## **BOARD OF DIRECTORS**

POSITION:

#### NAME:

John Lakey Chairperson Carla Lasley Vice Chairperson Candi Koenig Treasurer Lisa Casullo Secretary losh Burke Seamus Kelly Paulissa Kipp Claude Louishomme Mary McHale William Voss

CITY: Kearney Lincoln Kearney Waverly Lincoln Omaha Omaha Kearney Omaha Scottsbluff

Chief Executive Officer

. Staff Attorney

..... Intake Specialist

... Legal Assistant

.. Law Clerk

.... Law Clerk

... Administrative Secretary

In western Nebraska

Scottsbluff, NE 69361

1517 Broadway, Suite 101

## **OUR STAFF**

Eric Evans Judy Sinner ...... Tania Diaz ..... Legal Services Director Dianne DeLair ...... Senior Staff Attorney Michael |. Elsken..... Staff Attorney Amy A. Miller..... Madison Wurtele......Staff Attorney John Murphy...... Values-Based Program Director Patricia Cottingham ...... Inclusive Education Lay Advocacy Coordinator Bradlev A. Meurrens Molly Klocksin.....Case Advocate Mindy Baird......Community Outreach Disability Advocate Yorleny Diaz-Sullivan..... Karen Masterson..... Case Advocate Nikki Evans ...... Representative Payee Reviewer Patricia Nichelson Sharon Ohmberger...... Communications Director lillian Ward ...... Anahissa Limon..... Tess Barnes ...... Marketing and Design Coordinator April Petereit ..... Program and Administrative Assistant Kitra Monnier..... Kato Craig.....

## **CONTACT US**

Disability Rights Nebraska 134 South 13th Street. Suite 600 Lincoln, NE 68508

Phone: 402.474.3183 | Fax: 402.474.3274 Toll Free: 800.422.6691

Email: info@disabilityrightsnebraska.org



Disability Rights Nebraska is a proud member of Give Nebraska. Learn more at GiveNebraska.org

# **ANNUAL REPORT**

## **DISABILITY RIGHTS NEBRASKA**

Protection and Advocacy for People with Disabilities.

# ERIC EVANS' STORY

"It's critical for us to remember that merely having access to community services will not itself result in inclusion, since inclusion involves creating real opportunities for people with disabilities to feel the sense of belonging that goes along with it."

When I started working in services for people with disabilities, I had little idea that it would become my life's work. Over the course of the past 49 years, I have been privileged to work at the personal level with people with disabilities as well as at the systems level. During this time, with the help of Dr. Wolfensberger and others, I developed a vision of what life could be like for people whose only option was living in large congregated, segregated, and isolated facilities. But even more important than the framework provided by Dr. Wolfensberger and others has been the opportunity to gain experience of being disabled directly from individuals with disabilities. The personal relationships I have made with people with disabilities over the decades has been a major source of inspiration for much of my work. Certainly, we have made some progress in creating a more appropriate array of community-integrated service options. However, the reality is that we have not yet begun to achieve the promise of a fully inclusive life in the community for many people with disabilities.

It is critical for us to remember that merely having access to community services will not itself result in inclusion, since inclusion involves creating real opportunities for people with disabilities to feel the sense of belonging that goes along with it. This is why the advocacy approach we use at Disability Rights Nebraska is so unique among our counterparts nationally. Not only do we advocate at the individual, group and systems level, but we also support an advanced form of personal advocacy, i.e., Citizen Advocacy. It is through our work in citizen advocacy that we are able to provide people with disabilities (proteges) the opportunity to become engaged with a member of their community (advocate) who is willing to stand by their side and vigorously advocate on their behalf. But citizen advocacy is more than just protection and advocacy work, citizen advocates also work to create opportunities for their proteges to develop relationships with other members of the community that result in their having a greater sense of community belonging. I am so proud to have been part of this work and hope to be able to continue my advocacy for inclusion and belonging.

## FINANCIAL REPORT FY OCTOBER 1, 2020 – SEPTEMBER 30, 2021

## SUPPORT AND REVENUE

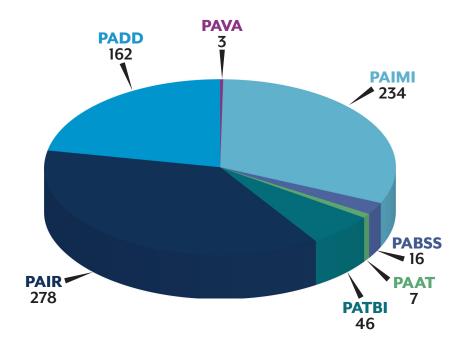
US Dept of Health & Human Services	\$993,685
US Dept of Education	
US Social Security Administration	
NE Dept of Health & Human Services	
Developmental Disabilities Council	\$9,659
Woods	\$20,000
University of Nebraska Medical Center	
Donations, Interest & Other Income	\$102,443
Total Revenue	\$2,087,558

## **EXPENSES**

Salaries & Benefits Operating Expenses Travel Expenses Educational Expenses Contractual Services	\$155,706 \$2,362 \$44,016 \$7,174
Citizen Advocacy Support Total Program Services Expenses	
Total Program Services Expenses	
Fundraising	\$9,994
Management & Administration	
Total Support Services Expenses	\$339,508
Total Support and Revenue	\$2,087,558
Less Total Expenses	
Change in Net Assets	
Net Assets, beginning of year	\$136,476
Net Assets, end of year	\$145,310



# SERVICE REQUEST NUMBERS



#### **US Department of Health and Human Services**

- PADD Protection and Advocacy for Persons with Developmental Disabilities
- PAIMI Protection and Advocacy for Individuals with Mental Illness
- PAAT Protection and Advocacy for Assistive Technology
- **PAVA** Protection and Advocacy for Voting Access
- PATBI Protection and Advocacy for Persons with Traumatic Brain Injury

#### **US Department of Education**

PAIR Protection and Advocacy for Individual Rights

#### **Social Security Administration**

PABSSProtection and Advocacy for Beneficiaries of Social SecurityPABRPRepresentative Payees of Social Security

#### Nebraska Department of Health and Human Services

HHS Department of Health and Human Services

The Protection and Advocacy System for the State of Nebraska. This publication was made possible by funding support from the U.S. Department of Health and Human Services - Administration for Community Living; Substance Abuse and Mental Health Services Administration; Social Security Administration; Nebraska Department of Health and Human Services; and U.S. Department of Education. Disability Rights Nebraska is an independent 501(c)(3) non-profit organization. These contents are solely the responsibility of Disability Rights Nebraska and do not necessarily represent the official views of these funding agencies.

# **CITIZEN ADVOCACY**

Citizen Advocacy programs build long-lasting, voluntary relationships between ordinary citizens who are unpaid and independent of the human service system, and people with intellectual and/or developmental disabilities or mental illness. Citizen advocates make a commitment to representing their partner's rights and interests as if they are their own. Because so many people with disabilities repeatedly have people in and out of their lives it is important that the relationship be long lasting. Since many people with disabilities have no family or community contacts, citizen advocates provide a vital link to the community. A number of advocates have found people jobs, talked to property owners, found people better places to live, introduced people to family and friends, and defended the rights and interests of their partner. Strong friendship bonds are formed as the relationship grows. The advocate's only loyalty is to the person with whom they have the relationship and not human service agencies or even to the Citizen Advocacy program.

Funding through the legislature is provided for the direct operation of local Citizen Advocacy programs and a program of ongoing training, technical assistance, and consultation to local Citizen Advocacy offices.

## **KIERSTYN & JARED**

Kierstyn and Jared met while Kierstyn was living in a supportive home, but her social circle did not extend much beyond her own family. Kierstyn said that for her it had sometimes been difficult to meet new people because of her autism. Jared and Kierstyn were able to identify with one another through shared interests. Jared is an established artist in the community and Kierstyn has a passion for drawing and developing characters, designs, and stories. Jared has brought Kierstyn into his art community and has introduced her to a new world of friends who recognize her for her gifts and talents. She has sold some of her own artwork while attending events with Jared and continues to work on pieces to share at art jams and other events with fellow artists who have become part of her new social circle.

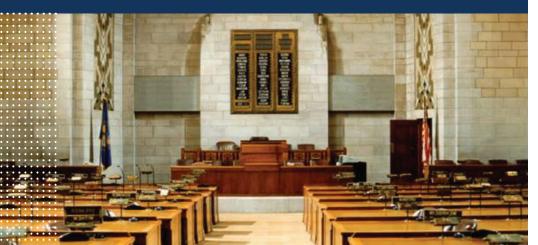
Link to YouTube: voutube.com/results?searchquery=disability+rights+nebraska

# **PUBLIC POLICY**

We noticed that there were some problems with Nebraska's state statutes dealing with civil rights. Nebraska's laws completely left out people with disabilities from discrimination protection in public accommodations. The laws also talk about the full participation in social and economic life as well as full and free use of public accommodations for persons with disabilities, but limits these rights to individuals who are blind, deaf, or who have a physical disability. The statutes also used outdated language like "handicapped." We pointed these issues out to Senator Walz and suggested language to fix the glitches. She agreed and introduced Legislative Bill 540.

Disability Rights Nebraska testified in support of the bill as did the Nebraska Equal Opportunity Commission. The ACLU of Nebraska and the Arc of Nebraska were also in support. Most importantly, our two policy interns each provided written testimony about the importance of the bill to them, from their perspective, as young people with disabilities. The legislation faced no opposition at the hearing or any other stage of the legislative process. The bill was passed by the legislature May 19, 2021 on a 39-0 vote and signed into law by Governor Ricketts on May 21, 2021. See our website for our testimony on this bill and others.

We again worked to stop legislation that would loosen restrictions on the use of restraints and seclusion in schools. Along with testifying in opposition to Legislative Bill 673 at its public hearing, senators received letters outlining all of our concerns when they were debating to amend the language of LB 673 into another school funding bill. Senator Matt Hansen, who was helping lead an effort to "run out the clock" on the proposed amendment, stood up and read our Public Policy Director's letter in full, on the floor. At the Disability Pride Day event that summer, he publicly credited the testimony and letter, as well as Disability Rights Nebraska's consistent advocacy and leadership, as the key pieces that stopped the bill from advancing.



# **© OUR MISSION**

Disability Rights Nebraska uses a combination of legal advocacy, public policy advocacy, citizen advocacy, self-advocacy, and advocacy education to protect vulnerable people with disabilities, especially those who earn, live or work in isolated, segregated or congregated settings.

# **OUR VISION**

Nebraskans with disabilities, especially those who are the most vulnerable, will be free from harm and able to exercise the same rights, opportunities, and choices available to all citizens in order to live fully integrated and culturally valued lives.

### SOCIAL MEDIA FOLLOWERS

												G	Facebook1,758
												E	Twitter589
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•	•	•	•	•	•	•	•	•	•	•	•	C	YouTube34

- Press releases issued: 1
- Times a Protection and Advocacy System representative was interviewed or featured on TV or radio: 1
- Articles about the Protection and Advocacy System or its work in external mass media such as newspapers, radio, podcasts, blogs, or television: 16
- Social media followers: 2,381
- Absolute unique visitors to blogs/web pages where information about the Protection and Advocacy System is mentioned: 16,193
- Circulation of the Protection and Advocacy System's newsletter and/ or listserv updates: 517
- Articles by the Protection and Advocacy System; about disability rights issues published in newspapers, books, journals, or magazines: 6
- Links to other disability rights related information sources published on the Protection and Advocacy System website: 244
- Times the Protection and Advocacy System exhibited at conferences, community fairs, etc.: 7
- Presentations made to community groups: 33

# COMMUNITY ENGAGEMENT STORY

The Training Coordinator for Lincoln City Libraries (LCL) reached out to Disability Rights Nebraska in late spring of 2021. The Training Coordinator noted that, following a series of video trainings during the pandemic lockdown, library staff had expressed an interest in learning more about how to collaborate with both patrons and coworkers with disabilities. Disability awareness trainings were developed that focused on the life experience of people with disabilities from their own perspectives. The training expanded into three separate sessions based on types of disability:

Intellectual & Developmental Disabilities: presented by Erin Philips and Jen James, People First of Nebraska; and Mara Fritts, Autism Society of Nebraska

Sensory Disabilities: presented by Kim Davis, Nebraska Commission for the Deaf and Hard of Hearing (NCDHH); and Kelly Coleman, Nebraska Commission for the Blind and Visually Impaired

Mental Health Disabilities and the R.E.A.L. Peer Support Referral program: presented by Kasey Parker and Melissa Lemmer, Mental Health Association of Nebraska (MHA-NE); and Sargent John Walsh and Investigator Dolberg, Lincoln Police Department.



# THE INCLUSIVE EDUCATION LAY ADVOCACY PROJECT

"One of the best commitments you will make for yourself and for other families. It is a good training, and the support system is there."

The Inclusive Education Lay Advocacy Project is the product of a realization that families who are unhappy and confused by Special Education services are often caught in a cycle of referrals. The end result is often frustration and resignation. Through a strategic planning process, Disability Rights Nebraska determined that advocates who trained in the Individual Education Planning (IEP) process and were willing to advocate for families at IEP meetings could be a viable solution.

The project began in 2018 with a goal to train lay advocates in the specifics of Special Education and to have them assist families throughout the state to secure appropriate educational services in the least restrictive environment. The first training occurred in the fall of 2019 with a face-to-face format and nine (9) Lay Advocate volunteers. Due to the pandemic, the format was adapted to provide the same quality of training using an on-line format in the Spring of 2020. Since that time, The Inclusive Education Lay Advocacy Project has held five (5) trainings sessions and trained a total of 24 lay advocates who have assisted more than 30 families in their education journeys. New trainings are offered in the spring and fall.

## **SINCE 2019**

Training Cohorts	Advocates Trained	Families Helped		
5	24	>30		

"We are here to help families. We've been through this training. And we help each other a lot."

## MONITORING DURING THE PANDEMIC

Disability Rights Nebraska staff took the accumulated product of the monthslong remote monitoring investigation and produced a written report detailing the unmet needs of people with disabilities during the pandemic. The report, "A Widening Divide," which lifted up the areas where state or local officials and facility administrators had made laudable efforts but also provided clear and unwavering critiques of the gaps that put people with disabilities in peril of illness or death. We incorporated the lived experiences of Nebraskans with a variety of types of disabilities and lifted up models for change in policy and state laws for policymakers' consideration.

We distributed the report to every senator in the state Unicameral, stakeholder organizations representing congregate facility administrators, stakeholder organizations representing people with disabilities, and organizations representing people of color in light of the pandemic's disproportionate impact on those communities. We used this outreach with our report as a way to strengthen partnerships and remind the various entities of our work for future collaboration. As a result of our report recommendations, remedial legislation was proposed (LB 1104). Though the bill was favorably received with no opposition testimony and folded into the committee's priority bill (LB 512), time ran out before all priority bills could be debated before the close of the session. However, the Nebraska Emergency Management Agency ("NEMA") has moved forward with the spirit of the bill and invited Disability Rights Nebraska to participate in a new ad hoc advisory group. The group is charged with reviewing our state's plans to ensure they will include assisting people with disabilities in the case of natural disaster, future pandemic or another emergency.

The monitoring team then turned their attention to ensuring the vaccination plan would reach people with disabilities living in congregate facilities. The serious concerns about how the state's COVID-19 testing scheme failed to account for Nebraskans with disabilities-particularly those in congregate facilities-suggested there would be similar gaps in the vaccination plan. We contacted a sample of several types of facilities (long-term care nursing facilities, assisted living facilities for adults living with mental illness, and group homes for adults living with developmental disabilities) and interviewed the administrators to learn what their understanding of the state plan was and their preparations to vaccinate the people they serve. Our CEO and Legal Director met with leadership from the state Department of Health and Human Services to discuss our ongoing concerns with the need to vaccinate those Nebraskans unable to go to a vaccination clinic. While the Division of Developmental Disabilities then moved forward with a plan for in-home vaccination for the adults under their charge, we were unable to obtain the same commitment from the Division of Behavioral Health.



Disability Rights Nebraska staff continued their advocacy to ensure the state's vaccination plan would reach people with disabilities living in congregate facilities as well as those living independently but without the ability to travel to a vaccination clinic. The greatest unmet needs were among adults living with mental illness, since the state simply made no provision for their needs. Responsibility for vaccinations was placed with the local health department level so rather than continuing our work with the state, we had to realign our investigation to survey all 23 public health departments across the state. We reviewed each department's website and phoned each department to inquire about in-home vaccinations. We learned that less than half of the departments had a clear policy of bringing vaccinations to people's homes, and five agencies actually were clear in refusing to offer that service. After the survey, we wrote to each public health department with an individually tailored letter, either praising their accommodation or requesting they re-evaluate their program and offer in-home vaccinations. Good news resulted-all but three very small rural departments agreed to expand their vaccination program at our urging, meaning 90% of Nebraskans live in a county with in-home vaccinations.

Disability Rights Nebraska helped an individual with a mental illness transition out of an isolated, restrictive, and segregated facility into more appropriate housing. The individual was placed in the remote facility after having a temporary lapse in her mental health and remained there, inappropriately, for years. Prior to living at this facility, the individual resided in less restrictive environments and for many years lived on her own in an apartment. Until Disability Rights Nebraska became involved, the guardian ignored repeated requests from the individual to be moved. Disability Rights staff then advocated on behalf of the individual in court and is in the process of getting the individual put on the waiting list for a new guardian through the Office of Public Guardian.