Celebrating 35 years of Advocacy

The Disability Rights Center of Kansas (DRC) is pleased to celebrate its 35th Anniversary. 35 years ago the DRC (then known as Kansas Advocacy and Protective Services – KAPS) was founded. Throughout those 35 years, DRC has provided legally-based advocacy services for Kansans with disabilities. DRC staff members have fought tirelessly in the courthouse, schoolhouse and Statehouse for the civil and legal rights of Kansans with disabilities.

In particular, DRC has seen tremendous service growth over the last 10 years. Over that period the number of Kansans with disabilities DRC has served has increased by 560% while its budget has not kept pace. Total funding has increased by only 23% over the 10 years. Excluding funding for new programs results in a mere 9% increase over the last 10 years (or less than 1% increase per year in DRC’s core grants). Over this same period, the Consumer Price Index has increased by 25%.

When you drill down further, the results are even more impressive. The number of legal representation cases served by DRC per year skyrocketed by 2,325% and advocacy and self-advocacy support increased by 533% over the 10 years.

The past 10 years illustrates a growing need for DRC’s services. Clearly, the small increase in funding has failed to meet the huge demand for DRC’s services. There is a clear need for additional funding to DRC to provide more legally based advocacy services. For example, for every 17 people who request services, DRC can only provide legal representation to one.

While funding sustains DRC’s services, without the people with disabilities who rely on its services, DRC would not exist. In celebration of its 35th Anniversary, this newsletter provides a sample of some of the compelling work DRC has done, focusing on the past 10 years.

Enclosed with this newsletter is a survey detailing DRC’s proposed 2014 Priorities and Objectives. Please complete this survey and send it back in the enclosed self-addressed stamped envelope. DRC needs your input.

If you wish to provide comments in-person about DRC’s Priorities and Objectives sign up to testify at DRC’s public comment session on June 28, 2013. To testify in person please contact DRC at 1-877-776-1541 – toll free voice; 1-877-335-3725 – toll free TDD; 785-273-9661 – Topeka number, or email info@drckansas.org. Finally, you can fax your comments to 785-273-9414 or email info@drckansas.org. Your input is extremely important to DRC.
Leon’s Story: Standing up for Native American Student’s Rights

Leon Ricehill was born with Fetal Alcohol Syndrome (FAS), which resulted in a learning disability. After graduating from high school in Arizona in May of 2010, Leon applied to Haskell Indian Nations University in Lawrence, Kansas.

According to Haskell’s admission policy, students must meet two of the following three criteria to be accepted for admission: Score 15 or above on the ACT, earn a GPA of at least 2.0, or have a class ranking in the top 50% of his or her graduating class. Leon had missed the ACT requirement by only one point, scoring a 14, but his GPA was 2.96. However Leon’s high school had refused to include him in its class ranking because he had an Individualized Education Plan (IEP), which schools are required to implement for all eligible students with disabilities.

Because his high school in Arizona refused to include Leon in the class rankings, Haskell denied his application for admission. Leon’s mother contacted the Arizona Protection & Advocacy agency for assistance, which referred Leon to the Disability Rights Center of Kansas (DRC). DRC took Leon’s case.

The first thing DRC did was to advocate for Leon’s high school to include him in the ranking system, as required by federal law. Following several conversations with school district officials, Leon was finally ranked in his graduating class. Once included in the ranking, Leon was placed in the top 24% of his graduating class. The school then provided Haskell with an official transcript reflecting the ranking.

Amazingly, even though Leon now met Haskell’s admissions requirements, the university continued to deny him admission. Despite the university’s legal obligation to do so, Haskell officials claimed that the school could not offer Leon the educational supports and services that he may need as a person with a disability.

The DRC convinced Haskell University administrators of the school’s legal obligation to provide reasonable accommodations to eligible students with disabilities and to not discriminate based on disability. A mere four days before the semester began Leon was finally admitted to Haskell. He played football for the university that fall, and thanks to the DRC’s services, was able to pursue a college education.

Success for Family; Past Benefits Restored

A calculation error is more than just numbers when it comes to the lives of people with disabilities. Linda and her husband both have disabilities and have five children. They received food assistance until one of their children was awarded a settlement in a personal injury case.

The Department for Children and Families (DCF, formerly known as Social and Rehabilitation Services - SRS) terminated their food assistance after incorrectly calculating the settlement award as part of the family income. Linda contacted DRC to seek legal advice. DRC believed that the termination of benefits violated federal law.

This error was a huge hardship to Linda and her family. A DRC attorney assisted Linda in filing a formal complaint with the Office of Administrative Hearings within the agency. After receiving a negative ruling from this office, the DRC attorney filed a petition with the District Court claiming that DCF violated federal law.

The Court ruled in Linda’s favor and awarded the family almost $9,000 in lost benefits. However, DCF refused to reimburse the family. Instead, DCF insisted on placing the money on the family’s Vision Card with the additional restriction that the money be used only for food within the next 12 month period. These restrictions were not reasonable, as the family already paid for these costs out of pocket from being improperly thrown off of benefits.

The DRC attorney was forced to return to District Court on behalf of Linda. The judge ruled the family was entitled to the $9,000 in actual US dollars and clarified the money was not to be placed on the Vision Card. The family received a check from DCF and used the money to pay past bills and other expenses they incurred as a result of not receiving food assistance funds for just over a year.
Richard Owen is a truck driver from Bison, Kansas. Bison is a small community of 249 people in Rush County, northwest of Great Bend. Richard’s case is an example of how DRC’s professional, disability rights advocacy services helped a Kansan with a disability become a small business owner instead of being forced to go on social security or welfare.

Richard was at the end of his rope when he contacted DRC Kansas. Richard was fighting tooth and nail to maintain his livelihood, which is driving a commercial hauling and dump truck. However, Vocational Rehabilitation (VR – the state program that helps fund supports for people with disabilities to help them retain or get a job) kept trying the same thing over and over again, with the same negative result.

You see, back in 1975, Richard lost his right arm above the elbow while working on an oil drilling rig. After many challenges, three years later Richard started driving a hauling truck with a manual transmission using his left arm to shift gears. Unfortunately, in September 2004, the Kansas Department of Transportation revoked his commercial driver’s license. Richard had to now pass a special waiver and driving test showing he could, in effect, do the same job he had been doing successfully for nearly 26 years with his disability.

VR promised they would help Richard pass the test and get the waiver. However, VR’s response was to have him continue to try prosthetic arm after prosthetic arm, all of which lacked the maneuverability for Richard to operate the stick shift. At this pace, there was no way Richard would pass the test.

“No matter what kind of arm they put on me, I wouldn’t be able to operate a vehicle,” Richard said. After trying and failing with the fifth and final prosthetic arm, Richard was told by VR to search for other career opportunities. This was a huge blow for Richard, because he had been a truck driver most of his adult life. It was all he knew. He feared he would have to go on social security and other longer term government support programs.

Richard, understandably frustrated with VR, contacted DRC for help. As a result of DRC’s advocacy, Richard finally went to a physician specializing in rehabilitation in Hays, Kansas. The doctor immediately diagnosed that Richard would never benefit from a prosthetic arm because of his lack of arm mobility and the tight space in the truck. To continue driving trucks, the doctor said Richard would need a vehicle with an automatic transmission. Finally Richard had a medical reason why the only solution VR pursued was failing him miserably.

“I lost about $36,000 in income trying to figure this all out. But once DRC starting helping me, things got done,” Richard said. “Richard’s case was not an example of malice against him or incompetence, it was simply a lack of imagination,” said Rocky Nichols, Executive Director of the Disability Rights Center of Kansas. Unfortunately, around the time this solution was identified, Richard’s employer sold the business leaving Richard with no job, no truck and no license – another setback.

Unfazed, DRC advocated with VR and helped Richard submit a proposal for him to be a small business owner and have his own truck with an automatic transmission to accommodate his disability. Under this federal program, VR is allowed to help people start their own business as a successful employment outcome. Richard’s business plan was accepted and VR purchased an automatic 1999 Freight liner truck and paid for the initial company start up costs.

Thanks to the automatic transmission truck, Richard successfully completed the driving test, and he successfully ran his own business. Richard’s talent at being a truck driver was the only thing he knew to give him freedom and independence. With DRC’s services Richard became his own boss. Instead of being unemployed and forced to go on social security and other taxpayer funded public assistance, Richard became a small business owner, taxpayer and helped support the Kansas economy.
Independence and self care are rights under the Federal Medicaid Act. Laura Kust and Tabitha Wade request for power chairs fell under those right but they were denied based upon the State of Kansas’ restrictive criteria. Kansas’ criteria required adults to either work or attend school in order to obtain a power chair or accessories. Power accessories include devices which provide individuals with disabilities the ability to independently operate their power chairs. Kansas required adults to either work or attend school in order to obtain a power chair or power accessory.

DRC argued that the policy was both short-sighted and violated federal law because it was not based on medical necessity and made it impossible for many Kansans to obtain power chairs. First, some Kansans have such significant disabilities that they don’t work or attend school, but still need power chairs. Secondly, the policy also created a catch-22, because how is a Kansan who needs a power chair supposed to get or keep a job without one? The policy made it a prerequisite to either have a job or be in school.

Quite simply a power chair may be the only effective way that person can get around independently. To tie access to such a life changing device to some unnecessary standard is unacceptable and forced greater dependence on the system. This unfair criteria had never been challenged previously.

DRC knew that the state’s policy was wrong and represented Laura and Tabitha to challenge it legally. This is an example of an “impact case,” which is one where DRC represents a small number of people in order to try to obtain a change that will impact a much larger group of Kansans. According to National Center for Health Statistics (NCHS) it is estimated that upwards of 19,000 Kansans use power chairs or other mobility devices.

Laura has a diagnosis of Cerebral Palsy and uses a power chair for mobility. Tabitha has a diagnosis of Spina Bifida and uses a power chair for mobility. Both obtained separate evaluations from their local seating clinics which determined that their power chairs or accessories did not meet their physical needs and that new equipment was medically necessary.

Requests for the proper power chairs and accessories were submitted to Kansas Medicaid, but were denied because Laura and Tabitha were not working or attending school. Two DRC attorneys filed requests for a fair hearing challenging the denials. DRC asserted denials based upon criteria of working or attending school violated the Medicaid Act.

The DRC attorneys successfully persuaded the State of Kansas that the power mobility devices were medically necessary for Laura and Tabitha and that they must be provided pursuant to federal Medicaid law. Kansas Medicaid overturned its original denial and agreed to purchase the requested devices.

Even more important, challenging this case caused the State of Kansas to change the underlying flawed policy regarding power chairs and accessories! Effective January 1, 2013, Kansas eliminated the unnecessary requirement that an adult must be working or attending school to be approved for a power chair or accessory. Eliminating this misguided policy ensures that all Kansans with mobility impairments can have access to needed power chairs and accessories.
DRC’s End the Wait Campaign helps get $18.5 million recommendation from Governor for waiting lists

When it comes to policy advocacy, persistence often pays off. The End the Wait Campaign has persistently argued that a significant portion of any savings from the KanCare Medicaid program must be dedicated to reduce the waiting list for Home and Community Based Services (HCBS) for the Developmental Disability (DD) Waiver. End the Wait came up with this idea after reviewing the minute details of agreements between the federal government and State of Kansas and knowing the dire state of the long waiting lists.

The payoff is that Governor Brownback has thankfully agreed with this idea. As of the publication of this newsletter, the Governor recommended over $18.5 million in new dollars from KanCare savings be dedicated to reducing all HCBS waiting lists. KanCare is what the State calls its effort to move the majority of Medicaid into a managed care arrangement. If this $18.5 million is appropriated by the Legislature, it would represent one of the largest increases in funding to reduce the waiting lists in recent years.

End the Wait, a project of DRC Kansas, is a state-wide issue initiative to significantly reduce and eventually eliminate the HCBS DD Waiver waiting list. The campaign is a three year project funded through a generous grant from the Kansas Council on Developmental Disabilities. That three year funding cycle runs out at the end of 2013. End the Wait is actively seeking partners to continue funding for this successful campaign.

The DD waiting list has reached a crisis level, as waiting times can reach upwards of 10 years. The wait list has ballooned to over 5,000 Kansans with DD. Roughly 15 years ago the DD waiting list was barely over 50 persons and wait times were mere days, not years. Adding insult to injury, there is no long-range plan to systematically eliminate the Waiting Lists. End the Wait is fighting to change that.

Recognizing this problem was quickly reaching a tipping point, DRC along with the Kansas Council on Developmental Disabilities and numerous stakeholders launched an effort to educate the public and policy makers about why Kansas must take bold action to eliminate the DD waiting list. During 2011 and 2012, ETW and its partners were successful in advocating for $10.7 million in new dollars targeted at reducing the DD waiting list. This is in addition to the over $37 million in new dollars recommended by the Governor.

End the Wait has produced a documentary video that tells the story of several Kansas families forced to languish on waiting lists and what the state can do to fix this problem. You can watch this video and join the Campaign at the End the Wait website, www.endthewaitks.org.

Finally, our fellow advocates who are fighting to eliminate other HCBS waiting lists, such as the Physical Disability (PD) waiting list, should know that DRC always advocates for the elimination of all disability service waiting lists. DRC happens to have this one grant that can only be used for advocacy to eliminate the DD waiting list. However, DRC uses its other grant funds to advocate elimination of all HCBS waiting lists.
Advocates make Wichita Buses Accessible

People with disabilities face discrimination every day, even from governmental entities. For years, the Wichita bus system was not accessible to people with disabilities. The buses typically did not have ramps, Braille wasn’t available, etc.

DRC was one of several Kansas disability advocates who worked collaboratively on a case that established the right of people with disabilities to enforce the Americans with Disabilities Act (ADA) and the Rehabilitation Act, even if they happen to be a visitor to the city. This positive decision came from the Tenth Circuit Court of Appeals which is only one step below the US Supreme Court.

The case, Tandy v. City of Wichita, originated from numerous complaints to Mike Oxford, Executive Director of the Topeka Independent Living Resource Center (TILRC), about the Wichita Transit fixed route bus service. In the spring of 2001, advocates from Kansas American Disabled for Accessible Transportation (ADAPT) tested the Wichita Transit for access, services, Braille, and communication. The transit system failed terribly, leaving advocates stranded all over the community. Braille was not available, people’s wheelchairs were not secured, stops were not called, lifts were not on buses, and when lifts were on buses, drivers refused to deploy them.

Ten of the advocates filed a lawsuit in Federal Court against Wichita Transit for these serious accessibility issues, originally assisted by an attorney of TILRC. In District Court, Judge Thomas Marten issued a permanent injunction against Wichita for its long-standing policy and practice of refusing to deploy lifts on routes they designated as “not accessible.” This forced Wichita to transform its bus system and make the routes and buses accessible.

Unfortunately, Judge Marten also ruled that only three of the advocates were entitled to a trial, and dismissed the other seven for lack of “standing.” Standing is a legal term that determines if you can enforce your rights through litigation. The judge ruled that seven of the plaintiffs didn’t have standing because they were not residents of Wichita. Those seven advocates appealed to the United States Court of Appeals for the Tenth Circuit.

The case then came to DRC Kansas. DRC litigated the case from that point forward. The issue at the heart of the appeal was the legal standing of those advocates who didn’t live in Wichita.

The lower court decision had a negative impact for people with disabilities. Many times people with the most detailed knowledge about accessible services and disability rights may be visitors to the city in order to test the accessibility. Also, if that ruling stood, then visitors from outside Wichita would not have the same rights as those who happened to live there. The Wichita bus system is supposed to be accessible for all, whether visiting or not. So, DRC pressed this important issue with the Tenth Circuit.

A three-judge panel at the Ten Circuit Court of Appeals agreed with DRC and ruled that even one-time users who will return and use the transit system have the right to enforce the law.

This decision had a large systemic impact for people with disabilities. It required all courts in the 10th Circuit (Kansas, Oklahoma, Colorado, Wyoming, New Mexico, and Utah) to enforce the rights of people with disabilities to hold systems accountable.
Voting is a fundamental right and when Kansans with disabilities come together to vote, they can make important changes in their city, state, and nation. That’s why one of DRC’s major commitments is to the voting rights of people with disabilities.

In 2004, DRC helped to make huge strides in state law affecting the voting rights of Kansans with disabilities. Under a bill passed into law, Election Officials must make polling places accessible on Election Day. Whether the modification is permanent or temporary, this new law guarantees greater accessibility and fairness for Kansas voters with disabilities. This replaced an outdated law that dated all the way back to 1977!

In 2010, DRC again successfully advocated for the rights of voters with disabilities by supporting an Amendment to the Kansas Constitution to eliminate mental illness as a potential disqualification to voting. This referendum thankfully passed with the support of a solid majority of voters, ensuring that mental illness can never be used to keep a Kansan from voting. Now no disability can be used to strip an individual of their right to vote in the state of Kansas, a major accomplishment.

DRC has worked tirelessly to educate voters, election officials and poll workers about the rights of Kansans with disabilities to vote. In 2012, as part of a contract with the Kansas Secretary of State, DRC produced a number of educational materials in a variety of formats to ensure polling place accessibility. The project included resources to be used in poll worker training and a video on disability voting rights which can be viewed at www.ksdisabilityvote.org.

During the 2012 elections, DRC staff monitored a number of polling places throughout the state. Using the results of DRC’s accessibility checklist, DRC made recommendations to county election officials. Thankfully, as of 2013, DRC has already seen some election officials incorporate these recommendations. DRC will continue to work for easier, more accessible voting for Kansans with disabilities in the future.

www.ksdisabilityvote.org

- **Information on your right to vote in Kansas.**
- **Learn to navigate the new voter ID laws.**
- **Watch videos about your rights and much more!**
Brooke Seager contacted the Disability Rights Center (DRC) of Kansas in 2004 because her daughter, Jessica, faced a health care crisis that threatened her health, independence, and even her life. Jessica is a person with epilepsy and a neurological disability that requires her to use an electronic device called a VNS (Vagus Nerve Stimulator) to prevent debilitating seizures and to allow her to live a life of dignity, respect, and independence. The VNS device is similar to a heart pacemaker in size and electronically stimulates the vagus nerve to prevent seizures. The vagus nerve is derived from the Latin word meaning “wandering.” Thus, the vagus nerve wanders from the brain stem through organs in the neck, thorax and abdomen.

When Jessica was under the age of 21 the Kansas Medicaid program paid for the VNS implant through the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program, known in Kansas as Kan Be Healthy. EPSDT is a powerful part of the federal Medicaid law that requires the state to fund all necessary services for children and youth under 21. However, by the time Jessica was over the age of 21 she needed the batteries in her VNS unit replaced. Kansas Medicaid claimed that by policy it did not provide VNS treatment for adults over age 21. So, Kansas Medicaid refused to replace the batteries for the same unit it purchased and paid to surgically install just a few years earlier.

DRC believed this was terrible policy that lacked common sense. Most Medicaid programs in other states as well as private insurance programs cover this VNS treatment for persons of all ages. Without the replacement of these batteries, Jessica’s debilitating seizures would be uncontrollable and severely impact her daily functioning and quality of life.

Jessica’s mother, Brooke, came to DRC for help. Together they worked to educate the public and policy makers about this misguided policy. During hearings on the Medicaid budget in the Kansas Legislature, Brooke and DRC educated members of the House Social Services Budget Committee about the unreasonableness and idiocy of a policy that funds VNS implantation, but won’t replace the battery.

This policy advocacy, along with the support of several key legislators, caused Kansas Medicaid to make a formal review of their policy. As a result, Kansas Medicaid thankfully changed the policy and they now cover VNS battery replacements for situations like Jessica’s. Even bigger, Kansas also changed the policy to cover VNS devices in general, which was a positive change for all people with disabilities who need this life saving device. Jessica underwent her surgery to replace the batteries in her VNS on July 8, 2004, and Kansas Medicaid paid for the procedure.

Jessica’s story is an example of the huge impact that a dedicated group of advocates can have when they stand up for what is right. This advocacy was able to change Medicaid policy to the benefit of all Kansans with disabilities.

“Jessica and I are so appreciative of the work of the House Appropriations Committee and the advocacy of DRC to obtain this critical surgery for Jessica,” Brooke Seager said.

What Cases Does DRC NOT do:
Criminal defense, Workers Compensation; Social Security Eligibility or Appeals; Divorce cases; Estate planning; Child custody or Child In Need of Care (unless clear disability discrimination); or any legal representation that does not relate directly to disability rights.
Through DRC’s representation and professional advocacy services, Jennith Lucas’s goal of becoming a Special Education teacher was greatly improved through specialized training. As a recent high-school graduate, Jennith moved to Kansas from Georgia in 2007. She has Macular Degeneration, which has left her with limited vision, and will ultimately result in blindness. Because of her vision impairment, Jennith is eligible for Kansas Vocational Rehabilitation (VR) services and supports to assist her in attaining full-time employment as a teacher. Her VR Counselor recommended that she attend the University of Kansas (KU) while she still had sight. VR funded the education, and Jennith began classes in January 2009.

Jennith experienced difficulty in receiving the requested equipment and tools that she needed from KU, and she found that intense studying without these vision aids expedited her vision loss. This motivated Jennith to research and she discovered Blind, Inc., in Minnesota. Blind, Inc. provides a program which offers an immersive six-month training program to help people with blindness learn strategies and develop useful skills to accommodate their vision impairments.

Jennith applied to have the Kansas VR program approve and fund her participation in Blind, Inc. but her request was denied. She approached DRC because of its role as the Client Assistance Program, which provides independent advocacy services for recipients of Rehabilitation Act funding, including the VR program.

DRC attorneys and advocates contacted Jennith’s VR counselor to appeal the decision denying her request for funding to attend Blind, Inc. The appeal letter stated the legal and real-world arguments why Blind, Inc. would be advantageous for Jennith’s individual situation. Blind, Inc. provides a different approach to an individual who is losing or has recently lost their eyesight.

Because of DRC’s advocacy, VR reconsidered and approved Jennith’s request to attend the program, which she started in July 2009. Jennith credits DRC’s advocacy as the key reason why she obtained access to Blind, Inc.’s specialized training program.

**Advocacy Obtains Specialized Training at Blind Inc.**

**At DRC Everyone Is Provided Service...**

Every Person with a Disability who contacts DRC is provided a service, including:
- Legal Representation;
- Advocacy Representation;
- Self-Advocacy Support/Legal Advice;
- Information & Referral
Minimum Regulations on Seclusion and Restraint in Schools Passed...

Until 2013, Kansas was among only 12 states with no enforceable standards on the use of seclusion and restraint in public schools. In February, the State Board of Education adopted minimal regulations with a promise to address three key concerns raised by DRC Kansas, parents and other disability advocacy organizations.

DRC continues to work with members of the State Board of Education to address the three concerns: 1) ensuring effective investigation and enforcement by the State Department of Education, 2) tightening the definition of when these dangerous and sometimes deadly tactics can be used, and 3) requiring staff training prior to their use. These issues must be adequately addressed to ensure that the regulations are both effective and enforceable. As part of the motion to approve the minimal regulations, the State Board directed Kansas Department of Education (KSDE) to develop language to amend the new regulations to help address the concerns raised by DRC and parent advocates.

Alexis is a 10 year old student with a disability from Johnson County who was inappropriately restrained. She was then physically dragged by two school staff down the hall, out the school and to the bus. The staff were untrained in the safe use of restraint. Dragging a child like this is never a safe use of restraint. Because of this improper restraint, Alexis had to be rushed to the Children’s Mercy ER with multiple injuries, including a significant shoulder sprain, bruises and scrapes. After the incident her mother Cathy said, “This is unacceptable. Our children should not have to go through anything like this.”

While advocates should feel good about the progress that has been made on this issue over the past nine years, the three unresolved issues show that more must be done to protect kids from these harmful tactics. On this page and the next you will find some real life examples of Kansas students who were harmed by unnecessary and inappropriate seclusion and restraint. These children illustrate why more action by the State Board is needed to ensure the regulations are effective and enforceable.

“Without effective KSDE enforcement and the right standards controlling when these potentially deadly tactics can be used, these so-called regulations will be like a toothless tiger,” said Rocky Nichols, Executive Director of the Disability Rights Center of Kansas.

Skyler is a 7-year old Johnson County student who was physically restrained and placed in a seclusion room on more than one occasion even though he did not pose a danger to himself or others. According to his adopted mom and biological grandmother, Julie, the emotional and physical toll on little Skyler has been nothing short of overwhelming. Julie said, “The more he was placed in this room, his fears escalated to the point where he now has a phobia and he is deathly afraid of the dark, he cannot go to the bathroom by himself, and he has to have someone with him when he leaves the room.”
**Timeline of DRC’s advocacy:**

**2004** – DRC publishes a policy paper detailing the inappropriate use of seclusion and restraint to a Legislative Committee. Legislators express shock at the use of these tactics. Newspaper articles are written. For the first time, the Kansas public learns about these scary tactics.

**2005** – DRC obtains a bill introduction and hearing in the Senate Education Committee on a bill to limit the use of seclusion and restraint in schools. Dozens of parents fill the Committee room and offer passionate testimony as to why policy is needed. The Committee directs KSDE to adopt rules and regulations to address this growing concern.

**2007** – After DRC and other advocates work on language and a proposal for nearly two years, the State Board of Education balks at passing regulations with the force and effect of law. Advocates get within one vote of obtaining regulations. Instead “voluntary guidelines” are passed. State Board members encourage parents that the

A Wichita family had to home school their 2nd grade son with Asperger’s Syndrome after only 25 days in the Maize school district because the environment at school became “toxic.” During one incident Dylan was “on his back and to the surprise of his peers, his legs were pinned down while he screamed and hollered.” Ironically, his parents would have been turned into SRS if they did what the school did! And the school did this without the parents knowledge or consent!

**February 2013** – State Board of Education adopts a minimal set of regulations and promises to address the concerns raised about the regulations. Advocates continue the fight to amend the regulations to protect children. The stories on these pages tell why this fight is necessary.

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Ike is a typical 10 ½ year old child from Wichita. Ike has been secluded and restrained several times by school staff who lacked the proper training on how to de-escalate or safely apply these dangerous tactics, all without his parent’s knowledge or consent! Kris, one of Ike’s parents, personally witnessed a couple of the inappropriate uses of restraint, including a teacher slamming Ike to the floor while two other teachers held him prone, and another time when a staff member forced little Ike to stand against the wall like a criminal while she forced the significant weight of her body against his little legs and knees. Ike is lucky he doesn’t have permanent damage!

...Push begins to amend the regulations to be effective & enforceable
Imagine that your physical impairments as a parent do not allow you to provide the life-sustaining care your child needs. Now imagine you have another child with a disability and you are trying to care for them both. This was everyday life for Faraj’s parents. Faraj Chaaban and his brother both have a diagnosis of Cerebral Palsy.

His parents contacted DRC because they were no longer able to care for him and needed home and community based services. DRC provided services to Faraj’s parents, including technical support and free legal advice about extra medical services available through the Medicaid Early and Periodic Diagnosis Screening and Treatment (EPSDT) program.

EPSDT is a unique child health component of Medicaid that is designed to meet the special physical, emotional, and developmental needs of children. Under the EPSDT federal law, special rights and access to greater services are granted to children and youth under the age of 21 and it requires the state’s Medicaid plan to cover a comprehensive set of benefits. Unfortunately, EPSDT is not well advertised by the state of Kansas. Many parents and doctors are unaware that EPSDT services even exist.

A DRC attorney worked closely with Faraj’s doctor to inform him about EPSDT. DRC prepared an appropriate checklist for the doctor to fill out in order to obtain Medicaid authorization for Faraj to receive services in his home.

Faraj was also denied services under the DD Waiver and had been put on the statewide waiting list. Today in Kansas, individuals on the DD Waiver waiting list can wait upwards of 10 years for services. Fortunately, there is a crisis exception to the waiting list for those who are at imminent risk of institutionalization. Faraj’s parents applied for crisis funding but were denied because he lives with them. Due to their disabilities, Faraj’s parents cannot lift more than 50 pounds, which prevents them from providing Faraj with the care he needs.

Besides the day-to-day care that Faraj needed, he had recently undergone a 14-hour surgery which required a great deal more care. His parents could not provide this level of care for Faraj while continuing to care for their other child with Cerebral Palsy, and go to work. With help from a DRC Advocate, Faraj’s physician stated more clearly in a revised letter specifically identifying the scope of services Faraj required for the crisis-funding request.

The local Community Developmental Disability Organization (CDDO) reviewed the revised letter and approved Faraj for crisis funding services. The services will provide in home care for Faraj which will prevent him from being institutionalized.

His parents credit DRC’s advocacy with obtaining EPSDT and HCBS Waiver services, as they previously ran into numerous road blocks. With DRC’s legally based advocacy, Faraj avoided expensive and unnecessary institutionalization and continues to live at home with his parents and younger brother while receiving assistance through the HCBS DD Waiver.

**How does DRC decide if it will provide me free legal representation?**

1) You must be a Kansan with a disability with a disability rights issue  
2) DRC must have funding and staff time available  
3) Your issue must fall within DRC’s case Priorities  
4) What are the facts of your case? What’s the law say?  
5) Will a legal win help other Kansans?
Looking at the huge smile on Eldon Leighty’s face illustrates his joy at having Gracie by his side. Eldon is 7 years old from the small southwest Kansas town of Manter, near the Colorado border and north and west of Liberal, Kansas. Eldon has a diagnosis of autism and depressive disorder. Eldon has a service dog named Gracie which has been trained and certified by CARES, Inc. to help him manage the manifestations of his autism. Eldon has daily bouts of extreme anxiety, behavior problems, and runs off. He engages in self-injurious behavior and has trouble with transitions.

Gracie is trained to identify when Eldon’s behaviors are escalating and help address the situation by immediately going up to him and touching him to help cease his behavior. Gracie does not require a signal from Eldon to provide this type of support. Gracie provides a calming influence and sense of security which helps Eldon socialize and communicate. She is also trained to assist Eldon in ceasing repetitive behaviors and helps prevent him from other negative actions, such as leaving the school grounds.

Eldon attends elementary school and has an Individual Education Plan (IEP). His parents asked the school district several times to allow Eldon to have Gracie at school to assist him with his functional limitations in order for him to have the best chance to receive a quality education. The request was made pursuant to Title II of the Americans with Disabilities Act (ADA) and the Rehabilitation Act of 1973. The district refused each time, treating the request as an IEP issue instead of a request for a reasonable accommodation under the ADA and Rehabilitation Act.

A DRC attorney filed a complaint with the Civil Rights Division of the U.S. Department of Justice (DOJ) on behalf of Eldon. The DOJ accepted the complaint and began an investigation. DRC cooperated closely with the DOJ and advocated for Eldon’s rights. A DRC Attorney took great care to make certain that the case was prepared to enforce Eldon’s rights. The DOJ informed the school district that its refusal violated Eldon’s civil rights under the ADA and Rehabilitation Act. After meetings with the DOJ, the DRC attorney, and Eldon’s parents, the school district agreed to a plan to allow Gracie to accompany Eldon at school. At the end of Eldon’s first day of school with Gracie, he called the DRC attorney to say “Thank you for helping me have Gracie at school … I’m so happy!”

DRC believes that Eldon’s case offers a strategy to protect and enforce the rights of other students with disabilities to have a service animal at school.

We Want Your Input!
Please return the enclosed survey or go to our website www.drckansas.org before June 10 to provide your input!
Justice for Sexual Assault Victim

What if you learned there was a sexual perpetrator staying at the same nursing home as your loved one and the nursing home did nothing to protect them?

This is exactly the situation M.F. (name sealed by the courts to protect the victim’s identity) found himself in at Indian Trails Nursing Facility in Topeka, Kansas, after the facility accepted M.M., a perpetrator with an extensive history of sexual violence, which included sexually molesting children in the early 1970’s. While at Larned State Hospital, M.M. sexually assaulted other patients, specifically those patients with lower mental capacity and strength.

It is not surprising the same pattern of behaviors continued when M.M. was recruited to Indian Trails Nursing Facility, as this predator stalked and sexually assaulted M.F. Even though it has “nursing facility” in its name, this facility mostly serves adults with mental illness, many of whom are under the age of 65.

Despite M.M.’s long history of sexual assault, NO precautions were taken to protect other residents at Indian Trails Nursing Facility. The other residents and their guardians were NOT made aware of M.M.’s history. The records in the possession of Indian Trails Nursing Facility contained extensive information provided by Larned, a state mental health hospital. The records depict M.M.’s long standing issues with violent behaviors and a “…tendency toward inappropriate sexual behavior with low functioning male peers (over a 30 year span), impulsive sexual behaviors, claims of rape and killing, threats to staff,” etc. The facility administrator admitted to state officials that she recruited “challenging” patients like the abuser M.M. because “we have to keep the beds filled to keep the doors open.”

M.M. was not supervised appropriately given his sexually violent and predatory history. Within a few months of his arrival, he also refused to take his medications. Again, no additional precautions were taken by the facility or staff. As a result, M.M. beat and raped a long time resident, M.F. Staff members admitted that they thought that
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advocacy work to hold the negligent facility accountable, the case was settled in favor of the victim M.F., who received a financial settlement that he believed obtained justice for the horrors he was forced to endure.

After the controversy, Indian Trails underwent a reorganization and name change. It is now known as Providence Living Center. It is still licensed as a Nursing Facility for Mental Health in Kansas. The State of Kansas took no significant steps to hold this facility accountable for its actions. If not for DRC’s legal services, justice would not have been served in this case.

More Detail of DRC’s Funding Needs:

- **DRC’s funding cut by 5+% due to Federal Sequester cuts**
- **CPI has increased by 25% over last ten years**
- **DRC’s funding previously lagged behind, and is now being cut**
DRC wins Supreme Court case protecting rights of Kansans with TBI & DD

DRC won a pivotal case in front of the Kansas Supreme Court concerning the rights of people with traumatic brain injury (TBI), developmental disability (DD) and organic brain disorders.

The DRC attorneys successfully argued that the law clearly does not allow the State to involuntarily force people with these types of disabilities against their will to be committed to state psychiatric institutions, such as Larned and Osawatomie State Hospitals. Kansas law only permits the State to involuntarily commit those with mental illness, and then only under certain conditions.

The highest court in Kansas, the Supreme Court, agreed and ruled in DRC’s favor. The case positively impacted and protected the rights of upwards of 300,000 Kansans with disabilities to not be forced into these institutions.

The issue before the court was whether a person with a brain injury (such as TBI or other brain injuries, for example caused by stroke), DD or an organic brain disorder could be forced against their will into a state psychiatric institution. The State argued that someone with a TBI or a disability other than mental illness could be involuntarily committed into a state institution until they were deemed “competent” to stand trial. This is preposterous. Someone with a cognitive disability, brain injury, or DD (like down’s syndrome) will not magically awaken one day and no longer have that impairment and somehow become “competent” to stand trial.

This case concerned an individual involved in an auto accident, where he sustained a traumatic brain injury. Tragically the passenger, who was the best friend of the driver, was killed. The individual’s criminal defense attorney requested a competency exam. The results were conclusive; the individual was not competent to stand trial due to the brain injury.

The District Court ordered the defendant to be committed to a state psychiatric facility. The criminal defense attorney requested the District Court’s order be reconsidered because the state psychiatric hospital was unable to provide care and treatment for people with head injuries. The Court agreed and ordered the defendant to a head injury facility located out of state. This facility issued a report confirming the individual had a severe traumatic brain injury.

By the time DRC became engaged in the case, it had been decided by lower courts and appealed to a higher court for review. At its core, the case involved the fundamental right to substantive due process under the Fourteenth Amendment of the United States Constitution. An individual charged with a crime has the right to be competent before being tried for that crime. In this case, the client was declared incompetent to stand trial due to the traumatic brain injury. DRC was not his criminal defense attorney. DRC represented the individual to protect his disability rights.

DRC argued the case before the Kansas Supreme Court calling for judicial restraint and to side that a person with TBI, DD or a disability other than mental illness could not be involuntarily committed. The Kansas Supreme Court unanimously sided with DRC and affirmed the district court’s decision to dismiss the criminal case without prejudice. In doing so, the Court agreed that the involuntary civil commitment procedure cannot be used against a Kansan with a disability such as brain injury, developmental disability or impairment other than mental illness.
Right to Service Animal Protected

The Americans with Disabilities Act (ADA) clearly states that service animals are not pets and specific rights are granted for their use. However, it is not uncommon for people with disabilities to be denied access to utilize their service animals as a result of this common misperception.

David’s experience highlights this exact situation. David has Cerebral Palsy and uses a wheelchair. He also relies on a service dog for many tasks to make his life more manageable and to live independently. When David and his service dog tried to access transportation services to get to his medical appointments, the transportation provider denied David and his service dog access to the vehicle.

David contacted DRC for legal advice and assistance. With the help of a DRC attorney, David filed a complaint with the Kansas Human Rights Commission (KHRC). After an investigation, KHRC determined that the transportation provider violated David’s rights under the ADA. DRC filed a legal case on David’s behalf after mediation failed and due to this legal action the case was successfully resolved. The resolution included the company providing training on disability sensitivity and service animals to its employees and a monetary settlement for the client.

DRC Helps Student Self Advocate for Drivers License

Dallas Hathaway simply wanted to drive himself to high school just like all his friends. Unfortunately, Dallas was initially denied this typical teenage rite of passage by the Kansas Department of Motor Vehicles (DMV). DRC provides self-advocacy support and technical assistance to approximately 1,000 Kansans with disabilities each year. Self-advocacy support provides people with disabilities the tools, expert legal advice, and resources to successfully secure their disability rights. Like the old adage of teaching someone to fish, teaching self-advocacy empowers people with disabilities to address both their current and future concerns.

Dallas has a diagnosis of Cerebral Palsy and uses a wheelchair for mobility. Dallas was having difficulty communicating with the DMV in his attempts to obtain an instructional driving permit. His initial attempts at applying for the permit derailed when he was informed that his permit was revoked, although Dallas had completed the required training and added the mechanical aides to his vehicle.

DRC provided Dallas an individualized self-advocacy plan to address his problem. DRC and Dallas worked together to identify where the bureaucracy had failed him. Dallas, with support from DRC, was able to contact the necessary people at his doctor’s office. Dallas also completed the necessary mechanical driving aid training at the Rehabilitation Institute in Kansas City. Dallas resubmitted the documentation to the DMV. Thanks to the self-advocacy support provided by DRC, Dallas was able to finally get the DMV to reverse their decision and provide him a permit. Dallas is now a legal Kansas driver after passing his licensing exam!
DRC Helps Change Hospital ASL Policy

DRC worked on a legally based advocacy case that not only helped the individual client, it also helped change the policy regarding access to American Sign Language (ASL) and communication accommodations for the largest American hospital corporation. This is an example of an impact case where DRC’s service helped a larger group of Kansans. According to Gallaudet University, there are over 108,000 Kansans who are Deaf.

Effective communication is critical in any situation. When people who are Deaf or hearing impaired are denied access to effective communication, the situation can become untenable. DRC clients John and Suzy (names changed to protect identity) found themselves in that exact situation. John and Suzy are Deaf. Their primary language is ASL. They have very limited written English skills.

Unfortunately, John and Suzy were in a car accident and had to be taken to Overland Park Regional Medical Center by ambulance. The hospital is owned by the Hospital Corporation of America/Midwest Division (HCA). HCA is the largest hospital corporation in the United States.

John and Suzy requested an ASL interpreter, as is their right under the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 (Rehab Act). The ADA and Rehab Act require the hospital to have a procedure for providing effective communication with patients with hearing impairments when providing emergency treatment. The purpose of these laws is to provide people with disabilities equal access to care and the opportunity to provide informed consent for medical treatment.

Communicating only by handwritten notes or other written communication – especially complex issues such as diagnosis and treatment – is not effective if a Deaf patient has only a limited ability to understand that form of communication. The hospital, however, failed to provide an ASL interpreter or any other effective means of communication. Instead, from the time they were admitted to the ER, examined, diagnosed, treated, and then discharged, John and Suzy had to exchange written communication with hospital staff. They could not understand what was being said to them and understandably were quite scared.

John and Suzy contacted DRC for assistance. DRC helped them file a Kansas Human Rights Commission (KHRC) complaint. The complaint alleged that the hospital failed to provide equal access to care and obtain informed consent for medical care because treatment was provided to John and Suzy without a reasonable accommodation of ASL or video translating in violation of the ADA and the Rehabilitation Act.

KHRC notified DRC that HCA wanted to settle the matter. HCA offered, and John and Suzy accepted, the maximum amount under the law for the injustice they endured.

Equally important, as a result of the complaint HCA changed its policies and procedures to provide effective communication to patients who are Deaf and hearing impaired. HCA is one of the largest private operators of healthcare facilities in the world. It operates 273 hospitals in 20 states, including eight in Kansas and ten in the Kansas City metro area. HCA assured KHRC that this case resulted in significant policy changes in all of their healthcare facilities. This outcome ensures that this case has a positive impact in the lives of people with disabilities in 20 states, including the over 100,000 Kansans who are Deaf.
Shaking and terrified, Barb looked at the DRC attorney and simply said, “I don’t want to be forced to be naked anymore. Please help me.”

With those words, Barb hired DRC to represent her, engaged DRC’s special investigative authority under federal law and started a chain reaction that led to finally shutting down the abusive group home and landed the operators in federal prison for perpetrating bizarre and terrible sexual abuse, physical abuse, and even involuntary slavery.

For over 20 years, Arlan and Linda Kaufman ran a group home in Newton, Kansas. Under the guise of “therapy” they did horrific things to the people with mental illness entrusted in their care. In the trial, prosecutors described it as a “house of horrors” where the Kaufmans forced their patients to be nude, including doing housework and tending the farm in the nude. The Kaufmans filmed all of this for what prosecutors described as their “private porno collection,” all the while billing Medicare and the taxpayers for the “therapy services.”

By May of 2004, DRC had assisted several residents to leave the abusive facility. In October 2004 DRC accompanied the FBI as they executed search warrants and arrested the Kaufmans during a raid on the facility. Federal authorities seized over 30 videotapes from the Kaufman’s bedroom, which vividly showed sexual abuse perpetrated on both male and female patients.

The Kaufman House was owned and managed by the husband and wife team of Arlan and Linda Kaufman. Arlan Kaufman was the so-called therapist, landlord, service provider and guardian/conservator of a number of the house’s residents, including some individuals the DRC helped free from the facility.

Without DRC and its subsequent authority under federal law as the protection and advocacy system, the Kaufmans could have continued their cruel and abusive reign of terror.

The State of Kansas had received numerous complaints about the facilities, but state agencies were never able to get residents out of the Kaufman House or take other necessary action against the facility. Despite these complaints, Kansas failed to adequately respond.

State government agencies had investigated the Kaufmans several times over a 20 year period. However, every time the State investigated them, they were never able to get through the front door. They did not have the same powerful access authority to conduct investigations as DRC Kansas.

In early spring of 2004, DRC used its special access authority under federal law to gain access to the Kaufman house and interview Barb without the Kaufmans present. Under federal law as the protection and advocacy system for Kansas, DRC has “reasonable unaccompanied access” to wherever the person with a disability resides, even an unlicensed group home like the Kaufman House. Barb hired DRC, and DRC immediately got her out of this abusive setting. Federal prosecutors, who had previously passed on prosecuting the Kaufmans, now had their first witness free from the Kaufman’s influence.

In the end, the Kaufmans were convicted on over sixty federal criminal charges, including involuntary slavery and servitude, Medicare fraud, mail fraud, and conspiracy. Both Arlan and Linda were sentenced to long prison terms.

Due to advocacy work of two former residents of the Kaufman House, Nancy Jensen and Lynn Kohr and DRC; Kansas has since changed several laws in reaction to the events uncovered at the Kaufman house, including enhanced reporting of guardians’ conflicts of interest to the courts and greater oversight and licensure of these types of facilities.

The DRC has also continued to work on behalf of the former Kaufman House residents, including ensuring that their rights are protected, necessary supports and services were
DRC Helps Boy Play Baseball

Matthew Whaley was a 7-year-old Kansas boy with Cerebral Palsy who wanted what many kids his age wanted, to play little league baseball. While Matthew had some mobility challenges, he requested no rule changes or accommodations; he just wanted to take the field with other kids his age. Yet solely because of his disability, the Scott City Recreation Commission refused to allow Matthew to play ball. His mother, Jennifer, knew that it wasn’t right to exclude Matthew simply because of his disability. She contacted the Disability Rights Center of Kansas (DRC) seeking information about Matthew’s legal rights.

The DRC’s legal team met with Jennifer and Matthew and quickly recognized that excluding Matthew from a youth recreation activity was a violation of Matthew’s civil rights under the Americans with Disabilities Act (ADA). Under the ADA, all public programs or services, including city sponsored recreational sports, must be accessible to and inclusive of people with disabilities. In response to Scott City’s denial of Matthew’s request to play baseball, DRC Attorneys filed a federal lawsuit on Matthew’s behalf to enforce his rights under the ADA.

After hearing the evidence, U.S. District Court Judge J. Thomas Marten looked at Matthew in the courtroom and said, “Matthew, you’re going to play baseball this summer.” Judge Marten imposed a preliminary injunction ordering the commission to allow Matthew to join the team and play ball. Judge Marten told Matthew that “Little league baseball is not just about fielding skills, hitting skills and winning. It’s about character and teamwork and toughness”. Matthew got his wish to play baseball. The ruling was a positive precedent for all Kansans with disabilities. It helped re-enforce the rights of all people with disabilities under the ADA and helped ensure that individuals with disabilities would enjoy full integration into all public programs and services, even recreational opportunities. As news of the decision spread, Matthew’s notoriety as a pioneer for the rights of people with disabilities grew. He received an autographed baseball from George Brett, a former Kansas City Royal and member of the Major League Baseball Hall of Fame. Kansas Governor Kathleen Sebelius had contacted Brett and asked if he would sign the ball in recognition of Matthew’s courage to stand up and fight for his rights.

The next summer, Matthew was honored in Washington D.C. at a celebration of the 15th anniversary of the (ADA). Matthew and Jennifer provided testimony to a Congressional briefing which was cosponsored by the Congressional Disability Caucus and the Consortium of Citizens with Disabilities. After the hearing, Jennifer, Matthew’s mom, said, “It meant a lot to have that honor because it is more than just a small issue with Matthew. We hope that our case will give other parents the courage to see that it is OK to stand up for their rights and their children’s rights.” Matthew’s story was so compelling that it was picked up by the national media and was featured as a case example of what is good about the ADA on NPR’s Morning Edition.

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Kaufman “House of Horrors” (cont.)

put in place, and ensuring that the victims received appropriate restitution. Because of the work on the Kaufman house case, DRC immediately saved the lives of seven residents and created a safer environment for countless others who may have been subjected to similar situations had the Kansas law not been changed.

Due to their advocacy, Nancy and Lynn were honored at the SAMHSA Voice Awards hosted by Mariel Hemingway.

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