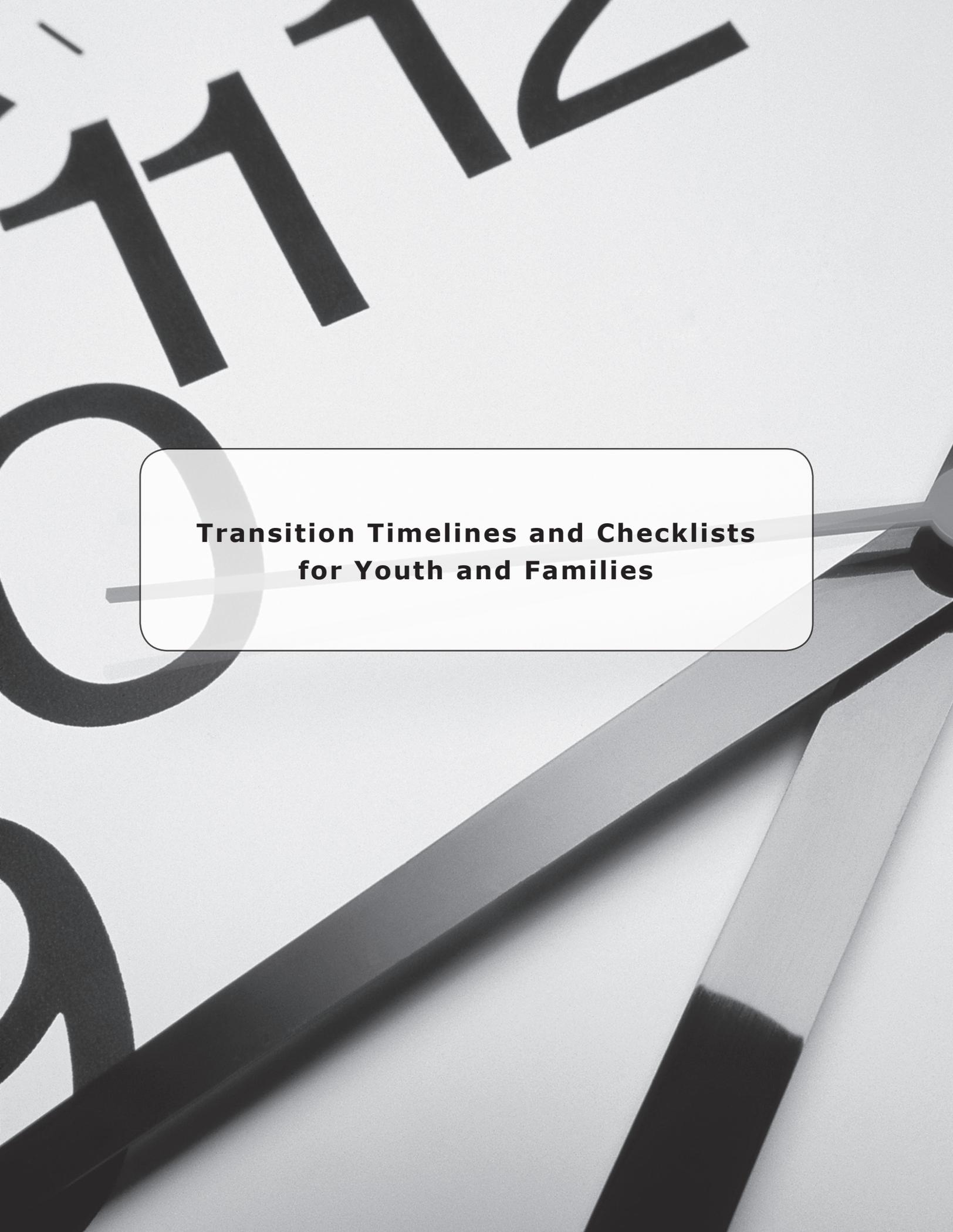


# **Health Care Transition Toolkit for Families of YSHCN**





The background features large, bold, black letters, possibly spelling 'TRANSITION', which are partially cut off by the edges of the page. A ruler is visible in the lower right corner, showing a scale in inches. The overall aesthetic is clean and professional.

**Transition Timelines and Checklists  
for Youth and Families**





www.hrtw.org

## Transitions - Changing Role for Youth

<b>Health &amp; Wellness 101 The Basics</b>	<b>Yes, I do this</b>	I want to do this	I need to learn how	Someone else will have to do this - Who?
1. I understand my health care needs, and disability and can explain my needs to others.				
2. I can explain to others how our family's customs and beliefs might affect health care decisions and medical treatments.				
3. I carry my health insurance card everyday				
4. I know my health and wellness baseline (pulse, respiration rate, elimination habits)				
5. I track my own appointments and prescription refills expiration dates				
5. I call for my own doctor appointments				
7. Before a doctor's appointment I prepare written questions to ask.				
8. I know I have an option see my doctor by myself.				
9. I call in my own prescriptions				
10. I carry my important health information with me everyday (i.e.: medical summary, including medical diagnosis, list of medications, allergy info., doctor's numbers, drug store number, etc.)				
11. I have a part in filing my medical records and receipts at home				
12. I pay my co-pays for medical visits				
13. I co-sign the "permission for medical treatment" form (with or without signature stamp, or can direct others to do so)				
14. I know my symptoms that need quick medical attention.				
15. I know what to do in case I have they have a medical emergency				
16. I help monitor my medical equipment so it's in good working condition (daily and routine maintenance)				
17. My family and I have a plan so I can keep my healthcare insurance after I turn 18.				



www.hrtw.org

## Transitions - Changing Role for Families

<b>Health &amp; Wellness 101</b> <b>The Basics</b>	<b>Yes,</b> <b>my</b> <b>child/</b> <b>youth</b> <b>can do</b> <b>this</b>	<b>I want</b> <b>my</b> <b>child/</b> <b>youth</b> <b>to do</b> <b>this</b>	<b>I need</b> <b>to learn</b> <b>how to</b> <b>teach my</b> <b>child/</b> <b>youth</b>	<b>Someone else</b> <b>will have to do</b> <b>this for my</b> <b>child/youth</b>  <b>Who?</b>
1. My child/youth understands his/her health care needs, and disability and can explain needs to others.				
2. My child/youth can explain to others how our family's customs and beliefs might affect health care decisions and medical treatments.				
3. My child/youth carries his/her health insurance card with him/her				
4. My child/youth knows his/her health and wellness baseline (pulse, respiration rate, elimination habits)				
5. My child/youth tracks appointments and prescription refills expiration dates				
6. My child/youth call to make his/her own doctor appointments				
7. Before a doctor's appointment my child/youth prepares written questions to ask.				
8. My child/youth is prepared to see the Doctor by him/her self.				
9. My child/youth orders his/her own prescriptions				
10. My child/youth carries his/her important health information everyday (i.e.: medical summary, including medical diagnosis, list of medications, allergy info., doctor's / drug store numbers, etc.)				
11. My child/youth helps file medical records and receipts at home				
12. My child/youth pays co-pays for his/her medical visits				
13. My child/youth co-signs the "permission for medical treatment form" (with or without signature stamp, or can direct others to do so)				
14. My child/youth knows his/her symptoms that need quick medical attention.				
15. My child/youth knows what to do if they have a medical emergency				
16. My child/youth knows how to monitor medical equipment so it's in good working condition (daily and routine maintenance)				
17. My child/youth and I have discussed a plan so they will continue to have insurance after they turn 18.				

# Children’s Special Health Care Services Transition Timeline for Youth and Families

## Age 14-16

- According to developmental ability youth can begin to:**
- Develop knowledge of their special health care needs
  - Take responsibility in making appointments and getting prescriptions refilled
  - Explore appropriate work and volunteer opportunities
  - Talk to medical providers about age appropriate information such as, physical, emotional, and sexual development

- According to their child’s needs, parents can begin to:**
- Make arrangements for the steps above if child is unable to be independent
  - Keep a health record for youth. Include all medical paperwork
  - Explore options of transition planning through the local school district
  - Explore the eventual need to transfer your child’s care to adult providers

## Age 16-18

- According to developmental ability youth can begin to:**
- Take responsibility in making appointments and getting prescriptions refilled
  - Contact Michigan Rehabilitative Services (MRS) to explore vocational assistance if needed
  - Attend all meetings where future plans are discussed (school IEPs or doctor’s office)
  - Research adult health care providers for transfer of medical care
  - Explore employment opportunities
  - Explore living arrangements

- According to their child’s needs, parents can begin to:**
- Make arrangements for the steps above if child is unable to be independent
  - Explore options for health care coverage
  - Check eligibility for SSI from the Social Security Administration
  - Research adult health care providers for transfer of medical care
  - Explore the option of legal guardianship or the many alternatives to guardianship if child’s special needs interfere with the ability to make financial and medical decisions

## Age 18-20

- According to developmental ability young adult can begin to:**
- Complete a CSHCS financial assessment. At age 18 only young adult’s income is reviewed
  - Take responsibility for signing all CSHCS materials
  - Finalize health care coverage as an adult
  - Transfer medical care from pediatric providers to adult providers
  - Check eligibility for SSI from the Social Security Administration
  - Contact Michigan Rehabilitative Services (MRS) to explore vocational assistance if needed
  - Contact the disability student services office if attending college and accommodations are needed
  - Explore employment opportunities

- According to their child’s needs, parents can begin to:**
- Make arrangements for the steps above, if young adult is unable to be independent
  - Complete and submit a release of information signed by young adult if parent/caregiver would like to participate in their care
  - Provide documentation of legal guardianship to all providers if needed

## Age 20-21

- According to developmental ability young adult can begin to:**
- Explore living arrangements. If assistance is needed contact the nearest Center for Independent Living
  - Learn about and continue to investigate adult services there may be need for
  - Investigate possibility of enrolling in a Medicaid Health Plan at 21 if currently enrolled in Medicaid
  - Transfer all medical care from pediatric providers to adult providers
  - Explore employment opportunities

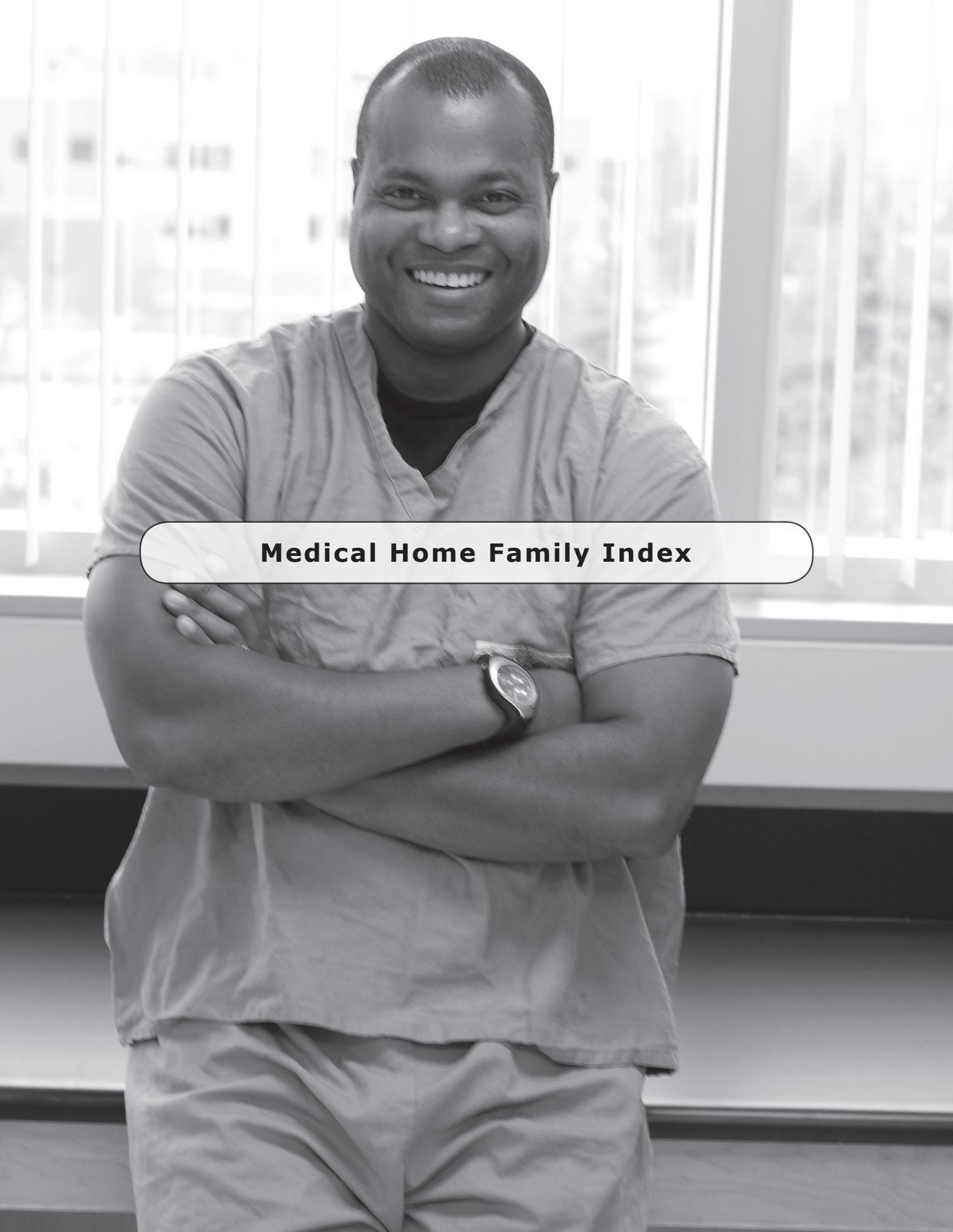
- According to their child’s needs, parents can begin to:**
- Make arrangements for the steps above, if young adult is unable to be independent
  - Complete and submit a release of information signed by young adult if parent/caregiver would like to participate in their care
  - Explore private duty nursing options if young adult is receiving in-home nursing. Young adult must qualify for and enroll in an adult Medicaid waiver program to continue nursing services as of age 21

Transition to Adult Services

Transition to Adult Services

Transition to Adult Services



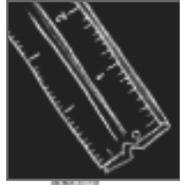
A black and white photograph of a man in his 30s or 40s, smiling broadly. He is wearing light-colored medical scrubs and has his arms crossed. He is standing in front of a large window with vertical blinds, through which a cityscape is visible. A watch is visible on his left wrist. A white rounded rectangular box is superimposed over his chest, containing the text 'Medical Home Family Index'.

**Medical Home Family Index**





Center for  
Medical Home  
Improvement



## THE MEDICAL HOME FAMILY INDEX:

### Measuring the Organization and Delivery of Primary Care For Children with Special Health Care Needs

A community-based primary care “medical home” is a health care practice in your community that is completely responsive to you and your child’s needs. This is especially so when your child has a chronic health condition or disability. A group at the Hood Center for Children and Families at Children’s Hospital at Dartmouth Hitchcock Medical Center (New Hampshire) has been asked to create a Medical Home Index to find out about the medical “homeness” of a health care practice or office.

Your child’s primary care provider fills out The Medical Home Index; this set of questions looks at the care activities that make the medical home “come alive” in practice. Health care providers will rate the care that they offer to children with special health care needs and their families. They will comment on how they partner with families in their children’s care and provide care coordination and other needed supports.

No questionnaire truly captures the medical “homeness” of a practice unless information is gathered from families. You are being asked to fill out this Medical Home Family Index and to report on the services and supports that your child actually receives. The Medical Home Family Index uses twenty-five questions to capture the family perspective, please try to answer each question to the best of your ability. Thank-you for your willingness to complete this set of questions and for your thoughtful comments written at its end.

Please turn to the next page . . .



## THE MEDICAL HOME FAMILY INDEX:

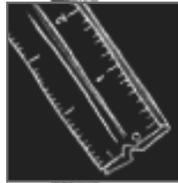
### Measuring the Organization and Delivery of Primary Care For Children with Special Health Care Needs

The following questions refer to the care that your child receives from his/her pediatrician or primary care provider (PCP) and the staff who work in their office. Next to each question circle the response that best describes your experience of care for your child.

	Never	Sometimes	Often	Always
1. Through this practice/office I can get the health care that my child needs when we need it (including after office hours, on weekends and holidays).	Never	Sometimes	Often	Always
2. When I call the office: (please answer for a, b, c, and d): a) Staff know who we are b) Staff respect our needs and requests c) Staff remember any special needs or supports that we have asked for d) We are asked if there are any new needs requiring attention	Never Never Never Never	Sometimes Sometimes Sometimes Sometimes	Often Often Often Often	Always Always Always Always
3. My primary care provider (PCP) uses helpful ways to communicate (e.g. explaining terms clearly, helping us prepare for visits, e-mail, or encouraging our questions): a) With me b) With my child (If (b) does not apply to your child ✓ here ____)	Never Never	Sometimes Sometimes	Often Often	Always Always
4. My PCP asks me to share with him/her my knowledge and expertise as the parent or caregiver of a child with special health care needs (CSHCN).	Never	Sometimes	Often	Always
5. I am asked by our PCP how my child's condition affects our family (e.g. the impact on siblings, the time my child's care takes, lost sleep, extra expenses, etc.).	Never	Sometimes	Often	Always
6. My PCP listens to my concerns and questions?	Never	Sometimes	Often	Always
7. Planning of care for my child includes: (please answer for a, b, c and d): a) The writing down of key information (e.g. recommendations, treatments, phone #) b) Setting short term goals (e.g. for the next three months) c) Setting long term goals (e.g. for the next year or more) d) Thorough follow-up with plans created	Never Never Never Never	Sometimes Sometimes Sometimes Sometimes	Often Often Often Often	Always Always Always Always
8. My primary care provider and staff work with our family to create a written care plan for my child. (If your answer is "never", then skip to Question # 11)	Never	Sometimes	Often	Always



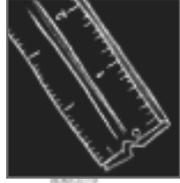
## Center for Medical Home Improvement



	Never	Sometimes	Often	Always
9. I receive a copy of my child's care plan with all updates and changes.	Never	Sometimes	Often	Always
10. My primary care provider (PCP) and his/her office staff (please answer a, b and c): a) Use and follow through with care plans they have created b) Use a care plan to help follow my child's progress c) Review and update the care plan with me regularly	Never Never Never	Sometimes Sometimes Sometimes	Often Often Often	Always Always Always
11. My PCP has a staff person(s) or a "care coordinator" who will: a) Help me with difficult referrals, payment issues, and follow-up activities b) Help to find needed services (e.g. transportation, durable equipment or home care) c) Make sure that the planning of care meets my child and my families needs d) Help each person involved in my child's care to communicate with each other (with my consent).	Never Never Never Never	Sometimes Sometimes Sometimes	Often Often Often	Always Always Always
12. When or if I ask for it, our PCP or office staff help me to: a) Explain my child's needs to other health professionals b) Get my child's school, early care providers or others to understand his/her condition (if (b) does not apply to your child ✓ here ___)	Never Never	Sometimes Sometimes	Often Often	Always Always
13. Someone at the office is available to review my child's medical record with me when or if I ask to see it.	Yes		No	
14. Office providers or staff who are involved with my child's care know about their condition, history, and our concerns and priorities.	Yes		No	
15. My PCP or his/her office staff sponsor activities to support my family (e.g. support groups, parent skill building or how to support other parents).	Yes		No	
16. Office staff help me to connect with family support organizations and informational resources in our community and state.	Yes		No	
17. My PCP is a strong advocate for the rights and services important to children with special health care needs and their families.	Yes		No	
18. My PCP assists me in finding adult health care services for my child. (Check here if due to your child's age this does not apply ____).	Yes		No	



## Center for Medical Home Improvement



19. My primary care provider (PCP) and office staff organize and attend team meetings about my child's plan of care that include us and outside providers (when needed).	Yes	No
20. My PCP and office staff organize and attend events to talk about concerns and needs common to all children with special health care needs (CSHCN) and their families.	Yes	No
21. I have seen changes made at the office as a result of my suggestions or those made by other families.	Yes	N
22. I know the practice has conducted surveys, focus groups, or discussions with families (in the last two years) to determine if they are satisfied with their children's care.	Yes	No
23. From my experience, I believe that my PCP and the staff at his/her office have a commitment to provide the quality care and family supports that we need.	Yes	No
24. The behavior which best demonstrates the needed care and compassion I need from my child's PCP is _____ (write in here).	Comments:	
25. The frequency that I observe and experience this behavior (in #24) is?	Never	Often
	Sometimes	Always

5

*Would you please go back over this Family Index to check for unanswered questions; try to answer them to the best of your ability. Please write down:*

The name of the practice where you go for your child's care: \_\_\_\_\_

The name of your child's primary care provider: \_\_\_\_\_

The length of time your child has been cared for by this practice? \_\_\_\_\_ Your child's age: \_\_\_\_\_

Your name, address, & social security #: \_\_\_\_\_

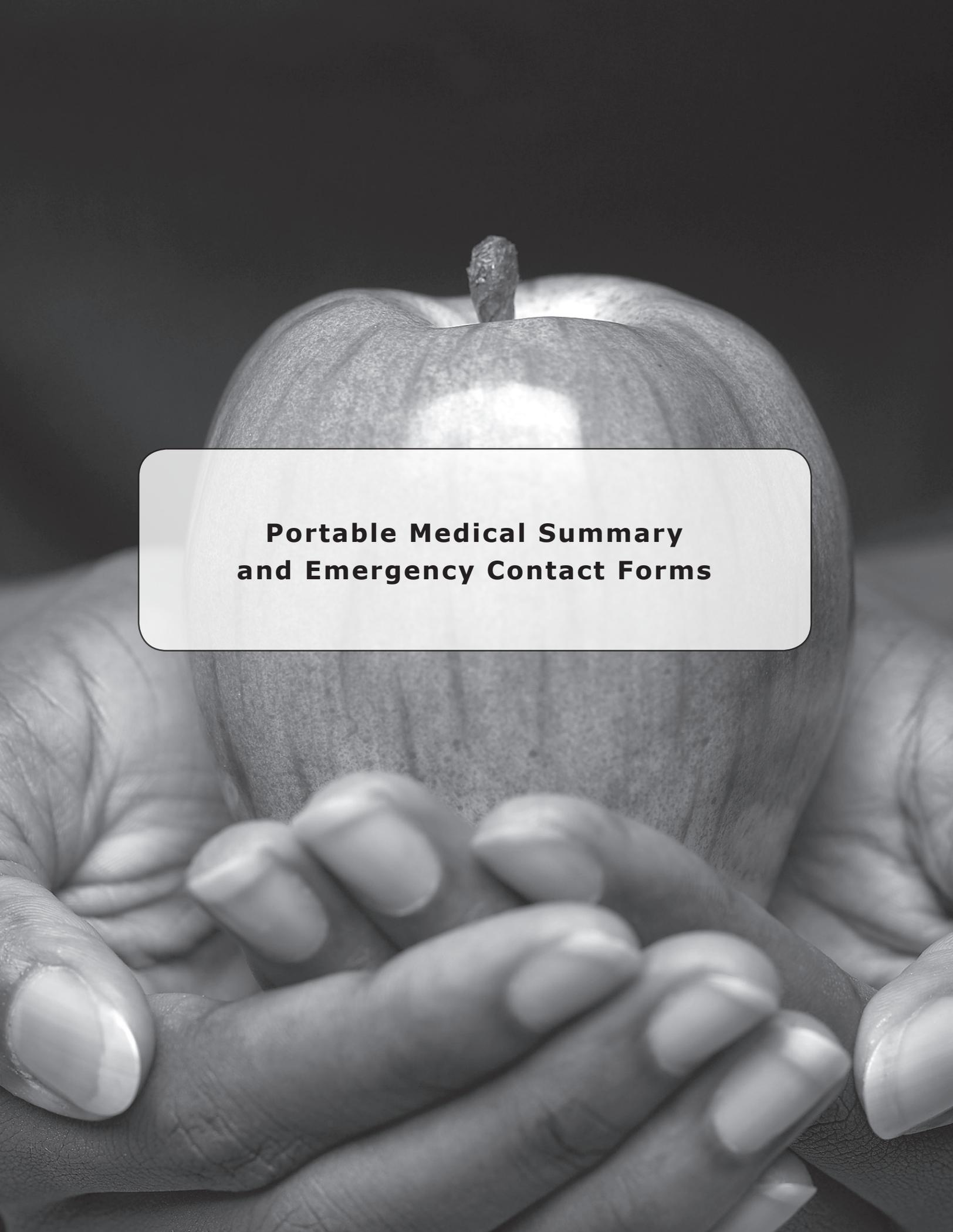
Address: \_\_\_\_\_ SS# \_\_\_\_\_

**(Optional)** What is the racial/ethnic background with which you most closely identify?

White, Non-Hispanic  African American  Hispanic  Native American/American Indian/Alaskan Native  Asian  Other (specify)

May we have your permission to contact you further about this project?  Yes  No

Other comments you would like to make? (Feel free to use the other side) \_\_\_\_\_ *Thank You for Sharing Your Experiences*

A grayscale photograph of a hand holding an apple. The hand is positioned at the bottom, with fingers gently cupping the base of the apple. The apple is the central focus, showing its stem and textured skin. A white rounded rectangle is overlaid on the center of the image, containing the text.

**Portable Medical Summary  
and Emergency Contact Forms**



**NAME**

Address, Home Phone, Cell Phone, Email

DOB 5/24/73 SS# 289-XX-XXXX

ALLERGY: Sulfa Drugs, Adhesive Tape

- 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.

PRIMARY DIAGNOSIS: AGE: 30 HEIGHT 4'3" (51inches) WEIGHT 80lbs approx

- NEURO/MUSCULAR** Spinal Muscular Atrophy Type 2 (Severe Anterior Horn Cell disease, dx 3/74)  
359 Muscular Dystr/335.1 SMA incomplete quad (has full sensation), no functional movement
- RESPIRATORY** Respiratory failure - trach and vent (9/01), Chronic RLL Atelectasis, Recurrent pneumonia  
V44 Trach, 518.81 Resp Failure Respiratory insufficiency, poor residual functions/reserved capacities  
486, Pneumo Org NOS
- GASTRO** Decreased esophageal motility, s/p feeding gastrostomy tube (7/83)  
V44.1 Gastro Status
- ORTHOPEDIC** Severe deformities: thoracic, pelvic obliquity, bilateral dislocated hips, flexion contractures  
737.4, 754.89, 754.81 spinal fusion (3/82 Lueke Rod), pectus excavatum
- UROLOGICAL** Undescended L testicle (since birth), intermittent cath (10/01), cath: 10 Fr,  
752.51 Cystoscopy/left ureteral stent (10/01), IVP (6/90)
- BLOOD TYPE** A + (positive)
- SPECIAL NOTES** IV: Porta Cath (10/24/01) RIS right clavicle (PC 0603880 - lot 36HI124)

**MEDICAL**

**ACUPUNCTURE PHYSICIAN**  
Barbara XXXXX RN, AP, Ocala, FL  
O: 352-xxx-xxxx

**HOSPITAL** North FL Regional Medical Center, Gainesville, FL  
4/95, 1/97, 5/01, 9-10/01

**INTENSIVIST:** Melvin XXXX, MD, Ocala, FL  
O: 352-622-xxxx

**IMMUNIZATIONS** Flu 02 Pneumo 79, 01 Tetanus 85  
DPT 73, 79 Measles 74 Mumps 74  
TB 78, 87

**PULMONOLOGIST:** Robert xxx MD, Gainesville, FL  
O: 352-xxx-xxxx Bpr: 352-xxx-xxxx

**ENTERAL** Pulmocare 237ml x 2 cans, nocturnal, 70 ml/hr

**MEDICATIONS**

- Rx DAILY**
- Alprazolam (xanax) 0.5 mg QID anxiety
  - Aspirin-Child 81 mg 1 x prevent clots
  - Temazepam 15 mg H S sleeping pill
  - DuoNeb 1 vial QID nebulizer  
(Ipratropium, Bromide & Albuterol)

**HERBS / DROPS**

- Lymphatic 5 x2
- Flu Balancing 10 x2
- Respiratory 7 x2
- Allertox -airborne 5 x2
- " " Aleer-Total 3 x3
- " " Allerdrain 10 x4
- Immune 6 x2
- Acute Rescue 5 x2
- Urinary 8 x2
- Digestive 3 x2
- Mucous 5 x2
- Cell 7 x2
- Muscular 4 x2
- Integumentary 8 x2
- Er Cheng Tang 1 tsp x2

**VENT / TRACH / O2**

VENT - Pulmonetic LTV 900  
Breaths 05  
Tidal Volume 310 Inspiration 1.1  
Pressure Support 13  
Sensitivity 02  
High 40  
Low 02  
TRACH: Shiley 6 cuffed (deflated)  
SPEAKING VALVE: Passy-Muir PMV007  
OXYGEN 1.5 liters

- Rx MONTHLY**
- Thiamine 100 mg monthly vitamin
  - Cyanocobalamin 1000 mcg/ml monthly (B12)

- Rx PRN**
- Darvocet-N pain
  - Zithromax SUS PFIZ 200/5ml 45ml antibiotic
  - Diphnoxylate/atropine 1-2 tablets diarrhea

**INSURANCE**

BlueCross BlueShield of Massachusetts  
**Primary Subscriber:** xxxxx xxxxx  
BC/BS PPO Plan Code 200  
Customer service: 800-296-xxxx  
XXP XXXXXXXX 10 PPO

BlueCross BlueShield of Massachusetts  
**Secondary Subscriber:** xxxxx xxxxx  
BC/BS Blue Choice Plan 2, POS Code 200  
Customer service: 800-222-xxxx  
XX XXXXXXXX 10

HEALTH SURROGATE Pxxxx Hxxxxx (mother) c 352-xxx-xxxx h 352-xxx-xxxx

**BC/BS Case Manager** Debra XXXXXXXX 800-392-xxxx ext. xx  
**Health Vendor** Option Care 800-825-xxxx 352-373-xxxx acc't. # xxxxx  
**Home Nursing Agency** House Calls 352-xxx-xxxx acc't. # xxxxx  
**Pharmacy** Bitting's 352-732-xxxx

<b>NAME</b>			
Address, Home Phone, Cell Phone, Email			
DOB	SS#	Allergy	DNR SIGNED: N/ Y – ADD DATE
<b>Learns best by:</b>			
<b>Supports Needed:</b>			
<b>Legal Decision Maker: __Self</b>		<b>Guardianship: __ Limited __ Full</b>	
NAME:		PHONE:	
ADDRESS:			
<b>Legal Health Surrogate:</b>			
NAME:		PHONE:	

PRIMARY DIAGNOSIS/ICD-9 CODES	AGE: XX	HEIGHT X'X" (XX inches)	WEIGHT XX lbs
1. 2. 3. 4. 5.			

<b>M E D I C A L</b>	
<b>DOCTORS</b>	<b>HOSPITAL</b>
<b>MEDICINES</b>  Rx <u>DAILY</u>  Rx <u>MONTHLY</u>  Rx <u>PRN</u>	<b>IMMUNIZATIONS</b>
ADD NAME OF INSURANCE COMPANY <i>Primary Subscriber:</i> ADD NAME ADD Plan Code # ADD Subscriber # Customer service: ADD PHONE #	ADD NAME OF INSURANCE COMPANY <i>Subscriber:</i> ADD NAME ADD Plan Code # ADD Subscriber # Customer service: ADD PHONE #

<b>Health Care/ Case Manager</b>	ADD NAME	ADD PHONE #	ext. xx
<b>Health Vendor</b>	ADD COMPANY NAME/CONTACT	ADD PHONE #	ADD acc't. #
<b>Home Nursing Agency</b>	ADD COMPANY NAME/CONTACT	ADD PHONE #	ADD acc't. #
<b>Pharmacy</b>	ADD COMPANY NAME	ADD PHONE #	ADD RX #s
<b>Dentist</b>	ADD NAME	ADD PHONE #	

# Emergency Information Form for Children With Special Needs



American Academy of Pediatrics



Date form completed By Whom

Revised  
Revised

Initials  
Initials

Last name:

<b>Name:</b>		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		
<b>Physicians:</b>			
Primary care physician:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Anticipated Primary ED:		Pharmacy:	
Anticipated Tertiary Care Center:			

<b>Diagnoses/Past Procedures/Physical Exam:</b>	
1 .	Baseline physical findings:
2.	
3.	Baseline vital signs:
4.	
Synopsis:	
	Baseline neurological status:

\*Consent for release of this form to health care providers

<b>Diagnoses/Past Procedures/Physical Exam continued:</b>	
Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1.	
2.	
3.	
4.	Prostheses/Appliances/Advanced Technology Devices:
5.	
6.	

<b>Management Data:</b>	
<b>Allergies: Medications/Foods to be avoided</b>	<b>and why:</b>
1.	
2.	
3.	
<b>Procedures to be avoided</b>	<b>and why:</b>
1.	
2.	
3.	

<b>Immunizations</b>											
<b>Dates</b>											
DPT											
OPV											
MMR											
HIB											
<b>Dates</b>											
Hep B											
Varicella											
TB status											
Other											

Antibiotic prophylaxis:

Indication:

Medication and dose:

<b>Common Presenting Problems/Findings With Specific Suggested Managements</b>		
Problem	Suggested Diagnostic Studies	Treatment Considerations

<b>Comments on child, family, or other specific medical issues:</b>	
<b>Physician/Provider Signature:</b>	<b>Print Name:</b>

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**Transition Care Plans**



**EPIC IC Medical Home Project  
Actionable Care Plan**

**Child's Name:** \_\_\_\_\_ **DOB:** \_\_\_\_\_ **Parents/Guardians:** \_\_\_\_\_

**Primary Diagnosis:** \_\_\_\_\_ **Secondary Diagnosis(s):** \_\_\_\_\_

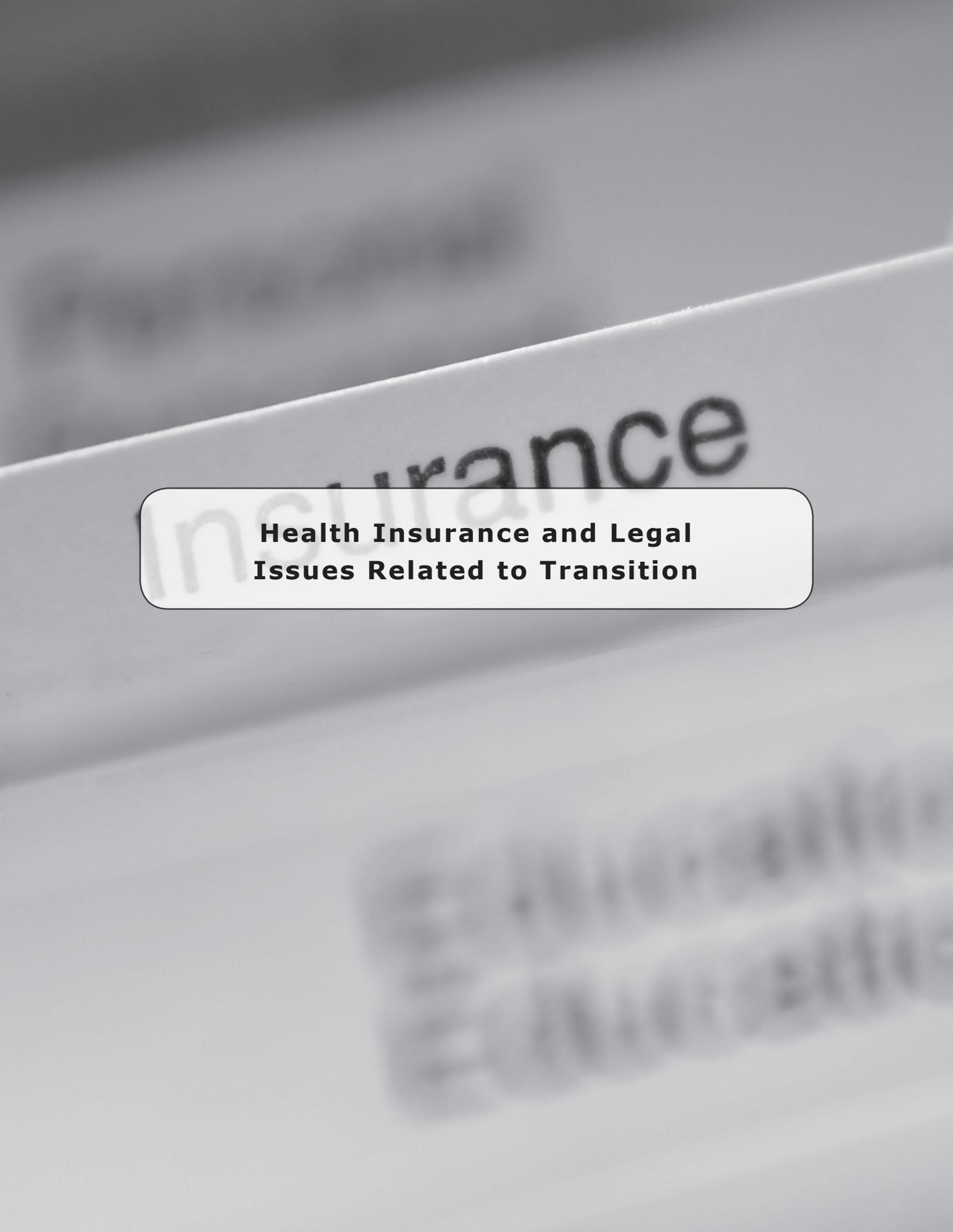
**Original Date of Plan:** \_\_\_\_\_ **Update to Plan:** \_\_\_\_/\_\_\_\_/\_\_\_\_

Main Concerns	Related Current Clinical Information (labs, etc.)	Current Plans/Intervention	Person(s) Responsible	Due Date & Date Completed

**Parent/Caregiver Signature:** \_\_\_\_\_  
**Clinician Signature:** \_\_\_\_\_

**Care Coordinator:** \_\_\_\_\_



The background is a grayscale, out-of-focus image of a document. The word "Insurance" is clearly visible in a large, bold font, slanted upwards from left to right. Below it, there are several lines of smaller, illegible text, suggesting a list or table of contents.

**Health Insurance and Legal  
Issues Related to Transition**



## Here is what we know:

- **NO HEALTH INSURANCE** - Two out of five college graduates and one-half of high school graduates who do not go on to college will experience a time without health insurance in the first year after graduation. (*Commonwealth Fund 2003*)
- **DROPPED FROM HEALTH INSURANCE** - Young adults are often dropped from their parents policies or public insurance programs at age 19, or when they graduate from college and struggle to find jobs with health benefits. Young adults are far more likely to be uninsured than older adults: four of 10 young adults between the ages of 19 and 29 can expect to be uninsured at sometime during the year--twice the rate of adults ages 30 to 64. (*Commonwealth Fund 2003*)
- **BARRIERS TO GETTING AND KEEPING HEALTH INSURANCE** - "Americans with disabilities face a number of distinct barriers in obtaining, maintaining, and using health insurance and in accessing and using health care services. At the same time, Americans with disabilities also confront the barriers, problems, and frustrations with which most Americans routinely struggle in the insurance and health care systems."  
(*National Council on Disability 2002 annual National Disability Policy: A Progress Report*)

## PUBLIC HEALTH INSURANCE: Changes after reaching majority age

### MAINTAIN MEDICAID

- Passed SSI Redetermination - continue benefits
- Emancipated Minor - by marriage or court decision may qualify or continue Medicaid due to income or disability status.

### DROP FROM MEDICAID

- Former childhood SSI recipient at age 18 did not qualify under SSI redetermination and loses benefits (income too high or does not meet disability criteria.)

### NOT APPROVED - SECTION 301: PROVISION TO CONTINUE RECEIVING SSI BENEFITS

- Individuals found ineligible during SSI redetermination may continue to receive SSI benefits *IF* they began receiving state vocational rehabilitation agency services before their 18th birthday.
- Section 301 allows the young adult to retain benefits (SSI & Medicaid) while he/she participates in approved vocational rehabilitation program.  
[Http://policy.ssa.gov/poms.nsf/lnx/0412515001](http://policy.ssa.gov/poms.nsf/lnx/0412515001)

### NEW to MEDICAID

- Child did not qualify for SSI under 18 due to family income.
- At age 18 may qualify for SSI and Medicaid as an adult single head of household.

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**NOTE:** "209B States," require separate application to Medicaid, not linked to SSI.

11 States have elected to have at least one more stringent requirement than the SSI rules for Medicaid eligibility: CT, HI, IN, IL, MN, MO, ND, NH, OK, OH, and VA.

## PUBLIC HEALTH INSURANCE: Continued Medicaid Eligibility

### **MEDICAID BUY-IN WHILE WORKING: Section 1619(b)**

- Still meets SSI criteria,
- Needs Medicaid in order to work; and
- Gross earned income is insufficient to pay for other supports

### **TICKET TO WORK**

- Worker could opt to buy-in and receive Medicaid benefits
- Program is too new to assess if states are providing full benefit packages and at what level of sliding fee

### **Creative** – MaineCare for Childless Adults

- Meets low income eligibility
- Plan pays insurance premiums for those who meet certain criteria
- Plan uses employer-sponsored insurance for the expansion

## PRIVATE HEALTH INSURANCE: Continued Benefits via Family Plan

### **ADULT DISABLED DEPENDENT CHILD**

- Youth over 18 may continue on family plan if dependent for life.
- Must be on the family plan prior to turning 18. (Legal Statute: 40 states)
- No substantial gainful employment
- Annual re-certification - disability & dependent

### **STUDENT STATUS**

- Proof of college class load each semester (often requires full-time status)
- Ages 18-22, sometimes older
- Annual re-certification

## PRIVATE HEALTH INSURANCE: Young Adult Pays Premium

### **OPTIONS to buy private insurance health care benefits:**

- College - student plan
- Employed - group plan
- Self-pay: single plan
- Ticket to Work (Medicaid Buy-in)
- COBRA
- State High Risk Pools

**Concern:** What happens if health status changes and affects continuous employment or attending school? There is no safety-net or easy on/off for health care benefits.

Tip Sheet Developed by: Patti Hackett & Glen Gallivan, Ocala, FL



The HRTW National Center [www.hrtw.org](http://www.hrtw.org) enjoys a working partnership with the Shriners Hospitals for Children and KASA. The National Center is funded through a cooperative agreement (U93MC00047) from the Integrated Services Branch, Division of Services for Children with Special Health Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS).  
**HRSA/MCHB Project Officer:** Monique Fountain, MD.

**HRTW Phase II Projects** are currently active in Arizona, Iowa, Maine, Mississippi, and Wisconsin.

*The opinions expressed herein do not necessarily reflect the policy or position nor imply official endorsement of the funding agency or working partnerships.*

**FERPA FACT SHEET**  
**(FAMILY EDUCATIONAL RIGHTS AND PRIVACY ACT – 1974)**

1. Anecdotal notes kept on a student **and** shared within the institution are considered part of a student’s education records and are subject to FERPA.

**Exception:** Unless the notes are kept in the sole possession of the maker and have not been created with or shared with anyone else.

**Summary:** Instructors who share anecdotal notes with other instructors, staff, etc., must file these notes in the student’s educational file in the Registrar’s Office. Instructors who keep such notes solely for their own use do not have to make such notes a part of the student’s educational file.

2. PARENT ACCESS TO AN ELIGIBLE STUDENT’S EDUCATION RECORDS

- At the postsecondary level, parents have **no inherent** rights to inspect their son’s or daughter’s education records. The right to inspect is limited solely to the student (regardless of the student’s age). Records **may** be released (including grades) to parents **only if at least one** of the following conditions have been met:

- (a) through written consent of the student specifying the records to be released
- (b) in compliance with a subpoena
- (c) by submission of evidence that the parents declared the student on their most recent federal income tax form

Note: An institution **is not required** to disclose information from the student’s education records to any parent of a dependent student. However, it (institution) may exercise its discretion to do so.

3. BIOLOGICAL, CUSTODIAL, AND NON-CUSTODIAL PARENTS

- In cases of divorce, separation, or custody (when only one parent declares the student as a dependent) an institution **may** grant equal access to information from the student’s education records to the other parent **unless** there is a court order, state statute, or legally binding document stating otherwise

Note: The institution is **not** required to provide such information to **either** parent. Even if written permission were granted by the student and/or dependent status determined, the institution is under **no** obligation to release education records (grades, etc.) under FERPA.

4. STUDENT PERMISSION TO SEND NON-DIRECTORY INFORMATION (i.e. GRADES) TO PARENTS

- Institutions are **not** required to send grades to parents (or notify parents) – whether the student is a dependent or not
- Institutions who decide to send grades (grade reports) to parents must obtain written permission from the student(s) to do so.

## PARENTS' ACCESS TO THEIR CHILDREN'S EDUCATION RECORDS ACCORDING TO FERPA – SUMMARY

- When a student reaches the age of 18 **or** begins attending a postsecondary institution, regardless of their age, FERPA rights transfer to the student
- Parents may obtain directory information **only and at the discretion** of the institution. John Brown University includes the following as directory information:
  - name
  - address
  - telephone
  - date/place of birth
  - major field of study and year in school
  - participation in officially recognized sports and activities
  - weight and height of members of athletic teams
  - dates of attendance
  - degrees and awards received
  - the most recent educational agency or institution attended
  - parents' names and address
  - marital status (and name of spouse)
  - religious preference
- Parents **may** obtain non-directory information (grades, etc.) **only at the discretion** of the institution **and after** it has been determined that their child is legally their dependent.
- Parents **may** obtain non-directory information (grades, etc.) if the institution obtains a signed consent from their child specifying the record(s) to be released.

### OTHER FERPA ISSUES

1. The posting of grades, either by student name, institution identification number, social security number without the student's written permission is a violation of FERPA.
2. Posting grades (or other education records) to an email distribution list or website by the methods mentioned above in #1 without the student's written permission is a violation of FERPA.
3. Sending an individual student's grade via email is allowed by FERPA; however, the institution would be held responsible for any unauthorized third party gaining access, in any manner, to a student's education record through any electronic transmission method.

Remedy: If an instructor(s) desires to post student/class grades, in any manner described above:

1. Obtain written permission from participating students
2. In a method other than name, student ID number, social security number  
For example, assign random numbers or alpha codes to students that are known only to the instructor and the students and do not post in last name alphabetical order/sequence
3. Do not send grades on a postcard. You may send grades in an addressed, sealed envelope.

(Source: The AACRAO 2001 FERPA Guide)



## **Medicaid as a Second Language: A Slightly Irreverent Guide to Common Medicaid Terms, Acronyms and Abbreviations**

### **Introduction**

This guide is designed for policymakers, advocates, legislators, consumers, family members, and providers – in short, for anyone interested in financing care for children and youth with special health care needs at the state level, and in particular through the Medicaid program.

Medicaid has its own language, one that can be daunting to outsiders. There are mysterious combinations of numbers and letters that refer to legislation, familiar terms that may have unfamiliar meanings (crowd-out, respite, health-based payment), and dozens of abbreviations used as shorthand to describe programs and agencies. And then there are the acronyms – S-CHIP, FMAP, TEFRA, COBRA; it's likely that some state also has a ZEBRA.

While it's not necessary to be fluent in this language to discuss state policy, it helps to have some familiarity with these terms, or at least a place to go to look them up. In the hopes of providing a useful start, the Catalyst Center has adapted definitions without shame from other glossaries and updated or added to them to create *Medicaid as a Second Language*.

We start with an overview of some of the basic structural features of Medicaid, and follow with a glossary of terms commonly used in the Medicaid program.

## **Medicaid: The Lay of the Land**

The Medicaid program was established by Title XIX (19) of the Social Security Act in 1965, to provide coverage for health care and health-related services to low-income and other specific categories of individuals. Since it was developed, the Medicaid program has evolved in many ways. It is a national program, overseen by the federal government, but administered by states, with significant state latitude for decision-making about eligibility and coverage.

## **Mandatory and Optional Benefits**

All states must cover Mandatory Medicaid benefits, which include:

- Inpatient hospital services (except institutions for mental disease)
- Outpatient services including those delivered by federally qualified health centers and rural health centers
- Laboratory and x-ray services
- Pediatric and family nurse practitioner services
- Nursing facility services for beneficiaries age 21 and older
- EPSDT services
- Family planning services and supplies
- Physician services
- Medical and surgical services of a dentist
- Home health services (to those eligible for nursing facility care)
- Nurse/Midwife services
- Pregnancy-related services
- 60 days postpartum pregnancy-related services

States may choose to offer a range of Optional Medicaid benefits. Examples include:

- Prescription drugs
- Optometry services
- Psychologist services
- Private duty nursing
- Physical, occupational and speech therapy
- Audiology services
- Dental services
- Prosthetics
- Eyeglasses
- Rehabilitation services
- Personal care services

### **Eligibility Categories**

The most common Medicaid eligibility categories include:

- Pregnant women and infants;
- Children aged 1 to 18, including children in the child welfare system;
- Caretaker relatives of dependent children;
- Adults and children with disabilities who meet SSI standards or state disability standards (see 209b states below);
- People over the age of 64; and
- People who are blind.

States may choose to cover other groups also, such as people living with HIV; the working disabled; or uninsured women under 65 who screen positive for breast or cervical cancer or precursor conditions. In all cases, the individuals within each category must meet “low-income” eligibility criteria.

### **Waivers**

A waiver is permission from the federal government for a state to disregard one or more of the federal rules governing the Medicaid programs under specific conditions. For example, federal rules state that benefits must be comparable for all Medicaid beneficiaries – a state can not offer certain benefits to one group of people but deny them to another group. However, states can request that this rule be waived if they can demonstrate that certain

benefits might help a specific group of people live in the community instead of an institution. Waivers must be approved by the Centers for Medicare & Medicaid Services, the federal agency that oversees the Medicaid program.

*1915(b) Waiver*

A waiver that addresses the federal rule that Medicaid beneficiaries must have “freedom of choice” of provider. It allows a state to restrict Medicaid beneficiaries’ choice of providers by assigning recipients to a primary care case manager or by enrolling recipients in a Managed Care Organization (MCO).

*1915(c) or Home and Community-Based Service (HCBS) Waivers*

These waiver programs waive the federal Medicaid requirement that all beneficiaries receive comparable benefits for specific groups of individuals who qualify for institutional care under the Medicaid program. HCBS waivers allow states to offer benefits that Medicaid does not normally cover for most beneficiaries such as specialized home health services, personal assistance, adaptive equipment, assistive technology, home modifications, case management, respite care and family support services.

A single state may have multiple HCBS waivers targeting different populations — those with spinal cord injuries or developmental disabilities, for example.

Waiver programs can also expand the income eligibility for Medicaid. HCBS waivers must demonstrate that the cost of providing services under the waiver are no higher than the cost of providing services without the waiver.

As a result, the waiver application must include the number of people that can be enrolled in the waiver, also known as the number of waiver “slots.” Multiple HCBS waivers may exist within a state targeting different populations such as people with spinal cord injuries, developmental disabilities, HIV, medically fragile children, etc.

### *1115 Research and Demonstration Waivers*

Section 1115 of the Social Security Act allows the Secretary of Health and Human Services to waive multiple program rules and authorize demonstration projects likely to promote the objectives of the Medicaid program. These waiver programs are intended to demonstrate a policy or approach that has not previously been demonstrated on a widespread basis. Many states have used 1115 waiver authority to expand Medicaid eligibility to new populations or people at higher income levels, while also mandating enrollment in Medicaid managed care. Other 1115 waivers have introduced new services or new means of service delivery, such as the Cash and Counseling demonstration projects that provide adults and children with disabilities a cash budget and counseling to purchase their own long term support services. 1115 waivers are generally approved for 5-year periods, but states may submit renewal requests. They must be budget neutral over the life of the project, and the projects must be evaluated.

### **Alpha-Numeric Soup: Common Medicaid Terms**

**209(b) states:** In 209(b) states, SSI does *not* confer automatic Medicaid eligibility – people with disabilities must submit a separate application for Medicaid benefits and are generally required to meet stricter income, asset or disability criteria. The 209(b) states are CT, HI, IL, IN, MN, MO, NH, ND, OH, OK and VA.

### **Activities of Daily Living (ADLs)**

ADLs include bathing, dressing, eating, mobility, transferring, toileting and grooming. The need for assistance with ADLs is often part of the criteria to qualify medically for institutional or community-based long term care services.

### **Applied Behavioral Analysis (ABA) Therapy**

A treatment for children with autism spectrum disorders that uses intensive, highly repetitive teaching to modify behavior.

### **Assets**

Money and property. Most health benefits administered by

Medicaid programs have “asset tests,” a maximum amount of money, property, or goods a person can own to qualify for health care benefits.

### **Balanced Budget Act (BBA)**

Federal legislation passed in 1997 designed to balance the federal budget by 2002. The BBA includes many reforms to both the Medicare and Medicaid programs, including a relaxation of rules that require states to obtain a waiver in order to implement mandatory managed care programs for certain Medicaid beneficiaries.

### **Capitation**

A fixed sum that an insurer pays to a health plan or provider for each person served, usually on a monthly basis and regardless of the extent of services used. The capitation payment may cover all or part of the individual’s benefits, depending on the agreement that is negotiated between the insurer and the health plan.

### **Centers for Medicare & Medicaid Services (CMS)**

(Formerly HCFA, the Health Care Financing Administration.) The federal agency that administers Medicare and oversees the states’ administration of Medicaid.

### **COBRA**

The Consolidated Omnibus Budget Reconciliation Act of 1986, which requires most employers to permit workers who leave employment to purchase continued coverage for themselves and their dependents in the employer health plan *but wholly at their own expense* for 18 months. If employees file an application for SSA disability they may receive another 11 months of coverage under COBRA.

### **Consumer-Directed Care**

Care for an adult or child with disabilities that is directed by that individual or his or her family, who may decide how limited funds, services, or other resources are used and who may choose to hire or direct personal care staff. May also be called Family-Directed Care. This use of the term “consumer-directed” should not be confused with its use to describe low-cost, high-deductible health plans.

**Co-Payment**

A specified dollar amount that an insured individual must pay out-of-pocket for covered services at the time they are rendered. Also called a co-pay.

**Cost-Sharing**

The portion of medical expenses that patients themselves are required to pay. Cost-sharing can include premiums, deductibles, coinsurance and co-payments. As a general rule, cost-sharing in Medicaid programs is limited because beneficiaries have very low incomes.

**Crowd-Out**

A concern that when public programs are created or expanded to offer health insurance coverage, people with private coverage may switch to public coverage. This can happen if employers reduce or drop their private insurance options for employees or if individuals drop their more expensive private coverage to enroll in less expensive public programs.

**Deductible**

A fixed amount that an individual must pay for medical care, usually each year, before his or her health insurance coverage begins.

**Disease Management**

The use of research-based care management protocols that provide guidelines for how individuals with specific diagnoses will receive services. The care management protocols are intended to improve quality of care and also promote efficiency in service delivery. Patient and family education are important elements in many disease management programs.

**Durable Medical Equipment (DME)**

Health-related equipment that is not disposable, such as wheelchairs, walkers, or oxygen concentrators.

**Early Intervention (EI)**

Developmental services provided to children between birth and age 3 who have, or in states with broad eligibility are at risk of, developmental delay. State Early Intervention programs can receive federal education funds to subsidize these services.

**Early Periodic Screening, Diagnosis, and Treatment (EPSDT)**

Medicaid benefits and services for children and youth under 21; designed to assure preventive treatment and to promote early diagnosis and treatment of identified health needs. Under EPSDT, Medicaid programs must pay for medically necessary services such as dental care, eyeglasses, hearing aids, special therapy, etc., without cost-sharing, even if they are not ordinarily covered by the Medicaid program.

**Family-Directed Care**

See Consumer-Directed Care.

**Family Opportunity Act (FOA)**

Federal legislation that gives states the option of providing Medicaid coverage to children who meet the disability standard used in the Supplemental Security Income (SSI) program, but who are over the income limit for SSI. Under the FOA, Medicaid benefits are made available to disabled children in middle-income families whose employer-sponsored health insurance does not offer the equipment, home health, mental health, transportation and specialized services that Medicaid offers. The FOA also amends Title V of the Social Security Act (Maternal and Child Health Services) to provide appropriations for the MCHB Division of Services for Children with Special Health Care Needs to develop Family-to-Family Health Information Centers in each of the fifty states.

**Federal Match (FMAP)**

The Federal Medical Assistance Percentage (FMAP) is the percentage that the federal government pays to states for certain program expenses, including Medicaid services and the

administration of the Medicaid program. The FMAP ranges from 50%-76%, with a higher federal match going to those states with a lower per capita income.

**Federal Poverty Level (FPL)**

The threshold used as a basis for determining eligibility for many public benefits programs, including Medicaid. The current FPL chart is available on the Web at <http://aspe.hhs.gov/poverty/>.

**Fee-For-Service (FFS)**

A payment system in which an insurer pays the provider directly for each medical service after it is provided. The financial incentive in this system is to provide lots of services because each service is paid for. FFS payment is distinguished from capitation payment, where an insurer or provider is paid a set amount for a package of services for a given individual, regardless of how many services that individual uses.

**Federal Financial Participation (FFP)**

The funds that the federal government pays as a match for the state funds expended for Medicaid services. Only services recognized as covered services by the federal government are eligible to receive FFP.

**Formulary**

A list of prescription drugs covered by Medicaid, a private insurance plan or an HMO.

**General Assistance (GA), General Relief (GR), Temporary Disability Assistance (TDA), or Home Relief (HR)**

Welfare payments -- and often medical assistance -- provided to low-income, unemployed, incapacitated and/or disabled childless adults who have not yet been determined disabled through the SSA disability determination process.

**Home and Community Based Services (HCBS) Waivers**

See 1915c waivers.



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### **Health-Based Payment**

A reimbursement strategy that pays health plans a higher capitation rate for members with complex medical needs, including individuals with disabilities. Health-based payment provides an incentive for plans to provide good quality care to individuals with costly care needs, as opposed to limiting care to avoid financial risk.

### **Health Maintenance Organization (HMO)**

A type of health insurance plan that delivers a pre-defined set of health benefits to enrolled members. The HMO typically is paid a capitation rate from a payer or employer for a group of enrollees and provides the covered health services through a network of providers that contract with the HMO.

### **Instrumental Activities of Daily Living (IADLs)**

IADLs include meal preparation, medication management and administration, money management, communication (such as use of the telephone), transportation, employment and sometimes, laundry and other household chores. The ability to perform IADLs is often used as part of the criteria to qualify for long-term care and support services.

### **Integrated Delivery Model**

Health service programs, often developed for a particular target population, that provide multiple types of services, such as medical care, mental health care, family support services or school-based services, through a single system or provider.

### **Intermediate Care Facility (ICF)**

A facility that provides health and related services above the level of basic custodial care but below the level of care available in a hospital or skilled nursing facility.

### **Intermediate Care Facility for the Mentally Retarded (ICF/MR)**

An ICF as described above that serves people with mental retardation. Federal regulations specify that these institutions must provide “active treatment.”

**Katie Beckett Waiver**

See TEFRA State Plan Option for Severely Disabled Children.

**Long-Term Care**

Health, and in some cases, custodial and social support services, including respite, home and personal care, for people with chronic conditions, disabilities, or mental illness. Services can be provided in community-based or institutional settings.

**Managed Care**

A system that manages health care delivery in order to control costs and/or coordinate health services. Managed care usually relies on a primary care provider to serve as a gatekeeper to other services.

**Managed Care Organizations (MCOs)**

Health insurance plans that offer managed care products as described above. MCOs can include HMOs, but may also include health plans that are not officially licensed as HMOs.

**Mandatory Managed Care Enrollment**

A managed health care program in which Medicaid beneficiaries are required to enroll. People may be required to enroll in two or more managed care plans, a single PCCM program, or a choice of managed care plan or PCCM program.

**Medicaid Buy-In Program**

Medicaid buy-in programs allow families who meet certain eligibility criteria (often disability-related) but who are over-income to purchase Medicaid benefits to cover services that are not covered or are covered inadequately by employer-sponsored insurance plans.

**Medically Needy**

A category of Medicaid eligibility for individuals who are eligible for Medicaid by virtue of being aged, blind, disabled, or members of families with dependent children, but who have incomes and/or assets above the financial eligibility criteria for Medicaid. These individuals may deduct incurred medical expenses from their original “excess” income to become poor enough to qualify for

Medicaid. Participants in the medically needy programs generally have one, three, or six months to spend down their “excess” medical expenses, based on the state’s rules.

**Pay for Performance (PFP)**

A reimbursement strategy that pays health care providers according to how well they meet certain quality standards.

**Personal Care Assistance**

Services designed to help an individual with a disability perform activities of daily living at home or in the workplace. “PCA” generally refers to a Personal Care Attendant who provides these services.

**Premium**

The amount of money paid to a health plan to provide coverage for an individual or family over a specified time period.

**Premium Assistance**

The payment of all or part of an individual’s or family’s monthly private health insurance premium, usually by a public program such as Title V or Medicaid.

**Primary Care Case Management (PCCM)**

Many states offer PCCM programs, in which Medicaid contracts with a preferred network of primary care providers who in turn provide primary care, care coordination and referral services for their enrolled members. Most PCCM providers are reimbursed through fee-for-service, but may receive a nominal monthly payment per enrolled member for care coordination or may receive an enhanced visit fee.

**Real Choice Systems Change Grants**

Grants awarded by the Centers for Medicare & Medicaid Services to enhance home and community-based services and supports, thereby averting institutional placement of individuals of all ages who have disabilities.



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**Reinsurance**

A contract in which an insurer is itself insured, wholly or in part, against risk. Some state Medicaid programs offer to reinsure their managed care plans against extraordinarily high risks.

**Respite Care**

Temporary, short-term relief for a family caregiver. Respite care may be provided by a family member, a friend or a paid employee and may involve care of a child or an adult with disabilities.

**Risk Adjustment**

The adjustment of premiums to compensate health plans or providers for the increased risks associated with demographic attributes (e.g. age) or special health needs of their clients.

**Serious Emotional Disturbance (SED)**

Diagnosable mental health disorder in a child or adolescent that severely disrupts daily functioning in the home, school, or community.

**Spend-Down**

The process by which medically needy individuals — those who are eligible for Medicaid based on a medical condition but whose incomes exceed Medicaid's income limits — gain eligibility for Medicaid by using their "excess" income to pay medical bills.

**State Children's Health Insurance Program (SCHIP)**

A program established in 1997 to provide health assistance to uninsured, low-income children either through expanded eligibility for state Medicaid programs or through separate state programs. In most states, SCHIP programs expand health care coverage to children in families with incomes up to 200% of the FPL, but in some states it is as high as 350% of the FPL; in others it is lower than 200%. SCHIP programs may charge nominal premiums, and some programs also cover the uninsured parents of uninsured children.

### **State Plan/State Plan Amendment**

A state's Medicaid program plan, which must be approved by the federal government, spells out the state's Medicaid eligibility criteria, covered services, methods of administration, and fiscal and quality controls. If a state wants to change its menu of covered services or Medicaid eligibility criteria, it must submit a state plan amendment or waiver request to the federal government.

### **State Supplementary Payments (SSPs)**

Extra state payments added to federal SSI payments; states may choose to offer this through its State Plan Amendment.

### **Supplemental Security Income (SSI)**

A federal program for low income individuals with disabilities or over the age of 64 that pays cash benefits of up to \$603/month (2006). SSI disability status also confers Medicaid eligibility in all but 11 states. See 209(b) States

### **Take-Up Rate**

The number of people who accept or "take up" a benefit for which they are eligible.

### **Temporary Assistance to Needy Families (TANF)**

A federal block grant program designed to help welfare recipients find work, TANF replaced Aid to Families with Dependent Children in 1996. Most people who receive TANF benefits also receive Medicaid benefits.

### **Take-Up Rate**

The number of people who accept or 'take-up' a benefit for which they are eligible.

### **Targeted Case Management**

The provision of case management services to specific groups of Medicaid beneficiaries; designed to provide beneficiaries with needed services while promoting the cost-effective use of community resources.

**Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA)**

Federal tax legislation passed during the Reagan administration that included a Medicaid coverage option for children with severe disabilities.

**TEFRA State Plan Option for Severely Disabled Children**

The TEFRA state plan option allows states to provide Medicaid coverage to disabled children in their homes rather than in institutions. The TEFRA state plan option is also known as the Katie Beckett waiver or option, after the child who's mother advocated strongly for the legislation. To qualify for TEFRA, a child must meet both SSI disability criteria and institutional level of care criteria. However, children who live in institutions or receive extended care in institutions are not eligible for TEFRA benefits. In determining eligibility for TEFRA, the family's income is not counted, allowing middle-income children who are severely disabled to receive Medicaid benefits. The estimated cost of care for the child in the home can not exceed the estimated cost of institutional care.

**Title XIX, Title 19, T-19**

Shorthand for the Medicaid program, referring to Title 19 of the Social Security Act.

**Title XXI**

Shorthand for the State Child Health Insurance Program (SCHIP).

**Wraparound**

Services that are not included in a typical health insurance benefit package, but that enhance a child's functional status or overall well-being, or that facilitate access to care. Wraparound services may include family support, respite care and adaptive technologies.



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# Privacy and Your Health Information

## Your Privacy Is Important to All of Us

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

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

## Your Health Information Is Protected By Federal Law

### Who must follow this law?

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

### What information is protected?

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

## The Law Gives You Rights Over Your Health Information

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

- Ask to see and get a copy of your health records
- Have corrections added to your health information
- Receive a notice that tells you how your health information may be used and shared
- Decide if you want to give your permission before your health information can be used or shared for certain purposes, such as for marketing
- Get a report on when and why your health information was shared for certain purposes
- If you believe your rights are being denied or your health information isn't being protected, you can
  - File a complaint with your provider or health insurer
  - File a complaint with the U.S. Government

You should get to know these important rights, which help you protect your health information.

You can ask your provider or health insurer questions about your rights. You also can learn more about your rights, including how to file a complaint, from the website at [www.hhs.gov/ocr/hipaa/](http://www.hhs.gov/ocr/hipaa/)



# PRIVACY



## For More Information

This is a brief summary of your rights and protections under the federal health information privacy law. You can learn more about health information privacy and your rights in a fact sheet called “*Your Health Information Privacy Rights.*” You can get this from the website at [www.hhs.gov/ocr/hipaa/](http://www.hhs.gov/ocr/hipaa/).

### Other privacy rights

Another law provides additional privacy protections to patients of alcohol and drug treatment programs. For more information, go to the website at [www.samhsa.gov](http://www.samhsa.gov).

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Civil Rights



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

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

- For your treatment and care coordination
- To pay doctors and hospitals for your health care and help run their businesses
- With your family, relatives, friends or others you identify who are involved with your health care or your health care bills, unless you object
- To make sure doctors give good care and nursing homes are clean and safe
- To protect the public’s health, such as by reporting when the flu is in your area
- To make required reports to the police, such as reporting gunshot wounds

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

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



## The Law Protects the Privacy of Your Health Information

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

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

# Medical Power of Attorney

## Effective Upon Execution

I, [NAME], a resident of [ADDRESS. COUNTY, STATE]; Social Security Number [NUMBER] designate [NAME], presently residing at [ADDRESS], telephone number [PHONE NUMBER] as my agent to make any and all health care decisions for me, except to the extent I state otherwise in this document. For the purposes of this document, "health care decision" means consent, refusal of consent, or withdrawal of consent to any care, treatment, service, or procedure to maintain, diagnose, or treat an individual's physical or mental condition.

This medical power of attorney takes effect if I become unable to make my own health care decisions and this fact is certified in writing by my physician.

**Limitations:** [Describe any desired limitations, for example, concerning life support, life-prolonging care, treatment, services, and procedures.]

**Inspection and Disclosure of Information Relating to My Physical or Mental Health:** Subject to any limitations in this document, my agent has the power and authority to do all of the following:

1. Request, review, and receive any information, verbal or written, regarding my physical or mental health, including, but not limited to, medical and hospital records;
2. Execute on my behalf any releases or other documents that may be required in order to obtain this information;
3. Consent to the disclosure of this information.

**Additional Powers:** Where necessary to implement the health care decisions that my agent is authorized by this document to make, my agent has the power and authority to execute on my behalf all of the following:

1. Documents titled or purporting to be a "Refusal to Permit Treatment" and "Leaving Hospital Against Medical Advice";
2. Any necessary waiver or release from liability required by a hospital or physician.

**Duration:** This power of attorney exists indefinitely from its date of execution, unless I establish herein a shorter time or revoke the power of attorney.

**[If applicable:** This power of attorney expires on [DATE]. If I am unable to make health care decisions for myself when this power of attorney expires, the authority I have granted my agent shall continue to exist until such time as I become able to make health care decisions for myself.]

**Alternative Agent:** In the event that my designated agent becomes unable, unwilling, or ineligible to serve, I hereby designate [NAME], presently residing at [ADDRESS], telephone number [PHONE NUMBER] as my as my first alternate agent, and [NAME], presently residing at [ADDRESS], telephone number [PHONE NUMBER] as my as my second alternate agent.

**Prior Designations Revoked:** I revoke any prior Medical Power of Attorney.

**Location of Documents:** The original copy of this Medical Power of Attorney is located at [Location].

Signed copies of this Medical Power of Attorney have been filed with the following individuals and institutions: [Names and Addresses].

I sign my name to this Medical Power of attorney on the date of [DATE], at [ADDRESS, COUNTY, STATE].

---

NAME

### Statement of Witnesses

I hereby declare under penalty of perjury that the person who signed or acknowledged this document is personally known to me (or proved to me on the basis of convincing evidence) to be the principal, that the principal signed or acknowledged this durable medical power of attorney in my presence, that the principal appears to be of sound mind and under no duress, fraud, or undue influence. I am not the person appointed an agent by this document. I am not related to the principal by blood, marriage, or adoption. I would not be entitled to any portion of the principal's estate on the principal's death. I am not the attending physician of the principal or an employee of the attending physician. I have no claim against any portion of the principal's estate on the principal's death. Furthermore, if I am an employee of a health care facility in which the principal is a patient, I am not involved in providing direct patient care to the principal and am not an officer, director, partner, or business office employee of the health care facility or of any parent organization of the health care facility.

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Witness

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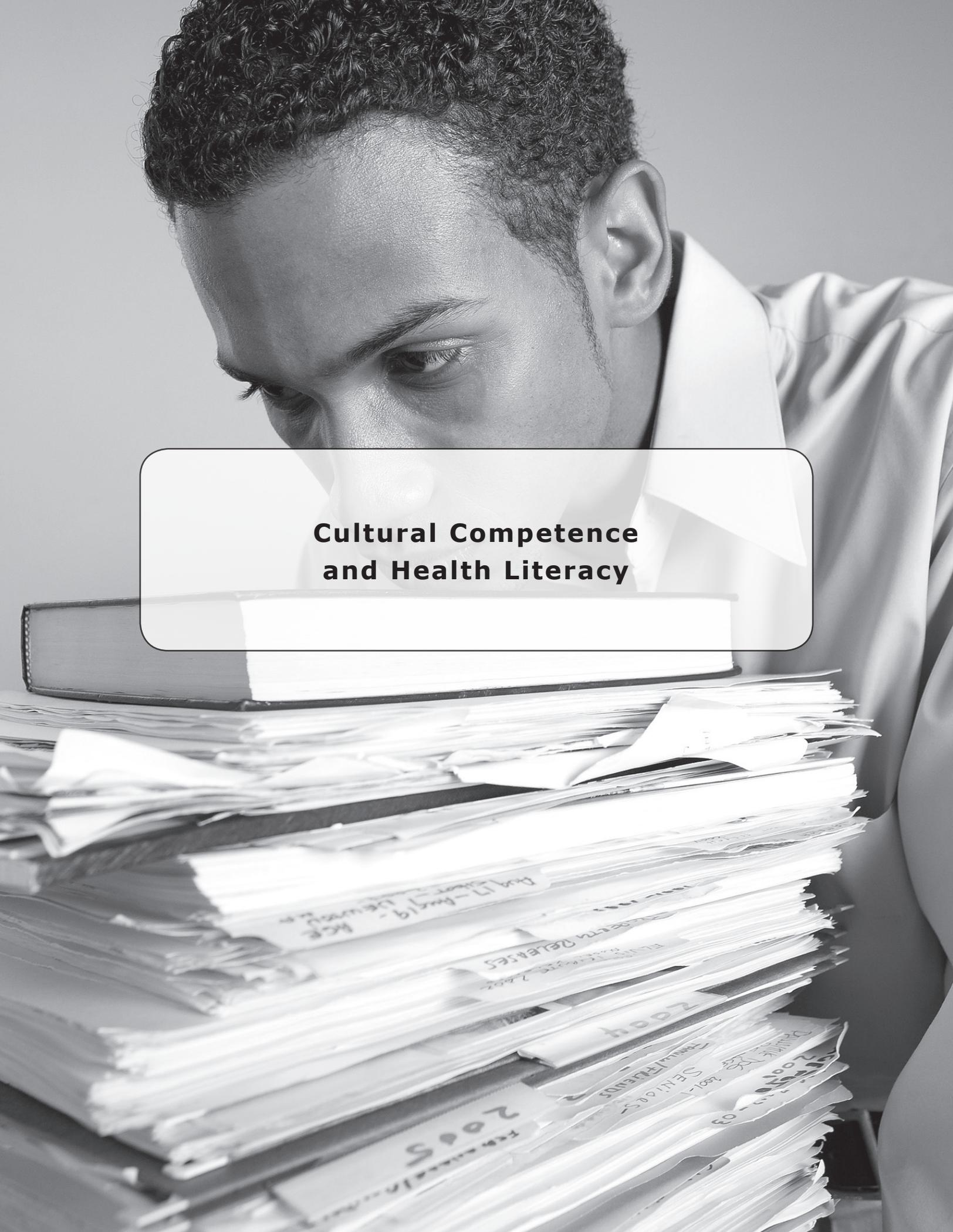
Witness

Subscribed and sworn to before me on [DATE].

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Notary Public, [COUNTY, STATE]

My commission expires \_\_\_\_\_.



**Cultural Competence  
and Health Literacy**



**Maternal and Child Health Bureau  
Division of Services for Children with Special Health Needs**

*THE ROLE OF CULTURAL COMPETENCE IN FAMILY-CENTERED CARE*

Cultural Competence is intricately linked to the concept and practice of “family-centered care”. Family-Centered Care honors the strengths, cultures, traditions and expertise that everyone brings to a respectful family/professional partnership, where families feel they can be decision makers with providers at different levels - in the care of their own children and as advocates for systems and policies supportive of children and youth with special health care needs. It requires culturally competent attitudes and practices in order to develop and nurture those partnerships and to have the knowledge and skills that will enable you to be “family-centered” with the many diverse families that exist. It also often requires building relationships with community cultural brokers, who can assist you in understanding community norms and link you with other families and organizations, such as churches, beauty shops, social clubs, etc. that can help promote your message or conduct outreach for services.

*DEFINITION OF CULTURAL/LINGUISTIC COMPETENCE*

Cultural competence is defined as a set of values, behaviors, attitudes, and practices within a system, organization, program or among individuals and which enables them to work effectively cross culturally. Further, it refers to the ability to honor and respect the beliefs, language, interpersonal styles and behaviors of individuals and families receiving services, as well as staff who are providing such services. At a systems, organizational, or program level, cultural competence requires a comprehensive and coordinated plan that includes interventions at all the levels from policy-making to the individual, and is a dynamic, ongoing, process that requires a long-term commitment. A component of cultural competence is linguistic competence, the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who are not literate or have low literacy skills, and individuals with disabilities.

*PRINCIPLES OF CULTURAL COMPETENCE*

**An organization should:**

- 1) Value diversity in families, staff, providers and communities;
- 2) Have the capacity for cultural self-assessment;
- 3) Be conscious of the dynamics inherent when cultures interact, e.g. families and providers;
- 4) Institutionalize cultural knowledge; and
- 5) Develop adaptations to service delivery and partnership building reflecting an understanding of cultural diversity.

**An individual should:**

- 1) Examine one’s own attitude and values;
- 2) Acquire the values, knowledge, and skills for working in cross cultural situations; and
- 3) Remember that every one has a culture.

Sources: Maternal and Child Health Bureau (MCHB), Guidance and Performance Measures for Discretionary Grants, Health Resources and Services Administration, U.S. Department of Health and Human Services, Denboba and Goode, 1999 and 2004.

Cross, Bazron, Dennis and Isaacs, Towards a Culturally Competent System of Care, 1989.

Goode and Jones, Definition of Linguistic Competence, National Center for Cultural Competence, Revised 2004.

Denboba, “Federal Viewpoint”, Special Additions Newsletter for Children with Special Health Care Needs, Spring/Summer 2005.





## Guide to Cultural Awareness for Public Education Campaign and Disaster Response Network Members

Every person has a culture: The many customs and beliefs that shape our perspectives and create a lens through which we see others. We are our own experts in the cultural experiences that influence our lives. Yet, when we try to communicate with people from other cultures, we need to ask ourselves if we are doing so in an effective and appropriate manner. It is impossible to become an expert in every culture. Even so, we can become more culturally aware, understand our own cultural influences, and respect and value differences of other individuals and groups.

Every day provides an opportunity for us to seek out experiences and opportunities to learn about cultures that are different from our own. Engaging in continuous learning about cultural commonalities and differences can help us expand our ability to communicate effectively with people, especially during challenging times.

If we strive to learn from and about those with whom we interact, we will naturally become more culturally informed.

### Tips for culturally informed communications

- **Think beyond race and ethnicity.** Opportunities to expand our cultural understanding exist everywhere, especially when we consider culture beyond its association with ethnicity. Culture is central to our identity and, as such, may be seen or unseen by others. Culture is shaped by personal experiences that may include: ethnic and racial identity; religion; age; educational level; body size; heritage and family tradition; physical and cognitive abilities; sexual orientation; gender identity; and geographic and socioeconomic experiences.
- **Think outside your own box.** We are influenced by our own values, beliefs, biases and life experiences. We need to carefully consider how our perspectives affect our understanding of other cultures and avoid making assumptions about others based on our own experiences. Becoming culturally aware starts with recognizing the limitations of our own cultural knowledge.
- **Experience culture.** Consider experiential ways that you can learn about other cultures and endeavor to participate in activities that may not be familiar to you. When possible, take part in social, community and educational activities like viewing films and reading books, attending faith-based services, festivals, parades, concerts, sporting events, art exhibits, workshops and lectures.
- **Use language that evokes images of people actively engaged in life** when working with people with disabilities. Avoid phrases that suggest helplessness or tragedy. For example, “Bob uses a wheelchair” versus “Bob is in a wheelchair.”
- **Listen carefully.** Hearing is not necessarily listening. Our own perceptions, biases and expectations sometimes make it difficult to really listen to and comprehend the overt and covert messages. Be mindful to focus on and identify the information being conveyed.

*“Gender is an important factor in many cultures. For example, in some cases men will feel uncomfortable talking with or learning from women, and vice versa. Learn how the genders communicate and interact.”*

MORE ▶

***“Recognize that common colloquialisms, slang terms and cliché phrases can be culturally specific and may be confusing.”***

- **Learn by asking.** People feel respected when others are genuinely interested in learning about their views and perspectives. Consider incorporating questions into conversations that demonstrate your desire to learn more about others’ cultural experiences. Use simple or open-ended questions that encourage dialogue. “What do you think?” “How can I be of assistance to you?” “What information is important for me to know about you and your culture?” “If I was a member of your community, how would I most likely react to/cope with this situation?”
- **Avoid insensitive comments.** In group contexts, individuals sometimes make insensitive and hurtful comments about others (e.g., jokes, slurs, etc.). Do not reinforce this behavior. If comfortable in the group context, make known your discomfort with what has been said and ask that no more insensitive comments be made.
- **Tune in to non-verbal behaviors.** Sometimes, behaviors can provide more details about how someone is reacting to a situation than what they may be comfortable saying. It is important to recognize welcoming behaviors as well as those that may be defensive so that you can adjust your approach accordingly. Similarly, be aware of your own body language. Does standing while others are sitting demonstrate authority or aggressiveness?
- **Expand your comfort zone.** It is likely that there will be individuals or cultural groups with whom you do not have experience working. Acknowledge this challenge and make an effort to learn as much as possible about the individual or group to build your confidence and benefit your outreach. Ask questions to make it clear that you want to learn more to ensure that you’re delivering information in a way that is useful.
- **Make local connections.** What community-based organizations and venues are respected and trusted by those with whom you work? Organizations like social clubs, advocacy groups, religious institutions, civic groups, unions, colleges and universities can help you deliver your messages in a forum that is relevant to your audience. In some cases, you may want to partner with leaders from these organizations to help you communicate even more effectively.
- **Exchange stories.** Storytelling and personal sharing are important communication techniques that transcend most cultures. Consider sharing relevant personal stories as a way to start a conversation or build rapport.
- **Respect language preferences.** Before approaching a new group of people, consider whether the materials you have to offer or your presentation need to be adapted to ensure that you are understood. In some cases, it might be necessary to translate materials or invite an interpreter to the presentation. Other times, such as when communicating with young children, simply adjusting your vocabulary might suffice.
- **Honor flexibility in people’s self-identification.** We may make assumptions about people’s cultural identity while they may have an entirely different perception of themselves. Listen for information about self-perception. For example, do they consider themselves as having a spouse or a life partner? People may identify with a particular aspect of their diversity at different times (e.g., being a lesbian may be very salient in some circumstances but not in others).

***“People often consider eye contact as a sign of honesty and interest in the conversation, but some cultures view direct eye contact as a sign of disrespect.”***

MORE ►

**Consider this: Engaging the community can help you communicate.**

- Religious beliefs and spirituality play a significant role in many communities. The opinions of religious and other spiritual leaders may be important to those with whom you work and may have an impact on their receptivity to psychological information. Find out if inviting faith-based leaders to partner with you is a welcome strategy.
- Culture can influence the manner in which individuals express their emotions. To best communicate with people in any community it is important to be open to differences in how people express their feelings. Ask community leaders to help you understand any differences and to identify effective ways to communicate and/or provide support. For example, individuals in some cultures may be uncomfortable

with any type of confrontation and, as a result, may go along with an idea you present when in reality they do not support it.

- Some cultures mistrust civil institutions such as police and law enforcement, health care systems, disaster relief, mental health agencies and others. This can present unique challenges, especially in disaster situations, that may need to be addressed. Consider partnering with individuals who are perceived as community leaders, natural helpers or organizations that the community trusts. Gaining their support can increase your credibility and help you deliver services more effectively. Learn about the culturally appropriate ways to engage community members (for example, speaking to elders, offering gifts, sharing food). Make sure you know who can authorize your presence in the community.

**What is ...**

**Culture?** The belief systems and value orientations that influence customs, norms, practices and social institutions, including psychological processes. All individuals are cultural beings and have a cultural, ethnic and racial heritage.

**Race?** The category to which others assign individuals on the basis of physical characteristics, such as skin color or hair type. These characteristics can be the basis of generalizations and/or stereotypes.

**Ethnicity?** The acceptance of the group mores and practices of one's culture of origin and the concomitant sense of belonging.

**Multiculturalism and Diversity?** Terms that have been used interchangeably to include aspects of identity stemming from gender, sexual orientation, disability, socioeconomic status or age.

**Multiculturalism?** A broad scope of dimensions of race, ethnicity, language, sexual orientation, gender, age, disability, class status, education, religious/spiritual orientation and other cultural dimensions, which are critical aspects of an individual's identity.

**Diversity?** An individual's social identity including age, sexual orientation, physical disability, socioeconomic status, race/ethnicity, workplace role/position, religious/spiritual orientation and work/family concerns.

American Psychological Association, 2002. Guidelines on Multicultural Education, Training, Research, Practice, and Organizational Change for Psychologists.

MORE ►

## Resources

More information is available through several offices within the American Psychological Association (APA; [www.apa.org](http://www.apa.org)), including the Office of Ethnic Minority Affairs; Lesbian, Gay, Bisexual and Transgender Concerns; and Disability Issues in Psychology.

The following is a sampling of the many available resources and references:

- Georgetown University Center for Child and Human Development, National Center for Cultural Competence, [www11.georgetown.edu/research/gucchd/nccc/index.html](http://www11.georgetown.edu/research/gucchd/nccc/index.html)
- National Multicultural Institute, [www.nmci.org](http://www.nmci.org)
- Association of Black Psychologists, [www.abpsi.org](http://www.abpsi.org)
- National Latina/o Psychological Association, [www.nlpa.ws](http://www.nlpa.ws)
- Asian American Psychological Association, [www.aapaonline.org](http://www.aapaonline.org)
- Society of Indian Psychologists, [www.geocities.com/indianpsych](http://www.geocities.com/indianpsych)
- APA Ethics Code, [www.apa.org/ethics](http://www.apa.org/ethics)
- APA's Office of Ethnic Minority Affairs, Valuing Diversity Project, [www.apa.org/pi/valuingdiversity/](http://www.apa.org/pi/valuingdiversity/)
- APA Presidential Task Force on Enhancing Diversity, [www2.apa.org/pi/oema/diversity\\_tf\\_report.pdf](http://www2.apa.org/pi/oema/diversity_tf_report.pdf)
- Guidelines on Multicultural Education, Training, Research, Practice and Organizational Change for Psychologists, [www.apa.org/pi/multiculturalguidelines](http://www.apa.org/pi/multiculturalguidelines)
- Guidelines for Psychotherapy with Lesbian, Gay and Bisexual Clients, [www.apa.org/pi/lgb/guidelines.html](http://www.apa.org/pi/lgb/guidelines.html)
- Therapeutic Cultural Competence in Theory and Practice Following Hurricane Katrina: Culturally Appropriate Therapeutic Responses to Disaster Relief, a presentation at the 115th Convention of APA
- Posttraumatic Silencing in Ethnic Minority Survivors of Disaster, Francis R. Abeug, PhD, Kaiser Psychiatry Inservice, June 28, 2007
- Multicultural Training: Implications for Disaster Assistance, Beth Boyd, PhD, Disaster Mental Health Institute, August 2007
- APA Disaster Response Network, 2007 Convention Symposium
- APA Monitor on Psychology, "Relief for All," October 2007, [www.apa.org/monitor/oct07/relief.html](http://www.apa.org/monitor/oct07/relief.html)
- Enhancing Your Interaction with People with Disabilities, [www.apa.org/pi/disability/enhancing.html](http://www.apa.org/pi/disability/enhancing.html)
- Cook, J.M. & Elmore, D.L. (in press). Disaster Mental Health in Older Adults: Symptoms, Policy and Planning. In Neria, Y., Galea, S., & Norris, F. (Eds.). The mental health consequences of disasters. New York: Cambridge University Press.
- Elmore, D.L. & Brown, L.M. (2008). Disaster Preparedness, Planning and Response for Older Adults: Implications for Public Policy. *Generations*, 31 (4), 66-74.
- Ethnogeriatric Educational Resources, <http://sgec.stanford.edu/resources/>.
- Fostering Resilience in Response to Terrorism: For Psychologists Working with Older Adults [www.apa.org/psychologists/pdfs/olderadults.pdf](http://www.apa.org/psychologists/pdfs/olderadults.pdf) by Antonette Zeiss and Joan Cook. Although titled as terrorism, they draw upon the trauma research.
- Geriatric Education Center, Stanford University, Curriculum in Ethnogeriatrics, <http://sgec.stanford.edu/resources/ethno.html>.
- Hinrichsen, G.A. (2006). Why multicultural issues matter to practitioners working with older adults. *Professional Psychology: Research and Practice*, 37(1), 29-35.



## Good Questions for Your Good Health

Every time you talk with a doctor, nurse, or pharmacist, use the **Ask Me 3** questions to better understand your health.

1

**What is my main problem?**

2

**What do I need to do?**

3

**Why is it important for me to do this?**

### When to Ask Questions

You can ask questions when:

- You see your doctor, nurse, or pharmacist.
- You prepare for a medical test or procedure.
- You get your medicine.

### What If I Ask and Still Don't Understand?

- Let your doctor, nurse, or pharmacist know if you still don't understand what you need to do.
- You might say, "This is new to me. Will you please explain that to me one more time?"

### Who Needs to Ask 3?

Everyone wants help with health information. You are not alone if you find things confusing at times. Asking questions helps you understand how to stay well or to get better.

The **Ask Me 3** questions are designed to help you take better care of your health.

To learn more, visit [www.npsf.org/askme3](http://www.npsf.org/askme3)

## Your Doctor, Nurse, and Pharmacist Want to Answer 3

Are you nervous to ask your health provider questions? Don't be. You may be surprised to learn that your medical team wants you to let them know that you need help.

Like all of us, doctors have busy schedules. Yet your doctor wants you to know:

- All you can about your condition.
- Why this is important for your health.
- Steps to take to keep your condition under control.

### Asking these questions can help me:

- Take care of my health
- Prepare for medical tests
- Take my medicines the right way
- I don't need to feel rushed or embarrassed if I don't understand something. I can ask my doctor again.
- When I **Ask 3**, I am prepared. I know what to do for my health.

**Bring your medicines with you** the next time you visit your doctor or pharmacist. Or, write the names of the medicines you take on the lines below.

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Like many people, you may see more than one doctor. It is important that your doctors know all the medicines you are taking so that you can stay healthy.

## Write Your Doctor's Answers to the 3 Questions Here:

**1** What is my main problem?

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**2** What do I need to do?

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**3** Why is it important for me to do this?

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**Ask Me 3™** is an educational program provided by the **Partnership for Clear Health Communication at the National Patient Safety Foundation™** – a coalition of national organizations that are working together to promote awareness and solutions around the issue of low health literacy and its effect on safe care and health outcomes.

Partnership for  
Clear Health Communication  
at the National Patient Safety Foundation™

[www.npsf.org/askme3](http://www.npsf.org/askme3)

The image features two modern, perforated plastic chairs. The chair in the foreground is a light grey color, while the one in the background is black. Both chairs have a perforated seat and backrest, and a circular cutout in the upper part of the backrest. They are set against a plain, light-colored background. A white, rounded rectangular text box is centered over the chairs.

**Advocacy, Support Networks**



# Circle of Friends

A Network of Support People Formed Around the Person with a Disability

## How to Hold a Circle of Friends Meeting:

### FOUR STEPS TO BUILDING A CIRCLE

#### 1) FOCUS on an individual -- GENERATE a vision

A vision of what the individual desires will help set guidelines and plan strategies. Do not take on too much. Starting small and insuring positive results will allow movement towards more difficult steps with confidence, especially if there seem to be more barriers to tackle. Knowing the vision will help everyone stay centered when barriers get in the way. Prepare a road map: "know where you are starting, where you are going, how you can get there, when and with whom."

#### Some hints for creating vision:

- Instead of knowing ideas, listen to the desires and wants of the individual. Build on the things they say. Listen to their feelings. Feelings are neither right nor wrong. They just are.
- Assist the individual to be "capacity seeking."
- Look at the person's gifts and contributions to make the vision come alive for them.
- How can the community become part of removing those barriers and making the vision real?
- Don't expect things to happen overnight.
- Let each person share/his/her gifts. Each person has his/her own unique contribution to make. The gifts are as various and as numerous as those who possess them.

#### 2) EMPOWER the focus individual or family, concerning what they see as a vision and work with them to achieve it

- Don't tell them what is right for their child or themselves.
- Help them see THEIR CAPACITIES and work toward the goal with them.
- Get them as close to the dream as possible.
- SELF EMPOWERMENT STARTS FROM THE INSIDE OUT! It does not work from outside in. People short-circuit the process for others by trying to do the task of self-empowerment for them. We tend automatically to think of doing something for them. We do not reflect that they can do something with and for us.
- Don't give the impression that professionals have all the answers.

### 3) WORK WITH interested friends, family and individuals who care

- Have the focus person or focus family invite family members, friends and neighbors to become part of the circle.
- Identify particular networks of people within your group.
- Look for the "gifts" of the people within the circle.
- View different ideas as ways to discover more and see new solutions to a problem.
- Develop strategies to overcome the obstacles and BRING THE VISION TO LIFE for the individual.
- Find ways that certain people in the circle can be a "bridge" for the person with a disability, into particular associations and activities in the community.

### 4) FIND CONNECTIONS within existing family, friend, and neighbor and community resources for getting more involved in community

- Where do relatives, friends work? What clubs do they belong to? What churches do they go to? How might they get you in the door to begin there?
- Who are they? Who are their families? What are their particular needs and interests?
- Look through local community newspapers and newsletters to find resources to meet the challenges of each person's vision.

Reprinted and adapted with permission from "One Candle Power: Building Bridges into Community Life for People with Disabilities", Pat Beeman, George Ducharme, and Beth Mount, 1989, p. 21 and 22, available from The Community Place by Mail, (860) 645-3177



## **Resources**



## Resources

### National

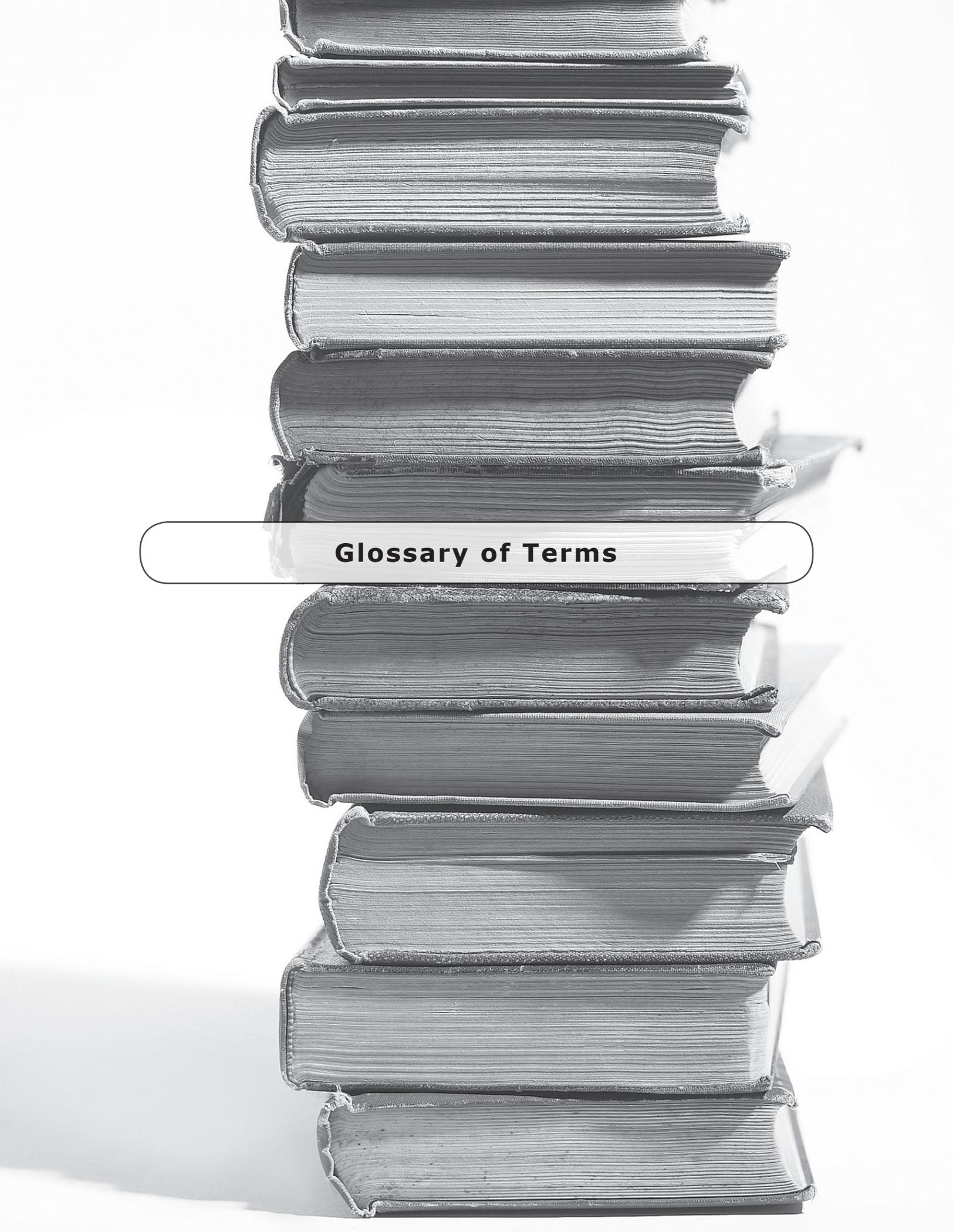
1. American Academy of Pediatrics – The National Center of Medical Home Initiatives for Children with Special Needs.  
[www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)
2. Center for Medical Home Improvement – Building a Medical Home Improvement Strategies in Primary Care for Children with Special Health Care Needs.  
[www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org)
3. Federation for Children with Special Needs – Informing, Educating, Empowering Families  
<http://fcsn.org/index.php>
4. Technical Assistance Partnership for Child and Family Mental Health (TA Partnership)  
[www.tapartnership.org](http://www.tapartnership.org)
5. Family Voices  
[www.familyvoices.org](http://www.familyvoices.org)
6. Pacer Center  
[www.pacer.org](http://www.pacer.org)
7. Healthy & Ready to Work National Resource Center  
[www.hrtw.org](http://www.hrtw.org)
8. Kids As Self-Advocates (KASA) of Family Voices  
[www.fvkasa.org](http://www.fvkasa.org)
9. The Family Village  
[www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

### State

1. N.C. Division of Vocational Rehabilitation  
<http://dvr.dhhs.state.nc.us>
2. N.C. Medicaid – N.C. Division of Medical Assistance  
[www.ncdhhs.gov/dma](http://www.ncdhhs.gov/dma)
3. Social Security  
[www.ssa.gov/atlanta/southwest/nc/north\\_carolina.htm](http://www.ssa.gov/atlanta/southwest/nc/north_carolina.htm)
4. N.C. Community Alternatives Program (CAP)  
[www.ncdhhs.gov/dma/commaltprog.htm](http://www.ncdhhs.gov/dma/commaltprog.htm)

## Care Notebook

1. My Child's Notebook and Organizer – The Swindells Center  
[www.providence.org/childcenter](http://www.providence.org/childcenter)
2. All About My Child – Family Support Network  
[www.FamilySupportNetworkWNC.org](http://www.FamilySupportNetworkWNC.org)
3. Care Notebook – Family Voices of North Dakota  
[www.fvnd@drtel.net](http://www.fvnd@drtel.net)
4. Care Notebook – Center for Children with Special Needs  
[www.cshcn.org](http://www.cshcn.org)
5. American Academy of Pediatrics  
[www.medicalhomeinfo.org/CareNoteBook](http://www.medicalhomeinfo.org/CareNoteBook)
6. ECAC's Care Notebook  
[www.ecac-parentcenter.org/education/documents/CareNotebook\\_R\\_10\\_16\\_08.pdf](http://www.ecac-parentcenter.org/education/documents/CareNotebook_R_10_16_08.pdf)

A vertical stack of approximately ten old, worn books with dark covers and yellowed pages. The books are stacked on a white surface, casting soft shadows to the right. A white, rounded rectangular callout box is centered horizontally across the middle of the stack, containing the text "Glossary of Terms" in a bold, black, sans-serif font.

**Glossary of Terms**



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## **Glossary of Terms**

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### **Advocate**

An advocate is one who speaks out for a person or a cause.

### **CYSCHN – Children and Youth with Special Health Care Needs**

Children up to age 21 who have, or are at increased risk for, chronic physical, developmental, behavioral, and/or emotional conditions that require health and related services of a type or amount beyond those generally required.

### **Care Coordination**

Your child and your family are linked with the right services and resources in a coordinated effort to help your child’s health and development.

### **Guardianship**

Person appointed by the courts to care for and manage the property of another, such as a minor or a person incapable of managing his or her own affairs.

### **Health Care Transition**

The purposeful, planned and timely transition from child- and family-centered health care to patient adult-oriented health care.

### **Health Literacy**

The ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions and follow instructions for treatment.

### **ICE – In Case of Emergency**

### **Medical Home**

An approach to providing health care services in a high quality manner.

### **Medical Power of Attorney**

Authority to act for another regarding medical decisions.

### **Transition Care Plan**

A written health care plan for your child that may include what medications or services your child needs and which specialists your child needs to see.

