

KENTUCKY SKY USE CASE 8

Amanda, 10 years old, was born with multiple heart defects that affected blood flow between her heart and lungs. Amanda was placed into foster care when she was five (5) after her mother, a substance abuser, was incarcerated for neglect of a dependent. She has had multiple open heart surgeries, bouts of pneumonia, and frequent ED visits.

Amanda's initial placement was with her aunt who could no longer care for her due to the stress of managing Amanda's level of care. Amanda's second foster home placement is with a family located in eastern Kentucky with two (2) additional foster children, ages 6 and 8, in the home. The family has one car and transportation is an issue when it is needed to transport Amanda to appointments with her PCP, pediatric cardiologist, behavioral health therapist, dentist, and other specialists. Amanda's foster father works full-time as an assistant bank manager and her foster mother does not work outside of the home.

Amanda is on thirteen (13) medications and is oxygen dependent. She frequently exhibits behaviors such as defiance, impulsivity, and disruptiveness. She has been diagnosed with depression and has extended crying spells that trigger tachycardia and cyanotic episodes. Amanda has growing fatigue and is refusing to eat anything other than yogurt, fruit, and breakfast cereal. Amanda has multiple caregivers who assist with activities of daily living, medication management, and monitoring oxygen levels. Amanda participates in home bound school services provided by the public school system, as her health permits.

Over the past six months, Amanda has been to the emergency room nine (9) times for respiratory/cardiac distress. She had three inpatient admissions for pneumonia and evaluation of her cardiac status. During her last visit with the pediatric cardiologist, the family was advised that Amanda's oxygen levels were worsening with significant changes in cardiac function. The pediatric cardiologist recommended another open heart surgical procedure, but advised the family that a heart transplant may be the only viable long-term solution. The foster family met with the cardiologist's Nurse Practitioner to develop a plan for building Amanda's strength prior to surgery or placement on a transplant list. The foster family is struggling to figure out how to keep up Amanda's spirits up and improve her appetite.

Amanda meets the designation of a Medically Complex Child pursuant to 922 KAR 1:350, The Kentucky SKY Contractor is responsible for providing Care Management and nursing consultative services to enrollees who are determined by the Medical Support Section staff to be Medically Complex.

Describe how the Vendor would address Amanda's situation and coordination with the DCBS Social Service Worker, Medically Complex Liaison, foster family, all providers, and community resources. At minimum, address the following programs and services:

- a. Care management, including the assignment of the Nurse Case Manager;
- b. Involvement of Medically Complex service team;
- c. Discharge planning between levels of care;
- d. Individual Health Plan development and maintenance within specified timeframes;
- e. Availability of and access to providers;
- f. The Medical Passport;
- g. Training and support for caregivers;
- h. Coordination of transportation, as needed;
- i. Coordination of physical and behavioral health services;
- j. Community resources;
- k. Assistance with the Individualized Education Plan;
- l. Social Determinants of Health;
- m. Planned respite care;
- n. Applicable evidence-based practices;
- o. Sharing and review of medical records; and
- p. Maintenance of the care plan.

Introduction

Carolyn and Mike Jacobs have been foster parents for seven years, and for the first time they are feeling overwhelmed and a little hopeless. Amanda is a 10-year-old girl who moved in with them five months ago. She is one of three children in the Jacobs' home. Amanda requires many times the energy expenditure of the other two, but Carolyn tells herself that she needs many times the compassion, too. Sometimes Carolyn worries that she is short-changing Philip and Carmen, the two younger ones, and she also senses they do not know how to respond to Amanda's outbursts. Right now, nothing seems to be helping Amanda, and it feels like she is fading a little in spite of her outward defiance and disruptiveness. They have had so many emergency moments in the last few months, and now they are being told what she really needs is a heart transplant or, at a minimum, another heart surgery. Carolyn is struggling to keep up with the many appointments that Amanda needs. She has seen so many doctors, caregivers and specialists, yet it seems that no one can help with Amanda's depression or get her eating well enough to be stronger again.

Background

Amanda is tired of being sick. This is the first time she has lived with other children, and the other two kids in the Jacobs' home get to be "normal." They get to attend school, and they come back from school bubbling over about what they did and learned. Over the summer they played outside all the time, and now that school is starting, they are getting to buy new school supplies. They get to do whatever they want, and Amanda is stuck being cared for and tethered to an oxygen tank. Instead of going to school, she is shuffled from one appointment to another. Even seeing the teacher is an appointment—just one that comes to her house. Amanda is tired, she does not feel well at all, and she is sad or angry most of the time. Sometimes she is scared. She has had so many doctors, medicines, therapists, and hospital stays, and no one is making her better. She has almost no control, and she wants the adults to understand that hospitals and doctors and changing caregivers is not the type of "normal" anyone should have to live through.

Establishing a Care Team

Jenna is Amanda's Passport Care Coordinator (CC). Amanda is new to Passport, so Jenna has been reviewing all that is available regarding Amanda's five-year history in Kentucky's foster care program and her current status. She accessed the Kentucky Health Information Exchange (KHIE) and has spoken with the Department for Community Based Services (DCBS) Social Service Worker (SSW), who helped her obtain Amanda's claims history from her previous managed care organization (MCO). Jenna has also reached out to the Office for Children with Special Healthcare Needs (OCSHCN) nurse consultant for Amanda's Individual Health Plan (IHP) and general history. Jenna likes to have all of the information that is available before she makes her first outreach call. She feels it helps to build some pieces of the assessment so that more informed questions can be asked and clarification can occur more quickly.

Back at home, the phone rings just as Carolyn is finishing Amanda's braid; Jenna introduces herself as being from Passport Health Plan. She quickly assures Carolyn that there is nothing wrong; she just wants to let her know that Amanda, who recently moved into Passport's Kentucky SKY Program, is being enrolled in the

Complex Care Coordination Program. Jenna informs Carolyn that Amanda is being assigned a team from Passport to support her and the family, and that she, Jenna, is their primary point of contact and their Care Coordinator. In addition to Jenna, there will be a Nurse Care Advisor (CA) as well as a Community Health Worker (CHW), a Behavioral Health (BH) Specialist, and a Peer Support Specialist all available to Amanda and the Jacobs; if needed, Passport also provides a Dietitian and a Pharmacist. Jenna provides contact information for key team members and the number for Passport's Care for You free 24-hour nurse advice line. The team will work together with the OCSHCN nurse, Medically Complex Liaison, DCBS SSW, practitioners and others to coordinate care and ensure that Amanda's needs are being met. Carolyn is already familiar with care management, and in a vulnerable moment, asks what the team will really be able to do to help Amanda.

Understanding the Member

Jenna takes a pause to ensure that Carolyn is done speaking and gently asks how she has been doing. Carolyn's voice quakes a little as all her worries and exhaustion pour out. She explains that she feels like she is failing all three foster children right now and tells her how scared she is for Amanda. Jenna listens empathetically and says that she understands and is amazed at how strong Carolyn is for taking on so much. Hearing Carolyn's distress, Jenna asks if it is an okay time to start getting to know what Amanda needs over the phone, or if she would prefer to wait until the first in-person team meeting. Carolyn feels heard and is also grateful that she has the chance to get answers to some of her questions over the phone. She does not want to feel this emotional when meeting in person with new people. At Jenna's request, Carolyn says that she will also share Amanda's Medical Passport to help Jenna fully understand Amanda's medical history.

Jenna goes through the Health Risk Assessment questions with Carolyn, and then they conference in Cassie, the Medically Complex Nurse CA assigned to Amanda and the Jacobs. Cassie wants to participate in completing the Kentucky SKY Pediatric Assessment (Enrollee Needs Assessment), which takes a biopsychosocial approach and includes environmental factors as well as trauma screening. Carolyn feels a bit sheepish when she explains that transportation has been a big barrier in getting Amanda to all of her appointments, particularly due to how far away some of the visits are. She also notes that Amanda has an Individual Education Plan (IEP) in place and is currently in homebound school, but that the teacher only comes two days each week during the school year. She is not sure that Amanda is as far along as she should be academically. She is also worried that Amanda does not have enough time with other children, and that she will feel even more isolated when the younger two children go back to school. Jenna confirms with Carolyn that she has already coordinated an appointment day and time for the Passport care team to meet with Carolyn in her home. Carolyn is grateful that this is one care meeting where transportation will not be an issue. Before they end their call, Cassie schedules a follow-up call with Carolyn to take place in three days to talk more in-depth about Amanda's medical care needs.

When Cassie calls in a few days, Carolyn is very happy to learn that Cassie once worked in a pediatric intensive care unit (ICU) and has experience caring for children with chronic, life-threatening conditions.

Cassie uses motivational interviewing to elicit Carolyn's greatest concerns. Carolyn is frustrated that Amanda is not eating well and is increasingly fatigued, which requires more assistance from Carolyn in her activities of daily living (ADL). She is also very concerned that the protracted crying spells Amanda has are triggering cyanotic episodes and that no one has been able to help Amanda manage her depression and irritability well enough to prevent these episodes. The multiple emergency department visits and inpatient stays for pneumonia cause fear for the whole family, have exhausted Carolyn and are just as scary and stressful for Amanda.

Cassie asks if Amanda and the family receive any support during those hospital stays. Carolyn reports that at both Kentucky Children's and Cincinnati Children's Hospitals, Amanda really enjoys the people who bring her toys and things to do, but her favorite is the musician who sometimes visits her room and plays the guitar. Amanda hums along even when she is having difficulty with her oxygenation. However, with the other two (2) children being at home, childcare is a significant issue when Amanda is in the hospital. Carolyn reveals that while she loves every child that she fosters, and this has always been a calling for her, they cannot reduce the number of foster children in the home due to financial reasons. Carolyn would have to work outside the home if they fostered fewer children at a time.

Creating a Plan

At the first Coordinated Care team meeting at the Jacobs' home, Amanda and Carolyn are present, as well as Jenna, Cassie, the DCBS SSW and Amanda's teacher. Amanda's Pediatric Cardiologist, BH Therapist and Dentist declined to participate, but the Cardiologist did call Cassie before the meeting to discuss findings from the Kentucky SKY Pediatric Assessment and share feedback about the current course of treatment. Jenna uses skills gained at a training for High Fidelity Wraparound Care to ensure Carolyn's and Amanda's concerns and ideas are heard first. She works to elicit input from all members of the care team who are present, and promises to follow up with Amanda's providers after the meeting to share care plan information.

It is very clear to the team that all of the traveling between appointments and home has been negatively impacting the health and quality of life of the entire family and causing undue stress. While Kentucky Children's Hospital was a great resource and closer to the Jacobs' home, if a heart transplant becomes an option, they would eventually have to travel to Cincinnati. Cincinnati Children's Hospital is closer to their home than Norton Children's, where Amanda has previously received care. This was a worry for Carolyn until Cassie helped her understand that Cincinnati Children's has a collaboration with Kentucky Children's for cardiac care and that coordinating records and appointments is easy to do. In addition, Cincinnati Children's Hospital could offer cardiology e-consultation to an in-network pediatrician closer to their home. With this new understanding, Carolyn now feels comfortable with keeping Amanda's immediate cardiac care needs housed at Kentucky Children's, per the recommendation from the OCSHCN nurse and Cassie, rather than using the pediatric cardiologists in Pikeville.

Knowledge of the care coordination between Cincinnati Children's, Kentucky Children's and the new pediatrician has helped Amanda and Carolyn feel more at ease. Moving forward, Jenna or the Cardiology

Nurse Navigator at Amanda's pediatric cardiologist's office will ensure that if there are multiple specialist appointments, imaging or other tests needed for Amanda, all would be scheduled on the same day. This further enforces maintaining care at a larger pediatric center where multiple specialists are housed in close proximity. For any care needed at Cincinnati Children's, the navigator or Jenna would help ensure that the family had overnight accommodations at Ronald McDonald House or a nearby hotel. Carolyn was assured that out-of-pocket hotel costs would be reimbursed because the family lives more than 40 miles away from the provider. Meals for one (1) caregiver would also be covered, and the family can request reimbursement from Passport for any mileage traveled beyond 40 miles each way.

From the information gathered by Jenna prior to the meeting, as well as from reports submitted by Carolyn and the SSW, the team also realizes that Amanda has received inconsistent and disjointed BH services in multiple settings because of her many recent acute hospitalizations. Amanda is currently seeing a licensed clinical social worker (LCSW) at the local community mental health clinic (CMHC), but she occasionally missed appointments due to concerns about infection risk, hospitalizations or transportation barriers. At the care team meeting, Amanda reports that she likes the LCSW. Carolyn feels it would be helpful if Amanda could be seen more often. The team agrees to work to increase the frequency of Amanda's therapy. Following the meeting, Jenna coordinates with the SSW to request this increase from the LCSW. The LCSW reports that she is able to provide telehealth to help mitigate the family's concerns about traveling and risks of infection. Jenna also works to ensure that, moving forward, BH providers associated with the hospital collaborate with the outpatient LCSW to allow for better coordination.

Facilitating Care

At the next care team meeting, the LCSW participates via phone. She reports she was able to speak with some of the providers who worked with Amanda in the hospital and thereby learned what types of reinforcers improved Amanda's disposition while she was inpatient. The family is now using the same reinforcers to reward Amanda for eating better meals and are starting to see small improvements. Thanks to the new collaboration between the hospital and cardiology group-based BH Director, the LCSW was also able to learn that in the past Amanda has refused to talk or eat when in the hospital for longer periods. It was usually linked to times when Amanda felt that she had the least control.

With this knowledge, the LCSW was able to help the cardiac team understand some of Amanda's early childhood trauma and how she believes it has impacted some of her current behaviors. Utilizing telehealth has allowed Amanda and the foster family to participate in a family session which provided the LCSW the opportunity to observe how the other two (2) children respond to some of Amanda's impulsive acts and disruptions. Also, since the other two (2) children have been back to school now for two (2) months, Carolyn has noticed that Amanda's mood has been worse on Sunday nights and Mondays as she adjusted back to the school schedule. Amanda tells the LCSW and the care team CHW that she wants to go to school like everyone else. Jenna and Cassie wonder if the school might be flexible with Amanda's homebound plan and if the medical team might provide consent for Amanda to attend a half-day each week in a classroom. They

obtain the necessary releases from the SSW to speak with the school. Amanda seems pleased that the adults are listening to her and trying to help her be more like a regular kid.

Cassie works with Amanda's cardiologist on parameters for physical health stability that will indicate when Amanda can safely tolerate a few hours in the classroom setting. Jenna and the SSW work together with the school, where the administration is amenable to having Amanda build a relationship with peers both in-person and through Skype. The process is informal because Amanda's IEP was not due to be re-evaluated until the following year, and because her medical condition is too fragile to predict when she might be able to tolerate more than the half day. The homebound teacher will continue to work with Amanda twice a week. At this news, Amanda's mood begins to improve slightly. She works with her LCSW and physical therapist to develop the short-term goals that must be achieved to be well enough to go to school one half-day per week. Amanda also agrees to begin adding two (2) new foods per week. Jenna contacts Passport's dietitian and asks her to collaborate with Carolyn to help increase the nutrition in Amanda's diet.

Jenna reinforces the importance of Carolyn continuing to update the notes and medical history in Amanda's Medical Passport and offers to supply past claims data, diagnoses and provider contact information to help her complete and maintain Medical Passport documentation.

Realizing Results

At the six (6)-month IHP meeting (which Jenna also uses as a care team meeting to make things easier for the family), the OCSHCN nurse notes remarkable improvement in Amanda. Amanda had a pre-albumin of 16 mg/dL at the previous appointment with her cardiologist. Through the Passport dietitian's and Carolyn's efforts, Amanda's dietary intake now includes high-fat protein shakes and other high-protein foods. As a result of her improvement, Amanda was rewarded with the opportunity to leave the house for activities other than medical appointments and was able to make friends with peers through her desired half day at school each week. Additionally, the care team coordinated with the cardiologist for safe activities that Amanda can do with her family. Her new goal is to attend the Zoo Day sponsored by Cincinnati Children's Hospital, and she was advised she had to increase her weight by five (5) pounds in order to do so. Motivated by having set her own goal and reward, Amanda achieved this by adding chicken and bacon back into her diet along with three (3) additional vegetables. Amanda met her weight goal just before the IHP meeting, and her pre-albumin is now 24 mg/dL. She is looking forward to Zoo Day, and as an added bonus, the hospital arranged for a scholarship to help the family with the cost of transportation.

Looking Forward

Carolyn worried about Amanda and how to best care for her throughout the first six (6) months of complex care coordination with Passport. Passport's care team continues to provide Carolyn with additional resources for support, including references to Little Mended Hearts' Lexington Chapter and the Pediatric Congenital Heart Association. The care team assisted in finding a qualified foster family who can provide respite for the family. Working with the DCBS SSW, Carolyn meets with a family a few towns away who is willing to assist one (1) day every other month. In order to ensure sufficient respite, Amanda's aunt is contacted by the SSW and she agrees to provide one (1) day on the opposite month until another family

member can be trained. Amanda's aunt receives additional education about how Amanda's behaviors were impacted both by her own illness fatigue and by her trauma history in early childhood. Her aunt agrees to join the care team and participate in meetings.

Finally, the Peer Support Specialist on the team begins working directly with Carolyn to address her feelings of inadequacy and burnout. As much as Carolyn has appreciated the efforts of the Care Coordinator and CA, she finds it most helpful to talk to someone who has walked in her shoes, and she now feels supported more than she ever has in the past around being a foster parent.

Conclusion

It has been 13 months since the first Care Coordination Team meeting. Because the team has been able to improve the coordination of appointments into a single day, the Jacobs family is better able to obtain the support of friends to get Mike to work so that Carolyn is able to have use of the car for those less frequent trips to pediatric specialists. At the one (1)-year anniversary of the first care team meeting, Amanda met her goal for a peer-supported activity and attended Zoo Day. She is attending school one (1) half-day most weeks during the school year and she now has a new goal: to attend the Fall Family camp the following year at the Kerrington's Heart family camp weekend, sponsored by a non-profit organization aligned with Kentucky Children's cardiology group. Attempts by DCBS to engage Amanda's mother since she was released from prison have not been successful. Although Amanda is able to have her next surgery, she still needs a heart transplant for long-term quality of life.

Carolyn and Mike decide that they cannot be the family to see Amanda through a transplant if they continue to foster multiple children. However, they have grown attached to her. They have been seeking community support to offset the financial losses they would incur if they streamline down to having just Amanda in their care moving forward. In conjunction with the OCSCN nurse, Jenna works to coordinate with the transplant center at Cincinnati Children's to help educate Carolyn and Mike on resources specific to transplant, such as KY Circuit Court Clerk's Trust for Life and Children's Organ Transplant Association (COTA). Carolyn has already reached out to Kerrington's Heart regarding assistance, should they retain care of Amanda for a transplant. While her mood has improved and her outbursts have decreased, Amanda is still often scared and tired of being "different," even on the days she feels better. But like the other lessons Amanda has learned, she has learned to hope.