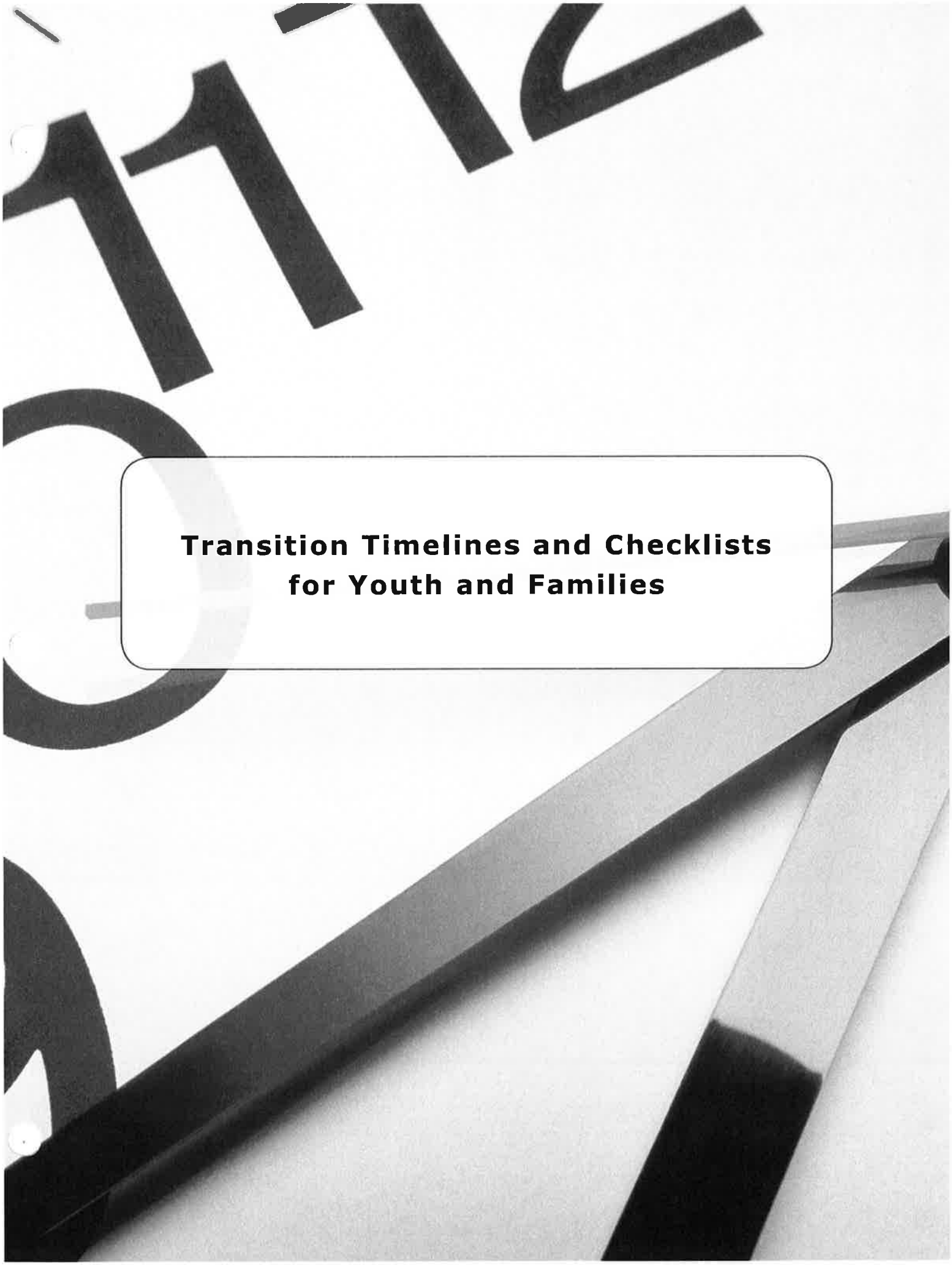
Health Care Transition Toolkit for Families of YSHCN



Transition Timelines and Checklists for Youth and Families

www.hrtw.org

Transitions - Changing Role for Youth

Health & Wellness 101 The Basics	**Yes,** I do this	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

Health & Wellness 101 The Basics	**Yes,** my child/ youth can do this	I want my child/ youth to do this	I need to learn how to teach my child/ youth	Someone else will have to do this for my child/youth Who?
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

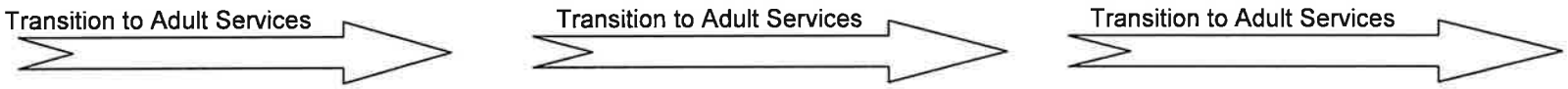
Age 20-21

According to developmental ability young adult can begin to:

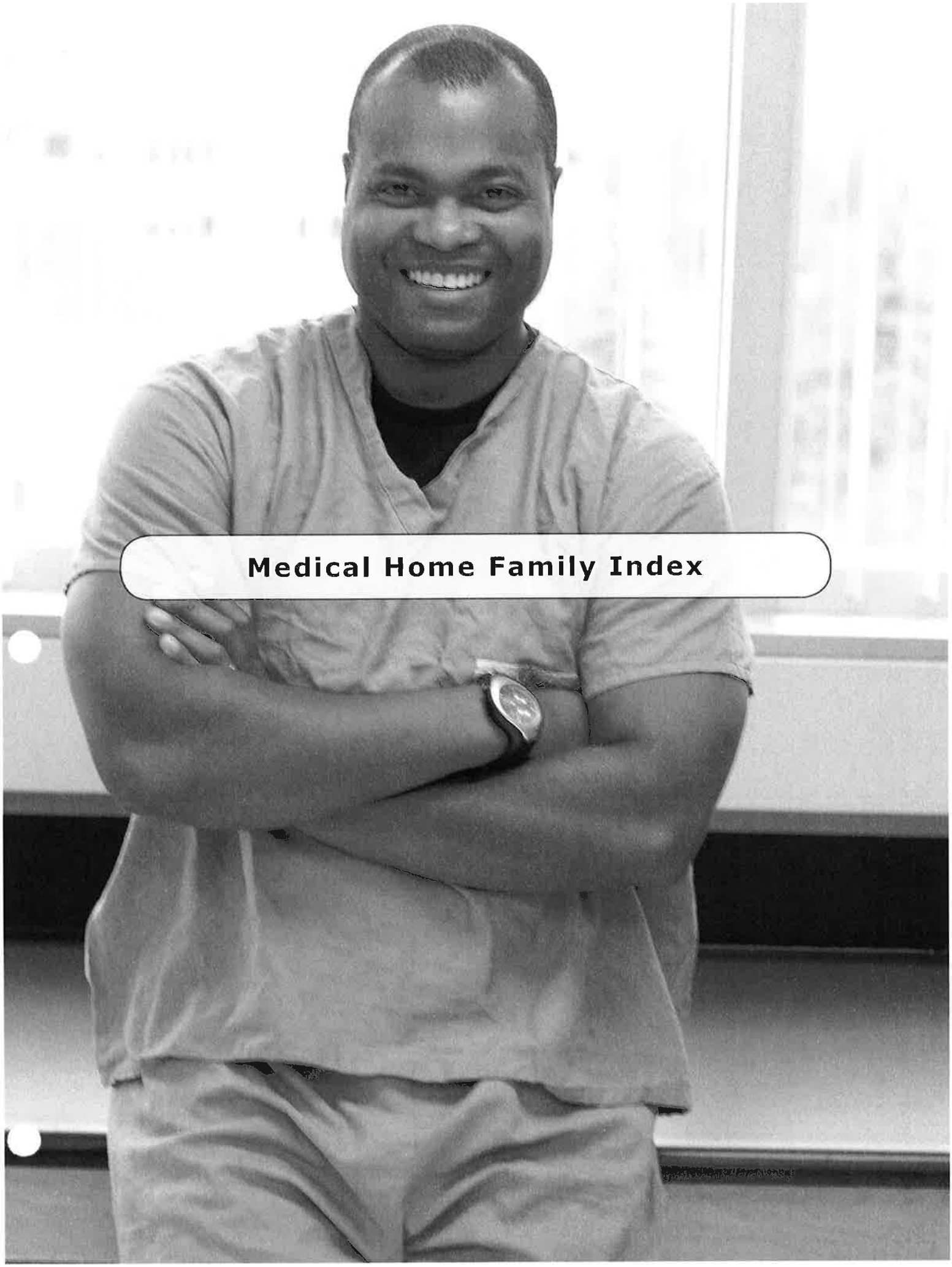
- Explore living arrangements. If assistance is needed contact the nearest Center for Independent Living
- Learn about and continue to investigate adult services there may be need for
- Investigate possibility of enrolling in a Medicaid Health Plan at 21 if currently enrolled in Medicaid
- Transfer all 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



Family Resource 4/05



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 ...

Center for Medical Home Improvement

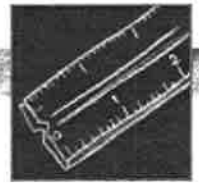
THE MEDICAL HOME *FAMILY* INDEX:

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

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.

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	Never	Sometimes	Often	Always
b) Staff respect our needs and requests	Never	Sometimes	Often	Always
c) Staff remember any special needs or supports that we have asked for	Never	Sometimes	Often	Always
d) We are asked if there are any new needs requiring attention	Never	Sometimes	Often	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	Never	Sometimes	Often	Always
b) With my child (If (b) does not apply to your child ✓here ___)	Never	Sometimes	Often	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 #)	Never	Sometimes	Often	Always
b) Setting short team goals (e.g. for the next three months)	Never	Sometimes	Often	Always
c) Setting long term goals (e.g. for the next year or more)	Never	Sometimes	Often	Always
d) Thorough follow-up with plans created	Never	Sometimes	Often	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



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 Sometimes	 Often Often Often Often	 Always 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	Sometimes	Often	Always

40

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 #: _____

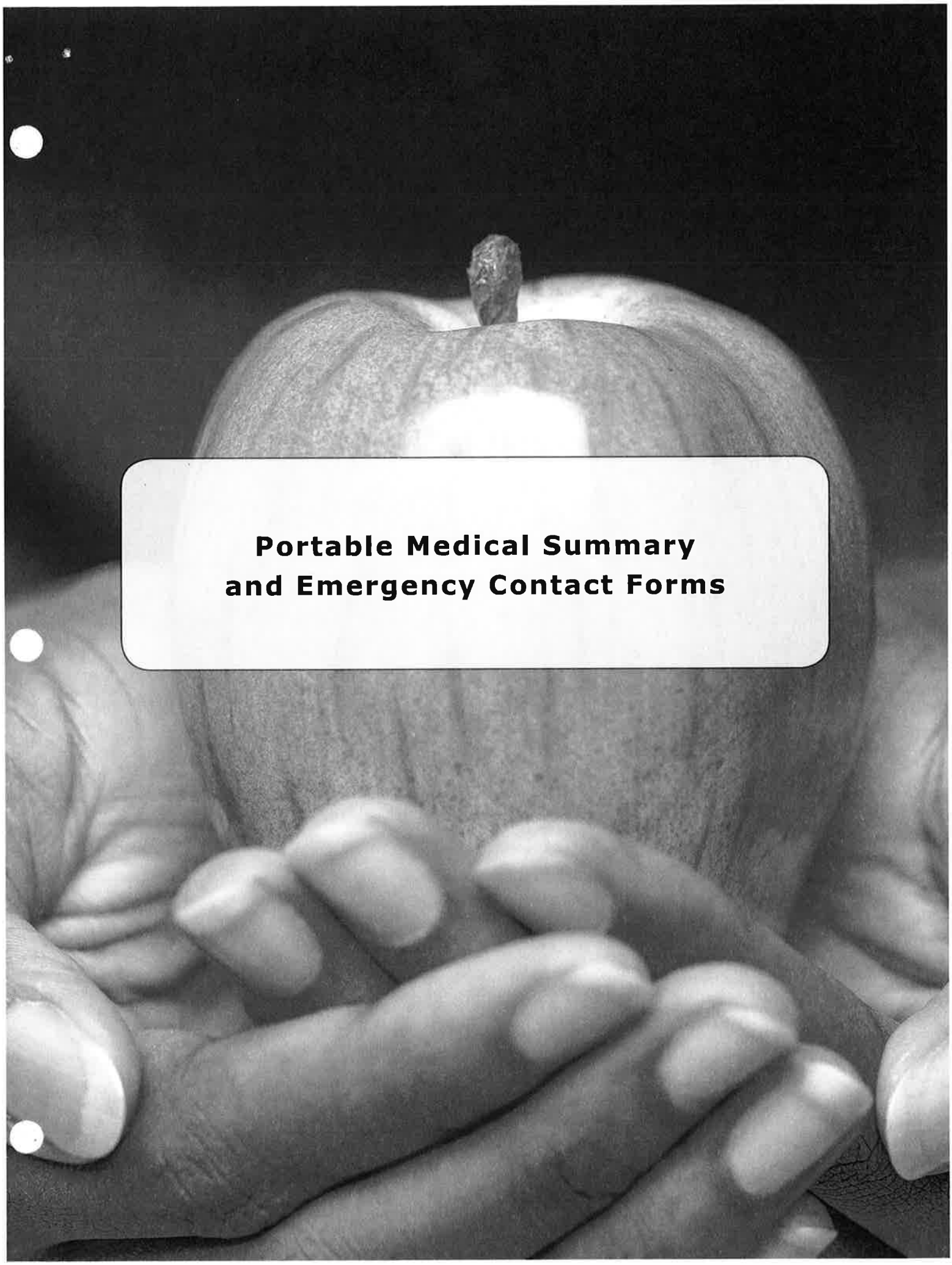
Address: _____ SS# _____

(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*



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**

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

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

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

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

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

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

MEDICATIONS

Rx DAILY

1. Alprazolam (xanax)	0.5 mg QID	anxiety
2. Aspirin-Child	81 mg 1 x	prevent clots
3. Temazepam	15 mg H S	sleeping pill
4. DuoNeb	1 vial QID	nebulizer
	(Ipratropium, Bromide & Albunterol)	

Rx MONTHLY

1. Thiamine	100 mg monthly	vitamin
2. Cyanocobalamin	1000 mcg/ml monthly	(B12)

Rx PRN

1. Darvocet-N		pain
2. Zithromax SUS PFIZ	200/5ml 45ml	antibiotic
3. Diphnoxylate/atropine	1-2 tablets	diarrhea

HERBS / DROPS

1. Lymphatic	5	x2
2. Flu Balancing	10	x2
3. Respiratory	7	x2
4. Allertox –airborne	5	x2
5. " " Aleer-Total	3	x3
6. " " Allerdrain	10	x4
7. Immune	6	x2
8. Acute Rescue	5	x2
9. Urinary	8	x2
10. Digestive	3	x2
11. Mucous	5	x2
12. Cell	7	x2
13. Muscular	4	x2
14. Integumentary	8	x2
15. Er Cheng Tang	1 tsp	x2

VENT / TRACH / 02

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

INSURANCE

BlueCross BlueShield of Massachusetts

Primary Subscriber: xxxxx xxxxx
BC/BS PPO Plan Code 200
Customer service: 800-296-xxxx
XXP XXXXXXX 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 XXXXXXX 10

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

BC/BS Case Manager	Debra XXXXXXX	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		

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

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

MEDICAL	
DOCTORS	**HOSPITAL**
MEDICINES Rx DAILY Rx MONTHLY Rx PRN	**IMMUNIZATIONS**
ADD NAME OF INSURANCE COMPANY *Primary Subscriber:* ADD NAME ADD Plan Code # ADD Subscriber # Customer service: ADD PHONE #	ADD NAME OF INSURANCE COMPANY *Subscriber:* ADD NAME ADD Plan Code # ADD Subscriber # Customer service: ADD PHONE #

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

Emergency Information Form for Children With Special Needs

Last name:

American College of Emergency Physicians*

American Academy of Pediatrics

Date form completed	Revised	Initials
By Whom	Revised	Initials

Name:	Birth date:	Nickname:
Home Address:	Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:	
Signature/Consent*:		
Primary Language:	Phone Number(s):	
Physicians:		
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:		

Diagnoses/Past Procedures/Physical Exam:

1.	Baseline physical findings:
2.	
3.	Baseline vital signs:
4.	
Synopsis:	
	Baseline neurological status:

*Consent for release of this form to health care providers

Last name:

Diagnoses/Past Procedures/Physical Exam continued:

Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1.	
2.	
3.	
4.	Prostheses/Appliances/Advanced Technology Devices:
5.	
6.	

Management Data:

Allergies: Medications/Foods to be avoided	**and why:**
1.	
2.	
3.	
Procedures to be avoided	**and why:**
1.	
2.	
3.	

Immunizations

Dates						**Dates**					
DPT						Hep B					
OPV						Varicella					
MMR						TB status					
HIB						Other					

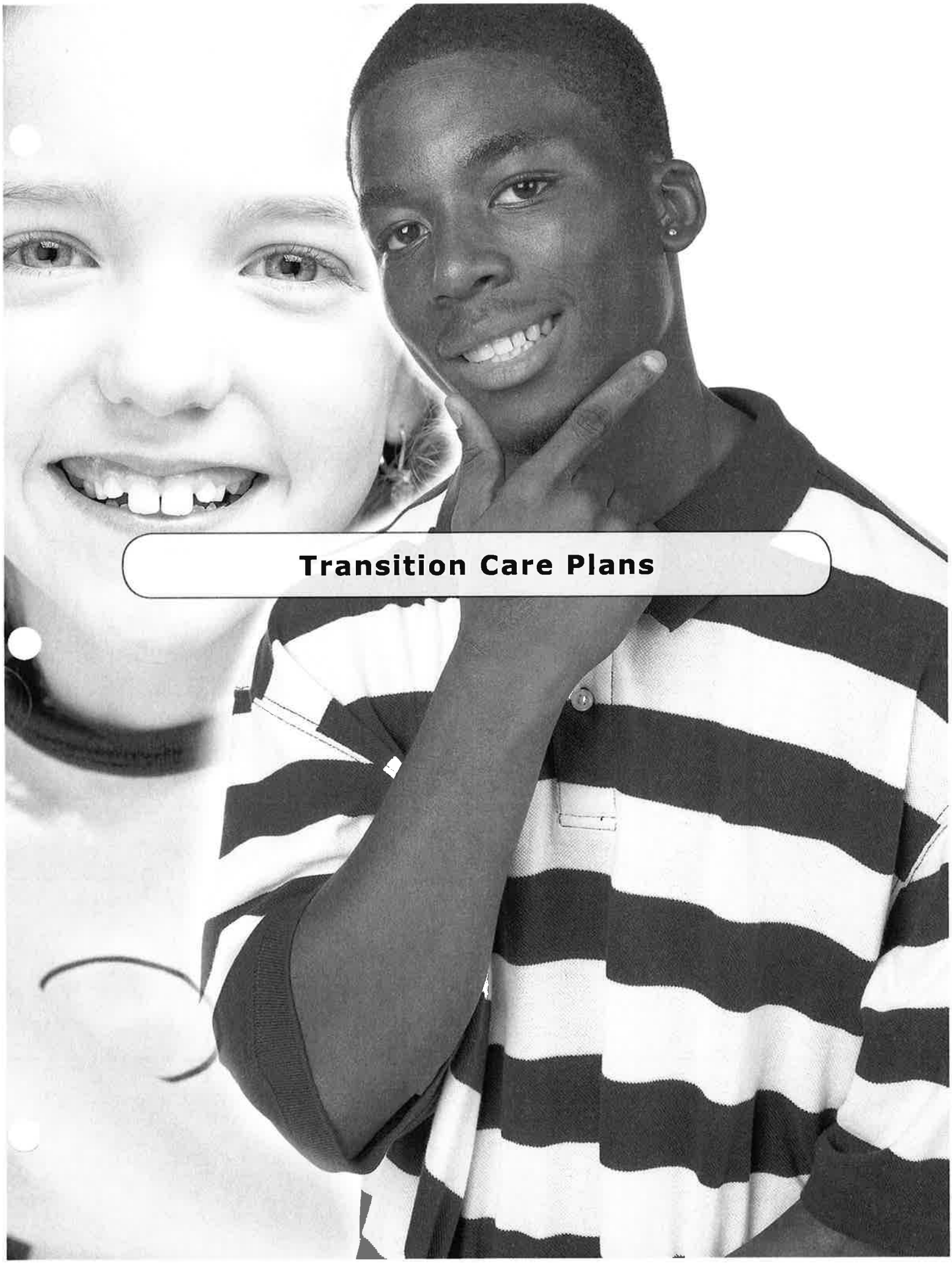
Antibiotic prophylaxis: Indication: Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature: **Print Name:**



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:** _____