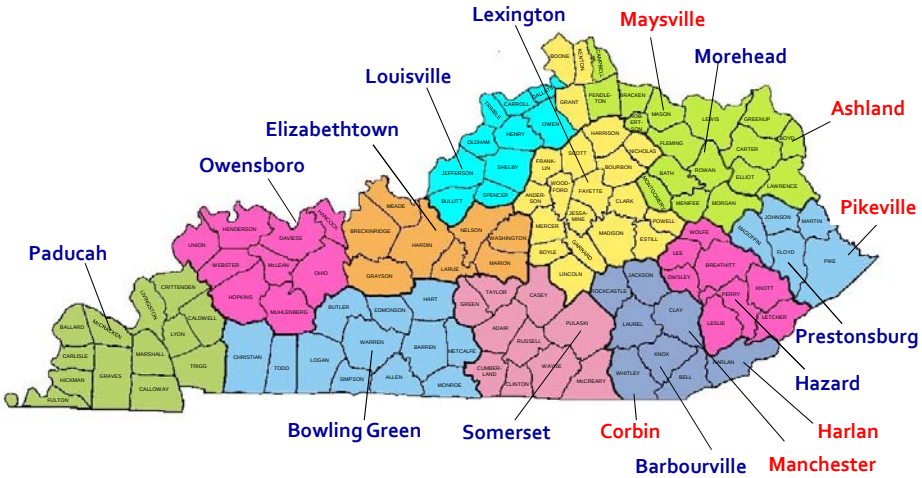
The Kentucky Office for Children with Special Health Care Needs

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Office for Children with Special Health Care Needs
Regional Offices
Satellite Clinics



Title V Care Coordination

- In FY 2017 the OCSHCN provided 78,302 services to 9,148 unduplicated patients through specialty medical clinic programs and augmentative programs.
- Staff mix includes registered nurses, social workers, administrative support staff, audiologists, speech language pathologists, dieticians and family support parents in our larger offices.
- Registered nurses, social workers, support parents and providers collaborate with patients and families to create a plan of care.
- The multidisciplinary team at the OCSHCN assists with linking the patient/family with needed medical and social resources to assist with transition as well as overcoming financial, language and cultural barriers.

Six Core Elements of Health Care Transition - KY

1. Transition Policy - Yes

- OCSHCN developed a transition policy utilizing the transition policy example on the Got Transition website.
- Staff were informed about the policy and their role in the transition process.
- The policy is posted in all 11 of our OCSHCN clinics.
- The policy is mailed with a transition letter to all 14, 16 & 18 year old patients on their birthday.

2. Registry - Yes

- OCSHCN uses an Electronic Health Record called CUP where all patient information is entered.

3. Transition Readiness Assessment - Yes

- The OCSHCN Transition Checklist is in CUP.
- Staff enter transition progress notes to support the transition checklist as they meet with youth and families during the clinical process.

Six Core Elements of Health Care Transition - KY

4. Transition Planning - Yes

- The OCSHCN Transition Checklist focuses on age appropriate transition questions for ages: (0-4, 5-11, 12-14, 15-17 & 18-21).
- Prior to age 18, youth are informed about: The need to choose an adult health care provider when he/she turns 18; Be familiar with health insurance and how it works– i.e. insurance plans, deductibles, co-pays, etc.; the importance of organizing and keeping medical records and receipts. The importance of taking care of his/her personal needs-i.e. (feeding, bathing dressing); The value of an education and how that will help with achieving work goals; The importance of connecting with support services for people with disabilities-i.e. (Vocational Rehabilitation, School to Work, Supported Employment, Adult Day Care, Etc.).

5. Transfer of Care - Yes

- Staff develop a portable medical summary that is given to patients to use upon transfer to an adult provider.

6. Transfer Completion – Yes

- Clinic surveys are completed by patients/family members during the clinic process.
- Transition phone surveys are attempted with each OCSHCN patient after the patient turns 21 years old and ages out of the OCSHCN.

Patient Aged Out Transition Phone Survey Calls

- From January 2015 through the first three months of this current year ending March 2018 there were a total of 235 patients that turned 21 years old and aged out of the OCSHCN program. Of those 235, contact was able to be made with 93 to ask them or their parent the brief aged out survey questions. (93 out of 235 is a 40% response rate).
- 92 of the 93 responded continued to have an adult practice provider after aging out of the OCSHCN. The 1 person that responded, who didn't currently have an adult provider, stated the OCSHCN had referred her to an adult provider. She just had not called the provider yet to schedule an appointment, but she was going to call.

Transition Standard: Transition to Adulthood

Standard: The OCSHCN will provide high quality transition support services to CYSHCN to assist them to make a successful transition to all aspects of adult life including health care, education, employment and independence to the full extent of their potential.

Activities:
- Information and patient education
- Linkage to needed services
- Facilitating access to service providers
- Advocacy and youth empowerment opportunities
- Support and encouragement
- Care Coordinators services for CYSHCN during transition to adult health care
- Youth Advisory Council

Performance Evidence:
- Patients and their families will attend clinics and be asked appropriate age group transition questions from the OCSHCN Transition Checklist in CUP. Patient and their family's responses to the transition checklist questions will be documented in the medical record.
- Patient follow up on referral services will be documented in the medical record.
- All transition support services will be documented in the patient record.
- Parents will participate in satisfaction surveys.

Age Specific Information Timetable with Focus on Transition to Adult Care

The OCSHCN Transition Checklist focuses on age appropriate transition questions for ages: (0-4, 5-11, 12-14, 15-17 & 18-21). Beginning at age 12 questions are directed at the patient. Below are some questions targeted at preparing the youth to transition to adult health care.

Health 12 – 14
I understand my diagnosis and can explain it.
I tell the doctor how I am doing and answer questions.
I take my medicine with or without supervision.

Health 15 – 17
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.

Health 18 – 21
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.

Recruitment of Physicians



Types of Providers Available:

- Family Medicine Practices
- Parent's adult PCP
- Federally Qualified Health Centers (FQHC)
- Medical Center Adult Health Care Clinics
- Adult Primary Care Provider

Process:

- OCSHCN staff perform regular outreach to area provider offices and FQHCs to provide information regarding transitioning youth with special health care need to adult care and the care coordination and assistance that can be provided to support until age 21 years.
- OCSHCN staff attend community partner meetings and community health fairs to learn about new area providers, stay in touch with current community providers and build relationships.

Portable Medical Summary

- Child's Name
- Child's Nickname
- DOB
- Health insurance
- Legal guardian
- Diagnosis
- Clinical summary
- Emergency Plan
- Allergies
- Medications
- Specialists
- Baseline Vitals (includes HT/WT)
- Problem List/Recommended Actions
- To be avoided
- Surgeries/procedures
- Labs/Diagnostics
- Equipment/Appliance/Assistive Technology provided
- Medical monitors provided
- School/Community Information

Transition & Family Support grants

- Healthy & Ready to Work grant (KY TEACH Project) (1999 – 2003)
- Family to Family Health Information Centers grant (F2F HICs) (2009 to Present): KY OCSHCN F2F HICs is run by two Co-Directors (both are parents of young adults who have special health care needs). They have trained volunteer Support Parents (who are parents of children with special health care) that are available to speak with families about resources/services. The F2F HICs provides assistance in a variety of ways, including support and referral through direct telephone, e-mail or in-person contact, training through workshops, advocating for and connecting families with resources.

Lessons Learned & Important Partnerships

- When working with children/youth on transition to adulthood issues, try to get the parents buy in, so they will understand the importance of the youth learning to become as independent as possible.
- It's important to have a good connection/relationship with your states Vocational Rehabilitation program when working with youth/young adults with disabilities on the importance of getting post high school education, skills training or supported employment assistance to help with gaining employment and independence.
- Collaborative partnerships developed with some adult practice providers who appreciate the connection with the OCSHCN Care Coordinators.
- When trying to connect with new adult practice providers, call the physician's practice for a good day and time to visit.
- Try to connect with the physician's nurse and try to establish a relationship with one contact person in the office.
- Patients and families express that they really like the Portable Medical Summary we developed for them.