

Name: _____ Date _____



Packaging Wisdom A Family Centered Care Coordination Notebook

Presented by:

Wyoming **FAMILY**  **FAMILY**
Health Information Center
A Project of Parents Helping Parents of WY, Inc.

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Wyoming Packaging Wisdom

First Edition 1997 Children’s Special Health, Diane Magill, Parent Coordinator

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Second Edition 2007 Family Voices, Rick Skagen

Third Edition 2012 Wyoming Family 2 Family Health Information Center

About WY Family Family

Wyoming Family 2 Family Health Information Center is a statewide center for families of children and youth with special health care needs (CYSHCN) and disabilities. We know families and care providers often struggle to find services and resources available, and WY F2F is here to help families find and access resources, while connecting them with other families for support. We offer technical assistance to help families make informed decisions regarding their children’s care.

We are a non-profit, 501(c) 3 organization; therefore, your donation is tax deductible. We welcome all donations. Every donation helps us strengthen our network of support for families.

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Section 1 Introduction

What is a family centered care coordination notebook?

Packaging Wisdom is a care notebook to help you organize information regarding your child's chronic health condition. In caring for your child with special health needs, you may receive information and paperwork from many sources. A care notebook such as *Packaging Wisdom* will help you record important information about your child's health care, and will make it easier to keep track of changes, share information with your child's care team, child care, school, and family members. It has a variety of worksheets that reflect questions most often asked by professionals or information that families most often must provide. These worksheets may be filled out to be used as a reference about your child's health and needs. A care notebook will also help in managing treatment as well as routine health care, and will allow for easier long term planning. Each section also includes useful information pertaining to that particular section's subject matter. Finally, planning for the assorted changes and transitions that will happen at different times throughout your child's life starts now, and your care notebook will help you all along the way.

You know your child best. You also have your child's best interests at heart, so you are in the best position to advocate for your child. You are the one most familiar with your child's history and the best one to document it. For this reason, care notebooks are very personal to your child and ideally should be personalized to reflect your child's medical history, current information and any other information you decide is important to track. A care notebook tells your child's story, and you and your child are the authors.

About Packaging Wisdom

Packaging Wisdom was developed by parents with children with special health needs. It is based on their personal recommendations as well as recommendations from national resources such as the American Academy of Pediatrics, Family Voices – National Center for Family/Professional Partnership, and the National Center for Medical Home Implementation. The notebook includes sections for the major areas of consideration when dealing with special health concerns: health care information; insurance coverage and financial resources; educational information; emergency preparedness; and transitioning into adulthood. There are also sections for correspondence, contacts, notes, commonly-used terms, resources and additional information. You may use *Packaging Wisdom* "as is", or you may customize the notebook as you wish, removing pages or sections, replacing them with forms from other sources, and adding articles and information.

Introduction 1.1

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The most important piece of this notebook is your child; therefore, the first section after the introduction is called **All About Me**. This section is devoted to your child, allowing others to not only get to know him or her beyond special health needs or disabilities, but to also understand how these special needs impact all areas of your child's life. **All About Me** can include information regarding your child's communication capabilities and needs, nutrition, friends, stressors and how to manage them and sleep habits. Many families choose to not only include their child in completing this section, but to also decorate the cover of their care notebook with their child's artwork or photos.

Setting up Packaging Wisdom:

Step 1: Gather information you already have.

Gather up any health information about your child you already have. Consider information you look up and use often. This may include reports from recent doctor's visits, recent summary of a hospital stay, this year's school health plan and/or Individualized Education Program (IEP for special education), test results, or informational pamphlets.

Step 2: Look through the pages of the Care Notebook

Can any of these pages help you keep track of information about your child's health or care? Use the Care Notebook as it is, remove pages or get more pages that will help you personalize your book to your child's need. Additional pages are available on the Packaging Wisdom CD or at www.wpic.org/WYF2FHIC/. You may also find additional care notebook resources at the following websites:

National Center for Medical Home Implementation
http://www.medicalhomeinfo.org/for_families/care_notebook/

Family Voices/National Center for Family-Professional Partnerships
<http://www.fv-ncfpp.org/>

Center for Children with Special Needs
<http://www.cshcn.org/planning-record-keeping/care-notebook>

Step 3: Decide which information is most important to keep in your child's Care Notebook

- What information do you look up often?
- What information do caregivers for your child need?
- Consider storing other information in a file drawer or box where you can find it if needed.

Introduction 1.2

Step 4: Assemble your Packaging Wisdom care notebook.

Everyone has a different way of organizing information. The KEY is to make it easy for you to find again. Here are some suggestions for supplies used to create care notebooks:

- 3-ring notebook or large accordion file to hold papers securely.
- Tabbed dividers to create your own information sections.
- Pocket dividers or sheet protectors to store reports.
- Plastic pouch for notebooks for holding notes, miscellaneous items.
- Plastic pages to store business cards and photographs.

Filling in and updating Packaging Wisdom:

- Track changes in your child's medicines or treatments.
- Add new information whenever your child's treatment changes.
- List telephone numbers for providers and contacts.
- Prepare for appointments.
- File information about your child's health history.
- Have information such as insurance documents.

Helpful Hints for using Packaging Wisdom:

- Store where it is easy to find. This helps you and anyone who needs information when you are not there.
- Share new information with your child's primary care physician, therapists, family members, school nurse and school staff, daycare staff, and others caring for your child.
- Take Packaging Wisdom with you to appointments and hospital visits so that information you need will be easy to find.
- Include your child when working on Packaging Wisdom. Let them know that the care notebook contains information about them and their care.

Access to Information:

You may wish to obtain copies of your child's medical records to assist you in the management of your child's health care. In recent years legislation has been enacted at both the state and federal levels to define when and how you can obtain this information.

Although your child's hospital and physician's records are their (the provider's) property, the information contained in that record is considered to be your property (or your child's, if he or she is over eighteen years of age).

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You have the right upon written request to review or receive copies of records. You can review and copy your child's medical history, bedside notes, charts, pictures and x-rays, and other information included in the hospital chart. Send your request to review and/or copy portions of the record **in writing** to the records administrator of the hospital or provider's office.

Again, in order for you to obtain copies of medical records, your request must be put in writing.

Often a hospital or physician will have a preprinted release form that you can complete and sign to request the reports. A handwritten note will usually be sufficient; however, the following information should be included in your note, or request:

- The date of the request, your contact information and where to send the information.
- Identifying information regarding your child, such as his or her full name, birth date and address.
- The name of the hospital, physician, or facility from whom records are being requested.
- A specific description of the material being requested, including the dates when your child received services, when possible. The more detailed the information, the easier it is for the physician or facility to promptly honor your request.
- Your signature, if your child is less than eighteen years of age, or your child's signature, if he or she is eighteen or older. If your child is older than eighteen and has a guardian, the guardian would sign the release.

Confidentiality:

Medical information is considered to be confidential and cannot be released by a physician or hospital without your written consent (or your child's consent, if he or she is eighteen years of age or older). Certain information may, however, be considered "non-privileged." This means that it can be shared without consent. This information includes the name, age, gender and address of your child and whether he or she is known to the facility or physician. Information can also be released in "statistical" form, if it does not reveal the identity of your child.

Introduction 1.4

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Section 2 All about Me!

My name is: _____

My nickname is: _____

My birthday is: _____

Insert Picture Here

The color of my eyes is: _____

The color of my hair is: _____

I am: _____ right _____ left handed

I like to: _____

I don't like to: _____

I have a pet: ___yes ___no My pet is a: _____ and is named: _____

My friends are: _____

My caregivers are: _____

When I am happy I: _____

When I am sad I: _____

I need help with: _____

I can do these things for myself: _____

If you need to know something else, call: _____

My Favorite Things

Colors: _____

Toys: _____

TV shows: _____

Games: _____

Hobbies: _____

Types of music: _____

All about Me! 2.1

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Songs: _____

Animals: _____

Favorite foods: _____

Least Favorite foods: _____

Child's Page

Use the rest of this page for your child's words and thoughts about his or her life now as well as later.

All about Me! 2.2

My Family

Mother's Name: _____ Occupation: _____

Address: _____

Work Phone: _____ Home Phone: _____ Cell Phone: _____

Employer: _____

Father's Name: _____ Occupation: _____

Address: _____

Work Phone: _____ Home Phone: _____ Cell Phone: _____

People who live with me:

Name: _____ Age: _____ Relationship: _____

Name: _____ Age: _____ Relationship: _____

Name: _____ Age: _____ Relationship: _____

Name: _____ Age: _____ Relationship: _____

Important Family Information:

Language(s) spoken at home: _____ Interpreter Needed? Yes: ___ No: ___

Preferred interpreter: _____ Phone: _____

Preferred religion: _____

Church: _____

Religious practices or customs that affect my treatment:

Family traditions:

All about Me! 2.3

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Activities of Daily Living

Use this page to describe your child's abilities to feed him/herself, bathe, get dressed, use the bathroom, comb hair, brush teeth, etc. Detail what your child can do by him/herself and any help or equipment your child uses for these activities. Describe any special routines your child has for bath time, getting dressed, etc.

Communication

Use this page to describe your child's ability to communicate and to understand others. How does your child communicate? How well does he or she understand directions? Include sign language words, gestures, equipment, or types of assistance your child uses. Include cues, signals and special words your family and child use to describe things.

Coping and Stress Tolerance

Use this page to describe how your child copes with stress. Stressful events might include new people, situations, hospital stay, or procedures such as having blood drawn. What upsets your child? What does your child do to self-calm? What happens when he/she has “had enough?” Describe your child’s way of asking for help and things to do or say to comfort your child. This could include specific words or phrases, holding them, playing a certain kind of music, a favorite stuffed animal or a warm bath.

Mobility

Use this page to describe your child's ability to get around. Include what your child can do by him/herself and any help or equipment your child uses to get around. Describe any activity limits and any special routines your child has for transfers, pressure releases, positioning, etc.

Nutrition

Use this page to talk about your child's nutritional and/or dietary needs. Describe foods and any nutritional formulas your child takes, any food allergies or restrictions, and any special feeding techniques, precautions, or equipment used for feedings. List your child's favorite foods and foods to avoid, and describe how you know when your child has had enough to eat. Discuss any special mealtime routines your family and child has.

Respiratory

Use this page to describe your child's respiratory care, and any special techniques or precautions you use when giving care. This could include a nebulizer or an inhaler. Describe how a caregiver would know if there is a concern and how to respond. Include any special routines your child has for respiratory care.

Rest and Sleep

Use this page to describe your child's ability to get to sleep and to sleep through the night. Describe your child's bedtime routine and any security or comfort objects your child uses. Does your child wake up in the middle of the night or have bad dreams? How do you handle these situations?

Social and Play

Use this page to describe your child's relationships with other children as well as adults. Describe how your child shows affection, shares feelings, or plays with other children. Describe what works best to help your child get along or cooperate with others. Describe your child's favorite things to do. Include any special family activities or customs that are important.

Section 3 Medical and Health Care Information

Your child has a special health care need. Medical appointments are a part of your life. You may be involved with one or with many physicians. Your child may require additional services recommended by the physician, such as occupational or physical therapy. Laboratory studies, x-rays or other specialized testing may be recommended to help the physician in learning more about your child's medical condition. Over the course of time you will find that you need to keep track of information regarding the medical services your child receives. This information will be useful when you take your child to a new physician, when your child becomes involved in a school program, or for some other reason you need to share information about your child's medical history. It may also help you in keeping track of his or her progress, in order that you can see the larger, overall picture of your child's needs and medical care.

Use this section to keep all information about your child's health care, health care needs, and care plans. This could include development and medical history as well as medication tracking, notes regarding changes in your child's condition or care, preparation for appointments, plans for care, well-child visits and immunizations, and therapy information.

Wyoming Department of Health, Maternal and Family Health Programs (MFH-Title V)

As part of a broad network of partners, assesses, monitors, and improves the health and well-being of all of Wyoming's mothers, infants, children, and adolescents by both the personal care and public health systems to assure access to quality comprehensive care. This includes Comprehensive state-wide needs assessment and the Healthy Communities initiative. MFH provides leadership to ensure that all Wyoming women, children and families, including those with special health care needs, have access to prevention services and public health programs to create a strong foundation for optimal lifelong health. For more information and a list of all their programs, go to <http://www.health.wyo.gov/familyhealth/mch/index.html#women> or call 1-800-438-5795

Children's Special Health (CSH)

Children's Special Health (CSH), a program of the Maternal and Family Health, Wyoming Department of Health, is for children and youth with special health care needs (CYSHCN). Our goal is to help these children receive the best possible care. Caring for a child is costly. Caring for a child with special health care needs can be even more costly. CSH helps families pay for specialty services. Caring for a child with special health care needs can also mean a lot of doctor's appointments. CSH can also help coordinate care.

Medical and Health Care Information 3.1

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Services provided by Wyoming's CSH program include:

- Coordination of care: helping families access services in their community.
- Financial assistance for qualifying medical conditions.
- Genetics and specialty care clinics.
- Funds for translation services required by CSH clients.
- Limited funding for transportation.
- Diagnostic evaluation to determine diagnosis.
- Some equipment and medications.

For more information on any of the CSH programs, call 1-800-438-5795

<http://www.health.wyo.gov/familyhealth/csh/index.html>.

Newborn Metabolic Screening Program

When a baby is born in Wyoming, a nurse takes a tiny bit of blood from its heel which is then sent to the laboratory. The lab tests this blood to make sure the baby does not have any disorders. Screening is required by Wyoming State Law for all newborns unless you sign a waiver to opt out of screening. <http://www.health.wyo.gov/familyhealth/newborn/index.html>

Genetics Clinic and Specialty Clinic Services

Genetic Counseling Services allows clients/families to gain a clearer understanding of inherited/genetic conditions and other birth defects, as well as the risk of recurrence. There is no financial eligibility requirement for an appointment.

These services are provided through The Children's Hospital of Denver, hosted at various locations throughout Wyoming. Out of state travel to your child's specialist can be a hardship to families. MFH has compiled a Specialty Clinic Directory for you to locate a clinic by specialty and location. <http://www.health.wyo.gov/familyhealth/csh/Metabolicsandgenetics.html>

Safe Kids of Wyoming

The Wyoming Department of Health and Cheyenne Regional Medical Center are dedicated to reducing unintentional injuries in children in Wyoming through the Safe Kids of Wyoming program.

The Safe Kids of Wyoming Campaign chooses to implement a statewide social marketing campaign to raise awareness among adults, especially parents, parents-to-be and caregivers that unintentional injuries are the leading cause of death in children age 1-18 and that they are preventable through active (behavioral) and passive (environmental and legislative) interventions. For more info on local coalitions in Wyoming: <http://www.safekids.org/in-your-area/coalitions/list.html> or call Safe Kids Wyoming 307-633-7525

Medical and Health Care Information 3.2

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Tips

- Prepare for appointments. If you have questions or concerns, let the person who schedules appointments know so they can schedule in extra time for discussion.
- Sometimes a physician may mention a possible diagnosis for your child's medical condition. Be sure that you understand whether a diagnosis is only suspected or is actually confirmed.
- Don't hesitate to ask questions. Take along a small notepad to jot down notes.
- If—between visits—you think of questions you would like answered by your child's physician, write them down and take them with you to the next appointment. Make two copies—one for you and one for your physician. Sometimes answers cannot be provided on-the-spot, and copy of your questions and concerns will help your provider in following up with you.
- If you are not able to understand the medical language used by your child's physician or other professionals, ask them to explain it. If you do not have the chance to ask, find a medical dictionary to use as a reference book (often available at your local library), or go online to research the issue using a reliable internet source.
- There may be more than one medical treatment option for your child's condition. Ask what the options are and what can be expected from each option. Then decide which treatment you think will be best for your child.
- Ask if a second opinion would be helpful, if you are uncomfortable or confused about the diagnosis or treatment and uncertain about making the right decision for your child. Keep in mind that, while second opinions can be helpful, be careful you do not become a medical "shopper," hunting for the doctor who says what you want to hear.
- Be sure you know what the specialist expects you to do next and what you can expect the specialist to do. Write those expectations down.
- Ask the specialist where he or she will send the medical reports. Make a list of people you would like to receive reports. Be sure that your child's pediatrician or your family doctor receives copies of reports from specialists, therapists, etc. Don't assume this will happen if you do not specify or give them the names.
- If your child is seen by more than one specialist, be sure that they are each aware of the others involvement and that they share reports.

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- When your child is referred to another doctor or specialist, ask about the purpose of the referral. Also find out what will be involved in the specialist's examination (such as lab work and x-rays). Ask about the reports the specialist will want to see and take them with you or ask (in writing) that they be sent. Be sure to follow up to see if they have been received before your appointment.
- Most physicians and hospitals have social services departments who work with "special needs" children and their families. These departments are usually aware that other, non-medical services are sometimes needed (for example, counseling services for financial support) and will be able to help with referrals for such services when they recognize the need or when parents request such assistance. Don't hesitate to ask them to explain other services for which your family or your child may be eligible to receive.
- Have the physician tell you the name of any medication that is prescribed. Then, be sure that this is the same medication that the pharmacist is providing. Handwriting can occasionally be misinterpreted or misread. Check to make sure that all prescriptions are filled correctly by reading the label and looking at the medicine's color and consistency. Check the size, shape and color of pills, if they have previously been prescribed, to see if they appear to be the same. If an error has been made, contact the pharmacist immediately.
- Ask the physician, nurse or pharmacist to explain to you any side effects of medications prescribed or situations in which a specific medication should not be used.
- Learn how to change milliliters (ml) into teaspoon measurements (1 teaspoon = 5 ml or 5 cc), or keep a conversion chart handy. This will be helpful when liquid medication is prescribed. There are many places on the internet to download a conversion chart, or the pharmacist might have one available as well.
- When possible, use the same pharmacist or pharmacy to fill all your child's prescriptions. This will allow the pharmacist to easily check to see what other medications your child is taking or has taken in the past and alert you and the doctor to possible medication interactions. He or she can also become familiar with any problems your child has with taking medication (such as reactions).
- Become familiar with any medication prescribed for your child, its purpose, side effects, etc. Pharmacists are required to provide printed information regarding the medications they dispense. Be sure to read what is provided and ask the pharmacist any questions you may have about the medication. You may want to keep this information in your care notebook.
- Check with physicians, nurses and therapists to learn if there is any equipment that could help with your child's care or development at home.
- Obtain maintenance information on any special equipment that your child uses, and write down the date you bought it on the front.

Medical and Health Care Information 3.4

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- When replacing equipment, be sure that the replacement item is the same as the original. Be sure that the equipment dealer provides a replacement item that meets the specifications of the original.
- Ask other parents about helpful tips they may have.

Things to Take To an Appointment

- Birth/Development and Family History. You may wish to take the appropriate pages from this book each time your child sees a physician for the first time or when he or she is being admitted to the hospital.
- List of all medications and the dosages your child is currently taking. Also list any allergies or negative reactions your child has had to medications in the past.
- List of questions and concerns (you may want to make you own list of questions to keep in this book). Leave room to write in the doctor's answers! Include questions your child may have about his or her condition. Again, make two copies—one for you and one for your physician.
- Information about insurance coverage and other payment sources.
- Amusements, snacks, and loose change to entertain your child while in the waiting area.
- Consider taking a neighbor, friend, or baby-sitter to watch your child if you plan to speak privately or at length with the physician after your child has been examined.

Medical and Health Care Information 3.5

Appointment Planning Sheet

Child's Name: _____

Parent: _____ Chart ID: _____ Date: _____

Questions/Concerns regarding:

My child's Health/ Diagnosis: _____

Medicines: _____

Specialists/ Therapy: _____

Lab Results: _____

School/ IEP's/ Education: _____

Money/Finances/Insurance: _____

Behavior problems: _____

Toilet Training: _____

Community Based Services (Early Intervention, child care, etc.): _____

Home Health: _____

Family Needs: _____

Transitions/Life changes: new school, Sexuality/Maturation, etc.: _____

Other:

Things I want to discuss:

Follow Up:

Call (date): _____

Next Visit (date): _____

Next Visit Agenda:

Medical and Health Care Information 3.6

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Developmental History

Indicate the age of your child when he/she

Held head up: _____ Followed object with eyes: _____

Rolled over: _____ Played with hands: _____

Reached for objects: _____ Crawled: _____

Sat up: _____ Sat unsupported: _____

Stood supported: _____ Stood alone: _____

Walked alone: _____ Ate solid foods: _____

Was toilet trained: _____

Child care Experience

Date started: _____ How long: _____

Name of provider: _____

Type of daycare: _____

Positive experiences: _____

Negative experiences: _____

Pregnancy and Birth History

Complications with pregnancy: _____

Complications with delivery: _____

Length of pregnancy: _____

Health issues during first two weeks of child's life:

Medical and Health Care Information 3.7

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Medical History

Diagnosed Medical Conditions

Condition	When diagnosed?	Who Diagnosed?

General Health: Good Fair Poor Explain: _____

Last Vision Exam: _____

Last Dental Exam: _____

History of Seizures, Convulsions, and/or Staring Spells: Yes No

Explain: _____

Detail Hospitalizations (serious illness, injury or allergic reaction)

Medical and Health Care Information 3.8

Family Medical History

Mother's Family

Relationship	Health Conditions/Illnesses	Date Diagnosed
Mother		
Grandmother		
Grandfather		
Aunt		
Uncle		

Father's Family

Relationship	Health Conditions/Illnesses	Date Diagnosed
Mother		
Grandmother		
Grandfather		
Aunt		
Uncle		

Child's Siblings

Relationship	Health Conditions/Illnesses	Date Diagnosed

Medical and Health Care Information 3.9

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Care Schedule

Time	Care
Morning	
Time	Care
Afternoon	

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Time	Care
Evening	
Time	Care
Overnight	

Medical and Health Care Information 3.11

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Medication Management: Tips to Avoid Problems

There are lots of things you can do to take prescription or over-the-counter (OTC) medications in a safe and responsible manner.

- Always read drug labels carefully. Learn about the medication, the reason it was prescribed, dosage information and potential side-effects.
- Learn about the warnings for all the drugs you take. Do not crush or cut pills before checking with your doctor or pharmacist.
- Keep medications in their original containers so that you can easily identify them. Also be mindful of storage conditions such as temperature, refrigeration and direct sunlight. If you need to take your child's medication to school and develop a health plan, be aware that school personnel must have the medications in its' original container.
- Ask your doctor what you need to avoid when you are prescribed a new medication. Ask about food, beverages, dietary and/or herbal supplements, and other drugs.
- Check with your doctor or pharmacist before taking an OTC drug if you are taking any prescription medications. Drug interactions can be deadly!
- Use one pharmacy for all of your drug needs.
- Keep all of your health care professionals informed about everything that you take.
- Keep a record of all prescription drugs, OTC drugs, and dietary and/or herbal supplements that you take. Try to keep this list with you at all times, but especially when you go on any medical appointment.

For More Information

FDA's Drug Development and Drug Interactions Website:

www.fda.gov/cder/drug/drugInteractions/default.htm

Consumer Education: Ensuring Safe Use of Medicine:

www.fda.gov/cder/consumerinfo/ensuring_safe_use_text.htm

MedWatch:

www.fda.gov/medwatch/

Preventable Adverse Drug Reactions: A Focus on Drug Interactions:

www.fda.gov/cder/drug/drugReactions/default.htm

Medical and Health Care Information 3.12

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Child's Name: _____

	Date	Physician	Reaction	Date	Physician	Reaction	Date	Physician	Reaction	Date	Physician	Reaction	Date	Physician	Reaction
Hepatitis B															
Diphtheria-Tetanus (Combined: DT)															
Diphtheria-Pertussis-Tetanus (Combined: DPT)															
Tetanus															
Polio															
Influenza Type B															
MMR (Measles, Mumps and Rubella)															
Measles (Rubeola)															
Mumps															
Rubella (3 day measles)															
Varicella Zoster															
Tuberculin Test (TB)															
Lead Screening															
Other Screenings															

Medical and Health Care Information 3.14

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Dental Record

Child's Name: _____

Dentist's Name: _____

Address: _____

Telephone: _____

Dentist has been informed of child's medical condition and medical specialists' recommendations.

All children should have routine dental care. Such care may be even more important when your child has a special health care need. He or she may need to be followed by a dentist with special skills. Consult with your family dentist or your child's medical specialist to determine if he or she requires specialized dental services.

Before your child is examined, the dentist should have information regarding your child's medical condition and current care. Any precautions recommended by your child's medical specialist should be discussed with the dentist. It is also essential that you provide the dentist with a list of current medications received by your child.

Medical and Health Care Information 3.15

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Allergies and Childhood Illnesses

Diseases

	Date	Duration	Treatment
7 day regular measles			
German Measles (rubella)			
Chickenpox			
Mumps			
Pertussis (whooping cough)			
Scarlet Fever			
Strep Throat			
Roseola			
Other (rashes, etc.)			

Medical and Health Care Information 3.17

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Equipment and Supplies

Medical Equipment Supplier (DME): _____

Contact: _____ E-Mail: _____

Phone: _____ Fax: _____

Address: _____

Item Name and Product Code	Quantity	Delivery Date	Reorder Schedule	Scheduled maintenance	Notes

Diet Tracking Form

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Tube Feeding							
Breakfast							
Lunch							
Dinner							
Snacks							

Notes:

AUTHORIZATION TO ADMINISTER MEDICATION

Name of Individual receiving medication: _____

I, _____, guardian/parent of _____

_____, authorize _____ to administer medications prescribed by his/her physician while in his/her care during our absence.

I understand that I will provide all dosage and administration information, and that I am responsible for understanding side effects of the medications and reporting these to the physician.

I understand that this authorization will be in effect one year from the date signed.

Name: _____ Date: _____

Signature of Parent/Guardian

Witness: _____ Date: _____

AUTHORIZATION FOR EMERGENCY MEDICAL TREATMENT

PLEASE COMPLETE THE FOLLOWING:

Child's Name: _____

Date of Birth: _____

Date of Last Tetanus Shot: _____

Current Medications: _____

Allergies to Medication: _____

Chronic Medical Conditions: _____

In the event of an emergency requiring medical treatment/aid due to illness or injury while in the care of, _____, I _____

(parent or guardian)

authorize medical or surgical care from a healthcare facility, physician, or dentist for my child. It is understood that a conscientious effort will be made to locate me before action will be taken. If this is not possible, treatment as deemed necessary by the healthcare facility/physician/dentist may be taken. I further consent to transportation of the above-named child to the nearest or most appropriate medical facility.

Insurance Company that covers the above-named child is: _____

Name of Insurance Company: _____

Address: _____

Phone: _____

Name of Policy Holder: _____ Policy #: _____

Medicaid Client: _____ Medicaid #: _____

ACS Phone #: _____

I authorize the hospital, and attending physician/dentist to submit claims to this company and to Medicaid, and hereby assign benefits directly to them.

Name: _____ Date: _____

(Signature of Parent/Guardian)

Witness: _____ Date: _____

Medical and Health Care Information 3.26

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Section 4 Insurance Coverage and Financial Resources

Medical care costs money, as does medication, special equipment, supplies and other services your child may need. Insurance may cover some or all of these costs. In addition, there are a variety of supplemental financial benefits available that your child may be eligible for, such as Children's Special Health Program and/or the Developmental Disability Waiver Services.

It is important to know what insurance coverage your family has and exactly what coverage is included. Take the time to read your insurance policy, visit your insurance provider's website, and to call your claims representative with any questions. Always document the name of the person you talk to, what information you received, and the date it you spoke to them.

If you are looking for insurance or alternatives to your current coverage, there are various points you should consider as you explore options. Below are some important questions to think about:

- What are my family's specific needs?
- What will out-of-pocket expenses consist of? Medication costs?
- What are the deductible, co-insurance and co-payment amounts?
- Are there specific limits that apply only to your child's special health care needs?
- Does the policy have in-network and out-of-network providers and guidelines?
- What limits are placed on benefits and services?
- Do I need a referral for various services?
- What are the policy's requirements for filing the claim? Does my provider file the claim, or must I?
- Does insurance coverage change with age or school status?
- Does insurance coverage change with employment status?
- If my insurance changes, are there certain services that will be less available after I reach a certain age?
- Does the plan cover home care?
- Does the plan cover durable medical equipment (e.g., wheelchair, glucose monitors, etc.)?
- Is physical, occupational, or speech therapy covered in the plan?
- What do I need to do to coordinate benefits from this policy with other insurance coverage or financial assistance programs?

Insurance Coverage and Financial Resources 4.1

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Financial Assistance Programs

Healthlink

Healthlink is an online application and screening tool for Medicaid and Kid Care CHIP health insurance programs. <https://healthlink.wyo.gov>

Children's Special Health (CSH)

Children's Special Health (CSH), a program of the Maternal and Family Health, Wyoming Department of Health, is for children and youth with special health care needs (CYSHCN). Our goal is to help these children receive the best possible care. Caring for a child is costly. Caring for a child with special health care needs can be even more costly. CSH helps families pay for specialty services. Caring for a child with special health care needs can also mean a lot of doctor's appointments. CSH can also help coordinate care. For more information on any of the CSH programs, call 1-800-438-5795. <http://www.health.wyo.gov/familyhealth/csh/index.html>

Services provided by Wyoming's CSH program include:

- Coordination of care: helping families access services in their community.
- Financial assistance for qualifying medical conditions.
- Genetics and specialty care clinics.
- Funds for translation services required by CSH clients.
- Limited funding for transportation.
- Diagnostic evaluation to determine diagnosis.
- Some equipment and medications.

Child Developmental Disabilities Home and Community-Based Waiver

In order to be eligible for the adult waiver, an individual must be no younger than 21 years of age, a citizen of the United States, and a resident of Wyoming. They must be mentally retarded or meet the federal definition for developmental disabilities and they must be eligible to receive the level of care of an Intermediate Care Facility for the Mentally Retarded (ICF/MR).

<http://www.health.wyo.gov/ddd/childwaiver/index.html>

Wyoming Health Insurance Pool (WHIP)

The Wyoming Health Insurance Pool was created by the 1990 Wyoming Legislature to provide health insurance coverage to residents of Wyoming who are denied adequate health insurance. This plan is specially designed to meet the needs of those individuals who are unable to purchase health insurance for themselves because of existing health problems. <http://insurance.state.wy.us/whip.html>

Social Security Income (SSI)

A person of any age can receive SSI, if they are disabled and meet the income and asset limits. In the case of minor children who live with their parents. We must also consider the parents' income and assets. Once a child is 18 we no longer consider parental income or assets.

<http://www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm>

Insurance Coverage and Financial Resources 4.2

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- Disabled means you have a physical or mental problem that keeps you from working and is expected to last at least a year or to result in death
- For more information about benefits for your young adult, please contact the Social Security Administration at 1-800-772-1213

Department of Family Services (DFS)

The Economic Assistance Division of DFS helps people by determining eligibility for health care (Medicaid), and connects them to health care benefits such as Medicaid.

<http://dfsweb.state.wy.us/economic-assistance/index.html>

Some of the supports and services target:

- Parent(s) with children who have qualifying income.
- Pregnant women.
- Children through the age of 18
- A child with special health needs who may be eligible for the Children's Special Health (CSH) program.
- Individuals receiving Supplemental Security Income (SSI) through Social Security.
- Individuals no longer receiving Supplemental Security Income (SSI) through Social Security.
- Individuals receiving Social Security benefits who are eligible for Medicare Part B Insurance.
- Individuals in need of nursing home care.
- Individuals who need care in an Assisted Living Facility.
- Individuals who are developmentally disabled.
- Individuals who need nursing home care but wish to remain in their home.
- Individuals who are disabled and working.
- Individuals who are in need of hospice care.
- Individuals with an acquired brain injury.
- Individuals who need help with prescription drugs.
- Individuals who are qualified or non-qualified aliens.

Prescription Drug Assistance Program

The Prescription Drug Assistance Program is a state funded pharmaceutical assistance program. For qualifying individuals, the benefit allows three (3) prescriptions per month. Prescriptions are limited to a month's supply and the co-pay is **\$10 per prescription for a generic drug and \$25 per prescription for a brand-name drug**. Eligibility for the program is determined by the Department of Family Services and clients are eligible for a period of one year.

<http://health.wyo.gov/pharmacy/PDAP.asp>

Additional Resources

[Possibilities: A Financial Resources for Parents of Children with Disabilities](#); a publication from PACER, Minneapolis MN 1-888-248-0822 or www.pacer.org.

Insurance Coverage and Financial Resources 4.3

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Insurance Information

Primary Insurance: _____ Plan number: _____

Group number: _____ ID number: _____

Subscriber's name: _____

Subscriber's Social Security Number: _____

Mailing address: _____

Phone: _____ Fax: _____

Secondary Insurance: _____ Plan number: _____

Group number: _____ ID number: _____

Subscriber's name: _____

Subscriber's Social Security Number: _____

Mailing address: _____

Phone: _____ Fax: _____

Other Insurance: _____ Plan number: _____

Group number: _____ ID number: _____

Subscriber's name: _____

Subscriber's Social Security Number: _____

Mailing address: _____

Phone: _____ Fax: _____

Insurance Coverage and Financial Resources 4.4

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Medical Bill Communication Log

Information About the Bill				Information About Who You Talk To				Notes
Account #	Provider	Date of Service	What bill is for:	Date of Contact	Time	Title	Name	

Insurance Coverage and Financial Resources 4.5

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Section 5 Contact Information

Communication with all of the people involved in your child's care and well-being is critically important. Having the information to contact them in one accessible place is helpful, especially during times of crisis. Use this section to create a personalized directory of your child's team. You may want to insert plastic pages for business cards, or even tape business cards to the pages themselves.

Insert Picture, Business Cards, Etc. here

Contact Information 5.1

Medical/Dental Healthcare Providers

Primary Care Provider: _____

Date of First Visit: _____

Office Nurse/Medical Assistant: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Community Hospital: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Dental Provider: _____

Date of First Visit: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Orthodontist: _____

Date of First Visit: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Specialty Care Provider: _____

Specialty: _____ Date of First Visit: _____

Office Nurse/Medical Assistant: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Contact Information 5.2

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Account Number: _____

Specialty Care Provider: _____

Specialty: _____ Date of First Visit: _____

Office Nurse/Medical Assistant: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Account Number: _____

Specialty Care Provider: _____

Specialty: _____ Date of First Visit: _____

Office Nurse/Medical Assistant: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Account Number: _____

Specialty Care Provider: _____

Specialty: _____ Date of First Visit: _____

Office Nurse/Medical Assistant: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Account Number: _____

Specialty Care Provider: _____

Specialty: _____ Date of First Visit: _____

Office Nurse/Medical Assistant: _____

Address: _____

Contact Information 5.3

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Phone: _____ Fax: _____ E-Mail: _____

Account Number: _____

Specialty Care Provider: _____

Specialty: _____ Date of First Visit: _____

Office Nurse/Medical Assistant: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Account Number: _____

Specialty Care Provider: _____

Specialty: _____ Date of First Visit: _____

Office Nurse/Medical Assistant: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Account Number: _____

Specialty Care Provider: _____

Specialty: _____ Date of First Visit: _____

Office Nurse/Medical Assistant: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Account Number: _____

Contact Information 5.4

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Therapists/Counselors

Occupational Therapist (OT): _____

Start Date: _____ End Date: _____

Agency/Hospital/Clinic: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Physical Therapist (PT): _____

Start Date: _____ End Date: _____

Agency/Hospital/Clinic: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Speech-Language Pathologist: _____

Start Date: _____ End Date: _____

Agency/Hospital/Clinic: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Contact Information 5.5

Counselor/Social Worker: _____

Start Date: _____ End Date: _____

Agency/Hospital/Clinic: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Other: _____

Start Date: _____ End Date: _____

Agency/Hospital/Clinic: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Contact Information 5.6

Respite Care

Respite Care Provider: _____

Start Date: _____ End Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Respite Care Provider: _____

Start Date: _____ End Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Respite Care Provider: _____

Start Date: _____ End Date: _____

Agency: _____

Address: _____

Phone: _____ Fax: _____ E-Mail: _____

Contact Information 5.7

Packaging Wisdom: A Family Centered Care Coordination Notebook

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Additional Service/Support Providers

Case manager, advocate, Department of Family Services contacts, waiver, support groups, etc.

Services: _____

Agency: _____

Contact Person: _____ Phone: _____

Services: _____

Agency: _____

Contact Person: _____ Phone: _____

Services: _____

Agency: _____

Contact Person: _____ Phone: _____

Insert Business Cards Here

Contact Information 5.8

Child Care/Preschool/Child Development

Child Care/Preschool/Child Development Program: _____

Address: _____

Hours of Operation: _____

Phone: _____ Fax: _____

Director: _____ email: _____

Teacher: _____ email: _____

Service Providers (Case manager, Family Service Coordinator, therapists, nurse, etc.)

Child Care/Preschool/Child Development Program: _____

Address: _____

Hours of Operation: _____

Phone: _____ Fax: _____

Director: _____ email: _____

Teacher: _____ email: _____

Service Providers (Case manager, Family Service Coordinator, therapists, nurse, etc.)

Contact Information 5.9

Special Care Plan for Child Care Providers

Facility Name: _____

Facility Address: _____

Child's Name: _____

Date of Birth: _____ Times and Days in Child Care: _____

1. Describe the child's special need during group care: _____

2. Child's present function level and skills: _____

3. What emergency or unusual episode might arise while the child is in care? How should the situation be handled? _____

4. Accommodation which the facility must provide for this child: _____

a. Are there particular instructions for sleeping, toileting, diapering or feeding? _____

b. Will the child require medication while in care? If so, attach the physicians instructions for the use of the child's medication: _____

c. Are special emergency and/or medical procedures required? If so, what procedures are required? _____

d. Are special materials/equipment needed? _____

5. Other specialists working with the child (e.g. occupational or physical therapist): _____

Primary Case Manager: _____ Phone: _____
(usually the doctor in charge)

Address: _____

On-site child care facility case manager: _____ Phone: _____

Contact Information 5.10

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Section 6 Early Intervention & Special Education

Early Intervention is a range of services designed to intervene during early stages of an infant and toddlers development to enhance their development to minimize their potential for developmental delays.

In Wyoming, early intervention services are provided through 14 regional child development centers for infants, toddlers and preschoolers. These centers contract with the Wyoming Department of Health, Behavioral Health Division, Developmental Disabilities Early Intervention and Education Program. These programs are designed to help your child and family receive the appropriate, individualized support and services, as needed. For more detailed information on the child developmental centers and early intervention services, call the Child Development Services at (307) 752-0687 or visit their website at www.cds.wy.org for a list of the regional development centers in Wyoming. For more information on families' rights and early intervention, call the Parent Information Center (PIC) for a free copy of their parent handbook for infants and toddlers, "*Baby Steps*," also available as a download at www.wpic.org or by calling 1-800-660-9742 or (307) 684-2277.

By the time your child is 6 years old, he or she should have transitioned into school. If they have not been evaluated for services or supports under the Individuals with Disabilities Education Act (IDEA) and do not have an Individualized Education Program (IEP) you should request an evaluation. This would only be necessary if their special health care need is negatively affecting their opportunity to learn or receive educational benefit. The IEP can address individual needs of your child, and the supports and services the school can provide to help them learn and get more from their education. For more information on parent's rights under IDEA, call the Parent Information Center, (PIC) to request our free handbook, "*Keys to confident and effective parent participation in the special education process*." This easy-to-read handbook is also available on cd, or online as a download. Call 1-800-660-9742 or (307) 684-2277 or go to www.wpic.org.

For students who do not need special education services and supports under the IDEA, an individualized health plan (IHP) can be developed. This plan is a formal written agreement developed by a team of school staff in partnership with the student's family, the student, and the student's health care provider(s). IHP's are important to achieve educational equality with health management needs, and make sure students with special health care needs have access to an education, whether or not the student is eligible for special education supports and services.

Keep copies of information related to your child's education in this section of Packaging Wisdom. This could include your child's school and health plans (IFSP, IEP's, IHP's- see Section 10 Glossary), any informational materials given to school staff, notes from meetings, school communication sheets, Adaptive Physical Education information, examples of your child's work, report cards and psycho-educational evaluations.

Early Intervention & Special Education 6.1

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Tips:

- There are many misunderstandings about special education and the services required by law. When you meet with people from the child developmental center or the school district to discuss your child's education, ask them to explain your rights to you. Don't hesitate to ask any questions you may have.
- Take an active part in your child's education. It is as important for you to be an active member of the educational team as it is for you to be an active member of the medical team.

It is usually in your child's best interest to share information about your child's medical condition with the school staff. You may need to help them learn about your child's special health care needs. This record may be very helpful to developmental center staff and school personnel.

- If your child is on medication, try to develop a schedule that will not require your child to take the medication at school. If your child must take medication during the school day, ask the school staff how they will insure the safe administration of that medication- and put it in a written health plan. Be sure they know what the medication is for and its side effects. Check with the developmental center or school staff to see if your child is having any problems with the medication.
- If your child is going to be out of school for medical reasons, be sure to let the center and/or school know. For the developmental center and related services, they will want to make up time lost, and for school, classwork and homework will need to be shared. Plans will need to be made for your child to make up school work and/or if need be, for a teacher to provide instruction in the hospital or in your home until the child can return.

School systems often do not understand the health care system and vice versa. Your child will be receiving services from both systems and you can help bridge the gap by asking.

Ask your child's special education team leader or teacher to explain terms and abbreviations used in describing your child's school program. The words and terms used may mean different things in different school districts. Keep asking until you completely understand your child's school program.

Early Intervention & Special Education 6.2

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School Contacts

School District: _____

Address: _____

Phone: _____ Fax: _____

Website: _____

Special Education Director: _____

Phone: _____ Email: _____

504 Plan Coordinator: _____

Phone: _____ Email: _____

District Head Nurse: _____

Phone: _____ Email: _____

School: _____

Address: _____

Phone: _____ Fax: _____

Website: _____

Regular Classroom Teacher: _____

Phone: _____ Email: _____

Early Intervention & Special Education 6.3

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Special Education Teacher: _____

Phone: _____ Email: _____

Paraprofessional/Aide: _____

Phone: _____ Email: _____

School Nurse: _____

Phone: _____ Email: _____

Section 7 Emergency Preparedness

Emergency preparedness is important to all communities and families, but when children with special health needs and/or disabilities are involved, emergency preparedness planning becomes especially urgent. A disastrous event often involves the loss of electrical power. For technology-dependent children, the loss of electrical power (a common occurrence even in the absence of natural disasters) is critical. A simple temporizing measure is that all critical life-support devices should include an internal battery back-up, a power-failure alarm, and a secondary means of back-up power). Lack of access to medications, water, food, shelter, and transportation should also be considered.

You can begin this process by gathering family members and making sure each person is well-informed on potential hazards and community plans ([Getting Informed](http://www.fema.gov/plan/prepare/informed.shtm) - <http://www.fema.gov/plan/prepare/informed.shtm>). Discuss with them what you would do if family members are not home when a warning is issued. Additionally, your family plan should address the following:

Escape routes	http://www.fema.gov/plan/prepare/escaperoute.shtm
Evacuation plans	http://www.fema.gov/plan/prepare/evacuation.shtm
Family communications	http://www.fema.gov/plan/prepare/commplan.shtm
Utility shut-off and safety	http://www.fema.gov/plan/prepare/utilityplan.shtm
Insurance and vital records	http://www.fema.gov/plan/prepare/recordsplan.shtm
Special needs	http://www.fema.gov/plan/prepare/specialplans.shtm
Care for pets	http://www.fema.gov/plan/prepare/animals.shtm
Care for livestock	http://www.fema.gov/plan/prepare/livestock.shtm
Safety skills	http://www.fema.gov/plan/prepare/safetyplan.shtm

Emergency Preparedness 7.1

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Disability and Other Access and Functional Needs	Additional Steps
Visually impaired	May be extremely reluctant to leave familiar surroundings when the request for evacuation comes from a stranger. A guide dog could become confused or disoriented in a disaster. People who are blind or partially sighted may have to depend on others to lead them, as well as their dog, to safety during a disaster.
Hearing impaired	May need to make special arrangements to receive warnings.
Mobility impaired	May need special assistance to get to a shelter.
Single working parent	May need help to plan for disasters and emergencies.
Non-English speaking persons	May need assistance planning for and responding to emergencies. Community and cultural groups may be able to help keep people informed.
People without vehicles	May need to make arrangements for transportation.
People with special dietary needs	Should take special precautions to have an adequate emergency food supply.
People with medical conditions	Should know the location and availability of more than one facility if dependent on a dialysis machine or other life-sustaining equipment or treatment.
People with intellectual disabilities	May need help responding to emergencies and getting to a shelter.
People with dementia http://www.fema.gov/plan/prepare/dementia.shtm	Should be registered in the Alzheimer's Association Safe Return Program http://www.alz.org/safetycenter/we_can_help_safety_medicalert_safereturn.asp

If you have a disability or Other Access and Functional Needs: Find out about special assistance that may be available in your community. Register with the office of emergency services or the local fire department for assistance so needed help can be provided.

Emergency Preparedness 7.2

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Check for hazards in the home

During and right after a disaster, ordinary items in the home can cause injury or damage. Anything that can move, fall, break or cause fire is a home hazard. Check for items such as bookcases, hanging pictures, or overhead lights that could fall in an earthquake or a flood and block an escape path.

Be ready to evacuate

Have a plan for getting out of your home or building (ask your family or friends for assistance, if necessary). Also, plan two evacuation routes because some roads may be closed or blocked in a disaster.

- Create a network of neighbors, relatives, friends, and coworkers to aid you in an emergency. Discuss your needs and make sure everyone knows how to operate necessary equipment.
- Discuss your needs with your employer.
- If you are mobility impaired and live or work in a high-rise building, have an escape chair.
- If you live in an apartment building, ask the management to mark accessible exits clearly and to make arrangements to help you leave the building.
- Keep specialized items ready, including extra wheelchair batteries, oxygen, catheters, medication, prescriptions, food for service animals, and any other items you might need.
- Be sure to make provisions for medications that require refrigeration.
- Keep a list of the type and model numbers of the medical devices you require.
- Wear medical alert tags or bracelets to identify your disability.
- Know the location and availability of more than one facility if you are dependent on a dialysis machine or other life-sustaining equipment or treatment.

Additional Resources:

CDC Emergency Preparedness

<http://www.bt.cdc.gov/>

Estate Planning

<http://www.redcross.org/preparedness/FinRecovery/FinPlan/lovedones.html>

ARC: Prepare Your Home and Your Families

<http://www.redcross.org/portal/site/en/menuitem.d8aaecf214c576bf971e4cfe43181aa0/?vgnextoid=72c51a53f1c37110VgnVCM1000003481a10aRCRD&vgnnextfmt=default>

FEMA: Plan and Prepare for Families

<http://www.fema.gov/plan/index.shtm>

Emergency Preparedness 7.3

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Household Emergency Information

Address: _____

Directions from:

Fire Department Number: 911 or _____

Police Department Number: 911 or _____

Ambulance: 911 or _____

Poison Control Hotline: _____

Fire Escape Plan:

CHECK SMOKE ALARMS MONTHLY! CHECK FIRE EXTINGUISHERS MONTHLY!

Emergency Preparedness 7.4

Primary Emergency Contact Person(s)

Name: _____ Relationship: _____

Home Phone: _____ Work Phone: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Name: _____ Relationship: _____

Home Phone: _____ Work Phone: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Who else should be notified in the event of an emergency? (Clergy, other relatives, friends, etc.)

Name: _____ Relationship: _____

Home Phone: _____ Work Phone: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Name: _____ Relationship: _____

Home Phone: _____ Work Phone: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Name: _____ Relationship: _____

Home Phone: _____ Work Phone: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Emergency Preparedness 7.5

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Emergency Room Preparedness

Children with special health care needs are those who have, or are at risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount not usually required by typically developing children. Formulation of an emergency care plan has been advocated by the Emergency Medical Services for Children (EMSC) program through its Children with Special Health Care Needs Task Force. Essential components of a program of providing care plans include use of a standardized form, a method of identifying at-risk children, completion of a data set by the child's physicians and other health care professionals, education of families, other caregivers, and health care professionals in use of the emergency plan, regular updates of the information, 24-hour access to the information by authorized emergency health care professionals, and maintenance of patient confidentiality.

Emergency care of children with special health care needs is frequently complicated by a lack of a concise summary of their medical condition, precautions needed, and special management plans. This policy statement introduces a standardized information form that can be used to prepare the caregivers and health care system for emergencies of children with special health care needs. Emergency data sets, summaries, or "passports" have been used in several of the US Department of Health and Human Services, Maternal and Child Health Bureau, National Highway Traffic Safety Administration, Emergency Medical Services for Children. Children with special health care needs are those who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount not usually required by children.¹ Children with special health care needs frequently require emergency care for acute life-threatening complications that are unique to their chronic conditions. Emergency hospital and pre-hospital care is believed to be negatively affected by a frequent lack of accurate timely information about the children's special needs and particular histories.

To address this identified need for the group of children with special needs, creation of a passport plan or emergency medical information set has been advocated by the US DHHS-MCHB-NHTSA EMSC program through its Children with Special Health Care Needs Task Force Report of January 1997. The report notes:

"If the child is at risk for future medical emergencies, the child and family should participate in developing a written emergency care plan. Copies of this plan should be kept in easily accessible places at the child's home and any other location where the child regularly spends time. The plan should include provisions for any special training that will be needed by emergency medical personnel, family members, or other persons who may be called on to provide emergency care for the child."

Emergency Preparedness 7.6

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for transition is a process, not an event. If your child is receiving supports and services under the special education law, the IDEA 2004, your child's school's IEP will have a section in it for transition planning. However, a plan for transition can be developed outside of the special education process. As parents, how do you do that and where do you start? It can seem overwhelming to try to figure out how to make sure that all the aspects of transition are covered, but it is important to have a written plan. A written plan enables youth to monitor their progress and practice important self-advocacy skills.

Emergency Preparedness 7.7

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Section 8 Looking Ahead- Transition to Adulthood

Another important component of any transition plan is that it is person (youth) centered. Person-Centered plans build upon partnerships between the youth, their family, friends, professionals, and other supports to create collaborative plans to support the youth to meet their goals. Person-Centered planning provides a structure to ensure that the youth's dreams are honored and voice heard while allowing those who support them to collaboratively plan for the youth's future.

There are several Person-Centered Planning tools/models and resources that you could use to assist youth in creating a plan. Each model/tool has its strengths and they can be adapted based on a youth's preferences and styles. There are a variety of names for Person-Centered Planning on the internet, including whole life planning, personal futures planning.

Considerations for Transition Planning

Teens and young adults should be active participants in the transition planning. This is a time for parental support without being overprotective. "Letting go" is a necessary process experienced by both parent and young adult. Where do you start? Choose a goal that your young adult feels is most important to his or her independence and identify "safety nets." Safety nets are smaller steps taken to achieve independence and the support that is needed to assist them on their journey. Having these safety nets in place will make it much easier to transfer the responsibility to your young adult.

Guardianship

- At age 18, in Wyoming, adolescents reach the age of majority and are expected to make decisions about their own care.
- Parents discover that they are no longer legally active participants in many of their young adults' lives.
- Sometimes, a guardian is necessary to protect the interests of a young adult with a chronic illness or disability that prevents them from living and managing their affairs completely on their own.
- For more information on guardianship, contact the Wyoming Guardianship Program, in Cheyenne at (307) 635-8422 or visit their website at www.wyomingguardianship.org.

Supplemental Security Income (SSI)

- A person of any age can receive SSI, if they are disabled and meet the income and asset limits. In the case of minor children who live with their parents, Social Security Administration considers the parents' income and assets. Once a child is 18, the parental income or assets are no longer considered.
- Disabled means you have a physical or mental issue that keeps you from working and is expected to last at least a year or to result in death.
- For more information about benefits for your young adult, please contact the Social Security Administration at 1-800-772-1213 or visit their website at <http://ssa.gov/>.

Health insurance

Under President Obama's healthcare plan- *the Affordable Care Act*, if your health insurance plan covers children, your children can now be covered under their parents' health policy until they turn 26, whether or not they remain in school or college. Your children can remain on your policy even if they are:

- Married
- Not living with you
- Attending school
- Not financially dependent on you
- Eligible to enroll in their grandfathers plan*

* (There is a temporary exception: until 2014, "grandfathered" group plans do not have to offer dependent coverage to age 26 if a young adult is eligible for group coverage outside their parent's plan.)

Learn what questions to ask as you explore other insurance options. Be sure the plan will meet your young adult's needs. It may be helpful to refer back to the Insurance Coverage and Financial Resources section of Packaging Wisdom, and double check your current insurance policy, or call your claims representative to see what is available as your child gets older.

- Involve your young adult in discussions about health care financing.
- Does your young adult know how find and apply for medical insurance?
- Does your young adult understand his or her medical insurance, coverage, out-of-pocket expenses and limits?

Looking Ahead- Transition to Adulthood 8.2

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Health care providers

Allow time for your teen or young adult and the doctor to be alone during an appointment. It is important that he/she have time to ask the doctor questions when you are not present. This conveys to the doctor that they are competent to ask personal questions and get correct information.

You and your young adult should talk to your doctor about his or her future medical needs.

Adult Health Care

- Is your young adult able to take responsibility for making doctor appointments and getting prescriptions filled?
- Is your young adult able to manage medications?
- Does your young adult understand his or her illness or disability?
- Do they know their rights to medical information, to decline services, and to understand complications of a medical procedure?
- Are they able to communicate their needs to the doctor or be comfortable in asking that all communication be written down to help them remember correctly?
- Is your young adult able to seek independent living supports?

Health needs at work

- Is your young adult able to manage medication needs while at work?
- Is it necessary for an employer or a mentor to know about medications and the effects it could have on your young adult while they are at work? (Consider work schedule versus medication schedule.)
- Are there certain tasks and/or machinery that should not be assigned?

Sexuality

Knowing the answers to sexual questions reduces vulnerability. Parents are in the best position to teach sexuality to their teen or young adult. Parents are the constant in their child's life and they know them best. If you need further resources to introduce your teen or young adult to his or her sexuality, don't be afraid to ask for help. Disability organizations, parenting groups, teachers and doctors can provide resources and information.

Other Transition Areas to Consider:

If you have one, a copy of your most recent IEP should be included here.

Other questions to answer are:

- Do I need a vocational rehabilitation advisor (available through the Wyoming Division of Vocational Rehabilitation at www.wyomingworkforce.org/VR) to transition from school to work? If yes...

Name of Contact: _____

Phone number: _____

Date Contact Initiated: _____ First Meeting Date: _____

TO DO List Prior to the First Meeting:

- Do I need an independent living advisor to transition from home to adult living? If yes...

Name of Contact: _____

Phone number: _____

Date Contact Initiated: _____ First Meeting Date: _____

TO DO List Prior to the First Meeting:

- Do I need any additional help transitioning from secondary school to college or technical school? If yes...

Name of Contact: _____

Phone number: _____

Date Contact Initiated: _____ First Meeting Date: _____

TO DO List Prior to the First Meeting:

Looking Ahead- Transition to Adulthood 8.4

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- Do I need help managing my transportation needs in order to meet my transition goals? If yes...

Name of Social Worker: _____

Phone number: _____

Date Contact Initiated: _____ First Meeting Date: _____

TO DO List Prior to the First Meeting:

- Do I have any other needs that need to be met prior to implementing my transition plan? If yes list them here and talk to your doctor.

Resources:

NOWCAP Support Services <http://www.nowcapservices.org/>

Wyoming Statewide Independent Living Council <http://www.wyomingsilc.com/>

Wyoming Independent Living Rehabilitation <http://www.wilr.org/>

Wyoming Protection and Advocacy <http://wypanda.com/>

Looking Ahead- Transition to Adulthood 8.5

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Section 9 Correspondence/Communication

“If it was not written down, it was not said. If it was not written down, it did not happen.”
~~Pete Wright, parent rights attorney

Communication and the sharing of information is at the heart of your child’s care and an important piece of advocating for your child. Each phone call, letter, or email is a piece of your child’s story. Sometimes, questions or disputes may arise, and documentation is independent evidence that can clarify details, and help avoid future confusion and misunderstandings.

Types of Communication

Communication takes place in the form of phone calls, face-to-face meetings, emails, formal letters, memos and informational handouts.

Effective Documentation

Documentation of communications, regardless of the type, should record the “Who, What, Where, When, How, Why” of the topic. It is advisable to summarize verbal communications in the form of a letter or email to ensure understanding and to follow up on action items. Include the names of all people with whom you spoke. If you sign a consent or permission form, get a copy for your records. Your copy will serve as a record of what you agreed to. Calendars, telephone logs and journals can be useful tools as well.

Letter Writing

Letters are a good way of communicating with others about your ideas, requests and concerns. Putting your thoughts on paper give you the opportunity to take some time to think through what you want to say, and allow you to take as long as you need to state your issue clearly and specifically. Letters can also help avoid misunderstandings of what someone said, or thought they said.

Other reasons for writing a letter might be to:

- Discuss a problem.
- Request an evaluation (s).
- Request a meeting.
- Make contact with someone.
- Request records.
- Follow up with eligibility, services, any type of meeting or a discussion.
- Give positive feedback.

Correspondence/Communication 9.1

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THINGS TO REMEMBER:

- Keep a copy of the letter, plus all attachments. If sending a statement or bill- keep the original with you and send a copy.
- Have someone proofread your letters.
- Include attachment(s) or enclosure(s).
- If necessary, send copies of letter to any necessary people/providers.
- Letter should not be more than two (2) pages long (not including attachments).

What else do you need to say in your letter?

***Put your return address in your letter. Envelopes can be thrown away!

Be sure there is a date on your letter.

Thank them for their time and attention they are giving to your problem/issue.

Sample Letter

Today's Date (include month, day & year)

Your Full Return Address

City, State Zip Code

Full name of Person to whom you're writing

Title

Name of Organization/Medical Center/Agency

Street Address

City, State, ZIP Code

Dear (Name of person, use title and last name)

In this paragraph explain who you are, give the full name of your child and his or her health condition/ illness/ disability, and, VERY BRIEFLY, explain the reason you are writing.

In this paragraph explain what you would like to have happen or what concern or difference you are experiencing. This is the time to "tell your story". Be sure to clearly state how the issue affects you and your child. If possible, include a photo of your child.

This is the paragraph to clearly state what it is you want- summarizing the story. Be as clear and concise as possible. If what you want is in regards to reports/health documents, invoices and/ or payments, put all that pertinent information here- including invoice or statement date and account number. Again, this is where you need to clearly state what it is you want (not what you don't want).

State what type of response you want. For instance, do you need to meet with someone; do you want a return letter, or a phone call? Do you want a copy of records or billing? Set a reasonable date for them to respond to you.

Finally, give your daytime telephone number, address, e-mail and let them know you expect to hear from them soon (or give a day, "by the 10th").

Sincerely,

Your full name

Correspondence/Communication 9.3

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Section 10 Glossary of Commonly Used Terms

ACA	Affordable Care Act is the name of President Obama’s national healthcare act- passed in March 2010. It is also known as the Patient Protection and Affordable Care Act. www.healthcare.gov
Acute	A description of a disease, condition or illness that comes on quickly, and is short-lived, but can require urgent and/or emergency care.
Advocate	An advocate is someone that speaks or pleads in behalf of others. As parents, we are our child’s best advocate.
ADA	Americans with Disabilities Act – A federal law which prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, State and local government services, public accommodations, commercial facilities, and transportation. www.ada.gov
Assessment	A way of collecting information about a child’s needs, strengths, and interests, can be done with different testing and evaluation tools.
Care Coordination	Services are provided in a manner that the family’s lifestyle is interrupted as little as possible, and the family’s and child’s needs are met.
Case Manager	A person who works with the family to plan for services and who coordinates many service providers. They can also be called a Service Coordinator.
Chronic	A description of a persistent and long-lasting disease and/or health condition which usually lasts more than three months. It can be on-going -sometimes throughout a persons’ life. The opposite of chronic is acute.
Community-Based	High quality services necessary to meet the daily needs of the child and his/her family located near their home.
Confidentiality	Your child’s rights to privacy, which mean their records and information, will be shared only with people directly involved in your child’s care, (i.e. medical or educational providers, etc.).
CSH	Children’s Special Health - A state program to assist children who have special health care needs.

Glossary of Commonly Used Terms 10.1

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DDD	Developmental Disabilities (Division), a Division of the WY Department of Health, which now, through reorganization, is under the Behavioral Health Division and called Developmental Disabilities Section. www.health.wyo.gov/DDD/index.html
Diagnosis	The identification of the nature and cause of symptoms, often providing the name of a condition or illness.
Disability	The result of any physical or mental condition that affects a person's ability to develop, achieve or function.
Discharge Planning	A plan for continuing care after your child has a hospital stay. Another goal of discharge planning is to help the health care team make sure your child has the resources that he/she needs in their community.
DFS	Department of Family Services, a state governmental agency. www.dfsweb.state.wy.us
DME	Durable Medical Equipment - Health care equipment that can be used over and over again (e.g., hospital beds, ventilators, I.V. Poles, wheelchairs, and walkers).
EDHI	(WY) Early Hearing Detection and Intervention is designed to ensure that all infants, toddlers and preschoolers with hearing loss are identified as early as possible and provided with timely and appropriate follow up and intervention. www.wyomingehdi.org
EI	Early Intervention – is a range of services design to intervene during early stages of an infant and toddlers development to enhance their development to minimize their potential for developmental delays.
Eligible	Meeting specific requirements to qualify for a program or service.
EPSDT	Early Periodic Screening Diagnosis and Treatment is the child health component of Medicaid. Required in every state, it is designed to improve the health of low-income children, by financing appropriate and necessary pediatric services. www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-Periodic-Screening-Diagnosis-and-Treatment.html
Evaluation	A way of collecting information about a child's needs, strengths, and interests.

Glossary of Commonly Used Terms 10.2

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Family-Centered Care	Services are delivered in a way that respects the central role of the family as caregiver, advocate, and decision-maker for the child.
Genetic Disease or Disorder	A disease that passes by gene from parent to child.
Health Care Professionals	Workers who have healthcare skills (Including nurses, doctors, social workers, physical therapists, pharmacists, and so on).
Healthlink	Healthlink is an online application and screening tool for Medicaid and Kid Care CHIP health insurance programs. https://healthlink.wyo.gov
HMO	Health Maintenance Organization - A medical insurance program which gives care through specified doctors and hospitals. Members pay a fixed prepaid premium.
IDEA	Stands for <i>Individuals with Disabilities Education Act of 2004</i> , the federal law for specially designed supports and related services (special education) in schools. A student must meet specific criteria, covering a broad range of different disabling conditions, to qualify for IDEA supports and services to help them benefit from their education. http://IDEA.ed.gov
IEP	Individualized Education Program – a plan developed by a team which includes the family and the child as appropriate, for each student, according to their individual needs. The IEP is required by law for all students receiving special education services. It outlines your child’s educational goals and any services or supports your child needs to meet those goals.
IFSP	Individual Family Service Plan - A written plan for children with disabilities from birth to 3 years old and their family. Developed with the family and the team, the IFSP outlines services and goals of the family. It can include services from human services departments and public and private agencies. www.health.wyo.gov/ddd/earlychildhood/index.html
IHP	Individualized (School) Health Plan is a formal written agreement developed by a team of school staff, in partnership with the student’s family, the student, and the student’s health care provider(s).
LRE	Least Restrictive Environment - This means a child with special needs is educated as much as possible with children who do not have special needs. The school program must meet all of the child’s educational needs in the most appropriate setting as decided upon by the IEP team. Other words used for LRE are “Mainstream”, “Integration”, and “Inclusion”.

Glossary of Commonly Used Terms 10.3

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MFH / MCH	Maternal and Family Health is a section of the WY Department of Health that provides leadership to ensure all Wyoming Women, Children and Families, including those with special health care needs, have access to prevention services and public health programs to create a strong foundation for optimal lifelong health. In other states it is often called Maternal and Child Health (MCH). www.health.wyo.gov/familyhealth/index.html
Medical Home	Medical home is a partnership of pediatric health care team, the child and the child's families to assure all the medical and non-medical needs of the patient are met. It is not an abuilding, house, hospital or home healthcare service, but rather an approach to provide comprehensive primary care that is family-centered. www.medicalhomeinfo.org
OT	Occupational Therapy - Treatment to help a person develop mental or physical skills to aid in daily living. It focuses on hand and finger movement, and self-help skills such as dressing or using a fork and spoon.
PIC	Parent Information Center is Wyoming's statewide parent training and information center that provides support, training and referrals to families of children with disabilities and helps them navigate through the maze of special education services under the IDEA. www.wpic.org
Pediatric	A branch of medicine dealing with the care of children.
Pediatric Specialist	<ol style="list-style-type: none"> 1. A pediatrician who has a specialty area of knowledge and skills. Examples are pediatric oncologist and neonatologist. 2. A physician specialist who completed special training to treat children. The physician could be a pediatric surgeon, pediatric anesthesiologist or a pediatric urologist, for example.
Pediatrician	A doctor who specializes in the care of children.
PHN	Public Health Nurse
Primary Care Provider	A physician or clinician whose practice focuses upon internal medicine, family/general practice, pediatrics, and obstetrics/gynecology.
PT	Physical Therapy – is treatment of physical disabilities – usually gross motor- by a physical therapist. It includes the use of massage and exercise to help the person improve the use of bones, muscles, joints, and nerves.

Glossary of Commonly Used Terms 10.4

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PL	Public Law - Federal law that is passed. The number that follows “PL” identifies the law, (i.e. PL 101-476).
Respite (Pronounced RES-pit.)	Care for a limited time, in which a family gets a much needed “break” from caring for their child with special needs.
Service Coordinator	A person who works with the family to plan for services and who communicates with many service providers (Also called Case Manager).
SSI	Supplemental Security Income - A cash assistance federal program that pays benefits to children with disabilities under age 18 whose families have limited income or resources. You can get more information by calling 1-800-772-1213 or www.ssa.gov/pgm/ssi.htm
Special Needs	A term used to describe persons with one or more mental, emotional, or physical conditions that limit their capacity to participate in normal activities.
Title V	Title V of the Social Security Act is the federal law that provides funding in a block grant to each state to ensure the health and welfare of woman and children. In Wyoming, services provided through MFH are funded through the Title V block grant as well as the state general fund. www.amchp.org/abouttitlev/pages/default.aspx
WIC	Women, Infants and Children is a Special Supplemental Program through the Department of Family Services which provides food and nutrition education to prevent or correct malnutrition in pregnant women, new mothers and children up to age five. The program also screens for other health problems and makes referrals to other health and social services. www.health.wyo.gov/familyhealth/wic/index.html
WY F2F	Wyoming Family to Family Health Information Center is a family-run, family- directed statewide center that supports families of children and youth with special health care needs in finding, understanding and accessing healthcare services and public insurance programs for their children. www.wpic.org/WYF2FHIC

Glossary of Commonly Used Terms 10.5

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Section 11 Wyoming County Public Health Offices

Albany County Public Health	Laramie	307-721-2561
Big Horn County Public Health	Greybull	307-765-2371
	Lovell	307-548-6591
Campbell County Public Health	Gillette	307-682-7275
Carbon County Public Health	Rawlins	307-328-2607
	Saratoga	307-326-5371
Converse County Public Health	Douglas	307-358-2536
	Glenrock	307-436-3474
Crook County Public Health-	Sundance	307-283-1142
Fremont County Public Health	Lander	307-332-1073
	Riverton	307-856-6979
Goshen County Public Health-	Torrington	307-532-4069
Hot Springs County Public Health	Thermopolis	307-864-3311
Johnson County Public Health	Buffalo	307-684-2564
Laramie County Public Health	Cheyenne	307-633-4000
Lincoln County Public Health	Kemmerer	307-877-3780
	Afton	307-885-9598
Natrona County Public Health	Casper	307-235-9340
Niobrara County Public Health	Lusk	307-334-2609
Park County Public Health	Cody	307-527-8570
	Powell	307-754-8870
Platte County Public Health	Wheatland	307-322-2540
Sheridan County Public Health	Sheridan	307-672-5169
Sublette County Public Health	Pinedale	307-367-2157
Sweetwater County Community Nursing (Public Health)	Rock Springs	307-922-5390
	Green River	307-872-3944
Teton County Public Health	Jackson	307-733-6401
Uinta County Public Health	Evanston	307-789-9203
	Lyman	307-787-3800
Washakie County Public Health	Worland	307-347-3278
Weston County Public Health	Newcastle	307-746-4775

Wyoming County Public Health Offices 11.1

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