

Using Portfolios for Health Care Needs

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Kim Brown, MSW, RSW

University of Montana Rural Institute

www.ruralinstitute.umt.edu/transition

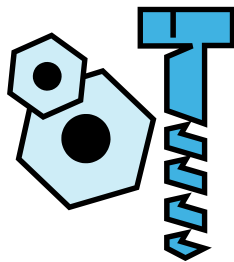
The Portfolio

- Originally a job development and representational tool used to negotiate Customized Employment
- Also used at IEP meetings and in other settings to introduce an individual
- Excellent tool for describing health care needs, especially when transitioning to adulthood
- Use with younger children...teach and develop health literacy, self-advocacy

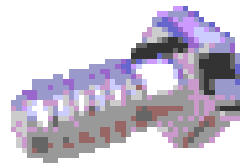
Why a Portfolio for Health Care?

- Helps develop health literacy
- Allows for self-advocacy and self-determination regarding health care needs
- Facilitates communication of health care needs, including sexual health
- Tool to ease the transition to handling one's own medical affairs
- Eases the navigation of health care services
- Describes impact of disability
- Can be used to interview prospective health care providers

Creating a Portfolio



Nuts and Bolts



Supplies:

- Digital camera (3.0 megapixels minimum)
- Floppy disk, USB connector, or other means of saving and transferring from camera to computer
- Charged batteries
- MS PowerPoint or other presentation program
- Presentation binder with clear sheet protectors
- Color printer

Example of Presentation Binder:



Step by Step...

- Decide on purpose of Portfolio
- Determine possible audience
- Outline areas to be covered
- Portfolios include both photos and written information (bulleted text), so...
 - Take pictures – lots of them!
 - Develop bullets to go with the pictures

Step by Step...

- Create the slides using presentation software
- Print slides in color
- Put slides into display binder
- Practice presenting the Portfolio
- Can also be shown on the computer (without printing it out)

Areas to Cover

- Impact of disability
- Previous diagnoses (if applicable and relevant)
- Medications
 - What they do
 - How long you've taken them
 - Side effects
 - Who prescribes
 - Cost
 - Pharmacy
- Allergies
- Dietary restrictions

Areas to Cover

- Seizure information
 - What kind
 - How long
 - How often
 - How to keep you safe
 - How to help you afterward
- Medical equipment information (feeding tubes, oxygen tanks, etc.)
 - Who maintains, refills, recharges
 - What to do if equipment fails
- Accommodations to help you manage your health
- Communication strategies



EXAMPLES

I wear a back brace to treat scoliosis (curvature of the spine). Because of back surgeries, I have to avoid physical contact and can only bend a small amount.



Rob is conscientious about managing his diabetes.



Checking blood sugar level



Eating a healthy snack

My fine motor skills are still developing, so feeding myself presents some challenges.

- During mealtime, I sit in a wooden chair that lifts me closer to the table top
- I need my food cut into bite-sized pieces
- I use a large-handled spoon and eat from a serving-size bowl
- I drink best with a straw
- Sometimes I need to be reminded to eat with my spoon (instead of my hands) and to take the spoon out of my mouth (instead of chewing on it)
- I also need to be reminded to take small bites
- I have been known to try and take snacks away from other students at school, so make sure I have regular meals and snacks
- I have two chipped teeth...I need to be careful when I eat hard foods so I don't damage the teeth more

How I communicate:

- Using facial expressions and sounds
 - I smile or say “ddd” and “ggg” when I’m happy
 - “mamama” is mom
 - “ninini” is no
 - “ahahah” is yes
- Tapping on or reaching for things I want
- Hitting my head or crying when I am in pain or upset
- Grinding my teeth when I’m anxious
- Slapping my leg when I need to use the restroom

Challenges I have and supports that work for me include:

- I like to explore and will sometimes run off if no one is watching me
 - Keep me in sight
 - Use light physical contact (like putting your hand on my back or shoulder) when we are shopping, walking or doing other things around town
 - Say “stop” loudly if I do start to run when I’m not supposed to
- I sometimes go places I shouldn’t go (like into the kitchen when something hot is cooking or into the school cafeteria during class time)
 - My family closes a gate to tell me when I should stay out of the kitchen
 - At school, they use cardboard “boundaries” to tell me where I should and shouldn’t go
 - The boundaries need to be tangible and at least two feet high (tape on the floor doesn’t work for me)

Challenges I have and supports that work for me include:

- I don't always go to the restroom when I need to
 - I do best when I'm reminded on a regular basis (every 90 minutes or so) to use the bathroom
 - It helps when people encourage me to drink plenty of liquids and eat fruit
 - I'm using the "Roll and Control" program to gain more control over my bodily functions
 - Exercise is good for me
- I have excess saliva that I can't control
 - I wear a medicine patch behind my ear to help keep the saliva in my mouth
 - I can wipe my chin but may need someone to point out when it's time to do so

Challenges I have and supports that work for me include:

- I sometimes get anxious, upset or uncomfortable, or my senses may become overwhelmed and I don't always know how to tell you this
 - Deep pressure or joint compression applied to my wrists and legs calms me down and helps me focus
 - A weighted blanket at night might help me sleep
 - I might rub my stomach, ears or head, rub my hands together, or tickle my head to relax and calm myself
 - Vibrating hairbrushes and neck pillows can help relax me
 - “Heavy work” can also help (hill climbing, pushing myself on a scooter on carpet, etc.)

MEDICAL NEEDS

- Jason has pulmonary hypertension. He is on oxygen throughout the day; his tank is filled every two hours.
- Jason has an auto subcutaneous pump attached to his abdomen, which delivers his heart medications.
- At bedtime, Jason takes medications, and then connects to a bipap machine, which forces air into his airways at all times throughout the night.

ADVOCACY

- Jason is a good advocate for his medical needs, letting staff know about any difficulties with his oxygen supply, and assisting with filling the tank.
- We are working on getting a cell phone for Jason, to be used by him or his caregivers in the event of an emergency.

ACCOMODATIONS

- Jason needs to sit down and rest every 20-30 minutes
- He needs space for a large oxygen tank with which to fill his smaller tank
- He needs to have access to a telephone to summon emergency assistance if necessary

Certain sensations bother me and make it hard for me to concentrate:

- The feel of my hands scraping or rubbing on paper
- When my hands get dirty
- Having my fingernails clipped
- Being touched by others without my permission

My Medications

- I take 30 mg of fluoxetine with my evening meal
- I have taken this medication since January 2010
- It sometimes makes me feel sluggish and tired
- ABC Pharmacy fills my prescription every 90 days and once a year I see my doctor for a new prescription

In these pictures I am making choices about what to eat, choosing what to wear, and asking for breakfast with my ECO talker.

My wheelchair is very well-fitted for my needs. I can reach to the ceiling. I can get into my closet for dishes. I can open the refrigerator and freezer. I have an elevator lift, right and left leg lifts, and tilt on my wheelchair .

This is my Invacare Air Mattress for my bed.



This is the hand brace I wear when I go to bed.



I use my bed control to raise or lower
my bed.



I have an Emergency Alert button so I can call for help if needed.



This is my ECO talker.



I also have a phone so I can call for help if I need to.



How I Communicate

- I hum when I'm happy
- When I am worried, feeling threatened, or my routine is changed, I may have a “melt down”
 - I sob, hit the sides of my head, bang my head, threaten to hit others, and/or pace
 - The melt downs can be prevented by preparing me for changes ahead of time
 - People can talk me through these episodes by reassuring me or they can distract me
 - My mom sometimes applies gentle pressure on my hands and arms to calm me (I'm learning to do this myself)

Certain smells and sensations bother me:

- The smell of ham and other meats can make me throw up
- My skin is sensitive to some fabrics and to garbage bags
- I don't like my hands to be sticky

Medication and Seizures:

- I take my seizure medication five times a day
- My medication makes me tired
- I have a history of grand mal seizures, but have not had one in several years

Challenges I have and supports that work for me include:

- ❑ I am completely deaf in my right ear and have a 50% hearing loss in my left ear
- ❑ I sometimes wear a hearing aid but when I do, sudden, loud noises startle me and I get headaches from loud places like movie theaters
- ❑ I need help changing the batteries in my hearing aid (the batteries are tiny)

My hearing aid looks like this:



Challenges I have and supports that work for me include:

- ❑ I hear better if I sit on the right hand side of classrooms
- ❑ It works best for me if you stand where I can see your lips as you speak to me or if you speak into my left ear
- ❑ It is important to be patient when you are trying to tell me or ask me something...it may take me some time or several tries to accurately hear what you are saying

I need the site around my feeding tube watched carefully for signs of infection.



DESIGNATION FOR PATIENT ADVOCATE FOR
CARE, CUSTODY, AND MEDICAL TREATMENT DECISIONS

Help with Doctors

I am Isaac Baldry and I live at 720 S. Jordan in Miles City, Montana. I want Theresa Baldry, my advocate, to help me if I am sick and if I need to go to the doctor.

My advocate read this paper to me before I signed the paper and I understood what they told me about this paper.

If I am sick, my advocate should take me to the doctor. If she is not at my house when I become sick, please call her to go the doctor's office. I would like the doctor to talk to her about what is the matter with me.

I would like the doctor to ask my advocate what we have decided the doctor should do. I would like the doctor to do what the advocate tells the doctor to do in regards to my treatment.

Sometimes a doctor says that I need to have a shot or some other care. Sometime the doctor says I need to take pills or medicine. My advocate and I will talk about it and decide if I should have the shot, or take a pill, or some other medicine. My advocate will also help me decide what other care I should have, but she will talk to me about what care I need.

If I am very sick, I might need to go to a hospital. My advocate will help me decide if I need to go to the hospital. I would like all the people at the hospital to speak with my advocate and myself about what the people at the hospital should do for me. I would like my advocate to assist me to decide about my care at the hospital even if I am unable to understand what the doctor says about me. This is very important since I want the people at the hospital to try very hard to care for me if I am sick. If I need to have an operation because am very sick, I would like to have the people at the hospital talk to my advocate. My advocate will say "yes" or "no" and that is what the people at the hospital are to do.

I understand that I want my advocate to help decide what care I need, and I want people to listen to her about my care.

If my advocate is not happy with my doctor, then she is able to get another doctor to take care of me.

Isaac T. Baldry

Check with your insurance to see what forms they have, so that someone can assist you in speaking with them.

Link to BlueCross Blue Shield of Montana
<https://www.bcbsmt.com/BlueDocs/AuthForDisclosureOfAnIndHealthInfo.pdf>

Blue Cross and Blue Shield of Montana
Authorization for Disclosure of an Individual's Health Information

Subscriber or Dependent Whose Information is to be Disclosed
 Please print information in this section.

Name _____		Policyholder's Healthcare ID Number _____	
Street Address _____		Daytime Telephone _____	
City _____	State _____	ZIP Code _____	

Person(s) or Entity(ies) to Whom Information May Be Disclosed
 Please print information in this section.

Name _____		Daytime Telephone _____	
Street Address _____		Daytime Telephone _____	
City _____	State _____	ZIP Code _____	

Information to be Disclosed by Blue Cross and Blue Shield of Montana at the request of the individual authorized to do so

Check all that apply.

- Health Plan Benefit Information:** Includes information contained in your benefit booklet (i.e., copayments, coinsurance, eligibility, and other benefit information.)
- Claims Information:** Includes information related to payment of your claims for services you received, including pertinent information located on a claim form (e.g., billed amount, general procedure descriptions, claim payment or denial reasons.)
- Authorization Information:** Includes information regarding pre-certification and authorization, including specific medical information related to requests and determinations.
- Premium Information:** Includes information related to billing cycles, bank draft changes, etc.
- Services from (provider or supplier and date(s)):** _____ from: _____ to: _____
(Includes information related to services rendered by a specific provider or supplier during the specific time period)
- Other:** _____
(Specify other information authorized for disclosure if it is not listed in one of the above categories; please be specific regarding the reason for disclosure)
- Other reason for disclosure (other than "at the request of the individual authorized to do so"):** _____

Length of Time for Which This Authorization is Valid

Under applicable law, this authorization is valid up to 24 months (or a shorter period of time if so indicated) or for a particular event that has occurred, as stated in the authorization. If you are making this authorization for an extended period, the authorization must be renewed after its expiration. This authorization will remain in effect until:

- 24 months from the date of signature of this authorization; or
 - Until _____ but no longer than 24 months from the date of signature.
(Month/Day/Year)
 - All information relating to a certain event or injury has been provided (e.g., "Back injury from April 2002" or "formal research").
 Specify event(s) and approximate date(s) of event(s) _____
- I understand that I may refuse to sign this authorization and that my refusal to sign will not affect my ability to obtain treatment or payment or my eligibility for benefits with BCBSMT. However, there may be consequences with the intended recipient of this information.
 - I understand this authorization is not valid without the required signature.
 - I understand I have the right to revoke this authorization at any time in writing, except to the extent that Blue Cross and Blue Shield of Montana has already provided the information. To revoke this authorization, contact Customer Service at 1-800-447-7828.
 - I understand that the recipient of this information may possibly re-disclose the information to others without my knowledge or authorization; therefore, the privacy law may no longer protect my information.

Print Full Name _____	Signature _____	Date _____
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RELATIONSHIP/AUTHORITY

Please check one. Include documentation with this form for items marked with an asterisk (*) below.

- Member
- Parent of Minor Child
- Power of Attorney*
- Legal Guardian*
- Other Personal Representative Designation*

Office Use Only { Tracking No. _____
 Name: _____

NOTE: The highlighted information is required.

Resources

- **My Health, My Choice, My Responsibility**
- iPad app by AbleLink Technologies, Inc.
- Session titles include:
 - Taking Charge of Your Health
 - Develop a Health Plan
 - Be a Health Self-Advocate
 - Get Moving
 - Eat Right
 - Be Healthy at Home
 - Feel Good about Yourself and Others
 - Stay on Track

<http://itunes.apple.com/us/app/my-health-my-choice-my-responsibility/id428382635?mt=8>

Resources

- **National Health Care Transition Center's Website**

<http://www.gottransition.org/>

- Youth, families, providers, states
- Got Transition Radio Episode 1
 - *Why this, why now – and what does it mean for me?*
 - 9/28/11
 - 1-1:30 Mountain Time

Resources

- **The National Alliance to Advance Adolescent Health**

<http://www.thenationalalliance.org/>

- **When You're 18 - A Health Care Transition Guide for Young Adults**

http://hctransitions.ichp.ufl.edu/pdfs/cms_wy18_lowres_09.pdf

- **Montana Youth Transitions Web Site – Health**

<http://www.montanayouthtransitions.org/index.php?p=health>

Resources

- **Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home**
From the American Academy of Pediatrics Clinical Report
<http://pediatrics.aappublications.org/content/128/1/182.full.html>

- **Montana Parent's Handbook on Transition: Adult Living (PLUK)**
http://www.pluk.org/Pubs/PLUK_Transition_Adult_04_2008.pdf

Resources

- **Six Core Elements of Health Care Transition**
from Got Transition? National Health Care Transition Center, Center for Medical Home Improvement
http://www.gottransition.org/UploadedFiles/Files/SixCoreElementsHCT_6_11.pdf

- **Making the Move to Managing Your Own Personal Assistance Services (PAS): A Toolkit for Youth with Disabilities Transitioning to Adulthood**
<http://www.ncwd-youth.info/PAS-Toolkit>

Questions?



- <http://ruralinstitute.umt.edu/transition/>
- <http://transition-toolbox.pluk.org/>