



Healthcare and Long-Term Care in Kansas for People with Disabilities

Topeka Town Hall – 8.7.12 Summary of comments

22 people attended

1. WHAT ASPECTS OF HEALTHCARE WORK FOR YOU NOW?

Transportation

- Cottonwood provides and arranges transportation for people in residential programs
- Parents and family members provide by choice

Access to healthcare and to healthcare facilities

- Cottonwood consumers can have staff member accompany them to help with appointments
- Dental:
 - Cottonwood has a small dental clinic and uses Douglas County Dental Clinic
 - Douglas County Dental Clinic will handle emergencies and serves all low income and uninsured (Julie Branstrom is director)
 - Community dentists accept a reduced rate
 - Dr. Larry Betsworth has accessible rooms that use the patient's wheelchair
- Pharmacies deliver free (Siegler Pharmacy in Lawrence, Heartland and Kmart in Topeka)
- Pharmacies provide helpful and educational services
 - Bubblepacks specify times for dispensing
 - Heartland provides an ID and info sheet about medications with a dispensing guide for staff to initial

- Sigler Pharmacy in Lawrence checks pills and provides info sheets with turn over day
- Cottonwood’s pre-surgery hospital form clarifies communication with providers regarding hospitalization and discharge instructions

My healthcare providers (knowledge, attitudes and communication):

- Developing relationships over time with a provider improves communication. These providers were praised for their responsiveness, effective communication methods and positive attitudes toward people with disabilities.
 - Doctors
 - Drs. Steuve (or Steuver?)and Dillon (Lawrence)
 - Drs. McKenna and Patrick (Topeka?)
 - Shawnee County Public Health Dept.
 - Michael Lexow, Cotton-O’Neil Clinic (GP)
 - Other general practitioners
 - Sleep apnea doctor at St. Francis clinic
 - Pediatric neurologist in Topeka
 - Dentists
 - Marion Clinic Dental
 - Douglas County Dental Clinic
 - Dentist in Lawrence takes Medicaid
 - Charlie Kincaid (Lawrence)
 - Larry Betsworth
 - Anita Murray Clary (pediatric) – worked on pt. while in wheelchair
 - Mental health providers
 - Dr. Bloomquist ?or Bloomberg
 - Dr. Whipple ? or Wimple (but not Medicaid)
 - Bert Nash Mental Health Center
 - Rhonda Halvesen, Pathways for Life (Topeka)
 - Hospitals
 - Stormont Vail Hospital excellent to work with as a team, good communication and provides documents quickly
 - Children’s Mercy team communicated well with Stormont Vail
 - Emergency Room accepted Mom as part of support system
- Women doctors are available

- Heartland Pharmacy is technologically connected to Cottonwood, so information is exchanged immediately about prescriptions
- Cottonwood developed a pre-hospital surgery form, which improves communication between medical staff and service providers about hospitalization and discharge instructions
- Educating healthcare professionals – increases their “comfort zone being with our consumers” (summer sessions?)
 - Cottonwood has hosted KU pre-med students for several years for educational sessions.
 - Other agencies have hosted nursing students and pharmacists.

Medicaid services

- For people over 65 with dual coverage, no problems. (Ex., 86-year-old having cataract surgery.)

Suggestions:

- Having someone who knows the person serve as a health navigator or care coordinator would help
- Build on Cottonwood’s pre-surgery form as a communication tool to use with health care providers
- Reimburse residential care providers for staying in hospital with consumers. They know how to communicate with them and how they communicate their pain, which helps achieve recovery and prevention.
- Provide training to nurses and KU medical students about people with IDD
- Good doctors could peer mentor others

Participant: Many docs don't accept new [Medicaid] patients and the ones that do an excellent job are already maxed out. If there is some way between the physicians' networking they could help educate their own -- the other doctors, that would be helpful versus somebody else trying to go in and say this is what you need to do.

2. WHAT DOESN'T WORK IN YOUR HEALTHCARE EXPERIENCE?

Transportation

- Family members must provide in rural areas because no other options available

Access to healthcare and to healthcare facilities

- Lack of training and equipment (lifts and scales) for wheelchair transfer at doctors, dentists and hospitals
 - One man unable to get a prescribed brain scan because they don't know how to transfer him from chair
 - Mother had to lift son for 20 years to baby scale at pediatric clinic
- Doctors don't accept Medicaid – especially specialists and dentists
- People who don't have family or others to advocate for them often get less and inferior care
- Can't get prescribed name-brand medication and generics don't work as well. After trying many different medications, the name-brand medicine often doesn't work as well if patient returns to it. (See also Medicaid services below.) Especially difficult to get appropriate treatment when pt. takes a combination of meds.
- Private insurance doesn't cover some services and parents don't qualify for Medicaid as secondary
 - Private pay causes family distress – when to sell house? Stay married?
 - Medications cause dental issues and require frequent cleanings, but not covered by private dental insurance
- Lack of continuity between insurance plans: Will a physician still treat child with private insurance after he/she turns 26 and goes on Medicaid?
- Some hospitals say you have to have someone with consumers from residential services around the clock, which relieves the medical staff of responsibility of trying to understand the person

My healthcare providers (knowledge, attitudes and communication):

- Dentist wouldn't perform cleanings without sedating patient, which parent refused (Dr. Anita Murray Clary, pediatric dentist also praised above)
- Oral pain experienced due to dental hygienist who said baby teeth were not a problem (an oral surgeon later removed them)
- Doctors don't listen, try to understand or take patient's complaint seriously

- Example: Doctor says leg spasms are normal state of affairs for wheelchair user and that the patient can't feel the pain he reports feeling
- Doctors don't take extra time to understand people who can't articulate well or have severe disabilities
- Doctors have negative attitude toward Medicaid patients
 - Example: Specialist wouldn't replace a temporary cast that was applied in the ER with a permanent one, despite pain caused by the temporary. On second visit, dr. only modified the first cast instead of replacing it.
- Medical and nursing schools need to educate about disability in their rotations.

Participant: You don't just move around in your power chair. It is where you live when you're not in your sleeping position. It is where you live. It is where you work. It is where you recreate.
- Physician assistants (PAs) keep changing at doctor's office, so lose continuity of care

Medicaid services

- Many doctors don't accept Medicaid, especially specialists and dentists
 - Tooth extractions are common, but prefer preventive care to avoid losing teeth
- Can't get prescribed name-brand medication when generics don't work as well. After trying many different medications, the name-brand medicine often doesn't work as well if patient returns to it.
- Reimbursement not provided for healthcare support team in hospital
 - No hospital reimbursement when PA, aide or service organization staff member stays with the patient, even though their support is expected and can be essential to getting the proper medical care. Case managers typically visit, but can't provide the appropriate level of care or stay long.
 - Doctor office visits not reimbursable for case managers, though they are the ones who often have the time to go to make sure that that person gets the health support and medical care that they need
- Medicaid recipients can't choose a different doctor
- Allowance for durable medical equipment is limited and doesn't consider preventive benefits

- Ex: Power chair options don't include chairs that tilt, although they help with pressure sores and poor circulation
- Ex: Acquisition of power chair through KNI very slow
- Ex: Denial of a special wheelchair cushion resulted in pressure sores that sent one woman to a nursing home for 7 months. (She was required to hold employment before cushion would be approved, but employment involved sitting.)