

Commission for Children with Special Health Care Needs

Transition Policy Statement

12/21/16

The Commission for Children with Special Health Care Needs (CCSHCN) is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change from a “pediatric” model of care where parents make most decisions to an “adult” model of care where patients take full responsibility for decision-making. This means that we will spend time during the clinic visit talking more with the teen to assist him/her in setting health priorities and supporting her/him in becoming more independent with his/her own health care. The CCSHCN uses a transition checklist that has age appropriate developmental milestone questions as a guide when speaking with teens about appropriate health care transition topics.

At age 18, a youth legally becomes an adult. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult’s consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for decision making.

At age 17 we will begin collaborating with youth and families to prepare the youth to transfer to an adult provider. We recommend this transfer occurs at age 18 or at least before the youth is discharged at age 21. We will assist with this transfer process, including helping to identify an adult provider, sending medical records, portable medical summary and communicating with the adult provider about the unique needs of our patients.

If you have any questions or concerns, please feel free to contact your local CCSHCN Care Coordinator.



(Parent Letter)

[Date]

[Parent/Guardian of 18 year old]

[Address]

[City, State, Zip]

Dear [Guardian Name(s)]:

As [child's first name] nears [his] [her] 18th birthday (happy birthday!), we want to mention that as a legal adult, [he] [she] will be responsible for [his] [her] health care and CCSHCN enrollment. We will only be permitted to speak directly with [child first name] about [his] [her] care, due to privacy laws – unless [he] [she] provides us permission. Enclosed is a form for [child first name] to complete in the event that [he] [she] will need your involvement after age 18. This form should be returned to [child first name]'s care coordinator, [name of care coordinator] at the [regional office] CCSHCN regional office, at [address]. Another important form, the Consent for Treatment form, is also attached; this permits us to continue to provide services to [child first name] and we ask that [child first name] also sign and return this form after [his] [her] birthday.

We'd also like to remind you that CCSHCN care coordinators, social workers, and family consultants are able to assist you and [Child first name] in planning for transition needs, such as:

- Performing important health care skills – like understanding [his] [her] medical condition and being able to talk with doctors and other health care providers;
- Considering [his] [her] future goals – such as obtaining job-training skills or college; and
- Learning how to become independent – by preparing to become an adult and knowing [his] [her] rights and responsibilities.

Our staff will be discussing topics such as these with you and [Child First Name] during clinic appointments, and we encourage you to help prepare [him] [her] for these conversations and think about [his] [her] interests and goals. We are able to assist with referring [child first name] to programs in the community which may be able to help, as well.

We try to post helpful resources about successful transitions to adulthood on our website (<http://chfs.ky.gov/ccshcn>) and our agency Facebook page (link available on our website).

If you have any questions about this letter, please do not hesitate to contact me at (800) 232-1160, ext. 2002, or [child first name]'s care coordinator, [Name of Care Coordinator] at [Phone Number]. We look forward to helping you plan for [child first name]'s future!

Sincerely,

Lee Gordon
Transitions Administrator

(Youth Letter)

[Date]

[Name of 18 year old]

[Address]

[City, State, Zip]

Dear [Name]:

As your 18th birthday approaches (happy birthday!), we want to mention that as a legal adult, you will be responsible for your health care and CSHCN enrollment. We will only be permitted to speak directly with you about your care, due to privacy laws – unless you provide us permission. Enclosed is a release form to complete in the event that you will want the involvement of your parent or another adult after age 18. It is very important to sign and return this form on or after your 18th birthday. Another important form, the Consent for Treatment form, is also attached; this permits us to continue to provide services to you and we ask that you also sign and return this form after your birthday. Finally, a Notice of Privacy Practices is included, which informs you about how CSHCN uses and protects your information. These forms should be returned to your care coordinator, [name of care coordinator] at the [regional office] CSHCN regional office, [address].

We'd also like to remind you that CSHCN staff are able to assist you in planning for future, and help you in areas like:

- Performing important health care skills – like understanding your medical condition and being able to talk with doctors and other health care providers;
- Considering your goals – such as obtaining job-training skills or college; and
- Becoming more independent – by preparing to become an adult and knowing [his] [her] rights and responsibilities.

Our staff will be discussing topics such as these with you during clinic appointments, and we encourage you to prepare by thinking about any assistance you may need with transitioning to adulthood.

We try to post helpful resources about transitioning to adulthood on our website (<http://chfs.ky.gov/ccshcn>) and our agency Facebook page (link available on our website).

If you have any questions about this letter, please do not hesitate to contact me at (800) 232-1160, ext. 2002, or your care coordinator, [Name of Care Coordinator] at [Phone Number]. We look forward to helping you plan for your future!

Sincerely,

Lee Gordon
Transitions Administrator

Dear parent/guardian:

As a part of our mission to enhance the quality of life for Kentucky's children with special health care needs, we would like to assist you in finding resources and help your child with developmental tasks. Please fill out the following questions. Bring back to clinic and return with registration.

Clinic date: _____ Patient Name: _____ Age: _____
 School _____

If 3 or older, does your child have an IEP: Yes/No

If yes, would you like a Commission staff member to attend IEP meetings? Yes/No
 If so, it is the family's responsibility to invite staff to each meeting in a timely fashion.

0-4	Yes	No	Would Like More Info	N/A
I would like to know about:				
I am aware of government assistance programs (financial or food) that may be available and know how to access these services.				
My child is reaching developmental milestones or is developing like other children.				
I know about First Steps and Head Start and how to get my child into these programs.				
My child needs additional therapies, therapists, services or resources.				
If your child has an IEP or special needs concerns, answer the following:				
I know how to apply for SSI for my child.				
My child is 3 years old or older with a disability and still in diapers and I know how to get assistance paying for diapers.				
I am aware of Medicaid waivers. These waivers provide a funding stream for Community Living Supports, Residential, Respite care, and other services. If you have one, which waiver do you receive?				

Is there something you are trying to overcome that we can help with? Yes/No? If yes, please explain.

Any questions or comments? _____

Dear parent/guardian:

As a part of our mission to enhance the quality of life for Kentucky's children with special health care needs, we would like to assist you in finding resources and help your child with developmental tasks. Please fill out the following questions. Bring back to clinic and return with registration.

Clinic date: _____ Patient Name: _____ Age: _____
 School _____ Grade: _____ Grades _____

IEP: Yes/No If your child has an IEP, would you like a Commission staff member to attend IEP meetings? Yes/No
 If so, it is the family's responsibility to invite staff to each meeting in a timely fashion.

Age 5-11	Yes	No	Would Like More Info	N/A
General information:				
My child/family has computer access.				
I understand my child should use a booster seat until age 8-12 or about 4'9".				
My child knows his/her address and phone number.				
My child does home chores.				
I keep a medical record of information on my child.				
I am aware of the benefits of activities and camps for my child...including activities and camps for children with special needs like The Center for Courageous Kids, Special Olympics, KSD Summer School, etc.				
I need behavioral support for my child.				
If your child has an IEP or special needs concerns, answer the following:				
I know about Special Needs Trust.				
I need help with a specialized car seat for my child.				
I am aware of adaptive equipment available for my child.				
I am aware of Human Development Institute's Comprehensive Disability Resource Manual.				
I need help obtaining diapers/briefs for my child with a disability.				
I am aware of Medicaid waivers. These waivers provide a funding stream for Community Living Supports, Residential, Respite care, and other services. If you have one, which waiver do you receive?				

Is there something you are trying to overcome that we can help with? Yes/No If yes, please explain. _____

Any questions or Comments? _____

Dear parent/guardian:

As a part of our mission to enhance the quality of life for Kentucky’s children with special health care needs, we would like to assist you in finding resources and help your child with developmental tasks. Please have your child answer the following questions and help them as needed. Bring back to clinic and return with registration.

Clinic date: _____ Patient Name: _____ Age: _____
 School _____ Grade: _____ Grades _____

IEP: Yes/No If your child has an IEP, would you like a Commission staff member to attend IEP meetings? Yes/No
 If so, it is the family’s responsibility to invite staff to each meeting in a timely fashion.

	Yes	Beginning	Caregiver Doing	No	N/A	I'd like help
12-14						
Health						
I understand my diagnosis and can explain it.						
I know the "danger signs" of my condition and when to seek medical help.						
I tell the doctor how I am doing and answer questions.						
I take my medicine with or without supervision.						
I know the name of my medication(s) and the possible side effects.						
Without parental prompting, I have good hygiene and am well groomed-clean hair, bathe regularly, brush/floss daily, wears clean clothes.						
I have questions regarding sexuality.						
For Girls Only – I have questions regarding my menstrual period.						
If your child has an IEP or special needs concerns, answer the following:						
I know how to take care of my medical equipment, i.e. hearing aids, wheelchair, leg braces, walker, breathing equipment, etc.						

(over)

12-14	Yes	Beginning	Caregiver Doing	No	N/A	I'd like help
Independent living						
I care for my own personal needs-i.e. feeding, bathing, dressing, grooming, or know how to attain help with them.						
I have an Emergency Plan of some type (health or natural disaster) and know how to call 911.						
I know how to study and am responsible for my homework.						
I spend time with friends for social activities.						
I do more advanced chores at home.						
I can name 3 things I am good at and have fun doing.						
I understand the value of an education and how that will help me achieve my work goals.						
If your child has an IEP or special needs concerns, answer the following:						
I can acquire a service animal, if needed.						
I understand the Americans with Disabilities Act/Individual with Disabilities Education Act.						
At age 14, I attend my IEP/504 meetings.						
I am aware of Medicaid waivers. These waivers provide a funding stream for Community Living Supports, Residential, Respite care, and other services. If you have one, which waiver do you receive?						

Please answer the following questions. Because things change, some questions may be asked every year.

I plan to be a _____ when I grow up to support myself financially.

I understand I will have to _____ to achieve this goal.

Is there something you are trying to overcome that we can help with? Yes/No If yes, please explain. _____

For parents, are you able to support your child's goals? Yes/No Please explain. _____

For parents, what do you see your child doing after graduation? _____

Any questions or comments? _____

Dear parent/guardian:

As a part of our mission to enhance the quality of life for Kentucky's children with special health care needs, we would like to assist you in finding resources and help your child with developmental tasks. Please have your teen answer the following questions and help them as needed. Bring back to clinic and return with registration.

Clinic date: _____ Patient Name: _____ Age: _____
 School _____ Grade: _____ Grades _____

IEP: Yes/No If your child has an IEP, would you like a Commission staff member to attend IEP meetings? Yes/No
 If so, it is the family's responsibility to invite staff to each meeting in a timely fashion.

15-17	Yes	Beginning	Caregiver Doing	No	N/A	I'd like help
Health						
I communicate problems/concerns to my doctor.						
I take my medication/do treatments as scheduled, if applicable.						
I'm an informed participant taking part in making medical decision for myself.						
I inform family of my need for medicine ordered and refills.						
I talk with my doctor/nurse/social worker about the need to choose an adult health care provider when I turn 18.						
I am familiar with health insurance and how it works-i.e. insurance plans, deductibles, co-pays, etc.						
I understand the importance of organizing and keeping my medical records and receipts.						
I know the importance of having health insurance coverage and what will happen to it at age 18.						

Any questions or comments? _____

(Over)

15-17	Yes	Beginning	Caregiver Doing	No	N/A	I'd like help
Independent living						
I help to plan and prepare meals/food.						
I can budget money and save up for something.						
I am deciding what my future plans-i.e. work, secondary education, vocational training, Job Corp, military, etc.						
I am learning about healthy behaviors such as exercise and nutrition that help me stay well.						
I have a part time job or volunteer.						
I am preparing for my future transportation needs by learning to drive, managing public/private transportation, understanding ADA transportation, or planning to be evaluated for the ability to drive, if applicable.						
I intend to register to vote at age 18. I understand the importance of exercising my right to vote. And if disabled, I understand the value of voting for candidate's who support disability rights and services.						
If your child has an IEP or special needs concerns, answer the following:						
I attend my IEP/504 meetings.						
I am planning for my future by being ready to list vocational goals on my IEP at age 16.						
I know to reapply for SSI at age 18 because only my income will be considered at that time.						
Issues of giving medical consent, guardianship, or POA at age 18 are being considered						
I understand how I can work and still draw disability. I know about Social Security Administration (SSI or SSDI) work incentives-PASS plan, 1619A&B, Ticket to Work.						
I am aware of services for the disabled including Voc Rehab, School to Work, Supported Employment, Carl Perkins, Adult Day Treatment, Adult Day Care, etc.						
I understand my rights under the American Disabilities Act.						
With a developmental disability, I understand, I can stay in High School until age 21.						
I am aware of Medicaid waivers. These waivers provide a funding stream for Community Living Supports, Residential, Respite care, and other services. If you have one, which waiver do you receive?						

Please answer the following questions. Because things change, some questions may be asked every year.

I plan to be a _____ when I grow up to support myself financially.

I understand I will have to _____ to achieve this goal.

Is there something you are trying to overcome that we can help with? Yes/No If yes, please explain. _____

For parents, are you able to support your child's goals? Yes/No Please explain. _____

For parents, what do you see your child doing after graduation? _____

Any Questions or Comments? _____

CUP ID # _____

Dear patient (or guardian, if applicable):

As a part of our mission to enhance the quality of life for Kentucky’s children with special health care needs, we would like to assist you in finding resources and help with developmental tasks. Please fill out the following questions. Bring back to clinic and return with registration.

Clinic date: _____ Patient Name: _____ Age: _____
 School _____ Grade: _____ Grades _____

IEP: Yes/No If you have an IEP, would you like a Commission staff member to attend IEP meetings? Yes/No
 It is the family’s responsibility to invite staff to each meeting in a timely fashion.

18-21	Yes	Beginning	Caregiver Doing	No	N/A	I'd like help
HEALTH						
I have plans for adult health care providers (Primary care, Specialty, Dental, DME, Pharmacy, Therapy and Mental Health) and have made initial appointments to establish care with them or are already seeing them.						
I make a list of questions to ask my doctors so I can remember to ask them.						
I make my own medical decisions or have other arrangements in place.						
I can explain to others how our family’s customs and beliefs might affect health care decisions and medical treatments.						
I follow up on any referrals for tests, check-ups, or labs.						
I call the doctor about any unusual changes in my health i.e. allergic reactions.						
I have chosen a pharmacy where my current and new prescriptions can be filled. I am aware of generic medications saving me money.						
I am aware of Prescription Assistance programs if I do not have insurance or do not have adequate insurance.						
I have a medical history summary that I carry which includes the list of medication I take and the dosage that can be given to new doctors.						
I manage my medical appointments and make arrangements for transportation to attend if needed.						
If I am no longer eligible for Medicaid, I have looked into options and applied for other funding resources.						
I know what to do for minor ailments like a cold and health emergencies like pressure wounds.						
I sign my own release of information forms or have a plan in place for guardianship, POA, conservator, etc.						
I am aware of support groups (for example, seizure or autism, etc.) in my area to supplement family support.						

(over)

18-21	Yes	Beginning	Caregiver Doing	No	N/A	I'd like help
Independent living						
I have plans for after high school.						
I know what to do to enroll in school or training and apply for financial aid.						
I have plans for independent living, housing, transportation.						
I know how to manage money and budget household expenses.						
I have a driver's license or state ID.						
I work or volunteer.						
I know about transferring records when I turn 21 years old.						
I have shopping, cooking, laundry, and housekeeping skills.						
I have registered to vote and understand the importance of exercising my right to vote. And if disabled, I understand the value of voting for candidate's who support disability rights and services.						
I can take care of my personal needs, have identified someone to help, if needed, or I know how to hire a personal attendant, if needed.						
If your child has an IEP or special needs concerns, answer the following:						
I know how to get any accommodations I need for work or school. I am aware of the Job Accommodation Network which is a free service.						
I am aware of Medicaid waivers. These waivers provide a funding stream for Community Living Supports, Residential, Respite care, and other services. If you have one, which waiver do you receive?						

Please answer the following questions. Because things change, some questions may be asked every year.
 I plan to be a _____ to support myself financially. I understand I will have to _____ to achieved this goal.

Is there something you are trying to overcome that we can help with? Yes/No If yes, please explain.

For parent/ guardian, are you able to support your young adult's goals? Yes/No Please explain. _____

For parent/ guardian, what do you see your young adult doing after graduation? _____

Any questions or comments? _____
