Kentucky Office for Children with Special Health Care Needs Transition Policy and Checklist

Section I: Resource Overview

Summary
Kentucky's state Title V program has incorporated health care transition services as part of their regional care coordination program for youth with special health care needs (YSHCN). Their program uses a Transition Policy [Link to policy] and a Transition Checklist [Link to Checklist] to inform and assist YSHCN and their families make a smooth transition from pediatric to adult health care.

Resource Description

The transition process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change at age 18 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. As a part of incorporating transition into care coordination activities, the Kentucky Office for Children with Special Health Care Needs (OCSHCN) has developed the following two resources:

- Transition Policy Statement: this one-page document is used to inform OCSHCN patients and their parent/guardian that the OCSHCN is committed to helping patients make a smooth transition from pediatric to adult health care.
- Transition Checklist: This is a tool used to assist children/youth with special health care needs with meeting age appropriate developmental milestones. The checklist focuses on age appropriate transition questions for ages: (0-4, 5-11, 12-14, 15-17 & 18-21). Ages (0 to 11), questions are directed at the parent/guardian. Ages (12 to 21) questions are directed at the youth/young adult to help prepare him/her to transition to adulthood.

Purpose

Both of these documents are intended to support the transition process. The transition policy is Intended to inform patients and parents/guardians of the changes that will happen when the patient is an adult at age 18, and to help the patient and parent/guardian prepare for transitioning to adult health care.

Often children/youth with special health care needs have issues reaching age appropriate developmental milestones at a similar pace as their peers who do not have special health care needs. The goal of the Transition Checklist is to help children/youth with special health care

needs reach developmental milestones to the best of their abilities. This involves communicating to the child's parent/guardian the importance of the child/youth becoming, to the best of his/her ability, responsible for his/her health care and independent living needs.

Intended User

The intended users of both documents are clinic staff (Nurses, Social Workers, Family Support workers, etc.). They can distribute the transition policy document to patients and parents/guardians in their offices.

Intended Beneficiaries/Target Population

Children/youth/young adults with special health care needs and their parents/guardian are the intended beneficiaries/target population of this tool, as it will help them to prepare for successful transition.

Materials Required

Transition Policy Statement: The only materials needed are printing supplies and an online platform. Agencies can hang the document up in their facilities, or post the policy to the website. The document can also be mailed to patients and families.

Transition Checklist: The best use of this tool is to have it programed into the electronic medical record system of the medical practice allowing the patient responses to the questions be recorded in the patient's medical record. This allows staff to track the patient progress toward reaching the various age appropriate development milestones. Hard copies of the checklist can be used if the medical practice does not have the capacity to incorporate the checklist questions into the electronic medical record.

Section II: Using the Resource

How to Use this Resource

Transition Policy Statement: Kentucky OCSHCN posts a copy of the one-page Transition Policy Statement in all OCSHCN clinics across the state where patients and their parents/guardians can see it. The policy is posted on the OCSHCN agency website. A copy of the policy is also mailed with transition birthday letters that the OCSHCNs sends to patients when they turn 14, 16 and 18 years old.

Transition Checklist: As described above, this resource is best used as a series of questions for patients and parents/guardians that is entered into the patient's electronic medical record. The (0-4 & 5-11) age group transition questions are directed at the child's parent/guardian. The (12-14, 15-17 & 18-21) age group transition questions are directed at the youth/young adult to help him/her become use to being responsible for his/her health care and independent living skills.

Internal Capacity (Staff Needed to Develop this Resource)

The OCSHCN Transition Administrator worked with the Director of Clinical Services to develop the transition policy. Then the OCSHCN Executive Director reviewed and gave her approval. After it was approved, the Transition Administrator presented it at the agency Branch Manager meeting so the Branch Managers could inform their staff about the policy. The policy was then emailed to staff and posted in offices and on the agency website. A designated support staff person mails transition birthday letters each month to patients turning 14, 16 and 18 years old. She includes a copy of the transition policy with the birthday letters.

The agency transition checklist was developed about 15 years ago by forming a diverse group of agency staff that included nurses, social workers, parent support coordinator, the transition administrator, and a few others. This group reviewed information from national resources such as Bright Futures and the National Health and Ready to Work Center, and state and local resource information. After review of the information, a list of age appropriate developmental transition questions was developed, targeting children/youth with special health care needs birth to 21 years of age. Agency leadership supports programs that improve transition for children and youth with special health care needs. After the transition checklist questions were developed, a training was held to inform staff how to use the checklist in the clinics to discuss transition topics with patients and their parent/guardian. The agency nurses and social workers are the main staff members who discuss the transition questions with the patients and their parent/guardian.

To develop similar policies and checklists in your agency, consider engaging your organization's leadership and local branches of your organization. Along with internal leadership, consider collaboration with stakeholders, including national resource centers, patients, and families (see below).

Collaboration/Partners (External Partners who Helped Develop the Resource)

The OCSHCN transition policy was developed using information from the www.gottransition.org website. In addition, once the policy was developed, the OCSHCN Youth Advisory Council reviewed it and gave their feedback and approval.

When the OCSHCN transition checklist was first developed, a staff member at the National Healthy and Ready to Work Center helped review and develop the resource. Later, when the National Got Transition Center was established, OCSHCN staff reviewed information from the www.gottransition.org website and two more questions were added to the OCSHCN transition checklist. Updates and changes to the checklist were also reviewed by the OCSHCN Youth Advisory Council.

Lessons Learned

Utilize the information on the www.gottransition.org website. It is helpful for developing organization-wide transition policies, checklists, and other important transition-related resources.

In addition to using outside resources to develop transition tools, it is also important to gather feedback from the intended users and beneficiaries. For example, when the agency integrated

the transition checklist into the electronic medical record staff using the checklist provided feedback that the questions were useful, but some were similar and could be eliminated or combined to help speed up use of the checklist during clinic visits. A committee was then formed with a diverse group of agency staff using the checklist (nurses, social workers, parent support coordinator, and the transition administrator). The group reviewed the questions and eliminated or combined some questions. The changes were presented to the OCSHCN youth advisory council for their input and approval. The updates eased the process of administering the checklist.

Next Steps

Transition Policy Statement: The policy continues to be posted in OCSHCN clinics across the state. We will continue to include a copy of the policy with the transition birthday letters that we mail to patients when they turn 14, 16 and 18 years old.

Transition Checklist: Staff continue to use the transition checklist with patients during clinic visits. Since 2015, the agency transition administrator has conducted random audits biannually of the transition checklist. This is done as a quality control/quality improvement exercise to monitor staff use of the transition checklist questions and provide feedback to staff on its use. These biannual audits will continue and adjustments will be made as deemed necessary.