

KENTUCKY SKY USE CASE 4

Kirk is a 3 year old with cerebral palsy (CP), hydrocephalus with a ventriculoperitoneal (VP) shunt, and seizures. He was placed in foster care when he was two months old after his parents terminated parental rights. Kirk has been in six different foster homes in four different Service Regions. He is on multiple medications for his CP symptoms, including anticonvulsant medication. His infant VP shunt was replaced when Kirk turned two years old but two foster homes have reported problems with the shunt and repeated follow-up visits with the pediatrician and pediatric neurosurgeon.

Access to a pediatric neurosurgeon and the availability of Kirk's medical records as his placements change have been a significant problem. In addition, medication management and pharmacy records are problematic for the DCBS Social Service Worker and foster parents.

Kirk's current foster family lives in a rural community in Webster County. They have discussed adoption with the Social Service Worker but expressed concerns with access to the care that he needs in the long-term. The family has attempted to access care at the nearest children's hospital but availability of appointments was problematic.

The family now must travel to Cincinnati Children's Hospital, which is more than a nine hour roundtrip commute. The travel and time off from work are hardships for the foster family but their primary concern is for Kirk's health. The foster family is concerned about availability of primary care and dental providers, clinical specialists (e.g., pediatric neurosurgeons), specialists to support his cognition, behavior, communication and developmental needs, medications to treat his CP symptoms and associated conditions, physical therapy, durable medical equipment, planned family respite care, etc. Describe how the Vendor would address Kirk's situation and coordination with the Social Service Worker, the foster family, in-state and out-of-state providers, and community resources. At a minimum, address the following programs and services:

- a. Care management, including coordination to address fragmented care and timeliness of care;
- b. Availability of services and network access, including out-of-state providers;
- c. Availability of services, such as skilled nursing services;
- d. Access to school based services;
- e. Applicable evidence based practices;
- f. Coordination of transportation, as needed;
- g. Community resources;
- h. Social determinants of health;
- i. Planned respite care;
- j. Provider education and support;
- k. Access to and sharing of medical records; and
- l. Maintenance of the care plan.

Introduction

Passport uses an integrated, whole-person approach to managing the care of Kentucky SKY members for sustained positive outcomes. Our approach identifies the critical factors that need to be addressed for the long-term success of children and youth in state custody, and it tailors services to support the goals of permanency, safety, health and well-being. For Kirk, the overriding goals are to develop a care plan and provide the support needed for him and his foster parents.

Understanding the Member

Upon enrollment, Kirk's foster parents, Cathy and James Smith, receive a phone call from Betty, who is a Passport Kentucky SKY Care Coordinator. She explains that in her role she is their primary partner, and she will coordinate all the care team members and services to support Kirk and the family. She conveys her understanding that his health care needs may feel overwhelming to the family, but also that having the presence of caring adults in his life is perhaps the single most important factor in his overall development and health. Betty arranges to do a home visit with the Smiths and asks permission to complete a health risk assessment (HRA), followed by a more detailed, complex care assessment to obtain all needed information.

Betty brings John, a Care Advisor, with her for the home visit. During the home visit, Betty and John meet Kirk, and then Betty completes the HRA while John works with the Smiths to complete an initial complex care assessment (member needs assessment). Going through this assessment is one of the first opportunities that Kirk's foster mother has had to think about his overall health care needs. The demands related to his cerebral palsy (CP), hydrocephalus and seizures have been the focus of her interactions with health care providers. While completing the assessment, Cathy has an opportunity to consider Kirk's broader developmental functioning and identify specific areas of concern, including the challenges imposed by limited mobility, the adequacy of positioning supports for eating and other family activities, and the lack of opportunity for social engagement outside the immediate foster family. John notes knowledge gaps related to Kirk's care, while Betty makes notes of Kirk's providers, who need to be engaged as part of the care team. John uses motivational interviewing techniques to talk with the foster mother, reflects on Kirk's challenges and successes, and affirms the positive steps that the parents have taken to address his needs. Betty contacts the social service worker (SSW) and uses information from previous assessments and care notes to help fill in gaps in the assessment. She asks the SSW for verification that the Cabinet for Health and Family Services (CHFS) wants to support this placement as a possible permanency option for Kirk. Betty also confirms with the SSW that Kirk has been designated medically complex.

Betty then requests electronic health records from health care providers and convenes the care team for the development of Kirk's care plan. The care team participants include Betty, John, Mrs. Smith, Mrs. Smith's mom (who sometimes cares for Kirk), the SSW, a liaison for medically complex members, providers, a behavioral health care manager, a family peer support specialist, pharmacists, a preschool education representative from Webster County, and the Department for Community Based Services (DCBS) representative. Betty was able to get input from a nurse consultant familiar with Kirk's care at Cincinnati Children's Hospital, although he declined the meeting invitation. Betty conducts the meeting from the foster

parents' home and uses a conference call line to provide access for those who are remotely located. The DCBS representatives and foster parents open with their concerns, and then the various other professionals help identify and prioritize Kirk's and the Smiths' needs. One thing that becomes clear in the meeting is that the foster parents have been traveling to Cincinnati for all of Kirk's health care needs (even fairly minor ones) because they feared that a local pediatrician could not manage his care. Due to his medical needs, Kirk has not been enrolled in public preschool services. The Webster County preschool representative notes that Webster County has a highly ranked preschool program and that they are committed to serving all kids in the county, especially in light of limited daycare options. Kirk could be integrated into their developmental program if they could receive some consultation on how to manage his needs. Kirk is present in the home for the meeting and, despite significant developmental and medical challenges, all care team members are impressed with his social responsiveness. Mrs. Smith notes that when her sister's children, ages six and eight, come to the house, they love to play with Kirk, and that Kirk lights up in their presence.

Based on the team's assessment meeting, Betty and John develop an initial care plan that incorporates the individual health plan and time frames for accomplishing the goals. The initial care plan focuses on (1) evaluating local primary care pediatricians to find a group practice comfortable with Kirk's unique issues, so that routine medical care can be delivered near the Smiths' home; (2) completing a preschool referral and providing support to allow Kirk to be integrated into an environment with other children; and (3) referrals and completion of a comprehensive developmental assessment to determine Kirk's need for further services. Initially, John and Betty schedule weekly contacts with the family and explain that they will monitor the implementation of the school and local medical care plan. They also engage Lori, the local Passport community engagement specialist, so that she can provide information on resources available within the community. Betty also arranges for a medication review by a Passport pharmacist, Susie, to educate the Smiths and Kirk's SSW about his medications. Susie conducts a medication reconciliation along with a comprehensive medication review to obtain an accurate and complete list of active medications. The medication review includes outreach to the Smiths and to Kirk's providers and care team members, and that information is captured in the care plan. Betty assists with referrals and appointments, while tracking Kirk's progress. She assists Mrs. Smith in reviewing all the local pediatricians and schedules several pediatrician interviews with providers who are comfortable with Kirk's medical needs.

Kirk visits a local dentist, and the appointment does not go well. Mrs. Smith feels that the dentist had issues with Kirk being seen in a typical dental chair and Kirk's troubles with keeping his mouth open. Betty suggests that Mrs. Smith take Kirk to the Office of Children with Special Health Care Needs (OCSHCN) in Owensboro for dental care, since they are very experienced in working with children with special needs.

John and the Smiths discuss the option of transferring Kirk's neurological care closer to home. Betty and the Smiths discuss a referral to the Cerebral Palsy Clinic in Owensboro, which is associated with the OCSHCN. In this clinic, Kirk can see specialists for neurology, pulmonology and orthopedics. Mrs. Smith agrees to the referral, saying that over time, they will probably want to transition his care to Kentucky-based providers. Mrs. Smith adds that she and her husband are confident in Cincinnati Children's Hospital, and she would like

to use the hospital only for services requiring in-hospital care/treatment. John advises the Smiths of transportation benefits available via Passport. Passport orients all new and existing providers to the unique needs of Kentucky SKY members. The training includes information about the Kentucky SKY population, Health Insurance Portability and Accountability Act (HIPAA)-compliant exchange of information, working with foster families, and other topics detailed in Passport's SKY Education and Support plan.

Based on the developmental assessment, Kirk is determined to need physical, occupational and speech therapy. Although services are available through Baptist Health in Madisonville (within 30 minutes of Webster County), the Smiths express concern about the multiple appointments required each week. Services are available through school as well, but the care team agrees that additional services in addition to school-based services in this early period would be beneficial. John discusses these concerns with the director of the Physical Therapy and Rehabilitation program. Baptist Health agrees to develop an at-home program of therapeutic activities and exercises. Kirk is scheduled to be seen monthly by the therapists to monitor his progress. The Smiths report being pleased with the option and begin talking about ways to incorporate Mrs. Smith's niece and nephew into the home therapy. John speaks with Kirk's pediatrician about skilled nursing services via a home health agency. Kirk's pediatrician agrees that this could be beneficial to Kirk, and he makes a referral to Baptist Health Madisonville Pediatric Home Care for a nurse evaluation. The nurse assists with Kirk's care, and this adds to the coordination between the family and Kirk's providers. If the nurse's evaluation determines more intense nursing services are needed for longer durations, private duty nursing could be available to Kirk via Early and Periodic Screening, Diagnosis and Treatment (EPSDT) special services. Mrs. Smith is relieved to know she will have some hands-on help on a regular basis.

Having established contact with Webster County's preschool staff (and with the SSW's and Mrs. Smith's consent), Betty discusses coordination of school-based services, which is a benefit that Passport covers. Given the complicated nature of Kirk's condition, Betty and the preschool staff agree to use the developmental assessment obtained during implementation of his care plan. They are surprised to learn that although Kirk has many speech and motor challenges that limit communication, his intellectual ability appears to be in the mild range of intellectual disability. Kirk receives an Individualized Education Program (IEP), which provides physical, occupational and speech therapy, and gives access to a developmental interventionist. In his regular calls with Mrs. Smith, John asks whether the home therapy program appears to be meeting Kirk's needs, and he offers to arrange for additional therapies to supplement those he receives in school during summer breaks or extended school vacations.

Passport's approach to managing complex care needs and care coordination relies on (1) the recommendations of the medical and behavioral professionals who evaluate and treat Kirk, (2) agreement with care decisions from his caregivers and his SSW, and (3) whether the treatment or service supports long-term gains. Kirk has multiple pediatric subspecialists involved in his care, and they follow evidence-based practices, which are the main guiding principles when deciding on the best approach for his care. Many different medications, dietary approaches and therapies are recommended for Kirk. Using evidence-based guidelines helps determine the most appropriate course of action, especially when some proposed treatment options will fall in the experimental and investigational category, given his complex issues.

Based on the assessment, the Smiths report that most of their basic needs are met. Both parents work and own their home. They have adequate access to food. Both foster parents express a desire to learn more about Kirk's condition and what they might expect in parenting a child with disabilities as he grows older. Betty provides links to a number of relevant organizations and resources for them to engage with (see below) and recommends attending a workshop in Owensboro, "Special Education Process (ages 3-21)," sponsored by KY-SPIN.

Passport's initial assessment includes a basic Social Determinants of Health (SDoH) screening to help ascertain what other pressures are having an impact on Kirk and the Smiths. Betty may also complete a more in-depth SDoH screening if the basic screening warrants it. This SDoH screening centers on five (5) domains: economic stability, neighborhood and physical environment, eHealth Care, and community and social context. For Kirk and the Smiths, the main social need is his lack of normal social activity for a three-year-old. The Smiths also share that they would like to be sure their home is Americans with Disabilities Act (ADA) compliant by widening the hallways and doorways, as well as building a ramp to the front door. They are also interested in learning about car seats that might support Kirk more comfortably and are exploring the possibility of adapting their vehicle for wheelchair accessibility. The concern for the Smiths is that making all of the needed changes will be a financial burden, and they are uncertain who can help with this. Betty engages the help of Lori, who can help to identify community resources that offer support from a financial or volunteer standpoint.

Mrs. Smith tears up a little and says that she really misses being able to have occasional evenings out with her husband. Prior to accepting Kirk, they would try to get out about once a month. She had thought that her sister would be able to help with baby-sitting when they became foster parents; however, her sister is uncomfortable keeping Kirk because of his complex needs. Betty arranges for the SSW to talk with her about training to become comfortable as a respite provider for a medically complex child. Together, Betty and the SSW work with the Smiths' Recruitment and Certification worker to get approval for not only Mrs. Smith's sister, but also other family to become respite providers for Kirk. John offers to work with Mrs. Smith to help train all of the adults on Kirk's individual needs. The goal of the training is to ensure there is caregiver support from all angles, and the family feels supported and confident in meeting Kirk's medically complex needs.

Specific to Kirk's needs, a Provider Relations Liaison helps nonmedical providers (e.g., schools, daycares) to understand and manage his conditions. Betty and John also connect with Cincinnati Children's Hospital providers for support with Kirk's complex care needs. Betty maintains a record of Kirk's medical and developmental services and providers in his care plan.

Passport intends to develop a comprehensive medical records release form to reduce the burden on DCBS of signing separate consent forms for each new provider. Betty and the SSW obtain all known medical, dental, vision, pharmacy, immunization, therapies and behavioral health records during the assessment phase of care planning. As the care plan/individual health plan is developed and implemented, Betty communicates with the SSW regarding new providers, treatments and medications. At a minimum, care

team members are updated at the monthly SKY care coordination team meetings. While adhering to all relevant laws designed to protect the privacy and security of Kirk’s medical information, Passport coordinates the open exchange of medical information for providers involved in this care.

After development of the initial care plan/individual health plan, Betty and John meet with Kirk and the Smiths once a month in their home. The medically complex service team meets every three months to review Kirk’s individual health plan and ensures that the plan is updated at least every six months or more often as needed. Copies of the individual health plan and the SKY care coordination team care plan are shared with care coordination team members.

Two (2) years after the first assessment team meeting, Mrs. Smith reports that Kirk is doing well in his school placement, and that she and her husband are finding the daily management of his needs easier with the support they have received. Working with more local specialists has made scheduling appointments easier, and now they do not have to miss days of work. Kirk’s strong social responsiveness, along with his quick adaptation to a new augmented communication device and improving motor skills, have contributed to his beginning to develop friendships with same-age peers. As a result, Mrs. Smith excitedly tells Betty that she has asked Kirk’s SSW to begin the required steps for them to adopt Kirk.