

AGES  
15 – 17

# Health Care Transition



# Planning Guide

**For Youth  
and  
Families**

A Product of the Health Care Transition Initiative of the  
Institute for Child Health Policy at the University of Florida

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# Health Care Transition Worksheets for Parents of Youth Age 15 – 17

## Introduction for Parents

Young people with chronic health conditions and disabilities who have reached their goals of being independent and having a good job, say that they had to do several things to be successful. They had to:

- take responsibility for themselves
- manage their own health care
- be as physically fit and healthy as possible.

This Health Care Transition Planning Guide will help you and your child think about future goals and identify things that your child is doing now to be independent in her/his health care. This planning guide will also help you to figure out what needs to be done to assure that your child's future transition from pediatric to adult-oriented health care and to other aspects of adulthood goes as smoothly as possible.

Health care transition is a purposeful planned process that supports adolescents and young adults with chronic health conditions and disabilities to move from child-centered (pediatric) to adult-oriented health care providers, programs, and facilities.

Have your child complete the Worksheets for Youth, which begin on page 21, and provide assistance as needed. Then complete the Parents Worksheets. You may find that some of the items on some of the worksheets do not apply to you or your child. If an item does not apply, put "NA" in the first column.

There are three Worksheets for parents. The first Worksheet asks you to think about what your child's life will be like when he or she is an adult...where they will live; who they will live with; what kind of job will they will have. The second Worksheet asks you to rate your child's ability to independently carry out many different health care activities. On the Youth Worksheet, your child will be rating her/his own ability to do these same health care activities independently.

The third Worksheet asks about what you are doing to help your child be more independent. After you have completed the third Worksheet, review your answers with your daughter or son and discuss what areas you both believe will be important to work on in the coming year. Talk with your daughter or son to select at least three health care transition goals that you and your child will work on during the next 12 months. On the Family Worksheet, write down the activities that you and your child will carry out to complete these goals.

Completing this planning guide will help you, your child, your doctors, teachers and others set goals for your child's future. And it will make clear what you and others need to do to help your child successfully reach these goals.

**NOTE:**

Families have told us that their child's cognitive abilities influence the types of transition activities that need to occur. If your child has a significant cognitive limitation, she/he may not be able function independently, but may still be transferred from pediatric to adult-oriented providers, facilities and programs. While many of the items included in this planning guide will not apply to you and your family, you must still address issues related to guardianship, maintaining health insurance coverage, and finding physicians who can provide care to your adult child. Information specifically designed for parents of children with a significant cognitive limitation is under development, but is not available as of May, 2005.

# Thinking about Your Child's Future

## Worksheet 1 for Parents of Youth Age 15 – 17

**Circle, check or complete the answer that is true for you.**

### 1. School and Work

- My child will go to high school .....Yes No
- My child will finish high school .....Yes No
- After high school, my child will get a job right away .....Yes No
- After high school, my child will go to a vocational, technical or other training program.....Yes No
- After high school, my child will go to a community college (2-year college). .....Yes No
- My child will go to a four year college or university .....Yes No
- My child will have a job when she/he is an adult.....Yes No

What job/jobs do you think your child would like to have? \_\_\_\_\_  
\_\_\_\_\_

### 2. Living Arrangements

When my child is an adult, she/he will live...

- In her/his own house or apartment (with or without a roommate, spouse or partner)
- She/he will continue to live at home with parent(s)
- With other members of the family (brother, sister, aunt)
- In supported community housing (group home)
- Another place (specify): \_\_\_\_\_

### 3. Planning

- I talk with my child about her/his future .....Yes No
- My child talks with her/his friends about the future. ....Yes No

## Your Child's Health Care Independence

### Worksheet 2 for Parents of Youth Age 15 - 17

#### Instructions

Please rate your child's ability to carry out each of the following health care activities by placing an X in the column that best describes her/his behavior. If an item does not apply, put "NA" in the first column.

|    | <i>Basic Knowledge</i>  | My child does this independently OR knows how to do this and directs others | My child does this with some help | My child cannot do this OR does this only with lots of help |
|----|---|---|-----------------------------------|---|
| 1. | My child can tell someone what her/his diagnosis, disability or health condition is.  |   |                                   |   |
| 2. | My child can describe her/his disability or health condition and its affect on her/his body   |   |                                   |   |
| 3. | My child can describe how her/his disability or health condition effects her/his daily life   |   |                                   |   |
| 4. | My child can tell a doctor or nurse her/his medical history   |   |                                   |   |
| 5. | My child can tell someone about the health problems her/his disability or health condition often causes.  |   |                                   |   |
| 6. | My child can list her/his allergies and get help when she/he has an allergic reaction.  |   |                                   |   |
| 7. | My child keeps a personal health notebook or medical journal  |   |                                   |   |
| 8. | My child carries a Medical Summary (a written form that has information about her/his diagnosis, medications, equipment, doctors, and what to do in a medical emergency.) | YES   |                                   | NO  |

Your Child's Health Care Independence (continued)

|    | <i>Health Care Practices</i>   | My child does this independently OR knows how to do this and directs others | My child does this with some help | My child does <u>not</u> do this OR does this only with lots of help |
|----|--|---|-----------------------------------|--|
| 1. | My child dresses, feeds, bathes, and care for her/himself  |   |                                   |  |
| 2. | My child completes daily or usual medical tasks  |   |                                   |  |
|    | List usual or daily medical tasks & rate your child's independence   |   |                                   |  |
|    | a.   |   |                                   |  |
|    | b.   |   |                                   |  |
|    | c.   |   |                                   |  |
| 3. | My child can tell someone what smoking, taking drugs or alcohol, or the lack of exercise can do to her/him                                 |   |                                   |  |
| 4. | My child makes good choices about friends, food, exercise, alcohol and smoking in order to stay healthy                                    |   |                                   |  |
| 5. | My child does a Testicular Self Exam or Breast Self Exam regularly   | YES   |                                   | NO   |
| 6. | My child knows about abstinence until marriage, safe sex practices, birth control and how to protect her/himself against STD's             | YES   |                                   | NO   |
| 7. | My child can tell someone about how her/his disability or health condition might effect her/his sexual development and reproductive health | YES   |                                   | NO   |

|    | <i>Medications, Medical Tests, Equipment and Supplies</i>  | My child does this independently OR knows how to do this and directs others | My child does this with some help | My child does <u>not</u> do this OR does this only with lots of help |
|----|--|---|-----------------------------------|--|
| 1. | My child can name her/his medications (using their proper names), and the amount and times she/he takes them |   |                                   |  |
| 2. | My child can tell someone why she/he takes each of her/his medications                                       |   |                                   |  |
| 3. | My child can tell someone what the side effects of her/his medications are                                   |   |                                   |  |
| 4. | My child takes her/his medications correctly   |   |                                   |  |

|     | <b><i>Medications, Medical Tests, Equipment and Supplies</i></b><br><i>(continued)</i>  | My child does this independently | My child does this with help | My child does <u>not</u> do this |
|-----|---|----------------------------------|------------------------------|----------------------------------|
| 5.  | My child can tell someone the difference between generic and brand name (proprietary) medications   |                                  |                              |                                  |
| 6.  | My child selects the medications she/he need when she/he has a minor illness (a headache or a cold)   |                                  |                              |                                  |
| 7.  | My child can tell someone about medications that should not be taken because they might interact with her/his medications   |                                  |                              |                                  |
| 8.  | My child can tell someone what happens if she/he does not take her/his medication correctly   |                                  |                              |                                  |
| 9.  | My child tells me when her/his supply of medications is low, and orders more  |                                  |                              |                                  |
| 10. | My child can list the medical tests she/he has regularly and makes sure these are done on time  |                                  |                              |                                  |
| 11. | My child uses and takes care of her/his medical equipment and/or supplies; contacts vendors about equipment problems and/or orders her/his supplies when they are running out |                                  |                              |                                  |

|    | <b><i>Doctor Visits</i></b>  | My child does this independently OR knows how to do this and directs others | My child does this with some help | My child cannot do this OR does this only with lots of help |
|----|--|---|-----------------------------------|---|
| 1. | My child tells her/his doctors and nurses what's wrong   |   |                                   |   |
| 2. | My child <u>answers</u> many of the questions during a health care visit   |   |                                   |   |
| 3. | My child <u>asks</u> many questions during a health care visit   |   |                                   |   |
| 4. | My child fills out her/his personal health history form at the doctor's office                                   |   |                                   |   |
| 5. | My child spends most of the time alone with the doctor(s) during health care visits                              | YES   |                                   | NO  |
| 6. | My child, her/his doctors and I decide together what medicines and treatments she/he needs                       | YES   |                                   | NO  |
| 7. | My child can contact her/his doctors to tell them about unusual changes in her/his health.                       | YES   |                                   | NO  |
| 8. | My child tells her/his doctors that she/he understands and agrees with the medicines and treatments they suggest | YES   |                                   | NO  |



|    | <i>Health Care Transition</i>  | My child has done this |  | My child has NOT done this |
|----|--|------------------------|--|----------------------------|
| 1. | My child has found out from her/his doctors if they stop seeing patients at a certain age (for example, if they do not take care of patients who are older than 21)  |                        |  |                            |
| 2. | My child has talked with her/his doctor or nurse about going to different doctors when she/he is an adult  |                        |  |                            |
| 3. | My child has talked with doctors and family about what things to consider when selecting adult doctors (for example: size of the practice, experience with taking care of people with her/his condition or disability) |                        |  |                            |
| 4. | My child has helped to identify some adult doctors that she/he might go to when she/he is older  |                        |  |                            |
| 5. | My child has set goals for taking care of her/his own health   |                        |  |                            |
| 6. | My child has taken more responsibility for her/his own health care by learning new skills  |                        |  |                            |
| 7. | My child has talked to older kids or young adults about health care transition   |                        |  |                            |
| 8. | My child has talked with her/his nurse or social worker about health care transition   |                        |  |                            |

|    | <i>Transition to Adulthood</i>   | My child does this independently OR knows how to do this and directs others | My child does this with some help | My child does <u>not</u> do this OR does this only with lots of help |
|----|--|---|-----------------------------------|--|
| 1. | My child has attended a school IEP or 504 meeting                                    |   |                                   |  |
| 2. | My child manages all of her/his regular medical tasks at school                      |   |                                   |  |
|    | List medical tasks that need to be completed at school and rate child's independence |   |                                   |  |
|    | a.   |   |                                   |  |
|    | b.   |   |                                   |  |
|    | c.   |   |                                   |  |
|    | d.   |   |                                   |  |
| 3. | My child tells her/his teachers or nurses about unusual changes in her/his health    |   |                                   |  |
| 4. | My child regularly does chores at home   |   |                                   |  |

Your Child's Health Care Independence (continued)

|    | <i>Transition to Adulthood (continued)</i>   | My child does this independently | My child does this with help | My child does <u>not</u> do this |
|----|--|----------------------------------|------------------------------|----------------------------------|
| 5. | My child participates in social activities in the community  |                                  |                              |                                  |
| 6. | My child uses a checking account or a debit card   |                                  |                              |                                  |
| 7. | My child has helped to develop a plan for her/his education, work, and living on her/his own                                     | YES                              |                              | NO                               |
| 8. | My child has applied for or received services from the state Vocational Rehabilitation Program (age 16 or older)                 | YES                              |                              | NO                               |
| 9. | My child has helped to find information about scholarships and other sources of funding for future education and/or job training | YES                              |                              | NO                               |

|    | <i>Health Care Systems</i>  | My child does this independently OR knows how to do this and directs others | My child does this with some help | My child does <u>not</u> do this OR does this only with lots of help |
|----|---|---|-----------------------------------|--|
| 1. | My child can tell someone the date and reason for her/his next health care appointment  |   |                                   |  |
| 2. | My child can call her/his primary care doctor's or specialist's office to make or change an appointment   |   |                                   |  |
| 3. | My child can tell someone the name of her/his health insurance plan   |   |                                   |  |
| 4. | My child can tell someone how her/his health insurance works (co-pays, deductibles, provider networks)  |   |                                   |  |
| 5. | My child can tell someone about limitations that her/his health insurance plan has and problems she/he need to watch out for when ordering supplies and/or medication and other equipment |   |                                   |  |
| 6. | My child can tell someone if she/he receives benefits from the Supplemental Security Income (SSI) Program and if she/he might be eligible for SSI when she/he turns 18                    | YES   |                                   | NO   |
| 7. | My child can tell someone the differences between a primary care doctor and a specialist  | YES   |                                   | NO   |

Your Child's Health Care Independence (continued)

|     | <i>Health Care System<br/>(continued)</i>  | YES |  | NO |
|-----|--|-----|--|----|
| 8.  | My child can tell someone what adult doctors expect their patients to be able to do (meet with them alone, answer and ask questions, make decisions about their health care)       | YES |  | NO |
| 9.  | My child can tell someone what new legal rights and responsibilities she/he will have when she/he turns 18 (for example, sign medical consent forms and make medical decisions)    | YES |  | NO |
| 10. | My child can tell someone how long she/he can be covered under the family health insurance plan, and what she/he needs to do to maintain coverage (such as be a full time student) | YES |  | NO |

## Parents Health Care Transition Activities

### Worksheet 3 for Parents of Youth Age 15 - 17

#### **Instructions**

Please place an X in the column that best describes what you have done about your child health care transition. If an item does not apply, put “NA” in the first column.

|     |   | <b>I do this often or regularly</b> | <b>I do this sometimes</b> | <b>I do this rarely or never</b> |
|-----|---|-------------------------------------|----------------------------|----------------------------------|
| 1.  | I encourage my child to take an active role in her/his health care. (For examples of some things your child could take responsibility for, see items in Worksheet 2.)                 |                                     |                            |                                  |
| 2.  | I help my child update information in her/his personal Health History Notebook or Medical Journal or her/his Medical Summary Form; and to become more independent in these activities |                                     |                            |                                  |
| 3.  | I help my child prepare questions to ask her/his doctors during a health care visit   |                                     |                            |                                  |
| 4.  | I involve my child in registering or checking in for appointments, and showing a health insurance card  |                                     |                            |                                  |
| 5.  | I involve my child in filling out her/his personal health history form at health care visits  |                                     |                            |                                  |
| 6.  | I encourage my child to see her/his primary and specialty care providers independently for most or the entire medical visit   |                                     |                            |                                  |
| 7.  | When my child sees the doctor by her/himself, I meet with doctors and my child at the end of the visit to review information; answer questions and address concerns                   |                                     |                            |                                  |
| 8.  | I work with the school staff to allow my child to manage her/his medical tasks in the school setting  |                                     |                            |                                  |
| 9.  | I give my child household responsibilities and expect her/him to complete chores  |                                     |                            |                                  |
| 10. | I encourage my child to have friends and support her/his involvement in activities in the community   |                                     |                            |                                  |

|     |  | <b>I have done this</b> |  | <b>I have NOT done this</b> |
|-----|--|-------------------------|--|-----------------------------|
| 11. | I help my child identify her/his vocational interests and to plan for education, training and/or employment after high school  |                         |  |                             |
| 12. | I have found out from my child's doctors if they stop seeing patients at a certain age (if they do not take care of patients who are, for example, older than 21)  |                         |  |                             |
| 13. | I have talked with my child about her/his future transition to adult health providers  |                         |  |                             |
| 14. | I have talked with my child and/or her/his doctors about what things need to be considered when selecting adult primary and specialty care doctors (for example: size of the practice, experience with taking care of people with her/his condition or disability) |                         |  |                             |
| 15. | I have identified some adult doctors that my child might go to when she/he is older  |                         |  |                             |
| 16. | I have participated in development of a Health Care Transition Plan for my child   |                         |  |                             |
| 17. | I have talked with parents of adolescents and young adults who have transitioned from pediatric to adult health care   |                         |  |                             |
| 18. | I have recommended that health care issues and tasks be included in my child's school Individualized Education Plan (IEP) or 504 Plan  |                         |  |                             |
| 19. | I have helped my child learn how to use a checking account or debit card and how to manage money   |                         |  |                             |
| 20. | I have helped my child apply for Vocational Rehabilitation services (age 16 and older)   |                         |  |                             |
| 21. | I have given my child a health insurance card  |                         |  |                             |
| 22. | I have told my child about health insurance problems to look out for when ordering supplies and/or medication and other equipment  |                         |  |                             |
| 23. | I have checked with my health insurance plan to find out about age limits and terms of coverage for my child   |                         |  |                             |

|     |   | <b>I have done this</b> |  | <b>I have NOT done this</b> |
|-----|---|-------------------------|--|-----------------------------|
| 24. | I have found out how my child's vocational and educational choices will effect her/his future health insurance options                                      |                         |  |                             |
| 25. | I have identified ways that my child can get health insurance coverage when she/he is an adult  |                         |  |                             |
| 26. | I told my child if she/he receives benefits from the Supplemental Security Income (SSI) and talked with her/him about applying for SSI when she/he turns 18 |                         |  |                             |
| 27. | I have discussed with my child the new legal rights and responsibilities she/he will have when she/he turns 18 (i.e. medical consent; confidentiality)      |                         |  |                             |

List below other things you have done, as a parent, to promote independence and prepare for health care transition.

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## **Health Care Transition Plan Family Worksheet Worksheet 4**

### **Instructions:**

You and your child should work together on the Health Care Transition Plan Family Worksheet.

First, compare your answers on Worksheet 1 (Thinking about your Child's Future) with what your child thinks her/his life will be like when she/he is an adult. Talk about the differences and similarities in the answers to the questions about where your child will live; who she/he will live with; what kind of job she/he will have.

Then compare your answers on Worksheet 2 (Health care Independence) to what your child said about his/her own ability to do health care activities on their own and talk about the differences and similarities in your answers. Then work together to identify several activities that your child could do more independently in the future.

Then review your answers on Worksheet 3 with your child. See if your child agrees with you about you do, as a parent, to help your child become more independent. Then work together to identify several activities that you could do to help your child be more independent in the future.

Finally, with these activities in mind, choose at least three General Goals from the list below that you and your child will work on during the next 12 months. In the space provided, write a more specific goal and identify the activities that you and your child will do to complete the specific goal.

## Health Care Transition Plan Family Worksheet

| <i>General Goals</i>  | Use the space in this column to write a more specific goal and the activities that you and your child will do to complete this specific goal |
|---|--|
| <p><u>Basic Knowledge</u><br/>My child will/ I will help my child learn more about her/his health condition.</p>  | Specific goal and activities.  |
| <p><u>Basic Knowledge</u><br/>My child will/ I will help my child be able to tell her/his health care providers about what she/he has learned about her/his health condition.</p>                                   | Specific goal and activities.  |
| <p><u>Health Care Practices</u><br/>My child will/I will help my child be more independent in dressing, feeding and self care and/or will take a lead role in directing others in the completion of these tasks</p> | Specific goal and activities.  |



|  |                                      |
|--|--------------------------------------|
| <p><u>Health Care Practices</u><br/>         My child will/I will help my child be more independent in completing daily/usual medical tasks and/or will take a lead role in directing others in the completion of these tasks.</p> | <p>Specific goal and activities.</p> |
| <p><u>Health Care Practices</u><br/>         My child will/I will help my child learn more about and practice good health habits.</p>  | <p>Specific goal and activities.</p> |
| <p><u>Medications, Tests, Equipment &amp; Supplies</u><br/>         My child will/I will help my child learn more about her/his medications and treatments</p>   | <p>Specific goal and activities.</p> |

|  |                                      |
|--|--------------------------------------|
| <p><u>Medications, Tests, Equipment &amp; Supplies</u><br/>         My child will /I will help my child be more responsible for ordering medications, maintaining equipment and ordering supplies.</p>                               | <p>Specific goal and activities.</p> |
| <p><u>Doctor Visits</u><br/>         My child will/I will help my child take a more active role in her/his doctor visits (For example, answer the doctor's questions, ask questions, see the doctor alone for part of the visit)</p> | <p>Specific goal and activities.</p> |
| <p><u>Health Care Transition</u><br/>         My child will/I will help my child learn more about health care transition.</p>  | <p>Specific goal and activities.</p> |

|   |                                      |
|---|--------------------------------------|
| <p><u>Transition to Adulthood</u><br/>My child will/I will help my child take more responsibility for her/his health care in the school setting.</p>              | <p>Specific goal and activities.</p> |
| <p><u>Transition to Adulthood</u><br/>My child will/I will help my child begin to prepare for transition to higher education, work and living on her/his own.</p> | <p>Specific goal and activities.</p> |

|  |                                      |
|--|--------------------------------------|
| <p><u>Health Care Systems</u><br/>My child will/I will help my child know more about the purpose of medical visits and how to contact her/his doctors.</p> | <p>Specific goal and activities.</p> |
| <p><u>Health Care Systems</u><br/>My child will/I will help my child know more about health care insurance.</p>  | <p>Specific goal and activities.</p> |

## Health Care Transition Worksheets for Youth Age 15 – 17

### Introduction for Youth

Young people with chronic health conditions and disabilities who have reached their goals of being independent and having a good job, say that they had to do several things to be successful. They had to:

- to take responsibility for themselves
- manage their own health care
- be as physically fit and healthy as possible.

This planning guide will help you and your family think about your future and identify things that you are doing now to be independent in your health care. This planning guide will also help you figure out what you and your family need to do to assure that your transition from child-centered (pediatric) to adult-oriented health care and to other aspects of adulthood goes as smoothly as possible.

Health care transition is the process that supports adolescents and young adults with chronic health conditions and disabilities move from child-centered to adult-oriented health care providers, programs, and facilities.

Your parents will fill out the Parent Worksheets, and you will fill out the Youth Worksheets. It's OK to ask your parents to help you fill out your Worksheets. You may find that some of the items on some of the worksheets do not apply to you. If an item does not apply, put "NA" in the first column.

There are two worksheets for youth. The first Worksheet asks you to think about what your life will be like when you are an adult...where you will live; who you will live with; what kind of job you will have. The second Worksheet asks you to rate your ability to do health care activities on your own.

After you have completed your two Worksheets, and your parents have completed their Worksheets, you and your parents will review your answers together. Then you and your parents can work together to select at least three health care transition goals to work on during the next 12 months. On the Family Worksheet, which is included with the Parents Worksheets, write down the activities that you and your family will work on to complete these goals.

Your answers to the questions that follow will help you, your family, your doctors, your teachers and others know what you want your life to be like as you get older; and what you and others need to do to help you reach your goals.

## Thinking About Your Future Worksheet 1 for Youth Age 15 – 17

**Circle, check or complete the answer that is true for you.**

### 1. School and Work

I plan to go to high school .....Yes No

I plan to finish high school .....Yes No

After high school, I plan to get a job right away .....Yes No

After high school, I plan to go to a vocational, technical or other training program. ....Yes No

After high school, I plan to go a community college (2-year college) .....Yes No

I plan to go a four year college or university .....Yes No

I plan to have a job when I am an adult .....Yes No

What kind of jobs would you like to have? \_\_\_\_\_  
\_\_\_\_\_

### 2. Living Arrangements

When I am an adult, I plan to live...

- In my own house or apartment (by myself or with a spouse, partner or roommates)
- With my parents
- With other members of my family (brother, sister, aunt)
- In supported community housing (group home)
- Another place (specify): \_\_\_\_\_

### 3. Planning

I talk with my parents about my future .....Yes No

I talk with my friends about my future .....Yes No

## Health Care Independence

### Worksheet 2 for Youth Age 15 - 17

#### Instructions

Please rate your ability to carry out each of the following health care activities by placing an X in the column that best describes your behavior. If an item does not apply, put “NA” in the first column.

|    | <i>Basic Knowledge</i>   | I do this on my own OR<br>I know how to do this and<br>direct others | I do this with<br>some help | I cannot do this OR<br>I do this only with<br>lots of help |
|----|--|--|-----------------------------|--|
| 1. | I can tell someone what my diagnosis, disability or health condition is  |  |                             |  |
| 2. | I can describe my disability or health condition and its effect on my body   |  |                             |  |
| 3. | I can describe how my disability or health condition affects my daily life   |  |                             |  |
| 4. | I can tell a doctor or nurse about my medical history  |  |                             |  |
| 5. | I can tell someone about the health problems my disability or health condition often causes  |  |                             |  |
| 6. | I can list my allergies and get the help I need if I have an allergic reaction   |  |                             |  |
| 7. | I keep a personal health notebook or medical journal   |  |                             |  |
| 8. | I carry a Medical Summary (a written form that has information about my diagnosis, medications, equipment, doctors, and what to do in a medical emergency) with me | YES  |                             | NO   |

|    | <i>Health Care Practices</i>  | I do this on my own OR<br>I know how to do this and<br>direct others | I do this with<br>some help | I do <u>not</u> do this OR<br>I do this only with<br>lots of help |
|----|---|--|-----------------------------|---|
| 1. | I dress, feed, bathe, and care for myself   |  |                             |   |
| 2. | I complete all my daily or usual medical tasks  |  |                             |   |
|    | List usual or daily medical tasks & rate your independence  |  |                             |   |
|    | a.  |  |                             |   |
|    | b.  |  |                             |   |
|    | c.  |  |                             |   |
| d. |   |  |                             |   |
| 3. | I can tell someone what smoking, taking drugs or alcohol, or the lack of exercise can do to me                            |  |                             |   |
| 4. | I make good choices about friends, food, exercise, alcohol and smoking in order to stay healthy                           |  |                             |   |
| 5. | I do a Testicular Self Exam or Breast Self Exam regularly   | YES  |                             | NO  |
| 6. | I know about abstinence before marriage, safe sex practices, birth control, and how to protect myself against STD's       | YES  |                             | NO  |
| 7. | I can tell someone about how my disability or health condition might effect my sexual development and reproductive health | YES  |                             | NO  |

|    | <i>Medications, Medical Tests,<br/>Equipment and Supplies</i>   | I do this on my own OR<br>I know how to do this and<br>direct others | I do this with<br>some help | I do <u>not</u> do this OR<br>I do this only with<br>lots of help |
|----|---|--|-----------------------------|---|
| 1. | I can name my medications (using their proper names), and the amount and times I take them                  |  |                             |   |
| 2. | I can tell someone why I take each of my medications  |  |                             |   |
| 3. | I can tell someone what the side effects of my medications are and what I should do if I have a side effect |  |                             |   |
| 4. | I take my medications correctly   |  |                             |   |



|     | <b><i>Medications, Medical Tests, Equipment and Supplies</i></b><br><i>(continued)</i>   | I do this on my own OR<br>I know how to do this and<br>direct others | I do this with<br>some help | I do <u>not</u> do this OR<br>I do this only with<br>lots of help |
|-----|--|--|-----------------------------|---|
| 5.  | I can tell someone the difference between generic and brand name (proprietary) medications   |  |                             |   |
| 6.  | I can select the medications I need when I have a minor illness (a headache or a cold)   |  |                             |   |
| 7.  | I can tell someone about medications I should not take because they might interact with the medications I take   |  |                             |   |
| 8.  | I can tell someone what happens to me if I do not take my medications correctly  |  |                             |   |
| 9.  | I reorder my medications when my supply is low and call my doctor when I need a new prescription   |  |                             |   |
| 10. | I can list the medical tests I have regularly and I make sure these are done on time   |  |                             |   |
| 11. | I use and take care of my medical equipment and/or supplies; contact the vendor when there are equipment problems and/or order my supplies when they are running out |  |                             |   |

|    | <b><i>Doctor Visits</i></b>   | I do this on my own OR<br>I know how to do this and<br>direct others | I do this with<br>some help | I do <u>not</u> do this OR<br>I do this only with<br>lots of help |
|----|---|--|-----------------------------|---|
| 1. | I tell my doctors and nurses what's wrong   |  |                             |   |
| 2. | I answer many of the questions during a health care visit                               |  |                             |   |
| 3. | I ask many questions during a health care visit   |  |                             |   |
| 4. | I fill out the personal health history form at the doctor's office                      |  |                             |   |
| 5. | I spend most of the time alone with the doctor(s) during health care visits             | YES  |                             | NO  |
| 6. | I decide with my parents and/or doctors what medicines and treatments I need            | YES  |                             | NO  |
| 7. | I can contact my doctors to tell them about unusual changes in my health                | YES  |                             | NO  |
| 8. | I tell my doctors I understand and agree with the medicines and treatments they suggest | YES  |                             | NO  |

|    | <i>Health Care Transition</i>   | I have done this |  | I have NOT done this |
|----|---|------------------|--|----------------------|
| 1. | I have found out from my doctors if they stop seeing patients who are older than a certain age (for example, if they do not take care of patients who are older than 21)  |                  |  |                      |
| 2. | I have talked with my doctor or nurse about going to different doctors when I am an adult   |                  |  |                      |
| 3. | I have talked with my doctors and/or family about what things I need to consider when selecting adult primary and specialty care doctors (for example: size of the practice, their experience with taking care of people with my condition or disability) |                  |  |                      |
| 4. | I have identified some adult doctors that I might go to when I am older   |                  |  |                      |
| 5. | I have set goals for taking care of my own health   |                  |  |                      |
| 6. | I have taken more responsibility for my own health care by learning new skills  |                  |  |                      |
| 7. | I have talked to older kids or young adults about health care transition  |                  |  |                      |
| 8. | I have talked with my care coordinator about my plans for health care transition  |                  |  |                      |

|    | <i>Transition to Adulthood</i>   | I do this on my own OR I know how to do this and direct others | I do this with some help | I do <u>not</u> do this OR I do this only with lots of help |
|----|--|--|--------------------------|---|
| 1. | I have attended my school IEP or 504 meeting   | YES  |                          | NO  |
| 2. | I manage all of my regular medical tasks at school                                       |  |                          |   |
|    | List medical tasks that need to be completed at school & rate your level of independence |  |                          |   |
|    | a.   |  |                          |   |
|    | b.   |  |                          |   |
|    | c.   |  |                          |   |
|    | d.   |  |                          |   |
| 3. | I tell my teacher or nurse about unusual changes in my health                            |  |                          |   |
| 4. | I regularly do chores at home  |  |                          |   |
| 5. | I participate in social activities in my community                                       |  |                          |   |
| 6. | I use a checking account or a debit card   |  |                          |   |

|    | <i>Transition to Adulthood (continued)</i>  | I do or have done this |  | I have NOT done this |
|----|---|------------------------|--|----------------------|
| 7. | I have developed a plan for my future education, work, and living on my own with my parents, or school counselor or doctor or nurse |                        |  |                      |
| 8. | I have applied for or receive services from the state Vocational Rehabilitation Program (age 16 or older)                           |                        |  |                      |
| 9. | I have found information about scholarships and other sources of funding for my future education and/or job training                |                        |  |                      |

|     | <i>Health Care Systems</i>   | I do this on my own OR I know how to do this and direct others | I do this with some help | I do <u>not</u> do this OR I do this only with lots of help |
|-----|--|--|--------------------------|---|
| 1.  | I can tell someone the date and reason for my next health care appointment   |  |                          |   |
| 2.  | I call my primary care doctor's or specialist's office to make or change appointments  |  |                          |   |
| 3.  | I can tell someone the name of my health insurance   |  |                          |   |
| 4.  | I can tell someone about how my health insurance works (co-pays, deductibles, provider networks)   |  |                          |   |
| 5.  | I can tell someone about the limitations of my health insurance plan and about the problems I need to watch out for when ordering supplies and/or medication and other equipment |  |                          |   |
| 6.  | I can tell someone if I receive benefits from the Supplemental Security Income (SSI) Program now and if I might be eligible for SSI when I turn 18                               | YES  |                          | NO  |
| 7.  | I can tell someone the differences between a primary care doctor and a specialist  | YES  |                          | NO  |
| 8.  | I can tell someone what adult doctors expect their patients to be able to do (meet with them alone, answer and ask questions, make decisions about their health care)            | YES  |                          | NO  |
| 9.  | I can tell someone what new legal rights and responsibilities I will have when I turn 18 years old. (for example, sign medical consent forms; make medical decision by myself)   | YES  |                          | NO  |
| 10. | I know how long I can be covered under my parent's health insurance plan and what I need to do to maintain coverage (like be a full time student)                                | YES  |                          | NO  |

## Credits

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Items included in the Planning Guides are based, in part, on material included in the following resources:

Audit Proforma for Paediatric to Adult Services Transfer. Research Unit of the Royal College of Physicians (London, England).

<http://hctransitions.ichp.edu/resources.html>

Get A Life: Transition Planning Book. Interdisciplinary Human Development Institute at the University of Kentucky. And the Kentucky Commission for Children with Special Health Care Needs. <http://www.ihdi.uky.edu/ktcp/materials/>

Getting On Trac (for youth) and Setting the Trac (for providers). Youth Health Program at Children's & Women's Health Centre of British Columbia

<http://www.cw.bc.ca/youthhealth/resources.asp#toolbox>

It's Your Future – Go For It ! A Transition Guide for Teens and Parents. Shriners Hospital for Children, Northern California.

<http://www.shrinershq.org/shc/northerncalifornia/patientinfo.html>

Transition Health Care Assessment (adolescent and provider versions), California's Healthy and Ready to Work (HRTW) Project.

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

Transition Planning for Adolescents with Special Health Care Needs and Disabilities: (Families & Teens and Professional versions) Institute for Community Inclusion at Children's Hospital, Boston and the Massachusetts Department of Public Health.

<http://communityinclusion.org/transition/providerguide.html> and <http://communityinclusion.org/transition/familyguide.html>

Transition Planning Materials. Illinois Division of Specialized Care for Children. <http://internet.dsc.uic.edu/dscroot/parents/transition.asp>

Transition Timeline, State of Washington's Adolescent Health Transition Project, <http://depts.washington.edu/healthtr/Timeline/timeline.htm>