

Kansas **ONLINE!** Disability Caucus 2020

EXECUTIVE SUMMARY



We the People...

OUR RIGHTS,
OUR
RESPONSIBILITIES,
OUR LIVES!

Background and Overview

In August of 2020, over 200 disability advocates experienced a Disability Caucus like no other. Due to the COVID-19 pandemic and limits on social gatherings, the Caucus was moved to a virtual platform and attendees experienced sessions and speakers on Zoom over a period of three days. The 15th Kansas Disability Caucus focused on two central themes relating to the rights, responsibilities, and lives of Kansans with disabilities. These themes were voting and the COVID-19 pandemic. While the focus was on these two topics, the Caucus also maintained its overall purpose to develop new disability leadership in Kansas, educate Kansans with disabilities about the process of policy making and encourage their participation in it, and determine major issues facing Kansans with disabilities and possible solutions for these issues. The Caucus started in 1988 where about ninety people gathered in Salina. In 1993, the Caucus was moved to Topeka and grew in attendance numbers, and subsequent years have followed. Each Caucus has had its own unique highlights and topics of discussion over the years, ranging from attendant care to employment, from transportation to health insurance. The Caucus is held every two years. This is the first time that the Caucus has been held virtually.

This year, Caucus attendees gathered in three virtual rooms for Caucus Regional Sessions to develop priority issues and specific solutions related to the COVID-19 pandemic and the needs of people with disabilities during the pandemic. In addition, breakout sessions focused on voting rights, the impact of voting, ways that advocates are working through the pandemic, and rights during the pandemic. Attendees also heard from empowering keynote speaker, Keri Gray, with the American Association of People with Disabilities.

*For more information about the Kansas Disability Caucus, Inc., contact:
Lou Ann Kibbee, Board President, at louannk@skilonline.com or 785-628-8019.*

Caucus participants attended West, East, or Central Caucus regional sessions virtually. These attendees included people with all types of disabilities of all ages, disability rights advocates, and disability service providers. Each region was assigned the task of discussing issues and barriers that people with disabilities have experienced during this time of a pandemic, as well as possible solutions to these obstacles. The following pages recap these areas of concern set as priorities, as well as solutions to some of these issues:

Issues and Barriers Experienced During COVID-19 Pandemic

OVERVIEW: The takeaway is that, regardless of the area of the state where disabled Kansans live, nearly every aspect of our lives has been affected by the COVID-19 pandemic. Existing barriers have been increased by new limitations. New ways of offering services in the community come with their own obstacles.

Healthcare – Medical and Behavioral

- Limited access to all kinds of care caused by shutdowns and limited appointments/services
- Testing barriers
- Safety concerns going into medical settings
- Barriers and limitations on virtual or telehealth services
- Mental health treatment limits
- Exacerbation of existing disability/health conditions

Long Term Services and Supports

- Institutional setting issues related to isolation from outside connections
- Specialized community-based services even more difficult to get
- Hospital discharge to home or institution
- Availability of personal protective equipment and supplies for workers, consumers, and family
- Protections offered by surveys and ombudsmen are limited

Direct Support Workers

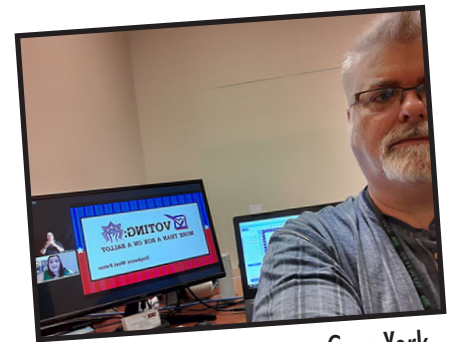
- Existing workforce shortages continue
- Concerns about COVID infection to/from workers and consumers
- Management of workers
- Pay for overtime or hazardous duty services not available

Community Access/Resources

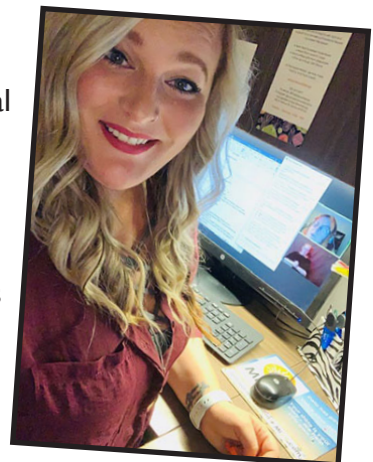
- Shortages of routine household items, over the counter supplies, personal protection equipment, sanitation products, and food
- Limits on availability of Internet and broadband services
- Increased costs for all types of goods and services
- Feeling like people need to “beg” to get basic needs met and supplies
- People lack non-cash ways to pay bills and other household expenses
- People are concerned about their ability to pay for their own or their loved ones’ funeral expenses and arrangements
- Lack of devices to use online services
- Closure or limited hours for social service offices
- Need training for new technologies
- While online ordering may be an option, people lack the ability to pick up ordered items
- Lack of information about sanitation and precautions
- Increased benefits ended but costs are still higher than before
- “Drive through” services of all types require people have private vehicles
- Masks are problematic for people with some types of disabilities; people who are politically opposed to masks are using Americans with Disabilities Act improperly



Kelsey Shinnick



Greg York



April Rickman

Issues and Barriers Experienced During COVID-19 Pandemic (cont.)**Housing**

- Unemployment or financial issues threaten ability to retain housing
- Some providers have increased rent
- Lack of accessible housing
- Limited access to management or rental offices to obtain housing or complete certification processes

Transportation

- Limited services and routes for transportation providers
- Safety concerns using any public transportation

School/Education

- Online learning obstacles
- Lack of access to therapeutic or support services traditionally offered in schools
- Loss of social connections
- Transition to college is up in the air over online college or in-person
- Virus transmission concerns related to return to school; exposure “healthy” family members may create for family members with disabilities
- Lack of support for in-home learning

Communication/Information

- Social services agency closures make communication difficult
- Conflicting or hard to find information about the virus
- Masks interfere with receiving and producing communication

Social/Recreational

- Limits on social, recreational, or wellness activities including religious services, volunteer activities, and exercise classes
- Isolation increased potential for abuse, neglect and exploitation
- Reduction in hygienic practices

Institutional Transition

- Decreased access in institutional settings means transition has to be coordinated over phone or Internet
- Other community organizations (jails) are not making referrals
- No ability to go in to facilities to provide information and outreach, so people have to rely on someone to make a referral to outside resources

Employment/Vocational Rehabilitation (VR) Services

- Finding and keeping employment very difficult during pandemic
- Problems with access to VR Services prior to the pandemic have increased
- Necessary to quit essential job to protect health
- People have lost jobs
- Shadowing and mentorship opportunities limited

Centers for Independent Living (CILs)

- Four CILs who do not receive Federal Part C funds did not get CARES Act funding for COVID related expenses
- Concern about ability to serve influx of people with post-COVID related disabilities



Sean Beebe



PILR Staff



David Powell



Lisa King

Solutions for Obstacles During COVID-19 Pandemic

OVERVIEW: While many people express a desire for a “return to normal,” COVID has highlighted many of the ways “normal” was not working for aging and disabled Kansans. If it is true that adversity yields opportunity, our state has a tremendous opportunity to redesign approaches to all aspects of community life so that equity and access are fundamental for people across all marginalization’s.

Medical/Health Care

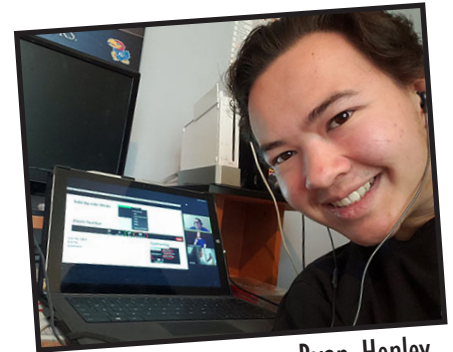
- Healthcare providers of all types should be given clear and concise guidance and expectations for services and safety measures, including development of “non-traditional” service options such as evening/weekend hours, telehealth options, modified “group” sessions, recognizing that “visitor policies” do not apply to paid or unpaid support people, and ensuring effective communication while using masks.
- Providers must identify limitations and payment barriers so that they can work with the state, managed care organizations, and other agencies to reduce service barriers for patients.
- Testing, using all different types of available tests (rapid response, nasal, saliva, etc.) should be made available and accessible, with a minimum of barriers or requirements. “Drive through” testing sites should offer walk-up options. Information about the testing process, and counseling to address fears associated with testing and results should be readily available alongside testing.

Long Term Services and Supports

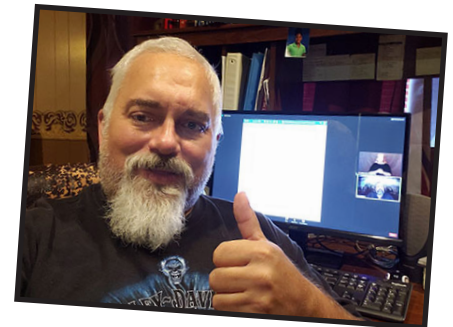
- Home and Community Based Services (HCBS) Waiver Amendments:
 - * Revise crises exceptions to allow more people to access HCBS
 - * Expand self-direction to include budget authority to set worker wages, overtime and pay differentials
 - * Include in available services the ability to cover fees for individuals to access resources who assist with locating workforce, such as Care.com
 - * Return control over worker background checks to self-directing consumers
 - * Remove barriers to obtain durable medical equipment
 - * Include mental health services in waivers without needing to get Institutions for Mental Disease (IMD) exclusion
 - * Develop a waiver or services that “cross” waivers/disabilities
 - * Increase flexibilities to add agency services or other services to meet exigent or emergency needs
 - * Provide technology equipment and access to waiver participants, much like phones in the current system
 - * Provide participants with personal protective equipment (PPE), sanitation, and other supplies that are made available to institutions
 - * Institute a “bed hold” policy for community – help provide resources to maintain housing during hospitalizations or planned brief stays for rehabilitation treatment.
 - * “Build in” emergency funds analogous to Acute Care Costs for each beneficiary’s waiver services to help cover expenses like PPE, technology access, increased transportation and other emergency-related expenses
- The state needs to re-start the Money Follows the Person program to create a formal structure for getting information about community options, consistent services to support transition, data collection, and re-balancing resources from institutional toward community capacity and options.



Julia Connellis



Ryan Henley



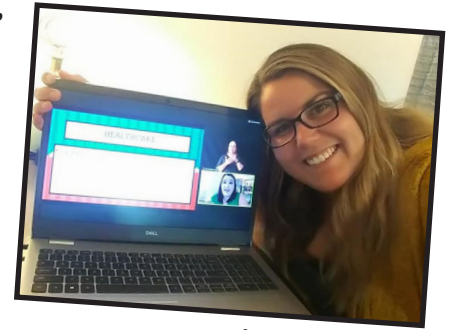
Jeff Schroeder



Mary Reynolds

Solutions for Obstacles During COVID-19 Pandemic (cont.)

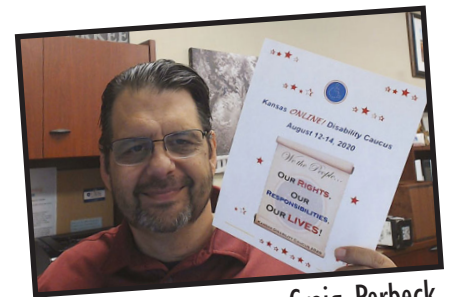
- Choice and options for leaving carceral, medical, or rehabilitation care of any type, including hospitals, whether the person has been there for COVID treatment or not, needs to make sure that people know about HCBS options. Social workers and discharge planners need to be provided with resource lists to make referrals to organizations to help people set up the services, supports and supplies they need to go home. People in these settings need to have ready access to technologies to communicate with people outside the institutions to coordinate and arrange transition services.



Laura Pederzani

Community Living Issues

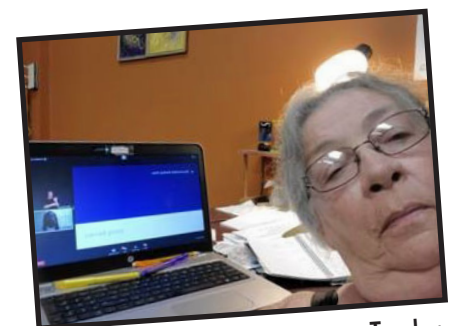
- Disabled Kansans need better access to technology, including devices, internet/data access, and training and information on how to use technology for education, employment, medical, and social activities. If the state through managed care is going to use telehealth to meet health and safety needs, the state through managed care needs to provide the means for people to be able to access medical treatment provided in that format, including training and information on how to effectively use technology.
- Develop a “living” website and other resources to inform the disability community of updated information, changes, call for advocacy, civil rights, fair housing rights, tenant rights, etc. during the pandemic
- Pass Medicaid Expansion to provide healthcare to many direct service workers/ personal care attendants.
- Create cooperatives with CIL involvement to bulk order and distribute PPE, sanitation supplies, and other household supplies that have been high demand.
- Recognize expenses for PPE, sanitation supplies, and technology related costs for spend-downs and premium adjustments (WORK program).
- Work with parks and recreation departments, private facilities, and other organizations to help people set up social, recreational, and wellness activities in their homes and communities, honoring social distancing and safety protocols. Offering and providing instruction to use simple exercise equipment at home, organizing gatherings in parks or outdoors to allow for social distancing, developing a call tree—sequence of friends calling friends, and providing resources for activities such as meditation and gardening.
- Work with local stores and grocery store “chains” to address barriers to use of online ordering and delivery services, allowing phone-in orders, or alternatives for picking up or delivering orders.
- The state needs to lead in meeting civil rights obligations by providing accessibility in communications, including plain language materials, and ensuring people have the materials, tools, and resources for disabled people to participate.
- Consumers need to be encouraged to self-advocate with local, state and federal policymakers to help them to understand what people are dealing with, encourage sound public health policy such as masks and social distancing, and to ensure our needs are included in budgets, policies, and priorities. Consumers need training. Advocates may need to look at new ways to “present” issues, including things like cut-outs at the Capitol, or a “COVID Quilt” with squares from individuals.



Craig Perbeck



Jean Hall



Sharon Traylor

Housing

- Local, state, and federal support is needed to help people keep and find affordable, accessible, integrated housing. Advocacy should continue at all levels.

Solutions for Obstacles During COVID-19 Pandemic (cont.)

- Redetermination processes should be placed on hold during the health crisis. Eviction and foreclosure moratoriums should be extended, including a hold on any proceedings to enforce estate recovery against real property.
- Re-purpose unused resources such as hotels to provide short-term or transitional housing, quarantine spaces, or emergency housing for people during the pandemic.

Transportation

- Enforce access rights and safety practices for transportation providers, including taxi companies, private hire vehicles, contract providers, and public transportation.
- Advocate for Non-Emergency Medical Transportation (NEMT) be mandatory for states to provide.

Employment

- Employment First, including Oversight Committee work, and independent agency, should be advanced as originally intended and supported to offer state employment to disabled people.
- CILs need to receive referrals from Vocational Rehabilitation and Workforce Centers to provide services supporting youth transition, and other employment services.
- A clearinghouse to help people interested in self-employment, such as selling products online, should be established to help people with technical assistance in doing this.

Educational Services

- Supporting disabled students in online and “low-contact” educational settings must be emphasized. Individuals with Disabilities Education Act (IDEA) and the terms of individualized education plans (IEPs) still apply; resources to support students and families with due process hearings and IEP enforcement are needed. Supportive services previously provided in school settings must be offered in alternative ways, including in-home and online. Student learning support needs may need to be filled by direct service workers/personal care attendants; training for these workers and a way to pay them without taking away from other needed services must be offered, whether by schools, or by Medicaid.

Capacity of Centers for Independent Living

- CILs need to be anticipating greater service demands as COVID survivors join the disability community. Advocates need to continue to press Kansas Rehabilitation Services for state funding for four CILs that did not receive federal Part C funds in CARES Act for COVID related expenses, and advocate for federal and state funding for CILs to provide services to many people with COVID related disabilities.

A BIG THANKS TO...

Facilitators: Steve Gieber, Dot Nary,
Macy Collins

Note takers: Jay Schulz,
Elena Redmond, Sarah Smith

CART: Jane Piles

ASL Interpreters: Kim Weidler-Hyten
and Jolene Benham

A huge thank you to everyone
who attended our online Caucus!

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