



REPORT FROM THE KANSAS SELF-DETERMINED TRANSITION TASKFORCE

Results from a Review and Analysis of Transition Policy and Practice in Kansas

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OVERVIEW

From Fall of 2020 through the Summer of 2021, the Kansas Self-Determined Transition Taskforce (KSDTT), consisting of youth and adults with intellectual and developmental disabilities (ID/DD), family members, professionals, researchers, policymakers, and other stakeholders, have engaged in a project funded by the U.S. Department of Health and Human Services Administration on Community Living (ACL) that sought to (1) advance knowledge of policy and practice gaps affecting successful transition from high school for students with ID/DD in Kansas and (2) expand our partnership to include people and groups supporting youth with ID/DD in underserved rural and urban areas, Hispanic and Latinx communities, and the juvenile justice system. This report documents the findings from a year-long comprehensive review and analysis of policy and practice that identified critical gaps in transition services that severely restrict opportunities and supports for youth with ID/DD transitioning from high school to competitive integrated employment (CIE), post-secondary education (PSE), and community living (CL) as described in detail below.

The KSDTT extended efforts from four previous coalitions and workgroups in Kansas, including: (1) Kansas Transition Taskforce (led by the Kansas Department of Education and the Disability Rights Center of Kansas to identify gaps in transition services), (2) End Dependence Initiative (led by Kansas Department of Health and Environment to test effective strategies to increase employment outcomes for people with disabilities), (3) Transition Transformers Coalition (led by the Department of Commerce to explore ways of aligning and adapting state policy), and (4) Kansas Self-Determination Coalition (led by the Kansas University Center on Developmental Disabilities [KUCDD] to develop an action plan to increase use of Supported Decision Making among youth and adults with ID/DD as well as older adults). We are grateful for the efforts of these previous coalitions, which provided valuable knowledge to the KSDTT comprehensive review and analysis.

The comprehensive review was conducted in two phases:

- (1) Listening sessions designed to understand the experiences of self-advocates, family members, and education professionals (e.g., special education teachers, transition specialists), employment support providers (e.g., Vocational Rehabilitation (VR) Counselors), state agency representatives, staff from provider organizations (e.g., HCBS providers or Centers for Independent Living); and
- (2) Policy review conducted by policy experts, state-level leaders, self-advocates, disability advocates, and other stakeholders, which was based on the findings from the listening sessions.

FINDINGS FROM LISTENING SESSIONS

Phase 1 of the KSDTT comprehensive review and analysis built on survey results from the Kansas Transition Taskforce. We conducted a rigorous qualitative analysis of stakeholder experiences collected through 7 state-wide listening sessions involving 57 participants, including 10 self-advocates, 10 family members, 11 education practitioners (e.g., special education teachers, transition specialists), 7 employment support providers (e.g., VR Counselors), 10 state agency representatives, 9 staff from provider organizations (e.g., HCBS providers or Centers for Independent Living). This analysis identified three main gaps in services affecting the transition from high school to competitive integrated employment, postsecondary education, and community living:

- (1) Communities need a more coordinated system of supports,
- (2) Students need systems that explore and focus on student-identified transition goals and family/cultural values, and
- (3) Students need support from systems who have high expectations for student transition outcomes and provide the limited opportunities and experiences needed to reach competitive integrated employment, community living, and postsecondary education goals.

We highlight specific feedback from listening sessions as well as specific policy issues for each gap below.

Need for a Coordinated System of Supports

Experiences of self-advocates, family members, and other stakeholders revealed fragmented services that permeate the current transition system. Services and supports were described as “siloed”, often with little communication among schools and providers. This system is difficult for people to navigate and results poor outcomes from many people not receiving needed services. One family member who participated in the statewide listening sessions described her frustration with the fragmented system, *“By the time my kid hit transition age, I’m already struggling, fighting, navigating health care, education, and now I finally get a hold of the handle on the whole transition and school stuff; and now we have adult services, too.”* Similarly, a statewide survey of Kansans conducted by the Kansas Transition Taskforce found that almost 75% of parents/guardians and educational advocates indicated the student with disabilities they supported did not know how to access VR services (Porter & Nichols, 2019).

Individually, key services across systems (e.g., CDDOs, 18-21 services in schools, Pre-Employment Transition Services [Pre-ETS] services from VR) operate differently in different parts of the state and differently than described in federal law or state policy. A transition coordinator summed up the fragmented system, *“Because again, silos are what lead to three plans, special education plan, VR plan, Medicaid waiver plan, with goals that are either redundant or contradictory. How does someone succeed when you’ve got three plans pulling you in three different directions?”*

Need for Exploration and Focus on Student Transition Goals and Family/Cultural Values

In Kansas, special education transition planning for students in special education must begin when they turn 14. Transition planning, as part of students’ Individualized

Education Program (IEP), must include and be informed by their interests, preferences, strengths, and support needs (Porter & Nichols, 2019). When students turn 16, their IEPs must include a coordinated set of services designed specifically to support them in the transition from school to adult life (Individuals with Disabilities Education Act, 300 U.S.C. 43[a][1]-[2]).

Despite this, and research demonstrating that students who lead their IEP process have better transition outcomes (Mason et al., 2004), data from the Kansas Transition Taskforce revealed that fewer than 40% of students with disabilities were even invited to an IEP meeting to discuss transition planning. One self-advocate, noted the importance of making decisions by saying: *“What went well for me was that I got to make my own decisions, but I know that doesn’t happen for most people.”* Further, 40% of students with disabilities indicated that their IEP did not contain a written transition plan while 55% did not know if it did (Porter & Nichols, 2019). Consequently, far too many students are disengaged and do not have goals that are aligned with their vision for education, competitive employment, and independent living outcomes. As one family member noted, *“I think the biggest issue we have is when they [employment specialists] work on finding them [students] jobs, but they’re not jobs that the kids like or that they could see themselves doing in the future. So, most of the time, they hardly last a week or two, and sometimes it’s things that they completely hate.”*

Active student participation in the IEP process along with other supports for self-determination is an evidence-based way to create opportunities for self-determination among students with disabilities through a student-centered approach to IEP development and implementation (Seong et al., 2015). Accordingly, our findings on IEP participation highlight an area of critical need to enhance opportunities and experiences for youth and young adults with ID/DD to build abilities, attitudes, and skills associated with self-determination in the context of transition planning, inclusive of opportunities associated with IEP meetings.

Need to Raise Expectations for Transition Outcomes for Students with Disabilities

Finally, KSDDT's comprehensive review and analysis revealed the narrow range of postschool opportunities discussed at IEP meetings in Kansas, which was identified as a systemic culture of low expectations for students with ID/DD. One self-advocate with ID/DD reflected on his recent transition from high school and noted, *"For that period of time [immediately after graduating from high school], it was kind of hard. I kind of graduated to the couch. And I got to watch a lot of C-Span, play video games."* A family member shared a similar story about her son, *"My son is struggling just to get through the VR process and to get a provider. Because of the pandemic and everything, it has taken a long time. So he is sitting in my house all day doing nothing, and I'm kind of done with that because he's capable of working a part-time job or potentially going to school."* Similarly, a recent statewide survey of Kansans found nearly 60% of students with disabilities and their family members indicated that college was not presented as an option even though 48% of students with disabilities indicated that they would like to continue their education after graduating from high school. For students interested in pursuing careers after high school, the survey demonstrated that 81% of students with disabilities wanted to have a community-based job but 40% reported that they were "supposed to" get a job in a sheltered workshop according to what was written in their IEP (Porter & Nichols, 2019).

These data suggest that youth and young adults with ID/DD in Kansas would benefit from planning for their post-school goals with a team that holds and supports them in building high expectations for their future.

FINDINGS FROM POLICY REVIEW

In Phase 2, KSDTT engaged over 40 representatives from organizations that support students with ID/DD and their families as they transition from high school, including: Families Together, Inc. and families who have experienced transition in Kansas, VR and Pre-Employment Transition Services, Kansas State Department of Education, Kansas Workforce Centers, Self-Advocate Coalition of Kansas and self-advocates who have been through transition in Kansas, multiple school transition and special education teachers, Community Developmental Disability Organizations (CDDOs), Centers for Independent Living, and Developmental Disabilities (DD) Act Partners, Kansas Council on Developmental Disabilities, and the Disability Rights Center of Kansas.

In monthly meetings, stakeholders reviewed comments made during listening sessions and developed an outline of areas of concern and discussed state and local policies and practices that could be contributing to the experiences stakeholders described. Many of these issues involve multiple federal and state laws, policies, and funding streams. Where possible, the group explored areas that could be targeted by changes in transition policy and practice to enhance transition outcomes.

Below are key findings from these efforts. We highlight gaps and inconsistencies in services that present barriers to successful transitions from high school and work to identify potential solutions that emerged from listening sessions and the work of KSDTT.

Overall, the KSDTT comprehensive review and analysis of Kansas policy and practices found a fragmented system where services are inconsistently offered across the state in both education and adult services. These fragmented services often cause confusion among practitioners, self-advocates, and families and make quality services difficult to obtain. The fragmentation also makes it difficult for the state to assess the quality of services offered.

Further, the Kansas Medicaid system typically does not utilize all supports available through Early Periodic Screening Diagnosis and Treatment (EPSDT), a key funding mechanism for

community living and employment supports. Further, the Kansas Medicaid Waiver has a long and non-transparent Waiting List. When people do receive services, Kansas programs are not optimized, to emphasize employment first, despite the state law mandating that supports and services focus on competitive integrated employment. Key findings are highlighted in Table 1 and described below.

Table 1: Key Gaps in Policy and Practice Affecting Transition from High School for Students and Families with ID/DD

10+ Year Waiting List for HCBS Waiver Services
Need to Prioritize Competitive Integrated Employment over sheltered settings
Inconsistent Access to and Delivery of 18-21 Transition Services and Supports
Inconsistent Application of Qualification Criteria for HCBS Services
Need to expand use of federal funding streams (e.g. EPSDT) to support community living
Need Greater Focus on Addressing Needs of Marginalized and Underserved Communities

10+ Year Waiting List for HCBS Waiver Services

The “waiting list” for HCBS services in Kansas is at least 10 years and families do not receive an expected date they can expect to receive services. School transition personnel report that this makes a smooth handoff from school to community-based services almost impossible, as most students graduate without HCBS services in place or available. This “graduating to the living room” means students lose skills developed through years of education, including special education services and supports. The waiting list has been cited as the single biggest barrier to ensuring a smooth transition for students eligible for the I/DD Waiver. One self-advocate reflected on his recent transition from high school and noted, “*For that period of time [immediately after graduating from high school], it was kind*

of hard. I kind of graduated to the couch, as it were. And I got to watch a lot of C-Span, play video games.” A family member shared a similar story about her son, “My son is struggling just to get a provider, so he is sitting in my house all day doing nothing, and I’m kind of done with that because he’s capable of working a part-time job or potentially going to school.”

In the *Olmstead* case, the Supreme Court stated that states can comply with the community integration mandate by having a comprehensive plan for ensuring that people with disabilities are served in the least restrictive setting, and a waiting list that moves at a “reasonable pace.”¹ Unfortunately, as shown by our review, the waiting time for HCBS services in Kansas is actually increasing and therefore, by definition, not moving at a “reasonable pace.” In addition, the lack of uniform standards and application of supports by and between CDDOs mean people in some parts of Kansas may receive HCBS services at different times and in different ways than similarly situated people in other parts of the state, demonstrating a lack of comprehensive, working plan in Kansas.

Need to Prioritize Competitive Integrated Employment over sheltered settings Kansas has the lowest reimbursement rate for HCBS Supported Employment in the nation. This has resulted in Kansas having one of the worst rates of employment for people with disabilities, a lack of vendors available to provide job development and coaching services, and a lack of expertise in the HCBS Waiver system in employment services provision benefits counseling. Key gaps in practices that result in low employment outcomes include: CDDOs do not consistently affiliate with VR vendors to ensure access to employment services for the people they serve; HCBS Day Service providers are not required to be VR vendors; the Ticket To Work program is severely under-utilized and not prioritized by the state of Kansas; VR rates do not take into account the needs of people who have more significant support needs, including behavioral health; the comprehensive federal

¹ *Olmstead v. L.C.*, 527 U.S. 581 (1999)

resources to maximize access to competitive-integrated employment are not utilized, creating a system that is disjointed and that has inadequate networks of vendors and supports available to people with disabilities wanting to work. Through the Workforce Innovation and Opportunities Act (WIOA), the primary federal workforce development legislation designed to bringing about increased coordination among federal programs, changes have made progress but there are still disincentives for serving people with disabilities for the local workforce boards that need to be addressed.

Inconsistent Access to and Delivery of 18-21 Transition Services and Supports

Despite clear IDEA mandates surrounding eligibility for 18-21, families report that there are disparities in access to 18-21 services statewide, even within the same district, particularly the degree to which these experiences are community based and consistent with best practices. Some districts offer an array of services including center-based 18-21 programs or integrated job experiences, while some districts offer little to no 18-21 services. Families are often confused by the discrepancy between federal law and school district practices regarding access to 18-21 services. Parents do not know what to advocate for or what to expect because these services are administered inconsistently statewide. The application of 18-21 services is largely based on the individual school district. Because HCBS does not pay for services during the day for people under 21, this means there are gaps in services when students who do have the waiver are exited at age 18 from special education services.

The inconsistency statewide by schools in addressing the community living and other needs of 18–21-year-old students is a primary concern of students and families. Under the Individuals with Disabilities Education Act (IDEA), schools must provide comprehensive

transition services to students beginning no later than the year they turn 16.² Transition services must include supports designed to “facilitate the child’s movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation” as well as “instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills.”³

Thus, ensuring that students have access to the supports and services they need to transition to full, participatory, and inclusive lives in the community is a primary responsibility of schools. As IDEA establishes, this should include providing supports and services to help students gain employment-based skills, community experiences, and community living skills.

Transition services should also be “coordinated” with other available supports.⁴ Thus, schools should work with other programs providing similar services, such as those from the Vocational Rehabilitation (VR) through the Kansas Department for Children and Families. VR may provide many of the same types of supports required by IDEA, including services to enhance education, employment, and independent living.⁵ In addition, VR can provide pre-employment transition services re designed to help young adults receive job exploration counseling; work-based learning experience including internships; counseling on opportunities for enrollment in comprehensive transition or postsecondary educational programs; workplace readiness training to develop social skills and independent living; and

² 20 U.S.C. § 1414(d)

³ 20 USC 1401(34)

⁴ *Id.*

⁵ *e.g.*, 34 C.F.R. § 361.48.

instruction in self-advocacy.⁶ Thus, Kansas schools can and should work in tandem with VR to increase access to and provision of appropriate supports and services designed to help students transition to productive, and community-based adult lives.

Inconsistent Application of Qualification Criteria for HCBS Services

Families and advocates report that the single point of entry to HCBS services in Kansas, the Community Developmental Disability Organization (CDDO) do not operate with a consistent set of policies statewide. CDDOs are chosen by local County Commissions by statute (K.S.A. 1999 Supp. 39-1801 through 39-1810). Each of these 27 CDDOs operate through contract with the state of Kansas to serve in their capacities and are governed by regulation and policy from the state but have their own boards and governance systems. CDDOs by regulation have key roles to fulfill regarding eligibility determination, access to crisis (Olmstead), provider/affiliate development, service innovation and access to competitive-integrated employment. However, these roles are not consistently applied across all CDDOs, resulting in inequitable service provision for Kansans with ID/DD in different areas of the state.

These continuing and growing problems raise concerns that Kansas is not complying with the Americans with Disabilities Act's "Integration Mandate," which requires states to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."⁷

⁶ *Id.*

⁷ 28 C.F.R. 35.130(d).

Need to expand use of federal funding streams (e.g. EPSDT) to support community living

Mechanisms do not exist to use “braided funding” to fully support people with IDD, especially during transition. As a result, families rarely have access to all available services to support a positive transition. For example, Vocational Rehabilitation (VR) can pay for a variety of services to support competitive integrated employment, however there can be barriers to using a full range of VR services. One example of a barrier to VR services is that VR vendors are not available in many parts of the state, creating barriers in access to basic job exploration and career readiness options which could include things like transportation training, due to a lack of VR vendors. Further, while there are individual examples due to family advocacy, many families are unaware that VR can pay for post-secondary education opportunities such as certificate programs, creating a barrier to post-secondary education for many students with ID/DD.

While barriers to VR services exist, it should be recognized that VR in Kansas underwent a major leadership change in last year and efforts are being made to enhance access to services.

EPSDT (Early Periodic Screening Diagnosis and Treatment) is a critical component of the Medicaid program and when properly utilized can be a key funding stream for enhancing community living and employment for youth with ID/DD. Under EPSDT, states must ensure that Medicaid recipients under 21 receive medically necessary supports and services that will correct, ameliorate, or maintain – fix, help, or keep from getting worse – identified limitations or needs.⁸ While states may limit Medicaid services or funding for adults in many circumstances, they may not limit the scope, limit, or cost of ESPDT services. Thus, children and young adults receiving Medicaid may receive virtually any medically

⁸ 42 C.F.R. § 441.50, *et seq.*

necessary supports that will help increase their health and participation including medical and mental health care, treatment, therapies, assistive technology, and support for activities of daily living necessary due to support needs related to a person's disability.

Unfortunately, our review found that the EPSDT benefits in Kansas Medicaid are vastly under-used. For example, most community support providers, school districts, and families are unaware of the availability of EPSDT to provide funding for medically necessary supports to help students and young adults transition to adulthood. The Kansas Managed Care Organizations (MCOs) who manage Medicaid in Kansas are the gatekeepers of these services and can and should do more to promote availability and network adequacy for these services statewide.

In particular, schools should make use of EPSDT to provide medically needed supports and services to students who receive Medicaid. Under EPSDT, if schools become state Medicaid providers, any medically necessary supports and services for students receiving Medicaid will be paid for by EPSDT so long as they are in the student's IEP.⁹ Thus, schools could have the ability and funding to provide critical supports like health, occupational, behavioral, and other therapies, assistive technology, and additional supports and services to students who need them to transition to community employment and community living.

Working Healthy is a program that allows people to keep Medicaid and HCBS services if they are employed and make more money than is allowed under SSI. Through this program, people with disabilities have access to benefits specialists who can work with them to ensure they do not lose benefits because they are working, however the state has

⁹ e.g., <https://www.cms.gov/research-statistics-data-and-systems/computer-data-and-systems/medicaidbudgetexpendsystem/downloads/schoolhealthsvcs.pdf>

too few benefits specialists to support families, and many families express that fear of losing benefits is a main reason to postpone or not seek employment for their child with a disability.

The Kansas STEPS (Supports and Training for Employing People Successfully provides employment and independent living supports and is a pilot program out of the Kansas Department of Health and Environment. This program, started July 1, 2021, is a 5-year pilot program seeking to coordinate supports so that people waiting for services can obtain and keep employment. Many features of this program, including benefits specialist access and higher-level service coordination, may meet some of the recommendations related to “braided funding” above. However, it is a pilot program and has a limited number of slots available.

Need Greater Focus on Addressing Needs of Marginalized and Underserved Communities

Kansas has a large population of non-native English speakers, including a large Spanish-speaking population across the state, a large Vietnamese population in Garden City, and a population who speaks Swahili in the Kansas City Metropolitan Area. Access to services, especially Special Education and Autism services, for these families can be challenging. Many of these families do not seek services out of fear and others do not learn of services because information is not translated to their primary language. Further, when families do access services, planning meetings are not always culturally responsive (cultural broker not present, goals do not align with cultural values). There are efforts across multiple groups to provide outreach and assistance, but these are not specifically coordinated to outreach around transition for families experiencing disability. There is a large opportunity for a project to focus on these families.

One outcome of students with disabilities from marginalized communities not receiving necessary services is that these students are over-represented in the justice system. Many students become involved with the justice system because of behaviors related to their disability, including during school hours, and often do not receive mandated

IDEA/Special Education services. Youth in the justice system are often overlooked for employment or other programming; there is also a strong racial disparity on youth involvement in the justice system.

Kansas has also experienced significant challenges in its foster care system and is currently engaged in settlement of a lawsuit to make practice improvements to improve placement stability and make sure that children in DCF custody have access to behavioral and mental health services.¹⁰ This specifically involves kids with ID/DD and Autism and has major implications for kids in transition.

RECOMMENDATIONS OF THE KSDTT TO ADDRESS GAPS

The overall goal of KSDTT partnership was to better understand transition supports and services in Kansas, particularly the gaps in services leading to poor competitive integrated employment, post-secondary education, and community living outcomes. To address the gaps in services outlined above, KSDTT gathered feedback from stakeholders to identify possible actions that could lead to better outcomes. Table 2 lists 12 recommendations that were identified by KSDTT stakeholders to address the gaps identified above and lead to positive outcomes.

¹⁰ E.g. <http://www.dcf.ks.gov/Documents/Settlement/NoticeofSettlement.pdf> and https://www.kdheks.gov/download/Doc_140_Order_Granteeing_Unopposed_Motion_for_Settlement.pdf

Recommendations

1. Change Kansas Employment Rates and structure to incentivize organizations to support people with ID/DD to work in competitive integrated employment. This could include
 - Changing state policy so that HCBS Day Service providers are required to be VR vendors
 - Rebalance reimbursement rate structure to incentivize serving people with more significant support needs in the WIOA system.
2. Continue to grow Kansas Pre-ETS and VR programs. Kansas Pre-ETS and VR services are growing, including adding more staff, increasing the number of vendors, and deploying new technology to be more accessible. Enhancing VR capacity to serve more people with ID/DD has been a positive development and Transition Stakeholders should continue to establish partnerships.
3. Develop quality indicators or guidance for 18-21 programs and study CDDO eligibility and child-find/accessibility practices to provide statewide systems mapping regarding transition.
4. Develop quality indicators or guidance for CDDO assessment and eligibility processes
5. Study the waiting list for HCBS services to understand needs of people on the waiting list and potential strategies for serving people on the waiting list.
6. Invest in and participate in providing key data on HCBS Waiver and Medicaid systems that can be used to make data-driven decisions, for example: psychotropic med use, employment outcomes, economic and demographic data on HCBS recipients.
7. Renew support for local and regional Transition Councils and include ongoing technical support from KSDE and the DD Network in Kansas, led by KUCDD.
8. Investigate with MCOs and KDHE to clarify EPSDT services, establish clear points of access for families and people with disabilities and pilot the use and billing of EPSDT for provision of these services to aid in transition.
9. Continue work on critical areas like youth in justice system and foster care, Spanish-speaking families, and access to behavioral health
10. Create a community of practice for Transition in Kansas
11. Explore creation of a single point of entry for Transition for families

Table 2: KSDTT Recommendations to address policy and practice gaps in Kansas and promote strong competitive integrated employment, post-secondary transition, and community living outcomes for people with ID/DD.