

Title V Health Care Transition Protocol
Children with Chronic Health Conditions
Updated 02/27/2020

The Maternal Child Health Title V definition of transition is the percentage of adolescents with special health care needs who receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. Arkansas has chosen Transition as a National Performance Measure (NPM) for the Title V Children and Youth with Special Health Care Needs (CYSHCN) Program. The NPM for Health Care Transition is the percentage of adolescents with and without special health care needs, ages 12 through 17, who received services necessary to make transitions to adult health care.

In January of 2015, Title V staff statewide began utilizing the protocol for health care transition readiness. Feedback from the Title V Care Coordinators, families and CYSHCN is used to update the protocol as needed.

Title V will focus on youth receiving care coordination from Title V:

- Title V Status X- children with Arkansas Medicaid, whose families have chosen Title V to be their care coordinator on their annual Title V Application.
- Title V Status A- children without Arkansas Medicaid, who Title V assists with the deductible and co-insurance up to one month's gross monthly household income amount, when funding allows.
- Title V Status K- children with ARKids B that have gaps in ARKids B coverage that are eligible for Title V, when funding allows.

All Health Care Transition (HCT) activities will be progress noted in child's record:

- Mailing or providing the family with a copy of the Title V HCT Protocol.
- Mailing a 12-year old letter or 13-year old letter and anticipatory guidance enclosures from CDC and Bright Futures.
- HCT Readiness Checklists that were mailed to family. Progress note should specify which checklist was mailed to the family.
- Dates of reminders set (ticklers set) and the HCT follow-up when the tickler is due.
- HCT Readiness Checklists for Families, Families and Youth, Youth, or Complex Medical Needs that were completed face-to-face, on the telephone, or by mail. Progress note should include which checklist was completed and whether it was completed face-to-face, on the telephone, or by mail.
- A specified Health Care Readiness Checklist keyed into Survey Monkey.
- Individualized Transition Goals and Objectives added or updated to the child/youth's Service Plan that are age and diagnosis specific.
- HCT follow-up at six months.
- HCT resources given to family that are appropriate for the child/youth's age and diagnosis.
- Phone calls and face-to-face HCT discussions with parent and/or youth.

Title V has a transition letter for the 12-year old and another letter for the 13-year old. The Transition Readiness Checklist is being used by the Title V Care Coordinators for parents of children and youth with special health care needs (CYSHCN) ages 14 through 17.

The Title V Care Coordinators will utilize their Transition Aged Youth monthly report for Title V status X, A and, K to identify CYSHCN age 12 through 17. These youth and their families will be the focus for health care transition when their birth month corresponds to the current calendar month.

- CYSHCN that are turning 12 or 13 years of age will be mailed either a transition letter for 12-year olds or a transition letter for 13-year olds.
- CYSHCN that are turning 14 through 17 will be assessed by a Transition Readiness Checklist.
 - Title V has two Transition Readiness Checklists for families:
 - One for families with youth with special health care needs (YSHCN) and
 - One for families with youth with complex medical needs.
 - Youth with complex medical needs will need total assistance in self-care, decision making, and in expressing themselves.
 - A third checklist exists if the youth themselves are available to complete it, the Title V Transition Readiness Changing Roles for Youth Checklist.
- The health care readiness process **should** begin earlier than their birth month for youth that are about to turn 18 years of age or those newly admitted into the Title V Program of transition age; otherwise the family would miss the opportunity for assistance with health care transition.

The transition process will be documented in the Title V Needs Assessment for Title V Status X (under Transition Plan- List Participants in Transition Planning) by placing the youth's age and the date when the checklist was completed. Transition related activities will be included on the child's Title V Care Plan. For Title V Status A and K, the transition process will be documented in the same way but using the Title V Needs Assessment under Transition Planning or Other Concerns on page 2, if additional space is needed.

Protocol- Utilizing Transition Age Youth Monthly Reports. All families will be provided with a copy of the current Title V Health Care Transition Protocol.

- I. Transition letters will be sent to parents of 12 and 13-year olds along with:
 - a. Positive Parenting Tips for Healthy Child Development, Young Teens (12-14 Years of Age), *Positive Parenting Tips for Healthy Child Development Young Teens*, CDC.gov, January 2017; and
 - b. Bright Futures, Early Adolescence, 11-14 years, Patient and Parent Handout. Bright Futures is a national health promotion and prevention initiative led by the American Academy of Pediatrics and supported, in part, by the US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.
- II. Transition Readiness Checklists will be used for youth 14 through 17 years of age.
 1. Contact the family & youth
 - a. When it is the birth month for the youth set a tickler for the end of the month to ensure the transition checklist is complete, attempt at least two phone contacts with the family within two weeks.
 - b. If family is reached by phone discuss the transition process including age related issues like self-care for the diagnosis and abilities of the child, then:
 1. Set an appointment for face to face appointment to complete the transition checklist, or
 2. Arrange to work with the family to complete the checklist over the phone, or
 3. Arrange to work with the family to complete the checklist through the mail.
 - c. If the initial two attempts of phone contact are not successful, mail the Transition Readiness Checklist and cover letter to family.

1. Title V has a Spanish version of the cover letter and the Transition Readiness Checklist for youth with special health care needs.
2. File a copy of the cover letter in the correspondence section of the youth's record.
3. It is not necessary to file a copy of the transition checklist in correspondence at the time that it is mailed to the parent.
- d. When tickler comes due at the end of the month:
 1. If contact was made and the transition checklist was completed, set a tickler reminder for five months to check-in with family's transition progress from their Title V Care Plan.
 2. If contact was not made, attempt one last phone contact with parent. Set a five-month tickler, if unable to contact.
- e. When tickler comes due at six months:
 1. Follow up with the family and youth and document it in the Title V Care Plan.
 2. If the Transition Readiness Checklist was sent to the family and no response was received after six months, complete the bottom of the second page of the checklist and mark "Mailed the checklist, no response after six months."
2. Complete the Transition Readiness Checklist with Family Quality Measurement questions
 - a. Administer the Transition Readiness Checklist face to face
 1. If in-person isn't possible, the interview may be done over the telephone after mailing parents the checklist. Document on the second page of the checklist that it is completed 'over the phone';
 - b. Provide appropriate resources and referrals for the age, diagnosis and abilities of the child;
 - c. Go over Family Quality Measurement questions after completing Transition Readiness Checklist;
 - d. Under "How was the checklist completed? Check one box", capture the highest level of interaction.
3. Document the Transition Readiness Checklist has been completed
 - a. Update the client's Title V Needs Assessment based on needs identified on the checklist.
 - b. Add new items to the client's Title V Service Plan, including resource materials given to family.
 - c. Key the responses from the Transition Readiness Checklist into the corresponding Survey Monkey:
 1. Transition Readiness Changing Roles for Families
 2. Complex Medical Needs Transition Checklist
 3. Transition Readiness Changing Roles for Youth Checklist.
 - d. Data obtained from the checklist regarding the transition needs of our youth and their families will be used to formulate objectives and goals for the Arkansas NPM on Transition.
 - e. File Transition Readiness Checklist in youth's record in Section I behind the DHS 4000's.
4. Set tickler to follow-up with family on transition issues in six months.
5. Repeat the Transition Readiness Checklist only once every 12 months.
 - a. If the Transition Readiness Checklist is completed within one month of the youth's next birthday, set ticklers for follow-up as outlined above.
 - b. Title V Care Coordinator is not required to send family and youth another checklist. In this example, Title V Care Coordinator will go through the transition process in 13 months during the month of the youth's birthday.
6. For purposes of the Title V Block Grant Application, an unduplicated count of the transition age YSHCN will be compiled from the Transition Aged Youth Reports from Therap.

Legal Changes at Age 18 in Privacy and Consent

In Arkansas, when a person turns 18 years of age, he or she becomes a legal adult with all associated rights and responsibilities. Unless the 18-year old has a guardian appointed through a court of law, they can give or refuse consent for medical procedures.

Medical records, including Transition Readiness Checklists, are considered confidential and are only accessible by:

- The patient,
- Parents when the patient is a minor under the age of 18 and
- Health care providers involved in the patient's health.

Arkansas Medicaid begins adult coverage of medical services at age 21.

Title V eligibility will end at age 18 for the Title V Status A and K. The coverage for Title V Status X will end when the young adult graduates from high school or obtains a certificate of completion.