



Health Care Transition Workbook

**For CMS Enrollees
Age 12 – 14**

**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 Parents.....	3
Introduction for Parents.....	3
Thinking about Your Child’s Future (Worksheet 1 for Parents)	5
Your Child’s Health Care Independence (Worksheet 2 for Parents).....	6
Parents Health Care Transition Activities (Worksheet 3 for Parents).....	10
CMS Health Care Transition Plan Family Worksheet (Worksheet 4 for Parents).....	12
Health Care Transition Worksheets for Youth.....	18
Introduction for Youth	18
Thinking about Your Future (Worksheet 1 for Youth)	19
Health Care Independence (Worksheet 2 for Youth).....	20
Credits	24

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Health Care Transition Worksheets for Parents of Youth Age 12 – 14

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 workbook 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 workbook 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 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.

Have your child complete the Worksheets for Youth, which start on page 18, 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 workbook will help you, your child, your doctors, and Children's Medical Services 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 Youth Age 12 – 14

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

1. School and Work

My child will go to high schoolYes No

My child will finish high schoolYes No

My child will go to collegeYes No

My child will have a job when she/he is an adult.....Yes No

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

2. Living Arrangements

When my child is an adult, she/he will live (Check the one best answer)

- In their 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. Planning

I talk with my child about her/his futureYes 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 12 - 14

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 affects 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 tells me or other adults about unusual changes in her/his health			
7.	My child can list her/his allergies and tell others if she/he has an allergic reaction			

	<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			

Your Child's Health Care Independence (continued)

	<i>Health Care Practices (continued)</i>	Does independently	Does with help	Does not do
2.	My child completes daily or usual medical tasks			
	List daily or usual medical tasks and rate 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 can tell someone about the changes that take place in her/his body during puberty			

	<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			
5.	My child tells me when her/his supply of medications is low so I can order more			
6.	My child can list the medical tests she/he has regularly			
7.	My child uses and takes care of her/his medical equipment and/or supplies; tells me when there are equipment problems and/or tells me when her/his supplies are running out			
8.	My child can tell someone what happens if she/he does not take her/his medications correctly			

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 <u>answers</u> at least one question during a health care visit			
3.	My child <u>asks</u> at least one question during a health care visit			
4.	My child spends some time alone with the doctor during a health care visits	YES		NO
5.	My child talks with her/his doctors and me about what medicines and treatments she/he needs	YES		NO
6.	My child tells her/his doctors that she/he understands and agrees with the medicines and treatments they suggest.	YES		NO
7.	My child can name the doctors she/he sees and tell someone why she/he sees each doctor	YES		NO

	<i>Health Care Transition</i>	My child has done this		My child has NOT done this
1.	My child has talked with her/his doctor or nurse about going to different doctors when she/he is an adult			
2.	My child has set goals for taking care of her/his own health			
3.	My child has taken more responsibility for her/his own health care by learning new skills			
4.	My child has talked to older kids or young adults about health care transition			
5.	My child has talked with her/his CMS nurse or social worker about health care transition			

Your Child's Health Care Independence (continued)

	<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 manages 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.			
2.	My child tells her/his teachers or nurses about changes in her/his health			
3.	My child regularly does chores at home			
4.	My child participates in social activities in the community			
5.	My child manages her/his own money			
6.	My child has attended an Individual Education Plan (IEP) or 504 meeting	YES		NO
7.	My child has talked about plans for her/his education, work, and living on her/his own with me, and/or a school counselor, doctor or nurse	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			
4.	My child can tell someone how health insurance works			

Parents Health Care Transition Activities Worksheet 3 for Parents of Youth Age 12 - 14

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 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 have made my child aware of her/his Health History Notebook or Medical Journal, and involve my child in updating information			
3.	I help my child to prepare questions to ask her/his doctors during a health care visit			
4.	I encourage my child to see her/his primary and specialty care providers independently for some of the medical visit			
5.	If my child sees doctors for part of the visit by her/himself I meet with the doctors and my child at end of visit to review information, answers questions, and address concerns			
6.	I work with the school staff to allow my child to play an active role in managing her/his routine medical tasks in the school setting			
7.	I give my child household responsibilities and expect her/him to complete chores			
8.	I encourage my child to have friends and support her/his involvement in activities in the community			

Parents Health Care Transition Activities (continued)

		I have done this		I have NOT done this
9.	I have talked with my child about her/his future transition to adult health providers			
10.	I have participated in the development of a Health Care Transition Plan for my child			
11.	I have talked with parents of adolescents and young adults who have transitioned from pediatric to adult health care			
12.	I have recommended that health care issues and tasks be included in my child's Individualized Education Plan (IEP) or 504 Plan			
13	I have helped my child to learn how to manage her/his own money			

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

CMS 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, and what kind of job she/he will have.

Then compare your answers on Worksheet 2 (Health Care Independence) to what your child said about her/his 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 what you do as a parent to help her/him 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.

If you would like assistance, please contact your child's CMS care coordinator.

Health Care Transition Plan (continued)

<p><i>General Goals</i></p>	<p>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>
<p><u>Basic Knowledge</u> My child will/ I will help my child learn more about her/his health condition.</p>	<p>Specific goal and activities.</p>
<p><u>Basic Knowledge</u> 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>	<p>Specific goal and activities.</p>
<p><u>Health Care Practices</u> 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>	<p>Specific goal and activities.</p>

Health Care Transition Plan (continued)

<p><u>Health Care Practices</u> 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> 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 & Supplies</u> My child will/I will help my child learn more about her/his medications and treatments</p>	<p>Specific goal and activities.</p>

Health Care Transition Plan (continued)

<p><u>Medications, Tests, Equipment & Supplies</u> 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> 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> My child will/I will help my child learn more about health care transition.</p>	<p>Specific goal and activities.</p>

Health Care Transition Plan (continued)

<p><u>Transition to Adulthood</u> 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> 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>

Health Care Transition Plan (continued)

<p><u>Health Care Systems</u> 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> 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 12 – 14

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:

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

This 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, 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, and 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. Finally, you will write down on the Family Worksheet 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, and Children's Medical Services 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 12 – 14

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

1. School and Work

I plan to go to high schoolYes No

I plan to finish high schoolYes No

I plan to go to collegeYes No

I plan to have a job when I am an adultYes No

What kind of jobs would you like to have?

2. Living Arrangements

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

- In my own house or apartment (with roommates or by myself)
- 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 futureYes No

Health Care Independence Worksheet 2 for Youth Age 12 - 14

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 affect 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 cause			
6.	I tell my parents or other adults about unusual changes in my health			
7.	I can list my allergies and tell others when I have an allergic reaction			

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 daily or usual medical tasks			
	List daily or usual medical tasks and rate your independence			
	a.			
	b.			
	c.			
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 can tell someone about the changes that take place in my body during puberty			

	<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			
4.	I take my medications correctly			
5.	I tell my parents when my supply of medications is low, so they can order more			
6.	I can list the medical tests I have regularly			
7.	I use and take care of my medical equipment and/or supplies, tell my parents when there are equipment problems and/or tell them when my supplies are running out			
8.	I can tell someone what happens if I do not take my medications correctly			

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 answer at least one question during a health care visit			
3.	I ask at least one question during a health care visit			
4.	I spend some time alone with the doctor during a health care visits	YES		NO
5.	I talk with my parents and/or doctors about what medicines and treatments I need	YES		NO
6.	I tell my doctors I understand and agree with the medicines and treatments they suggest	YES		NO
7.	I can name my doctors and tell someone why I see them	YES		NO

	<i>Health Care Transition</i>	I have done this		I have NOT done this
1.	I have talked with my doctors or nurses about going to different doctors when I am an adult			
2.	I have set goals for taking care of my own health			
3.	I have taken more responsibility for my own health care by learning new skills			
4.	I have talked to older kids or young adults about health care transition			
5.	I have talked with my CMS care coordinator about health care transition			

Health Care Independence (continued)

	<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 manage my regular medical tasks at school			
	List medical tasks that need to be completed at school and rate your independence			
	a.			
	b.			
	c.			
2.	I tell my teacher or nurse about changes in my health			
3.	I regularly do chores at home			
4.	I participate in social activities in my community			
5.	I can manage my own money			
6.	I have attended a school Individual Education Plan (IEP) or 504 meeting	YES		NO
7.	I have talked about plans for my education, working, and living on my own with my parents, or school counselor or doctor or nurse	YES		NO

	<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 can call my primary care doctor's or specialist's office to make or change an appointment			
3.	I can tell someone the name of my health insurance			
4.	I can tell someone how health insurance works			

Credits

This Workbook was developed by John Reiss, Ph.D. and Robert Gibson, Ph.D. and is based on products developed through their grant (#H133B001200) from the National Institute on Disability and Rehabilitation Research (NIDRR) to the Institute for Child Health Policy (ICHP) at the University of Florida. Development of the CMS Health Care Transition Workbooks was funded through a contract (COQFV-R1) from Florida Children's Medical Services Program (Florida Department of Health) to ICHP and carried out in collaboration with Susan Redmon (Contract Manager).

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.cahrhw.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.c.uic.edu/dscroot/parents/transition.asp>

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