

Empowering Youth to be Independent

What Families Can Do

Family & Youth Retreat, Wichita, KS
March 2011

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Leeds Maine

**Got Transition? National Healthcare
Transition Center**



Outcomes:

- Transition- and how **health** effects all aspects of life.
- How families can empower youth to be independent
- Small ways to move forward. Progress is possible

Health is Critical to School Success & Sustaining Employment

- Success in the classroom, in the community, and on the job requires that young people are healthy. (performance and productivity)
- Young people with life-long health issues need to learn early how to maintain and sustain health and wellness -- and to participate in their health care decisions.

Outcome #6: Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work and independence

-- CSHCN ages 12-17 only (derived)

Outcome not achieved	Outcome successfully achieved
- 58.8	+ 41.2



Opening Doors to a Healthy Future

Welcome to the National Health Care Transition Center's Website

Got Transition? If not, we can help! Our new, updated, website will soon have all of the tips and tools you need to get to **Yes! — Yes!** Youth can navigate towards the care and services needed in adulthood. **Yes!** Families can anticipate and plan to support their youth's independence. **Yes!** Pediatric and adult primary care and specialty care teams can assess transition needs and support a seamless and coordinated transfer to adult care.

Click here for more information about what Got Transition provides.

NOW FEATURING...



Learning Collaboratives

Primary and specialty health care teams in Washington DC, Denver and Boston are working with youth and families to implement best health care transition



Assisting Youth and Families with Health Care Transition.

HOT TOPICS & NEWS...

[FOLLOW US >](#)

Transition — What's the Status of the States?

Check out your state's progress on health care transition in Got Transition's new report, [Health Care Transition for Youth with Special Health Care Needs](#).

Register now for the March 23 Got Transition webinar featuring this report.

[About CMHI >](#)

[Contact Us >](#)

What is Transition?

- According to Webster:
 - Passage from one state, stage, subject or place to another.

Other Components

- Self-Determination
- Person Centered Planning
- Prep for Adult health care
- Work /Independence
- Inclusion in community life

What is Health Care Transition?

Transition is the deliberate, coordinated provision of developmentally appropriate and culturally competent health assessments, counseling, and referrals.



Comments From Young Adults

- **Youth Voice:** Youth voice is valuable and needs to be heard.
- **Dignity & Respect:** Understand that people with disabilities have a lot to contribute in the work environment.

- **Eliminate discrimination:** Make the community disability friendly
- **Knowledge:** Help us to know what is available, make sure youth/young adults know how to advocate for themselves. When parents have done all for them, they don't know what to do.

There is no one size fits all...



Transition does not discriminate!



Advocacy Begins at Home

- Knowing wellness baseline, Dx, being able to explain to others.
- Role in the household (chores, responsibilities)
- Speaking up at school.
- Having friends, being involved in activities

TOOL: Promote Individual

- **Families**
 - protective
- **Children / Youth**
 - being visible
 - community aware

***** be in charge
of something**

Simple ActsBIG Returns

Role in the family

- **Grocery Store**
- **Nightly Charge Wheelchair**
- **Get Family Mail /sorting**
- **Medications – pill box**
- **3 indicators on Rx bottle**

ADD NAME
Add Mailing Address
Email, home phone, cell phone

INSURANCE	BlueCross BlueShield of Mass	Primary	Subscriber Name and # XXX-XX-XXXX BC/BS PPO Plan Code 200	
		Secondary	Customer Service: 800-296-xxxx Subscriber Name and # XXX-XX-XXXX BC/BS Blue Choice Plan 2, POS Code 200, Customer service: 800-222-xxxx	

Legal Health POA *	Name	Relationship	C XXX-XXX-XXXX	W XXX-XXX-XXXX	H XXX-XXX-XXXX
	Name	Name	C XXX-XXX-XXXX	H XXX-XXX-XXXX	W XXX-XXX-XXXX

DOB 05-24-1973
SS# XXX-XX-XXXX

HEIGHT/WEIGHT: 4' 3", 80 lbs
BLOOD TYPE: A positive

DNR SIGNED: No
ADVANCED DIRECTIVES: Yes
ORGAN DONOR: No

- **High intelligence** (130 IQ), compliant patient, high tolerance to pain
- Incomplete Quad (has sensation), only movement left index finger 10 cm
- Need to explain EVERY procedure, when possible, ask for consent prior to doing
- **If unable to talk => one blink = yes / two blinks = no** - Read his lips - OR - letter/word board to direct his care.

ALLERGY: Sulfa, Adhesive Tape

HEALTH ISSUES		
Neuro Muscular	ICD-9 359 MD 335.1 SMA	Spinal Muscular Atrophy Type 2, dx age 9mos, 3/74 (Severe Anterior Horn Cell disease/Werdnig-Hoffman) Incomplete quad (has full sensation), no functional movement
Pulmonary	ICD-9 V44 Trach 518.81 Resp Failure 486 Pneumo Org NOS	Respiratory failure - trach and vent (9/01), Chronic RLL Atelectasis Recurrent pneumonia, Respiratory insufficiency, poor residual functions/reserved capacities, Elective Trach 3/82 for Ortho Surgery

MEDICATIONS			HERBS / DROPS	VENT - Pulmonetic LTV 900
<u>Rx DAILY</u>			1. Lymphatic 5 x2	Breaths 05
1. Alprazolam (xanax)	0.5 mg QID	anxiety	2. Flu Balancing 10 x2	Tidal Volume 310
2. Aspirin-Child	81 mg 1 x	prevent clots	3. Respiratory 7 x2	Inspiration 1.1
3. Temazepam	15 mg H.S	sleeping pill	4. Allertox -airborne 5 x2	Pressure Support 13
4. DuoNeb	1 vial QID	nebulizer	5. " " Aleer-Total 3 x3	Sensitivity 02
(Ipratropium, Bromide & Albuterol)			6. " " Allerdrain 10 x4	High 40
			7. Immune 6 x2	Low 02
			8. Acute Rescue 5 x2	TRACH: Shiley 6 cuffed (deflated)
			9. Urinary 8 x2	
			10. Digestive 3 x2	SPEAKING VALVE: Passy-Muir
			11. Mucous 5 x2	PMV007
			12. Cell 7 x2	
			13. Muscular 4 x2	OXYGEN 1.5 liters
			14. Integumentary 8 x2	
			15. Er Cheng Tang 1 tsp x2	
<u>Rx MONTHLY</u>				
1. Thiamine	100 mg monthly	vitamin		
2. Cyanocobalamin	1000 mcg/ml monthly (B12)			
<u>Rx PRN</u>				
1. Darvocet-N		pain		
2. Zithromax SUS PFIZ	200/5ml 45ml	antibiotic		
3. Diphnoxyllate/atropine	1-2 tablets	diarrhea		

MEDICAL HISTORY		
GI	SURGERY	Decreased esophageal motility, s/p feeding
	ICD-9 V44.1	Gastrostomy tube, Foley 24Fr Age 10, 7/83, Cincinnati Children's Hospital: Dr. Martin
Ortho	ICD-9 737.4	Severe deformities: thoracic, pelvic obliquity, bilateral dislocated hips,
	ICD-9 754.89	flexion contractures, pectus excavatum
	ICD-9 754.81	
	SURGERY	
	ICD9- 81.0	Spinal fusion /Lueke Rod Age 9, 3/82, Cincinnati Children's Hospital: Dr. Alvin Crawford
Urological	ICD-9 752.51	Undescended L testicle (since birth), Kidney Stones (3/79, 6/90); IVP (6/90)
	753.3, V13.02	Intermittent cath: Age 28, 10/01, cath: 10 Fr
	SURGERY	
	ICD9- 752.51	Cystoscopy/left ureteral stent, Age 28, 10/01
Other	SURGERY	IV: Porta Cath (10/24/01) RIS right clavicle (PC 0603880 - lot 36HI124)

IMMUNIZATIONS						
Tetanus '85	TB '78, '87	Pneumococcal vaccine '79, '01	Flu '02	Mumps '74	Measles '74	DPT '73, '79
PHYSICIANS						
INTENSIVIST	Melvin XXXX, MD	XXX-XXX-XXXX	XXXXXXXX, Ocala, FL	34482		
ACUPUNCTURE	Barbara XXXXX RN, AP	XXX-XXX-XXXX	XXXXXXXX, Ocala, FL	34482		
PULMONOLOGIST	Robert xxx XXXXX MD	XXX-XXX-XXXX	XXXXXXXX, Gainesville, FL	32608		
OTHER						
BC/BS Case Manager	Debra XXXXXXX	800-392-xxxx	XXXXXXXX, Ocala, FL	34482		
Rx-Pharmacy	Bitting's	352-732-xxxx	XXXXXXXX, Ocala, FL	34482		
Dental	Yvette Gaya, DMD	352-xxx-xxxx	XXXXXXXX, Ocala, FL	34482		

Handout: **Portable Medical Summary**

Carry in your wallet

Good Days

- *Cheat Sheet:* **Use as a reference tool**
- **Accurate medical history**
- **Correct contact #s**
- **Document disability**

Health Crisis

- **Expedite EMS transport & ER/ED care**
- **Paper talks when you can not**

Health & Transitions: YOU & Your Child

- HANDOUT: Changing Roles
- **Fears & Anxiety**
- **1 new step at a time strategies**

Carry & Present Health Insurance Card	1	2	3	4	5
YOU					
YOUR CHILD					
YOUR STUDENT					

Finding the Balance:

- Balance between childhood-
 - vs. growing up- taking responsibility

When there is the need to know and do/take action.

- Learning decision making
 - learning from parent
 - trial with monitoring support
 - trial effort: solo then reassess needs and kudos what's happening

FAMILIES: Prepare for Changing Roles

- **Temporary spokesperson on behalf of minor child**
(until age 18, or declared by the court)
 - 2 voices to be heard: families and CY
 - Circle of Support
 - Assent to Consent

handout: *Changing Roles*

Skills	Before 10	Before 18
• Carry and present insurance card	X	
• Know wellness baseline, Dx, Meds	X	X
• Make own Doctor appts	X	
• Call in Rx refills		X
• Learning Choice	X	
• Decision making (assent to consent)		X
• Prepare for Doc visit: 5 Qs	X	X
• Present Co-pay	X	X
• Assess: Insurance, SSI, VR		X
• Gather disability documentation		X

Informed Decision Makers

FERPA Family Education Rights & Privacy Act

HIPAA Health Insurance Portability and
Accountability Act

1. Privacy → Records

2. Consent → Signature (signature stamp)

- Assent to Consent
- Varying levels of support
- Stand-by (health surrogate)
- Guardianship (limited to full)

Maintaining Health Insurance

Mandates:	ME
Private Insurance	
- Extended the age of dependent coverage (age 25)	Y
- Adult disabled dependent coverage	Y
- Qualified Medical Child Support Order (QMCSO) ERISA-covered health plan to provide health benefits coverage to children by issuing a medical child support order	Y
-Divorce Decree, Support - Adult Disabled Children 18 states DO NOT have mandate: AL, CT, DC, KS, ME, MI, MA, MI, MT, NE, NH, NJ, RI, SD, TN, VT, WV, WI	Y
Public Insurance	
-Medicaid automatic with SSI 209 B states NOT automatic: CT, HI, IN, IL, MN, MO, ND, NH, OK, OH, and VA	Y

“No” is not because of YOU

- **"No" response - limited vision, or negative past experience.**
- **"No" is just the 1st answer - get more info or justification why they should say yes-**
- **Who has the authority to say YES.**

Surround Yourself with Positive People

- **Being a “Change Agent” takes time and energy.**
- **Feelings may be bruised, and hearing “no” gets discouraging.**
- **Creative thinkers help with other options -- encourage the dialogue until the problem is resolved**

Imagine the Possibilities....





Transition:

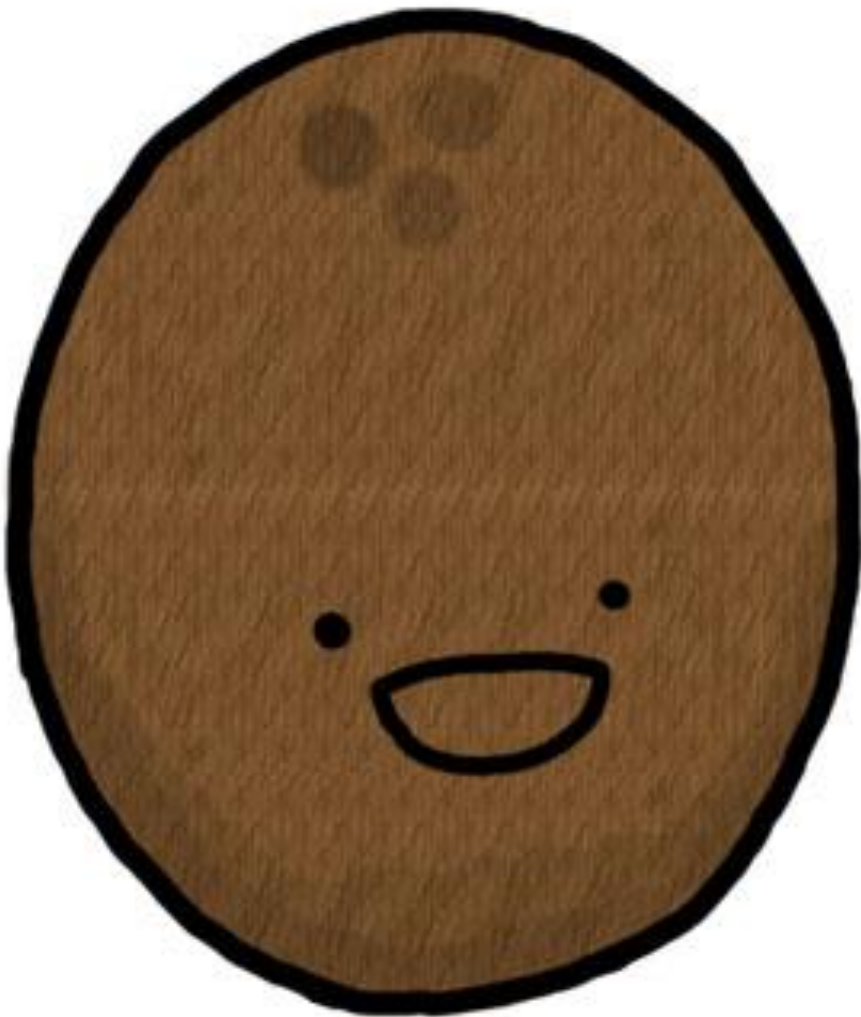
Remember the 3 A's

- Achievements (Accomplishments)
- Abilities
- Aspirations!!!!

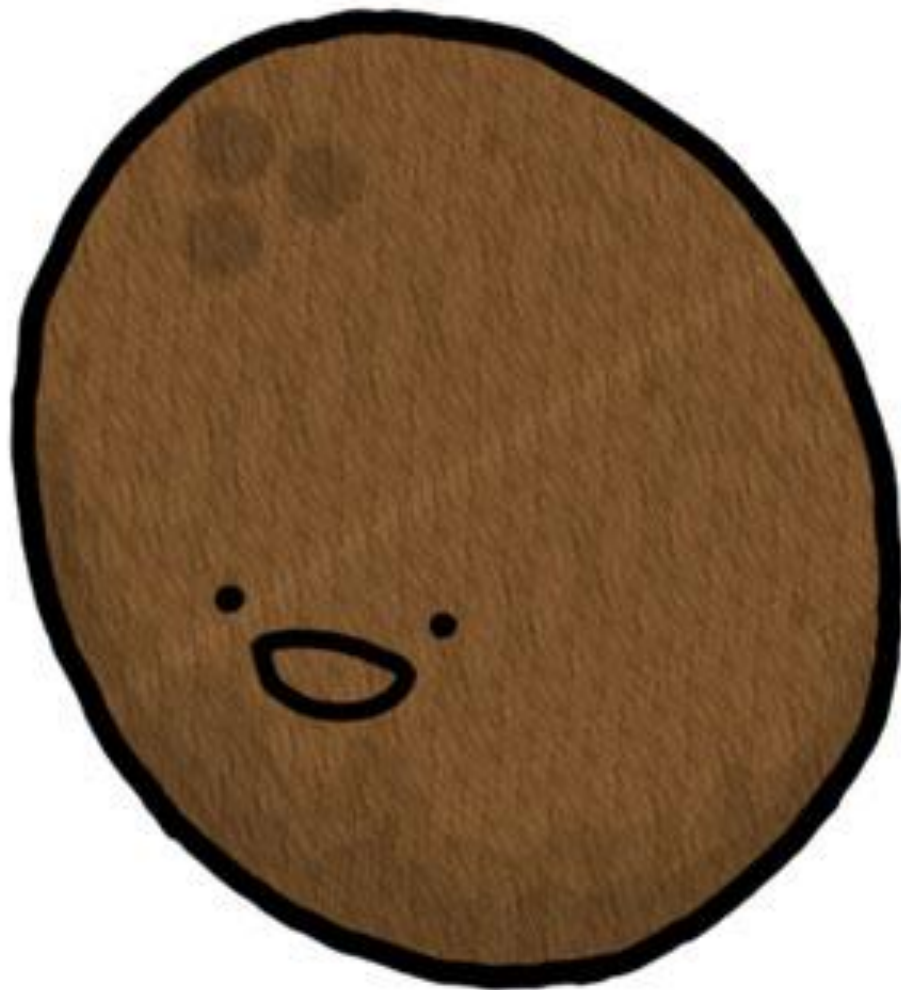
Questions to Ask:

- What classes are your favorites?
- What are you good at?
- What do you ENJOY doing?
- What are YOUR goals?
- What do you WANT to do?

i'm gonna be a
piña colada!



i'm gonna be
a bra!





Growing Up: Ready to Have Fun!

Putting LIFE

on the front burner

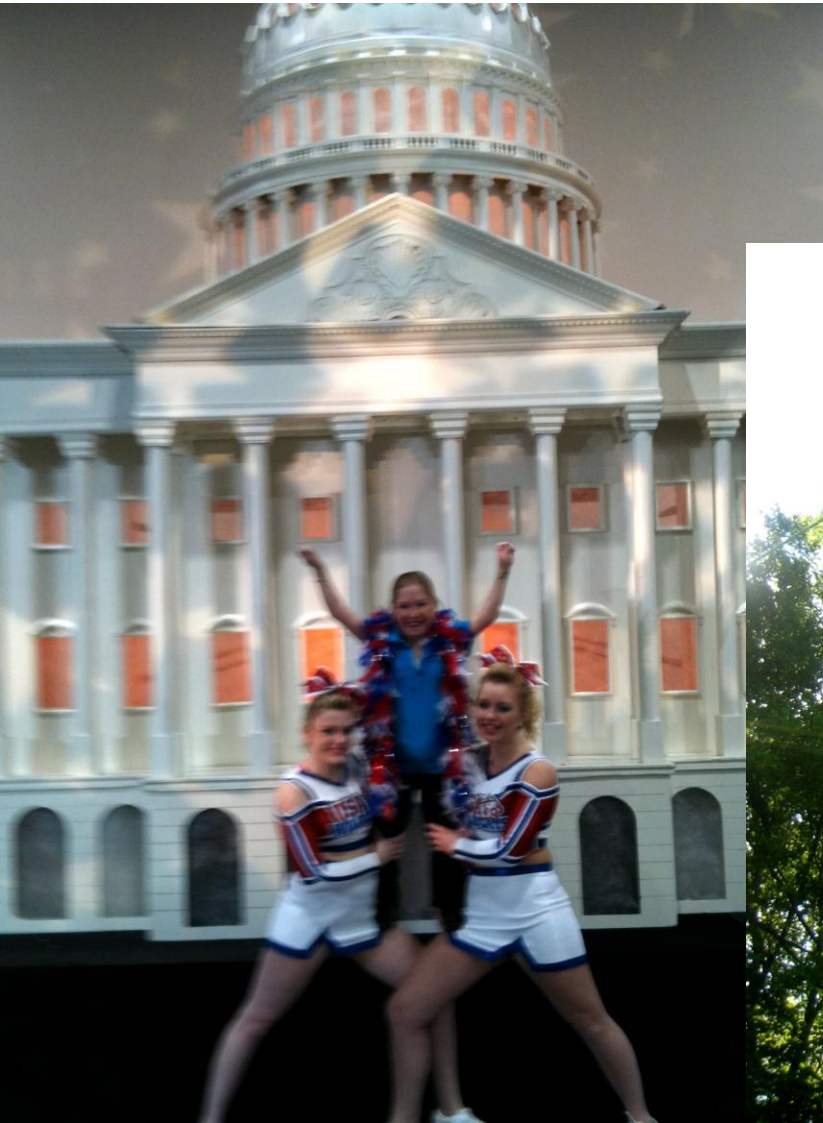
& the Dx

on the back burner



Not “can we”
but “how do we”

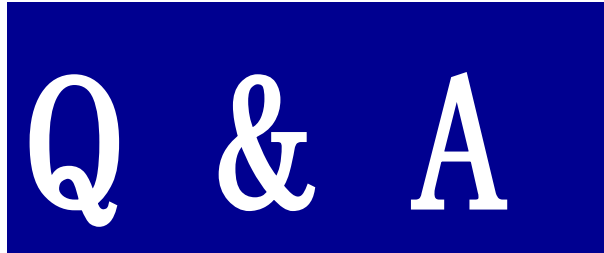
Growing Up, ready to take risks...



Action Plan	I Did It!
<p>7 days - Step 1:</p> <ul style="list-style-type: none"> In one week I will commit to do..... 	
<p>30 days - Step 2:</p> <p>By next month I will commit to do.....</p>	
<p>90 days - Step 3:</p> <p>In three months I will commit to do.....</p>	

Transition is a Journey...





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