

Legal Representation Wins the Day!

Magnolia is an energetic, bubbly five-year-old. She loves to swim, adores her brother and waves at everyone she sees. She loves being around people. Magnolia was also diagnosed before birth with Wolf-Hirschhorn Syndrome, which is a condition caused by a missing part of the 4th chromosome and affects motor and verbal skills.

Magnolia started occupational therapy (OT) at age two. OT is a standard service to be covered through Medicaid. In fact, for children and youth under the age 21, federal law has special protections that ensure they receive basically most any health or long-term care that they need. The program is known as “EPSDT” – which stands for Early Periodic Screening Diagnostic and Treatment. In Kansas it is branded as the “KanBe Healthy” program. When Magnolia started OT four years ago, she could barely hold an object in her hand and had no grip or wrist movement. Thanks to OT, she can now open containers, help dress herself, turn pages of books and so much more.

In August 2015, her Managed Care Organization, called Sunflower, denied Magnolia 30 minutes of OT

per week, acknowledging she was making progress, but stating she was not making enough progress and that “she might not get better with more therapy.” This was of course a ludicrous argument. EPSDT does not state that she has to be making “enough” progress to access OT. It simply must be medically necessary, which it clearly is.

Magnolia’s mom, Hilary, had enough of the bureaucratic run around from her MCO. She contacted DRC for legal representation. On October 1, 2015, DRC attorneys filed a request for an administrative hearing to seek to overturn Sunflower’s decision. DRC asserted that this denial violated federal law and that the OT was medically necessary. On May 30, 2016, the decision was reversed, and Sunflower was ordered to approve the requested OT services!

Magnolia continues to make huge strides because of the OT she is receiving. According to her mom, “She amazes us every single day! She is doing more at the age of 5 than I ever thought possible for her whole life! I truly see so much independence in her future because of OT.”



Magnolia has thrived since DRC won her case.

DRC: Protecting Kansan's Rights and Fighting the 47,000+ Medicaid Backlog

Tens of thousands of Kansans have been wrongfully denied timely enrollment in Medicaid over the last several months, and recent media reports detail how a “pretty epic screw up” by the State of Kansas “misplaced” an additional nearly 12,000 more Kansans who applied for Medicaid.

This has resulted in a huge backlog of Medicaid applicants being wrongly denied access to this life-saving program.

From Bad to Worse

It's gone from bad to worse. As of June 19, 2016, Kansas had a grand total of 47,174 unprocessed Medicaid applications and reviews. Over 73% of Kansans in two of the different categories have been backlogged more than the allowable amount of time required under federal law (either 45 or 90 days). The 47,174 figure includes the nearly 12,000 applicants Kansas failed to report to CMS until recently.

“Pretty Epic Screw Up”

Sean Gatewood from the KanCare Advocates Network rightfully calls this a “pretty epic screw up. How do you lose 12,000 people?” The state and its Medicaid contractor pointed the finger of blame at each other for these “misplaced” applicants. Meanwhile, Kansans suffer. DRC Kansas is a member of the KanCare Advocates Network.

In the midst of this crisis, DRC Kansas has been fighting to protect the rights of Kansans applying for Medicaid by calling on the State of Kansas and the federal government to work together to fix this huge problem. DRC is also working with stakeholders examining potential legal remedies for Kansans stuck in the Medicaid backlog.

Federal law requires Kansas to process Medicaid applications and to enroll individuals within 45 days, or 90 days if the individual is also applying for Social Security. Kansas is failing to enroll applicants timely, which created the massive backlog. This causes a huge hardship for Kansans. They accrue large medical and disability bills why they are unjustly waiting in backlogged status.

DRC – Working to Fix the Backlog

DRC has worked hard to fix this problem. DRC

Kansas first approached the state through a broad coalition of stakeholders starting in February of 2016. Answers were not forthcoming. DRC then wrote Secretary Susan Mosier of the Kansas Department of Health and Environment (KDHE) two letters, one on May 16 and the other on June 3, asking for action from the state as well as and data about the backlog in order to solve this horrible problem. Both letters went unanswered.

With the state ignoring its calls, DRC was then forced to turn to the federal government for help. On July 8, 2016, DRC sent a letter to the Centers for Medicaid (CMS) providing additional detail about Kansas' continued failure to process applications properly and within the time limits required by federal law. In the letter, DRC wrote: “The delays and violations are so widespread and systemic that we ask CMS to take any and all steps needed to protect the rights and health of those in need of Medicaid assistance.”

Federal Help?

In addition to asking CMS to restore accountability, DRC asked CMS to require the state to inform backlogged applicants of their right to appeal the untimely processing, and to tell applicants that their Medicaid benefits are retroactive up to 90 days pursuant to federal law. Doing this would go a long way to addressing this crisis. It would get the person's past bills paid, help address the medical debt they have incurred, and inform them of appeal rights, which will get Kansans enrolled in Medicaid quicker and improve accountability.

At this point, it is unclear whether Kansas will do the right thing or what the federal government will ultimately require. What is clear is that both the backlog and the persisting problems processing Medicaid applications is inflicting great harm on Kansans. This is a man-made crisis and one without no end in sight. See the article entitled “The Cost of the Medicaid Backlog” on page 8 about David, one such Kansan, who has been harmed.

It is for David and the tens of thousands of other Kansans harmed that DRC is working on legal and administrative actions to make the state fix this worsening problem.

“The Disability Rights Center of Kansas is the designated Protection and Advocacy Agency. The following federal funding partners shared in the entire cost of producing this brochure: The Administration for Community Living (grants 1401KSPADD, 1503KSVOTP, and 90AV0033-01-00); the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (grant 3X98SM002097-15); the Rehabilitation Services Administration (grants H240A150017 and H161A140013); the Social Security Administration (grant 6PAB13020318-01-03); and Health & Human Services, Health Resources and Services Administration (grant X82MC16930-06-02). These contents are solely the responsibility of DRC and do not necessarily represent the official views of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.”

EPSDT - A Key Protection for Children

People throw around the term “entitlement” a lot these days. Unfortunately, many attack the term “entitlement” as being something bad. Social Security is an entitlement to help people live with dignity in retirement. Medicare is an entitlement to help seniors gain access to health care. Medicaid is often times called an “entitlement,” however states are required to provide very few services under Medicaid. Unfortunately, much of Medicaid is not an entitlement at all. Most services are optional and left up to the state to decide what they will cover.

Thankfully, there is an incredibly powerful true entitlement under Medicaid, known as the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program. EPSDT is a set of expanded health and long-term care Medicaid benefits for children under 21. In Kansas, the EPSDT program is called Kan-Be-Healthy. For Medicaid members under 21, they are truly “entitled” to most any health care or long-term care service you can think of, as long as it is medically necessary. This includes a wide variety of medical or traditional health care services. However, it also includes long-term care services, such as home health services, attendant care services, in-home nursing services, other in-home community-based services, and respite services for caregivers.



How do I get EPSDT covered services?

Talk to your doctor to discuss what health, long-term care or in-home services may be necessary to correct, improve or maintain functionality regarding your child’s medical condition or disability. Have your doctor note the medical condition or disability on the KanBe Healthy screen that the service is helping address. To help make certain services are medically necessary, a medical professional needs to document that the requested services are necessary to correct, improve or maintain functionality a child’s medical condition or disability. The federal law uses the term “correct or ameliorate” the condition or disability.

Kansas has designed a specific form for an EPSDT screen. It is called a KanBe Health Screen that your doctor fills out. DRC has created a checklist of services covered under EPSDT. Your doctor should fill out this checklist and include it with the request.

The most important part of an EPSDT request is the doctor’s letter explaining why the services are medically necessary. The letter should contain a list of the child’s medical conditions and diagnoses, as well

as a detailed description of how the requested service corrects, improves or helps maintain functionality regarding their conditions.

After completing the screening, checklist, and letter of medical necessity, these documents are submitted to the Managed Care Organization (MCO) your child is enrolled in. MCOs are required to respond to an EPSDT request with a Notice of Action, explaining if the request was approved and the rationale for the decision.

If the EPSDT request is denied, you have the right to challenge the denial through an appeal. The appeal must be received by the MCO or Office of Administrative Hearings within 33 days of the date of the Notice of Action. Contact DRC Kansas if your request for EPSDT services has been denied by the MCO. We have advocates and attorneys who can provide free help to you.

Again, contact DRC Kansas if you have further questions on the EPSDT process or need assistance with denials and appeals.

Your Vote is Your Voice! Use It!

Justin Dart, who is often referred to as the father of the ADA, once said, "Vote as if your life depended on it – because it does!" Americans with disabilities represent at least 15% of the voting population. However, in the 2012 election, 57.2% of people with disabilities did not vote, which is a higher percentage not voting when compared to the population without disabilities.

DRC has joined forces with the Kansas Association of Centers for Independent Living to help empower Kansans with disabilities to vote through the REV UP campaign. REV UP (Register Educate, Vote, and Use your Power) is a non-partisan, national campaign from the American Association of People with Disabilities. The campaign strives to eliminate barriers to voting, promote accessibility of voting technology

and polling places, educate voters about issues and candidates, promote turnout of voters with disabilities, engage candidates and the media on disability related issues, and protect eligible voters' right to participate in elections.

Through the campaign, staff from all of the Independent Living Centers across Kansas were trained how to register voters and encouraged to develop their own voter registration drives. They also learned about voter rights and what accommodations are available for voters with disabilities.

DRC has also worked to help register voters, educate them on the registration process including the proof of citizenship and ID laws, help them obtain the

necessary documentation, provide information on their rights, check voting statuses for those already registered, and help sign up for permanent advance ballots. DRC has a federal program, called the Protection and Advocacy for Voting Access (PAVA) program, which allows us to help Kansans with disabilities register to vote and cast a ballot.



You've Gotta Fight for Your ... Voting Rights

The Help America Vote Act, or HAVA, ensures important accommodations to make sure all Americans have the ability to vote. Each polling place should be fully accessible and offer the option for curbside voting.

People with disabilities also have the right to sign up for a permanent advance ballot. Advance ballots will be mailed directly to the voter about 20 days before the election.

If you are a person with a disability, you are entitled to assistance in the voting booth if you request it. You can bring almost anyone you'd like to help you read the ballot, make selections on the ballot or screen, and explain the ballot in a way that makes sense to you. Your assistant cannot make decisions for you, make you feel forced to vote a certain way, share how you voted with anyone, keep information from you or give you false information.

If registering for the first time or reregistering after voting in another state, you must provide proof of citizenship in Kansas. A birth certificate or passport may be used as proof. If you don't have a copy of your birth certificate and were born in Kansas, you are eligible to receive a free copy. If you were not born in Kansas, you would need to contact the Office of Vital Statistics in that state.

On Election Day, you must present your valid photo ID at the polling place. If you are a registered voter, you can request a free ID. You can find the forms to request the documents on our website, or you can contact us to mail a copy to you.

The General Election is on November 8, 2016. Remember, your vote is your voice!

Go to www.ksdisabilityvote.org for more information about your voting rights and how to navigate the photo ID and proof of citizenship requirements.



Employer Held Accountable for Discrimination

Lewis Gladue has always loved working in the food industry. "I love meeting people and trying out new food," said Lewis. In August 2015 Lewis was working to find employment with his job coach through Bert Nash, the community mental health center in Lawrence. He was excited to learn Taco Johns in Lawrence was hiring. He applied right away. He was called for an interview with the assistant manager, who was very impressed with his experience, and he was told he would know something the following week.

When Lewis went in to check on his application, he was told by the manager he would not be hired because they already had someone with a disability working there, and they wanted someone higher functioning. This devastated Lewis. "I broke down in tears. It made me feel worthless. My job coach encouraged me to contact DRC," he said.

DRC Kansas was able to negotiate a settlement for Lewis, which included sensitivity training for all the staff of Taco Johns. Lewis is currently employed at Little Caesars and is thankful for DRC's legally-based advocacy. "I am very appreciative of the help DRC gave me. They kept me in the loop and were patient with me. I will always refer anyone to DRC if they need help."



Lewis Gladue celebrating his successful legal case.



**DRC wants YOUR
input!**

**Please Return the
Enclosed Survey Today!**

Service Animals Explained

Service animals are incredibly important for people with disabilities. Thankfully, federal and state laws protect the right to service animals in many situations, including places of public accommodation, employment, housing, education, transportation and air travel. The information below provides a summary of the different types of service animals and the protections.

A pet is not suddenly a “service animal” just because they are wearing a certain vest or the owner has a doctor’s note. There is a distinction between service dogs, therapy animals, and emotional support animals. Many people use the words interchangeably, yet each one has a distinct legal definition. Unfortunately, it doesn’t help that some in the media are not helpful in their portrayals of service animals.

Service Animals (Dogs, and sometimes miniature horses)

Title II and Title III of the ADA defines a service animal as any dog, and sometimes a miniature horse, trained to work or perform tasks for an individual with a disability. Tasks can vary from retrieving items, alerting a person to a sound like a knock, or predicting an imminent seizure.

Under the ADA, only a dog, and sometimes a miniature horse can act as a service animal, and the tasks performed by that animal must be directly related to the individual’s disability. However, entities must also make reasonable accommodations for miniature horses trained to complete tasks for individuals with disabilities. Miniature horses must be housebroken and under the owners control. The facility must also be able to accommodate the size and weight of the horse and not jeopardize the safety requirements for the facility.

To see an example of a service miniature horse in action, go to: <http://tinyurl.com/miniada>.

Some examples of service animals include hearing or signal dogs, psychiatric service dogs, and seizure response dogs.



Therapy Animals

Therapy animals provide affection and comfort to people in clinical settings like hospitals, nursing homes, schools, and disaster areas. Therapy animals are not necessarily service animals because they are not trained to complete a specific task for an individual with a disability. Therapy animals do not just work with individuals with

disabilities, so federal laws about service animals are not applicable to therapy animals.

Therapy animals are not limited to dogs.

Emotional Support Animals

Emotional support animals provide company and support for individuals with mental health and emotional conditions. Unlike service dogs, emotional support animals are not trained to complete specific tasks for individuals with disabilities. They don’t have to be trained at all. The animal’s only job is to provide love and comfort. The animal’s presence can help ease conditions like depression, anxiety, and panic attacks.

Emotional support animals are not limited to clinical settings like nursing homes or hospitals and emotional support animals aren’t limited by the type of animal.

Emotional support animals are federally protected under the Fair Housing Amendments Act (FHAA) and the Air Carrier Access Act (ACAA). Under the FHAA, individuals have the right to live with their emotional support animals. Only a current letter from a doctor or mental health professional is needed. Landlords or building managers are required to allow emotional support animals, regardless of any no-pet policies in place. Under the ACCA, individuals are allowed to have emotional support animals fly with them in the airplane cabins without any additional fees.

State and Federal Public Policy Round Up

This year there have been a number of changes in state and federal laws that will have a significant impact on people with disabilities. Here are a few key ones:

Seclusion and Restraint in Schools

The 2016 legislature passed SB 193 this year, which makes several updates the seclusion and restraint statute created last year. Last year's bill created a task force made up of stakeholders to study the use of emergency safety interventions. This year's bill made the changes recommended by the task force and also extended the sunset on the law by two additional years.

While many of the changes were simply administrative changes to make the policy work better for all involved, there were a few changes that will be very positive for parents. After an incident of seclusion and restraint, the report the school sends home will now include more information about the incident, including what happened before it, as well as how the student was incorporated back into the classroom after the incident.

The task force also heard testimony from parents where law enforcement used seclusion or restraint on their students, and while the school staff was aware of this, they never notified the parents. There was some testimony that some districts had policies that even prevented them from notifying parents. Under the new law, schools will now have to report those incidents involving law enforcement to parents. This is an important change because previously parents were not informed when law enforcement used seclusion or restraint on their child.

Helping Families in Mental Health Crisis Act Passes the US House

As originally written, HR 2646 (the "Helping Families in Mental Health Crisis Act") had several provisions which significantly harmed the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. The PAIMI program is DRC Kansas' largest federal program. There is good news on this front. Several members of the Kansas' Congressional delegation worked to remove the most damaging provisions to PAIMI from this bill.

The bill now is in the U.S. Senate. The Senate has their own mental health reform bill. If the Senate passes their bill, both bills could be considered in conference

to iron out the differences. The Senate bill currently does not include any changes to the PAIMI program.

Waiver Integration Delayed

The State of Kansas proposed eliminating the seven existing Home and Community Based Services (HCBS) Medicaid waivers and replacing them with one integrated Medicaid waiver. Thankfully, the Kansas Legislature passed a law delaying this huge change. As with any policy change, there are potentially positive, and negative, ramifications. As proposed it would have been the single biggest change to HCBS services. These major changes were being rushed through dangerously fast. Also, there were scant few details were provided regarding the waiver elimination/integration proposal.

Numerous advocates for people with disabilities, seniors, and other citizens who use the Medicaid waivers all had significant concerns about the proposal. Legislators also shared those concerns and ended up directing the State to present additional information next session and prevented Kansas from proceeding with waiver elimination/integration for next two budget years.

Abuse Neglect and Exploitation Unit Changes

The legislature made changes to the Abuse Neglect and Exploitation (ANE) Unit at the Kansas Attorney General's office that will bring it more in line with the original intent of the legislation that was passed in the wake of the horrific Kaufman House incident. With very limited resources, the Attorney General indicated he wanted to make sure the Unit was able to be as effective as possible. The changes made in the legislature this year will allow the Attorney General to focus resources on a smaller number of reports and be able to investigate those cases more fully and better obtain justice for victims with disabilities.



The Cost of the Medicaid Backlog

David Garcia moved to Kansas from New York in December 2014 to help take care of his sick mother. After moving, David began the application process to receive health benefits through KanCare.

David was diagnosed with liver disease in 2009 and through his Medicaid benefits in NY, he would get a monthly injection to keep his liver enzymes under control and prevent hepatitis. He has had multiple back surgeries stemming from a past injury and received physical therapy and pain management. David also took medication to control high blood pressure and cholesterol. All of this was covered by his New York Medicaid program, and his health was well maintained.

He first applied for KanCare in person in February 2015 and was denied on the spot. He reapplied in March and heard nothing until September when he was again denied. They claimed he was not a resident of Kansas. He submitted a letter from Social Security stating he had been a Kansas resident since December 2014.

Federal law requires applications for Medicaid be processed within 45 days (90 days if applying for Social Security disability at the same time).

Without coverage, David could not afford any of his medications. After running out of the 2-month supply of medication he moved to Kansas with, he quickly began to deteriorate. His liver began to harden; he also lost an extreme amount of weight as he struggled to eat. He was too weak to work and was in constant pain. His blood pressure was high, and he began

to have severe headaches. He had multiple visits to the ER, where they would stabilize him and send him home with prescriptions for medications he couldn't afford.

Thankfully David found out about DRC Kansas and its federally funded legally based advocacy services. He contacted DRC for help in February 2016. DRC immediately contacted the KanCare Ombudsman and sent a letter to the Medicaid Clearinghouse, stressing the dire need for coverage and the severity of his health issues. After no response, a second letter was sent and also ignored. We were forced to file for a fair hearing in early April.

Within a month, David was approved for KanCare and backdated his coverage to March 2015. It took over a year for the state's mistake to cleared up. Too many Kansans like David are getting harmed by Kansas' worsening Medicaid backlog.

Unfortunately, the damage had already been done. David recently found out he will most likely need a liver transplant. Of course, Medicaid will now have to pay for this liver transplant.

Because Kansas has set up such an ineffective and complex system, people like David experience real harm. It is unjust and also financially unwise. Think of how much less expensive it would have been if David was simply enrolled in Medicaid and he had access to prevention medical care and meds. He would not have to lose his liver.

Without DRC's legal representation, David would most likely still be waiting, like so many other Kansans.



David Garcia

DRC's goal is to make each newsletter understandable by and useful to the general public. Please forward any suggestions for improvements to DRC. The newsletter is not intended to provide specific legal advice. Please contact an attorney for advice or assistance based on your particular situation.