?
- Do you like the communication style with the doctor and in the office?
- Are you satisfied with office practices and access during an emergency or in urgent situations?
- Do you have access to hospitals and specialists if I need them?

Doctors who like to care for children are different from doctors who like to care for adults. For this reason, young adults seeking health care need certain skills:

- Ability and willingness to tell the doctor about your history, current symptoms, lifestyle, and self-care in just a few minutes (including carrying your own records and a summary of your medical history).
- Ability to ask questions about your condition and how it will affect your school, work, recreation, and social life.
- Ability to tell the doctor about your needs for education, technology, and accommodations and how your condition affects or might be affected by these.
- Willingness to follow medical recommendations that have been mutually developed by you and your doctor.
- More independence in following up with referrals and keeping all agencies informed.
- More involvement in keeping yourself well with diet and weight control, exercise and recreation, following medication, treatment and hygiene regimens, limiting risk-taking behaviors (such as drinking alcohol, smoking, taking non-prescription drugs, or unsafe sexual practices), and getting help when you feel angry, lonely or sad for long periods.
- Being more aware of your physical and mental symptoms and health needs before you have a serious medical crisis and knowing when to inform your doctor.
- Developing a plan for action for when you need emergency care: when to consult with the doctor, what hospital to report to, what care you want

and do not want, and naming someone who can let your wishes be known if you cannot (health care surrogate).

- Understanding how the health care benefits/insurance plan you have works for you: when to call for pre-approval, how to get reimbursements, what services are not covered, and how to file an appeal if you do not agree with decisions from the plan.
- Recognizing that as you become more capable in directing your care that you, not your parents, should make medical appointments, be the most knowledgeable about your health needs, know when to seek guidance in solving problems, and demonstrate that you are capable and competent and ready for adulthood!

*Source : KY Commission for Children with
Special Health Care Needs KY
TEACH Project*

*<http://chfs.ky.gov/ccshcn/ccshcntransition.htm>
Date: 2001*

Communicating With Doctors and Other Health Care Providers

Talking to doctors and other health care providers can be difficult, overwhelming and, at times, scary. What advice would you give someone going to the doctor? Here are some tips to help you communicate with health care providers. These tips were suggested by adolescents in the “Making Healthy Connections” program.

- Make sure to **ask for a long enough appointment**. Sometimes appointments are very rushed. If you know that you will have a lot to talk about with your doctor, ask for an extended appointment so you don’t run out of time.
- **Tell your doctor everything you can about yourself, what you do, and how you feel**. The more information the doctor has, the more helpful he/she can be.
- Bring a **list of questions and concerns**. It’s easy to forget things when you’re sitting there, in the doctor’s office. A written list of questions, concerns, or other things you want to make sure to tell the doctor will help you remember everything that’s been on your mind.
- **Say what you think**—and be honest.
- Tell the doctor to be honest and to tell you everything. **You’re entitled to know all** about your condition, your treatment, and any options that might be available to you.
- **Be assertive**. Be nice, but persistent.
- **Ask questions**. Remember—there’s no such thing as a stupid question. If you don’t understand an answer to a question, ask the doctor to explain it again until you do understand it.
- **Write down what the doctor says**. That will help you remember later on.
- **Bring someone with you**, if you’d like. Sometimes it helps to have someone else there for support, to hear what the doctor has to say, or to ask questions that you might not think of.
- Ask your parents to wait outside the exam room so you **have some time alone to talk to the doctor**, if you’d like. Sometimes that helps the doctor focus on you and what you have to say. Your parents can come back in after you’ve had a chance to talk to the doctor yourself. Then they can ask their questions.
- **If you need help, ask for it**.

When visiting a new doctor, **ask the doctor about his/her background and experience**.

Even if you've seen your doctor for a long time, **it's ok to ask about the doctor's background** and what his/her experience has been.

Call back if you have any questions after the appointment. Sometimes questions come up after you get home, or you forget something the doctor said. **It's ok to call and follow up with more questions.**

Learn about your insurance coverage. What services are covered and what procedures do you have to follow to get those services?

*Source: Institute for Community Inclusion at
Children's Hospital, Boston*

NAMI: The Nation's Voice on Mental Illness

About NAMI

Mission Statement: *NAMI is dedicated to the eradication of mental illnesses and to the improvement of the quality of life of all whose lives are affected by these diseases.*

NAMI is a nonprofit, grassroots, self-help, support and advocacy organization of consumers, families, and friends of people with severe mental illnesses, such as schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder, obsessive-compulsive disorder, panic and other severe anxiety disorders, autism and pervasive developmental disorders, attention deficit/hyperactivity disorder, and other severe and persistent mental illnesses that affect the brain.

Founded in 1979 as the National Alliance for the Mentally Ill, NAMI today works to achieve equitable services and treatment for more than 15 million Americans living with severe mental illnesses and their families. Hundreds of thousands of volunteers participate in more than one thousand local affiliates and fifty state organizations to provide education and support, combat stigma, support increased funding for research, and advocate for adequate health insurance, housing, rehabilitation, and jobs for people with mental illnesses and their families.

Local affiliates and state organizations identify and work on issues most important to their community and state. Individual membership and the extraordinary work of hundreds of thousands of volunteer leaders is the lifeblood of NAMI's local affiliates and state organizations. The national office, under the direction of an elected Board of Directors, provides strategic direction to the entire organization, support to NAMI's state and affiliate members, governs the NAMI corporation, and engages in advocacy, education and leadership development nationally.

Source: <http://www.nami.org>

Date: Accessed 9/05

Health Insurance Portability and Accountability Act (HIPAA) Privacy Protections

Your Privacy Is Important to All of Us

Most of us feel that our health and medical information is private and should be protected, and we want to know who has this information. Now, Federal law:

- Gives you rights over your health information
- Sets rules and limits on who can look at and receive your health information

Your Health Information is Protected by Federal Law

Who must follow this law?

- Most doctors, nurses, pharmacies, hospitals, clinics, nursing homes, and many other health care providers
- Health insurance companies, HMOs, most employer group health plans
- Certain government programs that pay for health care, such as Medicare and Medicaid

What information is protected?

- Information your doctors, nurses, and other health care providers put in your medical record
- Conversations your doctor has about your care or treatment with nurses and others
- Information about you in your health insurer's computer system
- Billing information about you at your clinic
- Most other health information about you held by those who must follow this law

The Law Gives You Rights over Your Health Information

Providers and health insurers who are required to follow this law must comply with your right to:

- Ask to see and get a copy of your health records

- Have corrections added to your health information
- Receive a notice that tells you how your health information may be used and shared
- Decide if you want to give your permission before your health information can be used or shared for certain purposes, such as for marketing
- Get a report on when and why your health information was shared for certain purposes

If you believe your rights are being denied or your health information isn't being protected, you can:

- File a complaint with your provider or health insurer
- File a complaint with the U.S. Government

You should get to know these important rights, which help you protect your health information. You can ask your provider or health insurer questions about your rights. You also can learn more about your rights, including how to file a complaint, from the website at www.hhs.gov/ocr/hipaa/ or by calling 1-866-627-7748; the phone call is free.

The Law Protects the Privacy of Your Health Information

Providers and health insurers who are required to follow this law must keep your information private by:

- Teaching the people who work for them how your information may and may not be used and shared
- Taking appropriate and reasonable steps to keep your health information secure

The Law Sets Rules and Limits on Who Can Look at and Receive Your Information

To make sure that your information is protected in a way that does not interfere with your health care, your information can be used and shared:

- For your treatment and care coordination
- To pay doctors and hospitals for your health care and help run their businesses
- With your family, relatives, friends or others you identify who are involved with your health care or your health care bills, unless you object

- To make sure doctors give good care and nursing homes are clean and safe
- To protect the public's health, such as by reporting when the flu is in your area
- To make required reports to the police, such as reporting gunshot wounds

Your health information cannot be used or shared without your written permission unless this law allows it. For example, without your authorization, your provider generally cannot:

- Give your information to your employer
- Use or share your information for marketing or advertising purposes
- Share private notes about your mental health counseling sessions

For More Information

This is a brief summary of your rights and protections under the federal health information privacy law. You can learn more about health information privacy and your rights in a fact sheet called "Your Health Information Privacy Rights". You can get this from the website at www.hhs.gov/ocr/hipaa/. You can also call 1-866-627-7748; the phone call is free.

Other privacy rights

Another law provides additional privacy protections to patients of alcohol and drug treatment programs. For more information, go to the website at www.samhsa.gov.

*Source: U.S. Department of Health & Human Services
Office for Civil Rights*

Date: Accessed 2005

Washington State-Healthcare for Workers with Disabilities

The *Healthcare for Workers with Disabilities (HWD)* program recognizes the employment potential of people with disabilities, and represents Washington State's response to the "Ticket to Work" legislation passed by Congress in 1999.

Under *HWD*, people with disabilities can earn more money and purchase healthcare coverage for an amount based on a sliding income scale.

HWD benefits include:

- Medicaid benefit package
- Greater personal and financial independence
- Members earn and save more without the risk of losing their healthcare coverage

Who qualifies for HWD? Washington residents who

- Are age 16 through 64
- Meet federal disability requirements
- Are employed (including self-employment) full or part time
- Have monthly net income* at or below 220% of the federal poverty level - \$1,755 for one person or \$2,353 for a married couple

What does it cost? Your monthly premium is based on a sliding scale. It cannot be more than 7.5% of your total income - but it can be less!

Interested in learning more? If you have been afraid of pursuing your career goals for fear of losing your health coverage, this program may be perfect for you. **To apply for HWD**, call toll free the number below, according to where you live in the state:

Region 1: 1-866-865-6150 *Counties:* Adams, Asotin, Chelan, Douglas, Ferry, Garfield, Grant, Lincoln, Okanogan, Pend Oreille, Spokane, Stevens, and Whitman.

Region 2: 1-877-980-9140 *Counties:* Benton, Columbia, Franklin, Kittitas, Walla Walla, and Yakima.

Region 3: 1-800-827-1808 or 425-438-4973 *Counties:* Island, San Juan, Skagit, Snohomish, and Whatcom.

Region 4: 206-272-2169 County: King.

Region 5: 1-866-755-4834 or 253-476-7300 Counties: Kitsap and Pierce.

Region 6: 1-800-960-5456 Counties: Clallam, Clark, Cowlitz, Grays Harbor, Jefferson, Klickitat, Lewis, Mason, Pacific, Skamania, Thurston, and Wahkiakum.

(For more information about HWD and the Ticket to Work program, see their website at <http://fortress.wa.gov/dshs/maa/Eligibility/HWD.htm>)

*Source: <http://fortress.wa.gov/dshs/maa/Eligibility/HWD.htm>
Accessed June 2006*

A Few Sexuality Resources for Youth with Disabilities

Books: Written for Typical Youth but Could be Adapted

1. My Body, My Self for Boys: The “What’s Happening to My Body?” Workbook. Authors: Lynda Madaras and Area Madaras
2. My Body, My Self for Girls: The “What’s Happening to My Body?” Workbook. Authors: Lynda Madaras and Area Madaras
3. My Feelings, My Self: Revised edition of Growing-Up Guide for Girls. Authors: Lynda Madaras

Books: Specific to Disability

1. Caution: Do Not Open Until Puberty! An Introduction to Sexuality for Young Adults with Disabilities. Author: Rick Enright

This book is written for young people with Spina Bifida, Cerebral Palsy, Spinal Cord injuries, Muscular Dystrophy, and other mobility disorders)

2. Living Your Own Life: A Handbook for Teenagers by Young People and Adults with Chronic Illness or Disabilities. Author: Nicole Roberts. Available from: PACER Center, Inc. 952-838-9000

Chapter 6 is “Sharing Life: the Human Need for Love and Affection”

Books: For Parents

1. The What’s Happening to my Body Book for Boys: A Guide for Parents and Sons. Author: Lynda Madaras with Dane Saavedra
2. The What’s Happening to my Body Book for Girls: A Growing up Guide for Parents and Daughters. Author: Lynda Madaras with Area Madaras
3. Adolescents with Down Syndrome. Authors: Siegfried M. Pueschel and Maria Sustrova
4. Autism-Aspergers and Sexuality: Puberty and Beyond. Authors: Jerry and Mary Newport.

5. Sexuality: Your Sons and Daughters with Intellectual Disabilities.
Authors: Karin Schwier and Dave Hingsburger.
6. Speak Up For Health: A Handbook for Parents. Author: Ceci Shapland and Kris Schoeller. Available from: PACER Center, Inc. 952-838-9000

Chapter 5 is "Sexuality, A Part of Health"

Books for Educators/Health Care Providers

1. Sexuality Issues for Youth with Disabilities and Chronic Health Conditions. Author: Cecily Shapland. Available from: Institute for Child Health Policy 352-392-5904, ext. 224
2. NICHY News Digest: Sexuality Education for Children and Youth with Disabilities. Volume I, Number 3, 1992. Available from the National Information Center for Children and Youth with Disabilities.
<http://www.nichy.org/outprint.asp#nd17>

Curriculum: Specific to Developmental Disability

1. Family Life and Sexual Health (F.L.A.S.H.): Special Education Secondary Edition (Public Health Seattle and King County: 206-296-4672;
<http://www.metrokc.gov/health/famplan/flash/>)

F.L.A.S.H. is a comprehensive sexuality education curriculum. The curriculum has been adopted and widely used by school districts in King County as well as throughout the United States and Canada, since it was developed by Public Health-Seattle and King County between 1985 and 1992. The revision of key lessons began in 2002 to accurately reflect advances in medicine. The F.L.A.S.H. Special Education Secondary Edition was written in the early 90's in response to requests from Seattle Public School educators for a special education edition of F.L.A.S.H.

2. James Stanfield has a number of curriculums but must be viewed first for appropriateness for audience: (Call for catalogue: 1-800-421-6534)

Circles I Intimacy and Relationships

Circles II Stop Abuse

Circles III Aids: Safer Ways

Life Horizons I The physiological and emotional aspects of being male and female

Life Horizons II The moral, social and legal aspects of sexuality

Sexuality Education for Persons with Severe Developmental Disabilities

Parts of the Female Body
Parts of the Male Body
Appropriate Social Behavior – Male
Appropriate Social Behavior – Female
Menstruation
Medical Examination – Women
Medical Examination – Men
Date Smart – 1 Teaches support for the choice for abstinence
Date Smart – 2 Teaches students how to control their emotions and avoid
impulsive reactions to intimate situations
Female Health Care Programs such as: Janet’s Got her Period, First
Impressions: Hygiene for Females

Source: Adolescent Health Transition Project
Date: Revised June 2005

More Health Transition Resources

Health – General

Healthy and Ready to Work National Center

<http://www.hrtw.org>

Provides information and connections to health and transition expertise – from those in the know doing the work and living it!

Adolescent Health Transition Project

<http://depts.washington.edu/healthtr>

The Adolescent Health Transition Project is designed to help smooth the transition from pediatric to adult health care for adolescents with special health care needs. The website is a resource for information, materials, and links to other people with an interest in health transition issues.

HealthCare Coach

<http://www.healthcarecoach.com>

HealthCare Coach.com is packed with facts and do-it-yourself tips on everything from health insurance to patient care – to help you help yourself. For over three decades, their non-profit group of health law specialist has given consumers the information they need to get the best out of the system.

Kentucky Cabinet for Health and Family Services- Health Transition Resources

<http://chfs.ky.gov/ccshcn/ccshcntransition.htm>

Website for children with special health care needs which has a section on transition resources.

MedicAlert

<http://medicalert.org>

A non-profit service that provides 24-hour emergency medical information services working together with an ID bracelet or pendant.

Disaster Preparedness for People with Disabilities

<http://www.redcross.org/services/disaster/beprepared/dissup.html>

Designed to help people who have physical, visual, auditory, or cognitive disabilities to prepare for natural disasters and their consequences.

Community Options Program Entry System (COPES)

<http://www1.dshs.wa.gov/basicneeds/dis2cope.html>

A Washington State program that pays for personal care and other services for people in their own homes, adult family homes, adult residential care facilities, and assisted living facilities.

Mental Health

Child and Adolescent Depression and Anxiety Kit

<http://www.cshcn.org/resources/mentalhealthtoolkit.cfm>

This tool kit has been developed in the form of a web page. The kit includes online health information resources focused on anxiety and depression in children and adolescents. Has links to resources or PDF documents included in the tool kit that can be printed and copied for your use.

Reasonable Accommodations for People with Psychiatric Disabilities: An On-line Resource for Employers and Educators

<http://www.bu.edu/cpr/reasaccom/>