

Health Care Transition Workbook

Ages 18 and older



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

Table of Contents

| | |
|--|-----------|
| Health Care Transition Worksheets for Young Adults..... | 3 |
| Introduction for Young Adults | 3 |
| Thinking about Your Future (Worksheet 1 for Young Adults) | 4 |
| Health Care Independence (Worksheet 2 for Young Adults)..... | 6 |
| Health Care Transition Plan Family Worksheet (Worksheet 3 for Young Adults) | 12 |
| | |
| Health Care Transition Worksheets for Parents..... | 17 |
| Introduction for Parents..... | 17 |
| Thinking about Your Child’s Future (Worksheet 1 for Parents) | 19 |
| Your Child’s Health Care Independence (Worksheet 2 for Parents)..... | 21 |
| Parents Health Care Transition Activities (Worksheet 3 for Parents)..... | 27 |
| | |
| Credits | 29 |

This Workbook was developed by John Reiss, Ph.D. and Robert Gibson, MSOTR/L, Ph.D. and is based on products developed through a grant (#H133B001200) from the National Institute on Disability and Rehabilitation Research (NIDRR) and a contract (COQFV-R1) from Florida Children's Medical Services Program (Florida Department of Health) to the Institute for Child Health Policy at the University of Florida

Copyright © 2005. All rights reserved. Institute for Child Health Policy at the University of Florida
Limited reproduction may be allowed for educational or personal use, not for resale!

You have permission to reprint any of the material here if you are using it for non-research purposes, provided full credit is given to both the authors and the Institute for Child Health Policy at the University of Florida

Health Care Transition Worksheets for Young Adults Age 18+

Introduction for Young Adults

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 Workbook 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 workbook 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, which start on page 17, and you will fill out the Youth Adult 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 young adults. The first Worksheet asks you to think about what your life will be like as 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 starts on page 12, 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 an adult; and what you and others need to do to help you reach your goals.

Thinking About Your Future

Worksheet 1 for Young Adults age 18 +

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

1. Education and Employment

What are your plans for the next five years? (Check all that apply)

- Get a job/keep working
- Go to/finish high school
- Go to/finish a vocational, technical or other training program.
- Go to/finish a community college (2-year college)
- Go to/finish a 4-year college or University
- Other: _____

What kind of jobs would you like to have? _____

2. Living Arrangements

As an I adult, I plan to live (Check the one best answer)

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

3. Living independently

As an adult, I think I will

- Manage my own moneyYes No
- Be financially independent; self-supportingYes No
- Be independently mobile in my homeYes No
- Be independently mobile in the communityYes No
- Drive a car or vanYes No
- Manage a householdYes No
- Get married or have a steady partnerYes No
- Raise a familyYes No
- Maintain friendshipsYes No
- Communicate well with health care providersYes No
- Arrange for and manage my own health care.Yes No
- Pay for my own health insuranceYes No

4. Planning

- I talk with my parents about my future.Yes No
- I talk with my friends about my future.Yes No
- I talk with my doctors and/or other professionals
about my future.....Yes No

Health Care Independence

Worksheet 2 For Young Adults, Age 18+

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 I know how to do this and direct others | I do this with some help | I cannot do this OR I do this only with 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 tell someone the effects that getting older may have on my disability or health condition. | | | |
| 4. | I can tell someone how my disability or health condition effects my daily life | | | |
| 5. | I can tell a doctor or nurse about my medical history | | | |
| 6. | I can tell someone about the health problems my disability or health condition often causes | | | |
| 7. | I can list my allergies and get the help I need if I have an allergic reaction. | | | |
| 8. | I keep a personal health notebook or medical journal | | | |
| 9. | I carry an up-to-date 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 |

Health Care Independence (continued)

| | <i>Health Care Practices</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 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. | | | |
| | e. | | | |
| 3. | I hire, train, supervise and fire my personal care assistants. | | | |
| 4. | I can tell someone what smoking, taking drugs or alcohol, or the lack of exercise can do to me. | | | |
| 5. | I make good choices about friends, food, exercise, alcohol and smoking in order to stay healthy | | | |
| 6. | I do a Testicular Self Exam or Breast Self Exam regularly. | YES | | NO |
| 7. | I know about abstinence until marriage, safe sex practices, birth control and how to protect myself against STD's. | YES | | NO |
| 8. | I manage my reproductive health. | YES | | NO |
| 9. | 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, Equipment and Supplies</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 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 | | | |
| 5. | I can tell someone the difference between generic and brand name (proprietary) medications | | | |
| 6. | I 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 pay for or arrange payment for my medications | | | |
| 11 | I can list the medical tests I have regularly and I make sure these are done on time. | | | |
| 12 | I use and take care of my medical equipment and/or supplies; contact vendors when there are equipment problems and/or order my supplies when they are running out | | | |
| 13. | I pay for or arranges payment for my equipment and/or supplies | | | |

Health Care Independence (continued)

| | <i>Doctor Visits</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 tell my doctors and nurses what's wrong | | | |
| 2. | I <u>answer all</u> the question during a health care visit | | | |
| 3. | I ask the questions during a health care visit | | | |
| 4. | I register or check myself in for appointments, show my health insurance card and fill out the personal health history form. | | | |
| 5. | I am alone with the doctor(s) or choose who is with me during health care visits | YES | | NO |
| 6. | I decide with my doctors what medicines and treatments I need | YES | | NO |
| 7. | I contact my doctors to tell them about unusual changes in my health | YES | | NO |
| 8. | I find and understand new health information and use it to make health care decisions. | YES | | NO |
| 9. | I sign medical consent forms for myself. | 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 decided on what things to consider when selecting adult primary and specialty care doctors (for example: size of the practice, experience with caring for people with my condition or disability) | | | |
| 4. | I have identified adult doctors and facilities that I will go to when I leave my current doctors and facilities | | | |
| 5. | I have transitioned to an adult primary care doctor or specialist. | | | |
| 6. | I have provided health information to a new doctor | | | |
| 7. | I have set goals for taking care of my own health. | | | |
| 8. | I have taken more responsibility for my own health care by learning new skills. | | | |

Health Care Independence (continued)

| | <i>Health Care Transition (continued)</i> | I have done this | | I have NOT done this |
|-----|---|------------------|--|----------------------|
| 9. | I have talked to other adults about health care transition. | | | |
| 10. | I have talked with my nurse or social worker 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 cannot do this OR do this only with lots of help |
|-----|---|--|--------------------------|--|
| 1. | I manage all of my regular medical tasks outside the home (at school, work) List medical tasks that need to be completed at school or work & rate your independence. | | | |
| | a. | | | |
| | b. | | | |
| | c. | | | |
| 2. | I work with my college's Disabled Student Services program, to get the accommodations and supports I need. | | | |
| 3. | I work with my employer, to get the accommodations and supports I need. | | | |
| 4. | I manage my household (pay my own bills, shop for food and clothes, clean, etc.) | | | |
| 5. | I participate in social activities in my community. | | | |
| 6. | I use a checking account or a debit card | | | |
| 7. | I advocate for myself, so that I get the accommodations I need; and so that my legal rights are not violated. | YES | | NO |
| 8. | I have decided on what I want to do for a living. | YES | | NO |
| 9. | I have applied for or receive Vocational Rehabilitation services | YES | | NO |
| 10. | I have gotten scholarships and/or other funding for my higher education and/or job training. | YES | | NO |
| 11. | I have found information about how my health condition or disability may effect my vocational options. | YES | | NO |
| 12. | I have managed my school IEP or 504 meetings | YES | | NO |

Health Care Independence (continued)

| | <i>Health Care System</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, premiums) | | | |
| 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 SSI and Medicaid | 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 gained when turned 18 years old. (for example, sign medical consent forms; make medical decision by myself) | YES | | NO |
| 10. | I can tell someone how long I can be covered under my parent's health insurance plan, and what I need to do to maintain coverage (such as be a full time student) | YES | | NO |
| 11. | I can tell someone how I will get health insurance when I am no longer covered under my parents plan/other current plan. | YES | | NO |

Health Care Transition Plan Family Worksheet Worksheet 3 for Young Adults

Instructions:

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

First, compare your answers on Worksheet 1 (Thinking about Your Future) with what your family thinks your life will be like as an adult. Talk about the differences and similarities in the answers to the questions about where you will live; who you will live with; what kind of job you will have.

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

Then review the answers on Worksheet 3 for Parents. See if you agree with your parents about what they say they do, as a parent, to help you become more independent. Then work together to identify several activities that your parents could do to help you 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 family 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 family will do to complete the specific goal.

| <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 |
|---|--|
| <u>Basic Knowledge</u> I will/my family will help me learn more about my health condition. | Specific goal and activities. |

Health Care Transition Plan Family Worksheet (continued)

| | |
|--|--------------------------------------|
| <p><u>Basic Knowledge</u> I will/my family will help me be able to tell my health care providers about what I have learned about my health condition.</p> | <p>Specific goal and activities.</p> |
| <p><u>Health Care Practices</u> I will/my family will help me 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> | <p>Specific goal and activities.</p> |
| <p><u>Health Care Practices</u> I will/my family will help me 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> |

Health Care Transition Plan Family Worksheet (continued)

| | |
|---|--------------------------------------|
| <p><u>Health Care Practices</u> I will/my family will help me learn more about and practice good health habits.</p> | <p>Specific goal and activities.</p> |
| <p><u>Medications, Tests, Equipment & Supplies</u> I will/my family will help me learn more about my medications and treatments.</p> | <p>Specific goal and activities.</p> |
| <p><u>Medications, Tests, Equipment & Supplies</u> I will/my family will help me be more responsible for ordering medications, maintaining equipment and ordering supplies.</p> | <p>Specific goal and activities.</p> |

Health Care Transition Plan Family Worksheet (continued)

| | |
|---|--------------------------------------|
| <p><u>Doctor Visits</u> I will/my family will help me take a more active role in my 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> I will/my family will help me learn more about health care transition.</p> | <p>Specific goal and activities.</p> |
| <p><u>Transition to Adulthood</u> I will/my family will help me take more responsibility for my health care at home, at work, and at school</p> | <p>Specific goal and activities.</p> |

Health Care Transition Plan Family Worksheet (continued)

| | |
|--|--------------------------------------|
| <p><u>Transition to Adulthood</u> I will/my family will help me be prepared for higher educations, work and living on my own.</p> | <p>Specific goal and activities.</p> |
| <p><u>Health Care Systems</u> I will/my family will help me 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> I will/my family will help me know more about how to get and use health care insurance.</p> | <p>Specific goal and activities.</p> |

Health Care Transition Worksheets for Parents of Young Adults 18+

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 Workbook will help you and your child think about future goals and identify things that your child, as a young adult, is doing now to be independent in her/his health care. This workbook will also help you figure out what needs to be done to assure that your child's transition from pediatric to adult-oriented health care and to other aspects of adulthood goes smoothly.

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.

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 Young Adult worksheet, your child will be rating her/his own ability to do these same health care activities independently. The third part asks about what you are doing to help your child be more independent.

After you have completed the third part, review your answers with your daughter or son and discuss what areas you believe will be important to work on in the coming year.

After you have completed the third Worksheet, review your answers with your daughter or son and discuss what areas you 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, which is included with Young Adults Worksheets, write down the activities that you and your child will carry out to complete these goals.

Completing this workbook 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 workbook 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 Young Adults - Age 18+

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

1. Education and Employment

Over the next five years, my child will:

- | | | |
|--|-----|----|
| Go to/finish high school. | Yes | No |
| Go to/finish a vocational, technical or other training program. | Yes | No |
| Go to/finish a community college (2-year college). | Yes | No |
| Go to/finish a four year college or university | Yes | No |
| Have a job | Yes | No |

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

2. Living Arrangements

As an adult, my child will live: (Check the one best answer)

- In her/his own house or apartment (with or without a roommate or spouse)
- 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. Living independently

As an adult, my child will:

- Manage her/his moneyYes No
- Be financially independent; self-supportingYes No
- Be independently mobile in her/his homeYes No
- Be independently mobile in the communityYes No
- Drive a car or vanYes No
- Manage a householdYes No
- Get married or have a steady partnerYes No
- Raise a familyYes No
- Maintain friendshipsYes No
- Communicate well with health care providersYes No
- Arrange for and manage her/his own health care.Yes No
- Pay for her/his own health insuranceYes No

4. Planning

- I talk with my child about her/his future.Yes No
- My child talks with her/his friends about the future.Yes No
- My child talks with her/his doctors and/or other professionals
about the future.Yes No

)

Your Child's Health Care Independence

Worksheet 2 for Parents of Young Adults 18+

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 someone the effects that getting older may have on her/his disability or health condition. | | | |
| 5. | My child can tell a doctor or nurse her/his medical history | | | |
| 6. | My child can tell someone about the health problems her/his disability or health condition often causes. | | | |
| 7. | My child can list her/his allergies and get help when she/he has an allergic reaction. | | | |
| 8. | My child keeps a personal health notebook or medical journal | | | |
| 9. | My child carries a up-to-date 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 him/herself | | | |
| 2. | My child completes all daily or usual medical tasks | | | |
| | List usual or daily medical tasks & rate your child's independence. | | | |
| | a. | | | |
| | b. | | | |
| | c. | | | |
| | d. | | | |
| | e. | | | |
| 3. | My child hires, supervises and fires her/his personal care assistants. | | | |
| 4. | My child can tell someone what smoking, taking drugs or alcohol, or the lack of exercise can do to him/her. | | | |
| 5. | My child makes good choices about friends, food, exercise, alcohol and smoking in order to stay healthy | | | |
| 6. | My child does a Testicular Self Exam or Breast Self Exam regularly. | YES | | NO |
| 7. | My child manages her/his reproductive health. | YES | | NO |
| 8. | My child knows about abstinence until marriage, safe sex practices and how to protect her/himself against STD's. | YES | | NO |
| 9. | 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 and what she/he should do if there is a side effect | | | |
| 4. | My child takes her/his medications correctly. | | | |
| 5. | My child can tell someone the difference between generic and brand name (proprietary) medications. | | | |
| 6. | My child selects the medications she/he needs when she/he has a minor illness (a headache or a cold) | | | |
| 7. | My child can tell someone about medications she/he should not take 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 reorders medications when her/his supply is low, and calls the doctor when she/he needs a new prescription. | | | |
| 10. | My child pays for or arrange payment for her/his medications | | | |
| 11. | My child can list the medical tests she/he has regularly and makes sure these are done on time. | | | |
| 12. | 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 | | | |
| 13. | My child pays for or arranges payment for her/his equipment and/or supplies | | | |

Your Child's Health Care Independence (continued)

| | <i>Doctor Visits</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 tells her/his doctors and nurses what's wrong. | | | |
| 2. | My child answers all of the questions during a health care visit. | | | |
| 3. | My child asks the question during a health care visit. | | | |
| 4. | My child registers or checks in for appointments, shows health insurance card and fills out her/his personal health history form. | | | |
| 5. | My child is alone with doctor during medical visits or chooses who is with her/him during health care visits. | YES | | NO |
| 6. | My child and her/his doctors decide together what medicines and treatments she/he needs. | YES | | NO |
| 7. | My child finds and understands new health information and uses it to make health care decisions. | YES | | NO |
| 8. | My child signs medical consent forms for her/himself. | 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 decided on 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 identified adult doctors that she/he will go to when she/he leaves her/his current doctors. | | | |
| 5. | My child has transitioned to an adult primary care doctor or specialist. | | | |
| 6. | My child has provided health information to new doctors. | | | |
| 7. | My child has set goals for taking care of her/his own health. | | | |
| 8. | My child has taken more responsibility for her/his own health care by learning new skills. | | | |

Your Child's Health Care Independence (continued)

| | | | | |
|-----|--|--|--|--|
| 9. | My child has talked to other adults about health care transition. | | | |
| 10. | 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 cannot do this OR does this only with lots of help |
|-----|--|---|-----------------------------------|---|
| 1. | My child manages all of her/his regular medical tasks outside the home (at school, work) | | | |
| | List medical tasks that need to be completed at school or work & rate your child's independence. | | | |
| | a. | | | |
| | b. | | | |
| | c. | | | |
| | d. | | | |
| 2. | My child has worked with her/his college's Disabled Student Services program, to get needed accommodations and supports. | | | |
| 3. | My child has worked with her/his employer, to get needed accommodations and supports. | | | |
| 4. | My child manages her/his household (pays own bills, shops for food and clothes, cleans, etc.) | | | |
| 5. | My child participates in social activities in the community. | | | |
| 6. | My child uses a checking account or a debit card. | | | |
| 7. | My child advocates for her/himself, so that she/he gets needed accommodations; and her/his legal rights are not violated | | | |
| 8. | My child has decided on what she/he wants to do for a living. | YES | | NO |
| 9. | My child has applied for or receives services from the state Vocational Rehabilitation Program. | YES | | NO |
| 10. | My child has gotten scholarships and other sources of funding for education and/or job training. | YES | | NO |
| 11. | My child has found information about how her/his health condition or disability may effect vocational options. | YES | | NO |
| 12. | My child manages her/his own school IEP or 504 meeting. | YES | | NO |

Your Child's Health Care Independence (continued)

| | <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 cannot 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 calls 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, premiums). | | | |
| 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 SSI and Medicaid. | YES | | NO |
| 7. | My child can tell someone the differences between a primary care doctor and a specialist. | 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 (like be a full time student). | YES | | NO |
| 11. | My child can tell someone how she/he will get health insurance when she/he is no longer covered under my health plan or another other current plan. | YES | | NO |

Parents Health Care Transition Activities

Worksheet 3 for Parents of Young Adults 18+

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.

| | | I do this often or regularly | I do this sometimes | I do this rarely or never |
|-----|---|---|--------------------------------|--------------------------------------|
| 1. | I support my child in taking the lead role in her/his health care. (For examples, see items on Worksheet 2.) | | | |
| 2. | When asked, I help my child update information in her/his personal Health History Notebook or Medical Journal or her/his Medical Summary Form; and support her/his independence in these activities.. | | | |
| 3. | When asked, I help my child prepare questions to ask her/his doctors during a health care visit. | | | |
| 4. | When asked, I help in registering or checking in for appointments. | | | |
| 5. | When asked, I help my child fill 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 the whole medical visit or to choose who is with her/him during visits. | | | |
| 7. | When asked by my child, I meet with doctors and my child to review information; answer questions and address concerns. | | | |
| 8. | When asked, I assist my child to work with her/his college's Disabled Student Services program, to get the accommodations and supports she/he needs. | | | |
| 9. | When asked by my child, I assist her/him to manage her/his household responsibilities (pay bills, shop for food and clothes, clean, etc.) | | | |
| 10. | I encourage my child to have friends and support her/his involvement in activities in the community. | | | |
| 11. | When asked by my child, I help my child to decide on what she/he wants to do for a living and to pursue that goal | | | |

Your Child's Health Care Independence (continued)

| | | I have done this | | I have NOT done this |
|-----|---|-------------------------|--|-----------------------------|
| 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 helped my child decide on what things need to be considered when selecting adult primary and specialty care doctors (for example: size of practice, experience with taking care of people with her/his condition) o | | | |
| 15. | I have helped my child identify adult doctors and facilities she/he will go to when she/he leaves her/his current providers | | | |
| 16. | I have participated in development of a Health Care Transition Plan for my child. | | | |
| 17. | I have talked with parents of 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. | | | |
| 21. | I have given my child a copy of her/his 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 and have provided this information to my child | | | |
| 24. | I helped my child find out how her/his vocational and educational choices will effect her/his future health insurance options. | | | |
| 25. | I have helped my child identify ways that she/he can get health insurance coverage when an adult. | | | |
| 26. | I have assisted my child to apply for and make good use of SSI benefits | | | |
| 27. | I have helped my child understand and exercise the legal rights and responsibilities she/he gained when turning 18 (i.e. medical consent; confidentiality) | | | |

Credits

This Workbook was developed by John Reiss, Ph.D. and Robert Gibson, MSOTR/L, Ph.D. and is based on products developed through a grant (#H133B001200) from the National Institute on Disability and Rehabilitation Research (NIDRR) and a contract (COQFV-R1) from Florida Children's Medical Services Program (Florida Department of Health) to the Institute for Child Health Policy at the University of Florida

Items included in the Workbooks 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.cahrtw.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>