SEDGWICK COUNTY DEVELOPMENTAL DISABILITY ORG.
2023 CAPACITY REPORT

I. Service Area:

According to the US Census Bureau, Sedgwick County, KS had an estimated population of 528,469 as of July 1, 2023. This represents a .9% increase since 2020. As of December 31, 2023, the Sedgwick County Developmental Disability Organization (SCDDO) had a total of 2,692 individuals determined eligible for the intellectual/developmental disability (IDD) system. Compared to the number eligible as of December 31, 2020 (2,604), this represents an increase of 3.4% which is significantly higher than the population growth in Sedgwick County during this time. As reported on the Sedgwick County website, the unemployment rate for the County was 2.3. Sedgwick County's rate is under both Kansas' and the US unemployment rates. The US Bureau of Labor Statistics lists Kansas's unemployment rate for December 2023 as 2.6 and the US employment rate as 3.7. An unemployment rate of 5% or lower is generally considered maximum employment, i.e. as close as possible estimation of when available labor resources can be employed within an economy at a given time (see Investopedia.com and Microsoft Copilot AI). As reported in previous capacity reports, Sedgwick County IDD service providers report hiring as one of the biggest barriers to increasing their capacity to serve more individuals or to serving individuals timelier.

With Kansas reporting a total of 8,950 individuals eligible for the IDD system, SCDDO's IDD eligible population accounts for 30% of this statewide total. The number waiting for access to the IDD Home & Community-based Services (HCBS) in Sedgwick County accounted for 18% of the statewide number (972/5,240). The wait for HCBS services is over 10 years.

TOTAL ELIGIBLE:	**2,692**
TOTAL ELIGIBLE BY AGE	
Age 0 to < 5	10
Age 5 to < 18	634
Age >= 18	2,048
SCDDO ACTIVITIES	**Total**
New Persons Added	195
Intakes Completed	128
Options Counseling Transactions	764
Functional Assessment	1,835
WAITING LIST	
*Unserved - waiting for HCBS only - Under 18	480
*Unserved - waiting for HCBS only - 18 & Above	492
Total Unserved - waiting for HCBS only	**972**
HCBS Waiting list offers	65
HCBS Waiting list acceptance	35
Waiting for Non-HCBS (Local Waiting List - Tier 0)	25

CASE TRANSFERS	**2023 Total**
In	42
Out	30

TARGETED CASE MANAGEMENT SUMMARY	
TOTAL TCM SERVED (unduplicated):	2,148
# WITHOUT TCM SERVICES*:	540

*Once determined eligible, individuals may choose TCM. If they do not have Medicaid Title IX, the service would be private pay and many choose to go without TCM. This does not reflect a waiting list for TCM services.

TOTAL RECEIVING HCBS SERVICES: 1,507

As mentioned above, more individuals were determined eligible for the Sedgwick County IDD system than those who moved or terminated their case. A total of 161 individuals terminated their case in 2023 and 30 cases were transferred out; while a total of 195 new persons were determined eligible and 42 cases were transferred in.

TERMINATIONS	
1-Deceased	22
7-Moved out of state	23
9-Self-termination	17
10-Moved out of county	30
11-Term by CDDO	8
12-Incarcerated	5
12-Non-Specified	46
12-State Hospital	1
12-Nursing Facility Placement	9
Total Terminated	**161**
GATEKEEPING	
Access request	0
Exits	3
Admits	1
Total # of persons in ICF	39

The number of persons in intermediate care facilities (such as Parsons State Hospital) has been decreasing over the years and was down to 39 in 2023. In 2022 there were 48 people in intermediate care facilities, and it has been as high as 60 in 2017.

II. Provider Network:

Sedgwick County is fortunate to have a relatively large network of IDD service providers with 43 as of December 31, 2023. This is down slightly from when we first started reporting on the IDD service system capacity in 2015 when there were 46 providers in the network. A key feature of the Sedgwick County IDD service network is the diversity of provider agencies. Agencies served from 0 or 1 up to nearly 700 individuals in 2023. For at least the second year, one agency has reported not serving anyone on the IDD waiver during the year. About 64% are for-profit organizations and 36% are nonprofit organizations.

In 2023, two new full-licensed residential providers were added but only one has opened for referrals. Residential is generally the most common service added during any given year. Applications for affiliation to provide residential supports in Sedgwick County do not typically come from existing businesses, which is more common for the other services. Applicants for residential are typically an individual starting up a first-time business.

SEDGWICK COUNTY IDD PROVIDER NETWORK
2023 SUMMARY

Service	# of Providers at Beginning of 2023	# of Providers Added	# of Providers Quit	# of Providers at End of 2023	Net Change in Providers in 2023
Assistive Services	4	0	0	4	-
Day Supports (Full)	18	0	0	18	-
Day Supports (Limited)	3	0	0	3	-
Enhanced Care (AD*)	1	0	0	1	-
Enhanced Care (SD**)	7	0	0	7	-
Financial Management Services	7	0	0	7	-
Medical Alert Rental	4	0	0	4	-
Overnight Respite (AD)	2	0	1	1	-1
Overnight Respite (SD)	7	0	0	7	-
Personal Care Services (SD)	7	0	0	7	-
Residential Supports (Full)	12	2[1]	0	14	+2
Residential Supports (Limited)	4	0	1	4	-1
Specialized Medical Care	4	0	0	4	-
Supported Employment	3	0	0	3	-
Supportive Home Care (AD)***	3	0	0	3	-
Targeted Case Management	10	0	0	10	-
Wellness Monitoring	7	0	0	7	-

*AD = Agency Directed

**SD = Self Directed

***Note, one Supportive Home Care provider limits participation to their program clients, one is limited to children which results in only one provider serving all ages.

[1] One new residential provider was licensed and affiliated in 2023 but did not serve anyone during that year.

Supportive Home Care is an area the Sedgwick County IDD service provider network is lacking. While three agencies provide Supportive Home Care, one only serves individuals participating in their activities and the other only serves children; this leaves only one Supportive Home Care agency to serve adults in Sedgwick County. This year the SCDDO has been reaching out to agencies signed up to provide Personal Care Services for the WORK program. So far, outreach has been made to 14 agencies and none were interested in serving individuals on the IDD waiver. The most common reason cited was lack of staffing but a few simply indicated a lack of interest in serving the IDD population.

A home health agency that provides Supportive Home Care on other waivers (Physical Disability, Frail Elderly and Brain Injury) approached the SCDDO early in 2024 with interest in serving the Sedgwick County IDD waiver population. It turned out, this home health agency is considered a preferred provider for two of the three Managed Care Organizations (MCO) and receives 20%

over the standard waiver rate for the service. This home health agency was willing to serve the Sedgwick County IDD waiver population if the SCDDO agreed to pay the extra 20% for the one MCO's members. When it was suggested the agency could chose not to credential with that MCO for the IDD waiver, it became clear the home health agency had other concerns. The agency has service hour minimums and broad authority to terminate services as it sees fit.

When asked what other concerns regarding issues that impact their ability to provide services or limit the independence and community integration of persons with IDD, providers gave the below responses.

Provider Concerns
Legislative language that requires multifaceted organizations to have all their staff meet KDADS requirements, regardless of whether they work directly with IDD clients.
quality staffing
Opening more waiver spots at a state level will impact capacity at the local level. Staffing is still top 2 concerns/roadblocks to building capacity for SHC. Financial pressure/demand is the other concern. (Rate)
I have concerns around final rules impact and interpretation of integration when it comes to work and community involvement.
The reimbursement rate for the nursing services we provide is so low, it is difficult to recruit nurses to fill the hours.
Staffing shortages Transportation Serving individuals with complex needs
Hiring and retaining staff
1. Staffing -An inability to fill positions and retain employees. Not only DSPs, but frontline supervisors, nurses, maintenance, and drivers. 2. Serving people with increased severity/frequency of behavioral health challenges. 3. Transportation -Lack of vehicles -Lack of funding -Increased cost of vehicles -An inability to find appropriate vehicles to purchase
Cost of transportation for residential providers; minimal to no support for providers in the community; high cost of training DSPs (CPR classes now being in-person, very costly on top of background checks).

III. Key Indicators:

a. Access to Service

The Sedgwick County affiliation agreement allows IDD service providers an average of 60 days to initiate services from the date of the referral. Before the pandemic this requirement was consistently enforced. Exceeding the 60 days to initiate services has never been an automatic contract violation, IDD service providers are simply expected to keep the SCDDO updated on the issue causing the delay and progress in addressing it. There are many reasons why services cannot begin within 60 days and not all are within the IDD service provider's control. It is not uncommon for individuals to want specific locations and agree to wait until they are available. However, timely access to services has never rebounded from the issues that came with the pandemic, and we have not been strictly enforcing the 60-day average for service access. SCDDO staff continue to track referrals and have conversations with IDD service provider organizations around start dates.

Service	Average # Days between Choice & Service Start Date
Assistive Services	0
Day Supports (Full)	57
Enhanced Care (AD)	17
Enhanced Care (SD)	17
Financial Management Services	27
Medical Alert Rental	181
Overnight Respite (AD)	2
Overnight Respite (SD)	2
Personal Care Services (SD)	21
Residential Supports (Full)	60
Specialized Medical Care	225
Supported Employment	0
Supportive Home Care (AD)	91
Targeted Case Management (TCM)	6
Wellness Monitoring	2

The above chart reflects the best data we have from our electronic medical record system for service access. The data relies on IDD service providers to report start dates, which is often a struggle. Additionally, the number of days between referral and service start can only be calculated when there is a start date; so, individuals referred but still waiting for the service would not be reflected. Currently (April 2024) SCDDO staff are tracking 65 referrals for service without start dates. The oldest referral dates to June 2023. Of these 65 referrals over 60 days old, 35% were for Day, 33% for Residential, 17% for Personal Care Services, 8% for Supportive Home Care and 8% for other services.

Another complicating factor is that it is not unusual for individuals to get tired of waiting and to rescind their options counseling; they might then select a new provider (restarting the timer) or decide to decline the service or forgo the new service provider. An example of this situation is an individual whose guardian first selected a local provider in the Fall of 2021 to bring their relative out of Parsons State Hospital. When it was taking too long for that provider, a different provider was chosen but that didn't work to the guardian's satisfaction. As of today, they are still working to bring their relative back to the community.

Interestingly, fewer providers indicated they struggled to meet demand for a service in 2023. In 2022 over half of the providers said they struggled to meet demand for at least one service but in 2023 only 37.5% of responding providers indicated strained capacity. Of the services referenced as difficult to meet demand for, TCM was mentioned the most. Half of all TCM providers indicated it was hard to keep up with demand for the service in 2023. This correlates with the number of holds on TCM referrals. Holds on TCM referrals were placed a total of ten times in 2023, with only one agency not requesting a hold during the year. Residential was the next most often mentioned service for capacity struggles with four agencies mentioning it. Specialized medical was indicated as hard to provide by three out of four (75%) agencies providing the service. Then Supportive Home Care was also a service listed as difficult to meet capacity.

b. Complex Needs

Individuals with complex support needs can present a challenge to IDD providers. Of the 1,507 individuals receiving HCBS services in Sedgwick County, 851 individuals in services had high medical needs (defined as a score of 9+ on health score and requires special health care procedures in Section 6 of the BASIS). A total of 1,177 had interfering behaviors (defined as a score of 98+ on maladaptive health or 2+ questions answered true in Section 13 of the BASIS). Of those eligible (including those in services) 1,049 reported one or more co-occurring behavioral health diagnosis. The most common behavioral health diagnoses are listed below.

1. Attention Deficit/Hyperactivity Disorder (all types combined)
2. Generalized Anxiety Disorder (including Anxiety Disorder NOS)
3. Oppositional Defiant Disorder
4. Intermittent Explosive Disorder
5. Depressive Disorder
6. Bipolar Disorder
7. Obsessive Compulsive Disorder

SEDGWICK COUNTY COMPLEX NEEDS
2017 TO 2023 COMPARISON

Complex Need Type	2017	2023	Percentage Change
Persons Served with High Medical Needs	704	851	+21%
Persons Served with Interfering Behaviors	779	1,177	+51%
Persons Eligible with One or More Co-Occurring Mental Health Diagnosis	793	1,049	+32%

Consistent with national data, the proportion of individuals with complex needs eligible for the Sedgwick County IDD system and/or receiving IDD services has grown over time. The Administration for Community Living in their "*Promising Recruitment and Retention Strategies,"* published in September 2021, indicated that nationally the proportion of individuals with behavior challenges more than doubled (15% to 31%). ACL's study indicated the proportion with anxiety and mood disorders has also increased.

The increasing number of individuals with dual mental health diagnoses lends urgency to the development of a consistent IDD Crisis Stabilization program for Sedgwick County. In 2024, the SCDDO received a grant from KDADS to assist individuals eligible for the IDD system who are experiencing a mental health crisis. This grant will allow the SCDDO to review current community mental health resources as to their ability to meet the needs of individuals with IDD and support the development of a multidisciplinary crisis stabilization plan process. The goal is to ensure individuals with IDD in the midst of a mental health crisis receive effective intervention, regardless of which IDD provider agency they have chosen for services.

Despite the large number of individuals with complex support needs in the Sedgwick County IDD system, IDD service providers reported relatively few extraordinary funding (EF) requests. During 2023, 7 agencies applied for EF for 32 people. Of those 32 applications, 3 were denied, 20 were approved and 2 were still in process. It should be noted that one agency with 8 applications did not report the results of their EF applications.

c. Provider Workforce

As with previous capacity reports, issues with hiring and retaining quality staff were at the top of the list for reasons agencies struggle to meet demand for services. This is not necessarily as big a concern for self-directed services, since the individual chooses the worker, and they are often family members. As can be seen from the two charts below, starting pay for direct support professionals (DSP's), Targeted Case Managers (TCM's) and Nurses has been on an upward trend since 2020; however, turnover is up from the prior year. Pay for agency-directed DSP's ranged from $10.50 to $17.54 per hour. A full 40% of agency-directed providers pay $15 or more per hour and only two providers start pay under $12 per hour. The average hourly rate for agency-directed DSP's of $14.31 is very close to the 2021 national average of $14.41 as reported by ANCOR in its "*The Case for Inclusion 2024: Transforming Temporary Progress into Long-Term Sustainability*."

STARTING PAY PER HOUR

Type of Worker	2020	2021	2022	2023	% Change b/w 2020 to 2023
DSP - Agency	$11.08	$11.37	$14.18	$14.31	+29%
DSP – Self-Directed	$10.45	$10.78	$12.67 non-exempt $16.16 exempt	$12.51	+20%
TCM	$15.06	$15.70	$17.04	$18.56*	+23%
RN	$24.17	$25.13	$25.44	$25.24	+4%
LPN	$19.83	$21.13	$22.60	$22.94	+16%

*Note: one TCM agency skipped this question.

Turnover was up for all positions where turnover has been measured over time. Sedgwick County's reported turnover for direct support professionals (39%) is slightly lower than the national rate of 43.3% for 2021 as reported by ANCOR.

Average Turnover

Type of Worker	2020	2022	2023
DSP – Agency	34%	32%	39%
DSP – Self-Directed	33.5%	26%	32%
TCM	30%	31.5%	42%*
Nurse (LPN & RN)	N/A	N/A	22.5%

*One TCM agency chose to skip this question.

Interestingly, turnover does not correlate perfectly with pay. Agency-directed service providers reporting turnover over 50% had an average starting pay of $14.58, slightly more than the system average. In fact, agency-directed service providers with pay at $17 or more averaged turnover of 57%. While not a perfect indicator, generally the smaller agencies had lower turnover.

Type of Worker	Turnover Range	% of Agencies Reporting Turnover 50% or Higher
DSP – Agency	0 to 80%	40%
DSP – Self-Directed	1 to 50%	33%
TCM	0 to 80%	50%
Nurse (LPN & RN)	0 to 100%	17%

The number of IDD service providers reporting turnover of more than 50% was striking, particularly for TCM. Both agency-directed DSP's and TCM's had turnover ranging up to 80%.

d. Financial Stability of Service Providers

Having made it through the pandemic in fairly good financial shape, IDD service providers were then challenged with the restart of Medicaid renewals. KDHE data indicates over 12,000 people in Sedgwick County have lost Medicaid, which includes populations other than just IDD. Statewide 7,843 individuals, with Medicaid due to long-term care needs, being elderly or disabled, have lost coverage. While complete data is not available, the SCDDO has worked to track individuals losing Medicaid coverage due to issues with the renewal process and ensure IDD service providers are aware. For the most part, IDD service providers have chosen to not stop services but are counting on Medicaid being reinstated; meanwhile, persons in services without Medicaid are running up large unpaid bills they will be responsible for if Medicaid is not reinstated.

IDD service providers are highly dependent on HCBS Medicaid revenue. On average, HCBS accounted for 70.8% of agency revenue. Over a quarter of responding agencies indicated HCBS was the sole funding source for their organization. Clearly, interruptions to this revenue source would have an outsized impact on IDD service providers.

In the 2023 capacity survey, 31% of agencies indicated they could not continue operations for three or more months using only reserves. This represents an increase from last year (24%) in the number of agencies without adequate reserves to cover three or more months.

IV. Analysis and Recommendations

There are a number of stressors on the Sedgwick County IDD system. The number eligible for the IDD system has grown faster than the general population. Our county is blessed/cursed with an extraordinarily low unemployment rate. The proportion of individuals with complex needs in the Sedgwick County IDD system has increased over time. Medicaid unwinding has resulted in a number of individuals in the IDD system losing Medicaid; while service providers have generally

not cut off services, they run the risk of a significant impact to their financial stability if Medicaid is not reinstated with retroactive coverage. Additionally, the loss of coverage could result in large debts for persons with very little ability to pay.

A lack of capacity for Supportive Home Care (aka agency-directed Personal Care Services) has been mentioned in nearly every Sedgwick County capacity report. No new Supportive Home Care provider has been added to the Sedgwick County network, despite active outreach and even one interested agency. In 2023, the Kaiser Family Foundation (KFF) published a report, "*Payment Rates for Medicaid Home- and Community-Based Services: States' Responses to Workforce Challenges."* This report included data on states hourly payment rates for specific HCBS services. Kansas' Personal Care Services ranked third from last out of all states reporting, coming in only higher than Texas and Wyoming. Kansas was 10 states lower than Oklahoma and 35 states lower than Missouri's Personal Care Services Rate (see: https://www.kff.org/medicaid/issue-brief/payment-rates-for-medicaid-home-and-community-based-services-states-responses-to-workforce-challenges/)

The DSP "workforce crisis" has been an issue for the IDD system for many years. However, it's critical that system stakeholders do not become complacent about the situation. Research conducted by the Council on Quality and Leadership (CQL) has shown that higher turnover is associated with negative outcomes for persons in services (see Friedman, C. (2021). The impact of direct support professional turnover on the health and safety of people with intellectual and developmental disabilities. *Inclusion, 9*(1), 63-73. https://doi.org/10.1352/2326-6988-9.1.63). High turnover resulted in persons in services experiencing on average: 61% more emergency room visits, 60% more injuries and 68% more abuse/neglect cases. Likewise, the ACL research demonstrated a correlation between provider quality and persons in services achieving their personal outcomes.

While hourly pay is not the sole factor impacting the high turnover, the importance of paying rates sufficient to support HCBS services should not be underestimated. The CQL research mentioned earlier examined the impact of increased HCBS payment during the pandemic on the continuity and security of persons in IDD services. There was a correlation between higher average increases in HCBS payment rates and better continuity and security of people in services. Anecdotally, the recruitment and retention payments provided to Kansas IDD providers during the pandemic were helpful in increasing hiring and retention of DSP's. As ANCOR noted in their 2024 Case for Inclusion report, states should establish a method to compel regular reviews of Medicaid reimbursement rates to ensure payments keep up with inflation.

Research indicates a number of ways to reduce turnover in the IDD system:

- Develop a pipeline of well-trained DSP's from high school: The "*Report to the President 2017 America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the US Economy"* identified the DSPaths program

from Ohio as a successful innovation to increase the number of DSP's. This program is implemented in junior and senior years of high school, has a credentialed curriculum and includes internships at agencies. Upon graduation, DSPaths participants are advanced credentialed DSP's ready to start employment. The SCDDO began working to replicate the program in Sedgwick County prior to the pandemic. The curriculum has been adapted by Wichita State University into online badge courses, which would allow the high school students to accumulate college credit through the DSPaths program. SCDDO's efforts were to target students interested in "caring" professions – like nursing, teaching, social work, psychology, etc. We are currently working to restart efforts to bring the DSPaths program to Kansas, potentially coupling with youth apprenticeships. The SCDDO would welcome KDADS as a partner in this effort.

- Increasing professional development and training of DSP's: while DSP work is often paid at a rate comparable to fast food or entry-level retail work, in reality it is a skilled profession. The increasing number of people with complex support needs has intensified the need for high quality DSP training. No one would stay long in a job they do not feel confident they have the appropriate training to do. Stress from the workforce crisis makes it difficult for providers to allocate DSP's time to training but it is actually self-defeating. As mentioned above, the SCDDO worked with Wichita State University to create DSP training badges. Completion of the series results in a nationally recognized DSP credential.

- Front-line supervisors play an outsized role in retaining quality DSP's: it's often said, people don't leave their job they leave their supervisor. It's not just DSP's who could benefit from additional professional development and training. Supervisors need to be skilled up to understand how to maintain a positive, yet accountable, work environment. Employers should implement systems to monitor supervisor performance and offer additional training when issues are identified.

- DSP's deserve respect and a say in decisions impacting their work: ANCOR's "*DSPs Speak Out: The Impact Training Can Have on Staff Retention,*" noted that DSP's want to be partners with their supervisors and upper management. DSP's may have ideas on how to best serve individuals and we would be well advised to listen.

- Showing appreciation for DSP's can impact turnover: DSP's need to know their hard work is appreciated, particularly when they go over and above the basic requirements. The SCDDO has a recognition program for IDD provider DSP, TCM and DSP Supervisor staff. Specifically, the awards are designed to recognize: Professionalism, Willingness to Collaborate, Advocacy, Robust Communication Skills, Ethical Behavior, Consumer Engagement and Self-Motivation. Quality Assurance staff at a provider location who observe a DSP going above and beyond immediately recognize the staff with a "You Got

Caught" token. Community members, persons served, guardians, affiliate organizations or volunteers may nominate a TCM or DSP Supervisor. At the end of the quarter, the names of all staff who were recognized are eligible to be recognized as an Employee of the Quarter. If there are multiples within a category, Community Council Executive Committee vote on the nominations. An Employee of the Quarter is awarded for each employee type (DSP, TCM and DSP Supervisor) and receives a certificate and $20 gift card for Quiktrip.

- It may seem obvious, but IDD providers need to take time to hire the right people: with overtime adding up, it can be very tempting to hire any warm body. However, poor hiring decisions can be very costly. Good DSP's will grow frustrated working with someone who does not show the same level of commitment and skill. This is an area where credentials could assist. Ideally, IDD providers and MCO's would recognize the importance of well-trained DSP's by increasing wages and reimbursement for services provided by credentialed DSP's.

Clearly, 2023 was a year which presented a number of challenges for the Sedgwick County IDD system. The SCDDO continues to work with IDD system stakeholders, including KDADS, the affiliate network, individuals with IDD, parents/guardians and MCO's, to meet these challenges. For 2024 we look forward to implementation of an IDD Crisis Stabilization process that will even out individuals' experiences when having a mental health crisis; as well as position the SCDDO to identify improvements needed for community mental health crisis resources to work better for individuals with IDD. Preliminary work is ongoing to gear up for bringing an estimated 100 Sedgwick County residents off the waitlist and into services. It is anticipated that this large movement off the waiting list will have a significant impact on system capacity. The SCDDO is reviewing what data we have and will be collaborating with IDD system stakeholders to prepare the system and reduce barriers to service access. The SCDDO appreciates the partnership with KDADS as we work to ensure the Sedgwick County IDD system is stable, supports choice, independence and community integration.