2021 Autism Task Team

Report to the Kansas Department for Aging and Disability Services

January 28, 2022

Acknowledgments

The Autism Task Team (*Appendix A*, page A-1) would like to thank the following individuals who provided supplemental expertise: Trisha Self (Associate Professor for the Department of Communication Sciences and Disorders at Wichita State University), Katelyn Gower (Vice President of Trellis Center at KidsTLC), Amanda Pfannenstiel (Clinical Services Director at Saint Francis Ministries), Sarah Fertig (Medicaid Director for the Division of Health Care Finance at the Kansas Department of Health and Environment [KDHE]), Emily Everitt (Health Care Data Analyst at KDHE), and Brittney Nichols (Emergency Medical Services for Children [EMSC] Program Coordinator at KDHE).

Additionally, the Autism Task Team extends special thanks to Kansas Health Institute staff Hina B. Shah, M.P.H., Wendy Dang, M.P.H., C.P.H., Peter F. H. Barstad (through Oct. 12, 2021, now with the Kansas Corporation Commission), and Kari M. Bruffett for providing process facilitation, research support, and report preparation under the direction of the Autism Task Team.

Table of Contents

Acknowledgments ii

Table of Contents iii

Report Overview v

Vision for Robust Autism Services vi

Executive Summary of Recommendations vi

Introduction 1

Autism Task Team Process 1

Workforce 3

Services 4

Recommendations 4

Tier One Recommendations 5

Tier Two Recommendations 12

Tier Three Recommendations 19

Appendix A. Membership of the Autism Task Team A-1

Appendix B. SWOT Analysis Chart B-1

Appendix C. Recommendation Rubric C-1

Appendix D. Considerations for Future Actions Steps D-1

Appendix E. Additional Background Summaries E-1

Individuals with Disabilities Education Act (IDEA) E-1

Charting the LifeCourse Nexus E-1

Missouri First Steps E-2

Kansas Autism Task Force E-3

Autism Resource Connection (ARC) App E-4

Forever, Home Campaign E-4

Appendix F. Examples of Statewide Autism Registries in Other States F-1

New Hampshire F-1
New Jersey F-1
Utah F-2
Appendix G. Endnotes G-1

Report Overview

The Autism Task Team (Task Team) was formed to develop new recommendations on autism services in Kansas. To achieve this directive, the Task Team utilized a roundtable format to engage professionals and individuals with lived experience to identify and address core issues within the autism services system. This report summarizes the work of the Task Team and its recommendations to the Secretary for Aging and Disability Services.

Navigating this Report

Task Team discussions that led to the recommendations in this report were focused on the topics of *workforce* and *services,* with components related to *funding* and *special populations* embedded. Recommendations were organized into three tiers by reviewing their potential to address four core issues. The Task Team identified those core issues as: 1) addressing the waitlist, 2) improving access to services, 3) ensuring early diagnosis and intervention for families, and 4) providing general family support.

In addition, recommendations with multiple action steps designate at least one or more action steps as either:

- **Immediate Action** are those that the Task Team believe can be completed in the next two years, and
- **Strategic Importance** are those that should be initiated in the near term but will be completed in the longer term.

Additional action steps that were not indicated as the highest priorities for immediate action and strategic importance were ranked by level of priority and can be considered as future steps supporting the recommendation. Recommendations in this report collectively form a strategic framework that can be considered a “living document” to support ongoing collaboration between contributing partners in autism services and government agencies.

Vision for Robust Autism Services

During the first meeting of the Task Team, members discussed their charge to articulate a vision. The following statement was developed to ensure that the Task Team's vision was reflected in each recommendation: *"Ensure families have direct and clear access to information and a robust service network that helps families grow and thrive and adequately covers all areas of the state for people with autism across their lifespan."*

Executive Summary of Recommendations

Figure 1. **Recommendations by Tiers**

TIER 1
Workforce Recommendation 1.0. Remove Barriers to ABA and Other EBP Services. The State of Kansas will reduce barriers to receiving autism services by establishing streamlined processes for an expanded network of providers that includes specialized care such as applied behavioral analysis (ABA) services, occupational therapists, speech and language therapists, and other evidence-based practices (EBP) and allows providers to access all codes for which they are credentialed including Medicaid ABA codes and other EBP codes while allowing supports to continue to be provided via telehealth to all areas of the state.

Figure 1 (continued). **Recommendations by Tiers**

TIER 1 (continued)
Workforce Recommendation 1.1. Incentivize Providers. The State of Kansas shall create incentives to provide autism services in rural and underserved communities. Incentives for practicing in the state under contract for two (2) years to five (5) years based on training program could include partial tuition reimbursement, vouchers to cover training costs, travel reimbursements, targeted free trainings in locations with few or no providers, and relocation packages. Other steps include: **1.** ***2022 – 2023 Immediate Action***: Ensure the Medicaid rates allow for the cost of required training, including support training, and remove all training requirements not required by commercial insurance for autism workers across all levels of services (e.g., autism specialists, registered behavior technicians, intensive individual services providers, and additional support such as peer-to-peer, parental, and family-to-family). ***Strategic Importance***: Create a plan for service expansion to ensure network adequacy statewide that includes incentives, provides clear definitions for "underserved," "telehealth," and "physical visits," and develops a geographic monitoring initiative to continuously identify underserved areas within the state.
Workforce Recommendation 1.2. Increase Rates. The State of Kansas shall increase rates for autism specific services to increase and diversify the provider network. *The state should re-evaluate rates annually.* Other steps include: 1. ***2022 – 2023 Immediate Action***: Review and standardize rates across behavioral health services including but not limited to autism waiver rates, severe emotional disturbance (SED) waiver rates, applied behavior analysis (ABA) rates, and board-certified behavioral analyst (BCBA) rates. 2. ***Strategic Importance***: Establish rates for *super workers* (see definition, page 8) and allow for *super workers* to bill across service systems, including vocational rehabilitation (VR), so families can retain one worker for their child.

Figure 1 (continued). **Recommendations by Tiers**

<table>
<tr><th>TIER 1 (continued)</th></tr>
<tr><td><u>Services Recommendation 2.0. Addressing the Waitlist through Revisions and Refinement of Service Options.</u> The Intellectual or Developmental Disability (I/DD) Modernization Task Force should explore initiatives to fully fund services that include removing or raising the age limit to 21 years old, eliminating the waitlists, and coordinating the continuum of services across the lifespan by exploring the utilization of a children's I/DD and community living supports waiver.</td></tr>
<tr><td><u>Services Recommendation 2.1. Access to State Plan Services</u>. The State of Kansas shall ensure access to state plan services, to include the following:

1. <u>2022 – 2023 Immediate Action:</u> Ensure applied behavioral analysis (ABA) or positive behavior supports are available statewide across the lifespan.

2. <u>Strategic Importance</u>: Create and fund a robust service array across the lifespan including trained navigators, service practitioners, and managed care organizations (MCOs) care coordination, including a plan for "family navigators" to help families identify and access resources across the lifespan in coordination with targeted case management.

Crisis-related

1. <u>2022 – 2023 Immediate Action & Strategic importance</u>: Require community mental health centers (CMHCs) and certified community behavioral health clinics (CCBHCs) to be cross-trained for intellectual or developmental disability (I/DD) population crisis behavior (e.g., Systemic, Therapeutic, Assessment, Resources, and Treatment [START] national training series for crisis responders).</td></tr>
</table>

Figure 1 (continued). **Recommendations by Tiers**

TIER 2
Workforce Recommendation 1.3. Individualized Budget Authority. The State of Kansas, in collaboration with stakeholders, will further develop systems that allow for individualized budget authority based upon systems like Work Opportunities Reward Kansas (WORK) and self-determination as done through TARC with an administrative cap for providers. Steps should include: 1. ***2022 – 2023 Immediate Action***: Allow individual budget and employer authority in self-direction to allow families to create the career path for self-directed *super workers* who can perform a variety of direct care tasks including personal care (including cuing and prompting), habilitation, employment supports, safety monitoring, and post-secondary education supports. 2. ***Strategic Importance***: Add individual budget authority across all seven waivers, including the intellectual/developmentally disabled (IDD) waiver, frail elderly (FE) waiver, physical disability (PD) waiver, technology assisted (TA) waiver, serious emotional disturbance (SED) waiver, autism waiver, and brain injury (BI) waiver.
Workforce Recommendation 1.4. System-Wide Competency-Based Clinical Training. The State of Kansas shall invest in and implement a system-wide competency-based clinical training for providers across systems, such as clinicians, crisis responders, front-line staff, and first responders, and ensure that cross-training is available to community mental health center (CMHC) staff, which could include components such as behavior management skills, medication management and training about waivers in Kansas. Other steps include: 1. ***2022 – 2023 Immediate Action***: Provide cross-training on mental health issues for intellectual or developmental disability (I/DD) providers and I/DD training for mental health providers. 2. ***Strategic Importance***: Review existing training models and programs from other states, identify potential agencies or entities that can provide training, and consider integrating the training models and programs to best meet the needs of rural, frontier, and urban areas in the state (with the Board of Regents).

Figure 1 (continued). **Recommendations by Tiers**

TIER 2 (continued)
Services Recommendation 2.2. Employment Support. The State of Kansas should work to develop a comprehensive employment and education support program for youth with autism. Steps include: **1.** ***2022 – 2023 Immediate Action & Strategic Importance****:* Improve partnership between Medicaid, vocational rehabilitation (VR), providers, advocates, and schools to improve employment outcomes for individuals with autism.
Services Recommendation 2.3. Centralized Reference Resource & Systems Navigator. The State of Kansas shall provide a single reference resource for families seeking resources for autism-related services and treatment by exploring innovative technology strategies to address the current barriers and issues within waivers and creating a centralized, user-friendly resource webpage that will serve as a resource navigation tool for families to easily access services across the lifespan and credentialed and trained providers based on region and accepted insurance. Specifics steps include: 1. ***2022 – 2023 Immediate Action***: Ensure that the online resource provides a user-friendly interactivity component for families to access resources based on geographic location, county, and ZIP code, such as available providers across managed care organizations (MCOs), to close gaps and address barriers to services through the study of system needs in real-time which would improve coordination of direct services. 2. ***Strategic Importance***: Contract with and fund community developmental disabilities organizations (CDDOs) to provide information for this centralized reference resource.

Figure 1 (continued). **Recommendations by Tiers**

TIER 2 (continued)
Services Recommendation 2.4. Continuum of Care. The State of Kansas shall improve the continuum of care by developing specialized service delivery programs modeled after evidence-based practices from other states, such as prevention service programs, crisis telephone services, mobile crisis outreach services, in-home crisis services, etc. Specific steps also include: **1.** ***2022 – 2023 Immediate Action & Strategic Importance*****:** Ensure all community mental health centers (CMHCs) and certified community behavioral health clinics (CCBHCs) have staff qualified to provide support (e.g., the array of outpatient services including functional assessments, etc.) for children and adults with autism and intellectual or developmental disability (I/DD), and introduce high-fidelity wraparound teams or health homes for adults and all multi-system involved children (e.g., crossover youth) before they are removed from the home. *Transitions* **1.** ***2022 – 2023 Immediate Action & Strategic Importance***: Explore an array of evidence-based step-down options for discharge from a psychiatric residential treatment facility (PRTF) or acute care that ensures readiness for all youth including foster care youth with autism to transition back to home, community, school, intensive outpatient program, professional resource homes, etc.

Figure 1 (continued). **Recommendations by Tiers**

TIER 2 (continued)
Services Recommendation 2.5. Early Intervention. The State of Kansas will work with early childhood partners, such as Birth to 3 programs and tiny-k, to create a pathway for families to access active treatment services such as applied behavior analysis (ABA) and other evidence-based practices (EBP) for their child that exhibits a need for services in order to decrease the wait for services, reach children at a younger age, and potentially decrease the number of children that go on to receive a full diagnosis of autism by the end of year 5. Other steps include: 1. ***2022 – 2023 Immediate Action***: Add an ABA therapy/services coaching model for parents and children with autism. 2. ***Strategic Importance***: Create informational campaigns for providers to be aware of all programs that are available in the communities where the child lives to ensure that they can start services early.

TIER 3
Workforce Recommendation 1.5. ASD Interagency Workgroup. The State of Kansas will create an interagency workgroup on autism spectrum disorder (ASD) comprised of state agency leaders, self-advocates, family members, and community-based providers to coordinate and concentrate efforts to move policy into action.
Services Recommendation 2.6. Autism Registry. The State of Kansas shall create an interconnected health care system by creating an autism registry that allows for better tracking of services, diagnosis, and treatments by leveraging technology and best practices for data storage and aggregation.

Figure 1 (continued). **Recommendations by Tiers**

TIER 3 (continued)
Services Recommendation 2.7. Foster Care Autism Support Positions. The State of Kansas will enhance resources to Kansas Department for Children and Families (DCF) case management providers. The resources could include additional training and coaching for staff, parents, and foster parents regarding transitions, including reintegration, and supporting youth with complex needs including autism, intellectual or developmental disability (I/DD), and other co-morbid conditions. Steps may include: 1. ***2022 – 2023 Immediate Action & Strategic Importance*:** Ensure right-time training and navigation resources are available to appropriate child welfare staff, foster parents, kinship parents, and biological parents related to autism interventions and resources.
Services Recommendation 2.8. Smart Home Technology. The State of Kansas shall explore the option to incorporate smart home technology into waiver services as a pilot program while complying with the new Centers for Medicare and Medicaid Services (CMS) remote monitoring requirements for privacy and the Health Insurance Portability and Accountability Act of 1996 (HIPAA) compliance in a manner that does not violate individual personal and civil rights.

Introduction

The Kansas Department for Aging and Disability Services (KDADS) formed the 2021 Autism Task Team (Task Team) with a directive as follows:

"Kansas is at a critical juncture with its autism services, including Medicaid State Plan Amendment (SPA) services and Home and Community-Based Services (HCBS) 1915c waiver services for children with autism. The waiver is currently beginning the 5-year renewal process with the federal agency, Centers for Medicare and Medicaid Services (CMS), with a deadline for submitting waiver language to CMS for review and approval before the end of the current calendar year (2021). The Autism Task Team, which will convene between August 2021-January 2022, is charged to develop recommendations to the Secretary for Aging and Disability Services on autism services in Kansas. KDADS need your assistance in asking, "how might we." Kansas Department for Aging and Disability Services, August 31, 2021.

To achieve this directive, the Task Team utilized a roundtable format to engage a wide range of professionals and individuals with lived experience in the discussion at each meeting. The Kansas Health Institute (KHI) provided administrative and process facilitation services. Two members from the Task Team volunteered to be co-chair representatives to assist in logistics, development of recommendations, and additional consultation with KHI in between each meeting when needed. This report summarizes the work of the Autism Task Team.

Autism Task Team Process

The Task Team began its effort by developing a vision statement to ensure that the Task Team's vision was reflected in each recommendation. The vision statement is as follows:

> *"Ensure families have direct and clear access to information and a robust service network that help families grow and thrive and adequately covers all areas of the state for people with autism across their lifespan."*

The Task Team conducted a Strengths, Weaknesses, Opportunities, and Threats (SWOT) Analysis to better understand and systematically capture the autism continuum of care in Kansas. Utilizing the results from the SWOT Analysis (See *Appendix B*, page B-1), the Task Team developed strategies to begin the process of developing recommendations. Once strategies were developed, the Task Team provided initial sets of recommendations around topics of *workforce*, *services*, *funding*, *special populations, and access/other*. Throughout the

process, individuals with supplemental expertise were invited to attend the Task Team's meetings to provide information on specific topics that were requested. As the Task Team discussed, reviewed, and updated its drafted recommendations, the Task Team discovered that all drafted recommendations included a *funding* and *special populations* component, while the *access/other* related recommendations were similar to *funding* and *special populations*. Therefore, the Task Team made a collective decision to develop recommendations focusing on two topic areas, *workforce* and *services,* with funding and *special populations* components embedded in the topics' recommendations.

To guide discussions, the Task Team adopted the Recommendation Rubric (*Appendix C*, page C-1) as a tool to assist in writing recommendations and in prioritizing those recommendations and actions steps when provided. To further prioritize the final list of recommendations, the Task Team organized recommendations into three tiers by reviewing their potential to address four core issues that the Task Team identified: 1) addressing the waitlist, 2) improving access to services, 3) ensuring early diagnosis and intervention for families, and 4) providing general family support.

Figure 2 (page 3) illustrates the structure of the Task Team's process, including a list of meetings held by each group, as well as the topics addressed. The Task Team met virtually 11 times from August 2021 to January 2022 from 11 a.m. to 2:30 p.m. unless noted. All of the Task Team's decisions were reached based on consensus. The Task Team adopted the following meeting commitments: to come ready to discuss and compromise, keep remarks succinct and on topic, not to hesitate to ask clarifying questions, information shared in meetings can be shared with others unless a member asks that it be kept confidential, define an acronym or abbreviation every time you use it, and to start and end meetings on time. As members discussed each topic and recommendation, decisions were made based on proposals offered by the members and adopted by verbal agreement or absence of objections.

Figure 2. **Autism Task Team Process Design**

Meeting #1 8/31/2021	Introductory Meeting and Complete SWOT Analysis
Meeting #2 9/14/2021	Recommendation Development – Workforce and Services
Meeting #3 9/28/2021	Recommendation Development – Funding and Special Populations
No Meeting 10/1/2021 to 10/8/2021	Survey Distribution – Recommendation Development
Meeting #4 10/12/2021	Refining Recommendations – Workforce
Meeting #5 10/26/2021	Refining Recommendations – Services
No Meeting 11/1/2021 to 11/8/2021	Survey Distribution – Prioritizing Recommendations
Meeting #6 11/9/2021	Finalizing Recommendation Language
Meeting #7 11/16/2021 (90-minute meeting)	Prioritizing Recommendations and Action Steps – Strategic Importance versus Immediate Action
Meeting #8 11/30/2021	Prioritizing Recommendations – Ranking into Tiers
Meeting #9 12/14/2021	Autism Task Team Report – Consensus on Final Recommendations and Identifying Implementation Lead, Key Collaborators and Outcome Measures for Each Recommendation
Meeting #10 1/11/2022 (60-minute meeting)	Autism Task Report – Ratify Report
Meeting #11 1/20/2022 (60-minute meeting)	Complete Ratification

Workforce

A well-trained workforce is one in which providers and their staff are providing autism services with adequate staffing and resources to meet needs across urban, rural, and frontier areas of the state. Building a well-trained workforce will require growing, retaining, and training the workforce.

The Task Team discussed and made recommendations recognizing the ongoing importance of studying and investing in the workforce for autism services in the state. Steps to grow, retain, and train the state's workforce for autism services include: improving and expanding provider network, developing a series of initiatives to create a career path in the field of autism and intellectual or developmental disabilities (I/DD), expanding access through telehealth and reciprocity, providing a system-wide competency-based clinical training, incentivizing providers

and staff to retain the workforce, improving training requirements for providers and staff, allowing individualized budget authority to all seven waiver, developing ongoing working groups and models to improve the quality of services, and removing any additional barriers that prevent providers and their staff from providing the services efficiently and effectively. Further, the Task Team repeatedly discussed the importance of receiving and utilizing sustainable funding to effectively retain the workforce and resources that are needed.

Services

A robust network of autism services is one where individuals with autism, their families, and providers can access an array of services across the state, regardless of geographic constraints, to provide necessary support and help for individuals with autism and their families across their lifespan. Building a robust network of autism services will require developing, coordinating, and continuously improving a system that will decrease barriers and establish a simplified, easily navigable process to access services and treatment for individuals with autism, their families, and providers.

The Task Team discussed and made recommendations recognizing the ongoing importance of continuously improving service navigation and addressing gaps in services to create a robust network of autism services. Steps to develop, coordinate, and continuously improve the state's autism system include: establishing a centralized reference resource and systems navigator, exploring initiatives to address current barriers, improving the continuum of care, providing early intervention services to ensure people are receiving services as soon as possible, and ensuring all services are available and accessible statewide especially for those in special population groups. In addition, the Task Team stressed the importance of receiving and utilizing sustainable funding to effectively support services that are necessary to provide an array of services for those who need it.

Recommendations

The recommendations are prioritized into three tiers. *Workforce*-related recommendations are labeled from 1.0 to 1.5. *Services*-related recommendations are labeled from 2.0 to 2.8. Figure 3 (page 5) is an overview of the 15 recommendations prioritized into three tiers. *The numbering of the recommendations is for ease of reference only and does not reflect priority order.*

Figure 3. **Recommendation Overview**

Tier 1	Tier 2	Tier 3
Rec. 1.0 Remove Barriers to ABA and Other EBP Services	**Rec. 1.3** Individualized Budget Authority	**Rec. 1.5** ASD Interagency Workgroup
Rec. 1.1 Incentivize Providers	**Rec. 1.4** System-Wide Competency-Based Clinical Training	**Rec. 2.6** Autism Registry
Rec. 1.2 Increase Rates	**Rec 2.2** Employment Support (High Tier 2)	**Rec. 2.7** Foster Care Autism Support Position
Rec 2.0 Addressing the Waitlist through Revisions and Refinement of Service Options	**Rec. 2.3** Centralized Reference Resource & Systems Navigator	**Rec. 2.8** Smart Home Technology
Rec. 2.1 Access to State Plan Services	**Rec. 2.4** Continuum of Care	
	Rec. 2.5 Early Intervention	

Tier One Recommendations

The Task Team adopted five recommendations in Tier 1.

Workforce Recommendation 1.0: Remove Barriers in ABA and Other EBP Services

Rationale: The Task Team discussed the importance of ensuring applied behavioral analysis (ABA) and other evidence-based practices (EBP) are accessible to families by streamlining processes to improve and expand provider networks, ensuring all billing codes for ABA and EBP are available to all credentialed providers and reducing barriers to those services. Under Medicaid, providers experience barriers that complicate the enrollment process and discourage providers from enrolling, which reduces the network of providers. For example, providers are required to enroll separately in Medicaid to provide state plan, autism, and intellectual or developmental disability (I/DD) waiver services. Other examples of those barriers include utilizing different taxonomies for a single provider agency and requiring direct care workers under ABA to enroll individually. Limiting the ability to bill for certain ABA and EBP codes to only select providers, rather than all credentialed providers qualified to provide those codes, unnecessarily limits access to services. In addition, Task Team members discussed increasing access to ABA and other EBP by expanding the utilization of telehealth to ensure access for rural and underserved communities.

<table>
<tr><td colspan="2">Recommendation 1.0: The State of Kansas will reduce barriers to receiving Autism services by establishing streamlined processes for an expanded network of providers that includes specialized care such as applied behavioral analysis (ABA) services, occupational therapists, speech and language therapists, and other evidence-based practices (EBP) and allows providers to access all codes for which they are credentialed, including Medicaid ABA codes and other EBP codes, while allowing supports to continue to be provided via telehealth to all areas of the state.</td></tr>
<tr><td>Action Lead:
Kansas Department of Health and Environment (KDHE)</td><td>Key Collaborators:
Kansas Department for Aging and Disability Services (KDADS), Kansas Behavioral Sciences Regulatory Board (BSRB), and managed care organizations (MCOs)</td></tr>
<tr><td colspan="2">Outcome Measures:
• Increase in number of providers enrolled.</td></tr>
</table>

Workforce Recommendation 1.1: *Incentivize Providers*

Rationale: The Task Team members discussed the importance of increasing staffing and services in rural and underserved communities by incentivizing existing and new providers to commit to providing autism-related services in those communities. Incentives may help expand the provider network in rural and underserved communities and increase access to services and additional support. The Task Team emphasized that training and traveling costs are major barriers for providers and discussed how reimbursements for training and traveling expenses could be an incentive, which could include travel reimbursement, partial tuition reimbursement, training vouchers, targeted free trainings, and relocation packages. The Task Team suggests increasing the Medicaid reimbursement rates to include the cost of required Medicaid trainings.

Recommendation 1.1: The State of Kansas shall create incentives to provide autism services in rural and underserved communities. Incentives for practicing in the state under contract for two (2) years to five (5) years based on training program could include partial tuition reimbursement, vouchers to cover training costs, travel reimbursement, targeted free trainings in locations with few or no providers, and relocation packages.

Action Steps:

2022-2023 Immediate Action: Ensure the Medicaid rates allow for the cost of required training, including support training, and remove all training requirements not required by commercial insurance for autism workers across all levels of services (e.g., autism specialists, registered behavior technicians, intensive individual services providers, and additional support such as peer-to-peer, parental, and family-to-family).

Strategic Importance: Create a plan for service expansion to ensure network adequacy statewide that includes incentives, provides clear definitions for "underserved," "telehealth," and "physical visits," and develops a geographic monitoring initiative to continuously identify underserved areas within the state.

Future Steps Supporting Recommendation:

1. Promote incentives to increase number of speech language pathologists (SLP) to provide early intervention services.
2. Consider using elementary and secondary school emergency relief (ESSER) funds to incentivize and retain current providers.
3. Implement a series of initiatives to create a career path for supporting individuals, especially families, interested in the field of autism and intellectual or development disability (I/DD) by adding individual budget authority to the autism and I/DD waivers.
4. Increase efforts to retain staffing by creating a loan forgiveness program to recruit potential candidates to underserved areas and paying rate differentials based on longevity, experience, or education.
5. Use American Rescue Plan Act (ARPA) funds to provide the necessary training of specialized resource parents and related support systems and for the placement of youth with autism.
6. Encourage the Kansas Department for Aging and Disability Services (KDADS) to engage in a strategic effort to determine needed resource development on behalf of Kansans with autism.
7. Allow temporarily licensed speech pathologists completing a clinical fellowship year to provide equitable services and complete the credentialing process to serve children on Medicaid in outpatient or home settings.
8. Consider collaborating with community colleges to recruit and provide training for interested individuals to the field of autism or I/DD to better respond to workforce needs.

Action Lead:	**Key Collaborators:**
Legislature and Board of Regents	Providers, Kansas Department for Aging and Disability Services (KDADS), Kansas Department of Health and Environment (KDHE), managed care organizations (MCOs), Kansas Department for Children and Families (DCF), Interhab, advocacy groups, families, community mental health centers (CMHCs), and community developmental disability organizations (CDDOs)

Outcome Measures:

- Increase in numbers of providers providing autism services by geographic area (urban, rural and frontier parts of the state).

Workforce Recommendation 1.2: *Increase Rates*

Rationale: The Task Team members discussed the importance of ensuring that Medicaid rates are reflective of staff capacity needed to provide autism services by increasing rates that are determined by the State of Kansas. Through the increase of rates, the Task Team members emphasized that providers could improve their organizational infrastructure, recruit and retain high quality staff, and create a more robust provider network. An example that the Task Team used was that current rates create a disincentive to provide employment supports under Supported Employment, which results in youth individuals going into day services and residential services as opposed to seeking employment. The Task Team members also emphasized that rates must be reevaluated annually to ensure that they are truly reflective of staff capacity needed for each service. To facilitate patient-centered planning, the Task Team discussed the need for *super workers*.

In addition, the Task Team members discussed the importance of ensuring that all recommendations are sustainable in practice. The Task Team members recommended utilizing sustainable funding where it is appropriate for enhancements through state budgets. To ensure ABA workforce development issues are addressed, the Task Team also recommended seeking funding opportunities that could maximize the resources available for autism-related services specifically.

As used in this report, ***Super workers*** are staff who can perform a variety of direct care tasks, including providing services related to supported employment and community integration.

Recommendation 1.2: The State of Kansas shall increase rates for autism specific services to increase and diversify the provider network. *The state should re-evaluate rates annually.*
Action Steps: ***2022-2023 Immediate Action:*** Review and standardize rates across behavioral health services including but not limited to autism waiver rates, severe emotional disturbance (SED) waiver rates, applied behavior analysis (ABA) rates, and board-certified behavioral analyst (BCBA) rates. ***Strategic Importance***: Establish rates for *super workers* and allow for *super workers* to bill across service systems, including vocational rehabilitation (VR), so families can retain one worker for their child.
Future Steps Supporting Recommendation: 1. Increase the rates and policy around supported employment to be competitive with other states and collaborate with VR. 2. Conduct periodic surveys to ensure reimbursement aligns with national rates and rates among neighboring states and across specialty populations. 3. Ensure that the increased rates apply to nurses who serve individuals with waivers. 4. Develop a performance incentive plan for managed care organizations (MCOs) to incentivize higher utilization rates of their providers for services.

Action Lead:	**Key Collaborators:**
Legislature, Kansas Department of Health and Environment (KDHE), and Kansas Department for Aging and Disability Services (KDADS)	Advocates, providers, Kansas Council on Developmental Disabilities (KCDD), vocational rehabilitation (VR), community mental health centers (CMHCs), and community developmental disability organizations (CDDOs)

Outcome Measures:

- Increase in numbers of providers willing to enroll in autism services.
- Increase in numbers of families served by geographical location. For example, urban areas versus frontier and rural areas.

Services Recommendation 2.0: *Addressing the Waitlist through Revisions and Refinement of Service Options*

Rationale: The Task Team discussed the negative effects of the ten-plus year wait to access waiver services and the importance of ensuring services are widely available across populations by exploring a children's intellectual or developmental disability (I/DD) and community living support waiver. Children would not be required to have an I/DD diagnosis to qualify if they met functional eligibility requirements. A key characteristic of a children's I/DD and community living supports waiver is the ability to target services needed to support families and to keep individuals out of foster care and institutions through cost-effective community supports that enable families to keep their children with autism at home, ensure their children get into competitive employment, and support them in family living. The Task Team acknowledged a review of how similar waivers were implemented in other states is necessary to determine the best approach for Kansas.

Recommendation 2.0: The Intellectual or Developmental Disability (I/DD) Modernization Task Force should explore initiatives to fully fund services that include removing or raising the age limit to 21 years old, eliminating the waitlists, and coordinating the continuum of services across lifespan by exploring the utilization of a children's I/DD and community living supports waiver.

Future Steps Supporting Recommendation:

Please see items in *Appendix D (page D-1)* *for the I/DD Modernization Task Force to consider as it explores waivers.*

Action Lead:	**Key Collaborators:**
Interhab and Kansas Department for Aging and Disability Services (KDADS)	Self Advocate Coalition of Kansas (SACK), Kansas Council of Developmental Disabilities (KCDD), Disability Rights Center of Kansas (DRC), Intellectual or Developmental Disability (I/DD) Modernization Task Force, providers, advocates, family members, Kansas Department of Health and Environment (KDHE), Kansas Department for Children and Families (DCF), and managed care organizations (MCOs)

Outcome Measures:
• Approved CMS waiver(s). • Reduction in waitlists. • Serving more children between age 8 to 21.

Services Recommendation 2.1: *Access to State Plan Services*

Rationale: Task Team members discussed the importance of ensuring people with autism and their families are able to access services that are necessary for them across the lifespan. In addition, the Task Team emphasized the importance of providing families access to support and services during crisis. Community mental health centers (CMHCs) provide community-based public mental health services and comprehensive mental health rehabilitation services, while certified community behavioral health clinics (CCBHCs) provide a comprehensive array of services needed to create access, stabilize people in crisis, and provide the necessary treatment for those with the most serious, complex mental illnesses and substance use disorders. The Task Team suggests cross training CMHC and CCBHC staff for intellectual or developmental disability (I/DD) population crisis behavior could break down silos and improve the crisis-related continuum of care.

Recommendation 2.1: The State of Kansas shall ensure access to state plan services, to include the following action steps:
Action Steps: ***2022-2023 Immediate Action:*** Ensure applied behavioral analysis (ABA) or positive behavioral supports are available statewide across the lifespan. ***Strategic Importance:*** Create and fund a robust service array across the lifespan including trained navigators, service practitioners, and managed care organizations (MCOs) care coordination, including a plan for "family navigators" to help families identify and access resources across the lifespan in coordination with targeted case management. *Crisis-Related:* ***2022-2023 Immediate Action & Strategic Importance:*** Require community mental health centers (CMHCs) and certified community behavioral health clinics (CCBHCs) to be cross trained for intellectual or developmental disability (I/DD) population crisis behavior (e.g., Systemic, Therapeutic, Assessment, Resources, and Treatment [START] national training series for crisis responders).
Future Steps Supporting Recommendation: 1. Ensure all children have access to Early and Periodic Screening, Diagnostic and Treatment (EPSDT) including reinstituting the statutorily mandated 1905(r5) extended state plan service process for children. 2. Increase access to EPSDT and state plan services that are currently available by implementing information campaigns and exploring innovative marketing.

3. Create opportunities to provide family with support, services, and resources, such as Systemic, Therapeutic, Assessment, Resources, and Treatment (START) team/behavior supports, in the meantime as the workforce is rebuilding their capacity and resources to provide autism-related services.
4. Ensure primary care managers, waiver cases managers, support teams, medical teams, and supported employments are working in full collaboration and have resources readily available to ensure a comprehensive care coordination of individuals with autism and their families.
5. Address gaps and barriers to state plan services including exploring health homes as a state plan service.

Crisis-related

1. Implement behavioral support and crisis services for children and adults with autism including connection to the 988 line and CMHCs serving children with autism in the State Plan Amendment (SPA) or severe emotional disturbance (SED) waiver.
2. Ensure that funding for crisis-specific services and resources is easily accessible when needed.
3. Prevent out-of-home placements and placement disruptions by supporting all families and providers across Kansas by ensuring that the 988 crisis supports include an immediate way to coordinate with behavior supports specific to beneficiaries with autism.
4. Ensure all specialized delivery service programs are available statewide, especially for rural families.

Action Lead:	**Key Collaborators:**
Kansas Department of Health and Environment (KDHE) and Kansas Department for Aging and Disability Services (KDADS)	Community developmental disability organizations (CDDOs), community mental health centers (CMHCs), Interhab, managed care organizations (MCOs), community service providers, target case managers (TCMs), families, people with autism, providers, tiny-k Early Intervention Program, Families Together, law enforcement officers, first responders, Kansas State Department of Education (KSDE), and foster care contractors

Outcome Measures:

- The coordination and navigation of services are improved.
- Members with I/DD and autism with crisis calls have trained responders (RE: 988 line)

Tier Two Recommendations

The Task Team adopted the following six recommendations in Tier 2:

Workforce Recommendation 1.3: *Individualized Budget Authority*

Rationale: Task Team members discussed the importance of allowing individuals with autism and their families to have decision-making authority over certain services and how funds are spent. This authority would allow people with autism and their families to have control over what services are necessary for them and encourage personal choice. Currently, individualized budget authority is not available across waivers in Kansas.

<table>
<tr><td colspan="2">Recommendation 1.3: The State of Kansas, in collaboration with stakeholders, will further develop systems that allow for individualized budget authority based upon systems like Work Opportunities Reward Kansas (WORK) and self-determination as done through TARC with an administrative cap for providers.</td></tr>
<tr><td colspan="2">Action Steps:
2022-2023 Immediate Action: Allow individual budget and employer authority in self-direction to allow families to create the career path for self-directed super workers who can perform a variety of direct care tasks including personal care (including cuing and prompting), habilitation, employment supports, safety monitoring, and post-secondary education supports.
Strategic Importance: Add individual budget authority across all seven waivers, including the intellectual or developmentally disability (I/DD) waiver, frail elderly (FE) waiver, physical disability (PD) waiver, technology assisted (TA) waiver, serious emotional disturbance (SED) waiver, autism waiver, and brain injury (BI) waiver.</td></tr>
<tr><td colspan="2">Future Steps Supporting Recommendation:
1. Explore and expand options across waivers, including individualized budget authority, that allow individuals and families to access and find supports and services that can comprehensively address their needs.
2. Kansas Department for Aging and Disability Services (KDADS) and Kansas Department of Health and Environment (KDHE) should convene a workgroup, including community mental health centers (CMHCs), community developmental disability organizations (CDDOs), families, self-advocates, and those with expertise in serving individuals across the autism spectrum and with I/DDs to better meet their needs.</td></tr>
<tr><td>Action Lead:
KDHE and KDADS</td><td>Key Collaborators:
Providers, families, individuals with autism, managed care organizations (MCOs), financial management services (FMS) providers, Centers for Medicare and Medicaid Services (CMS), CMHCs, CDDOs, advocacy groups, and vocational rehabilitation (VR)</td></tr>
<tr><td colspan="2">Outcome Measures:
• Approval for individualized budget authority to be across all seven waivers.
• Increase in number of individuals accessing self-direction and individualized budget authority.
    o There should be an increasing trend over time.</td></tr>
</table>

Workforce Recommendation 1.4: *System-Wide Competency-Based Clinical Training*

Rationale: The Task Team members discussed the importance of ensuring that the entire workforce is receiving a competency-based clinical training. In addition, the Task Team discussed trainings that are available for all levels of providers and community mental health center (CMHC) staff could break down silos, provide necessary services, and increase the workforce's efficacy in providing services. This training would be adaptable based on the appropriate levels of practice experience and formal education of the provider.

<table>
<tr><td colspan="2">Recommendation 1.4: The State of Kansas shall invest in and implement a system-wide competency-based clinical training for providers across systems, such as clinicians, crisis responders, front-line staff, and first responders, and ensure that cross-training is available to community mental health center (CMHC) staff, which could include components such as behavior management skills, medication management and training about waivers in Kansas.</td></tr>
<tr><td colspan="2">Action Steps:
2022-2023 Immediate Action: Provide cross-training on mental health issues for intellectual or developmental disability (I/DD) providers and I/DD training for mental health providers.
Strategic Importance: Review existing training models and programs from other states, identify potential agencies or entities that can provide training, and consider integrating the training models and programs to best meet the needs of rural, frontier, and urban areas in the state (with the Board of Regents).</td></tr>
<tr><td colspan="2">Future Steps Supporting Recommendation:
1. Include developmental screening and diagnosis in primary care residency training.
2. Ensure training programs are intentionally recruiting from diverse communities</td></tr>
<tr><td>Action Lead:
Interhab, Legislature, Kansas Department for Aging and Disability Services (KDADS), and Kansas Department for Children and Families (DCF)</td><td>Key Collaborators:
Providers, managed care organizations (MCOs), first responders, community mental health centers (CMHCs), and community developmental disability organizations (CDDOs)</td></tr>
<tr><td colspan="2">Outcome Measures:
• Increase numbers of cross-trained providers.</td></tr>
</table>

Services Recommendation 2.2: *Employment Support*

Rationale: The Task Team members discussed the importance of ensuring that the workforce system in Kansas is working for all people, including people with autism, by breaking down silos between systems, such as vocational rehabilitation (VR) and Kansas Department of Commerce Workforce Services. Currently, VR is not widely available for everyone, while Workforce Services are available for all people statewide. The Task Team discussed that collaboration and

partnership between programs and systems to ensure a comprehensive employment and education support program can improve employment outcomes for people with autism.

<table>
<tr><td colspan="2">Recommendation 2.2: The State of Kansas should work to develop a comprehensive employment and education support program for youth with autism.</td></tr>
<tr><td colspan="2">Action Steps:

2022-2023 Immediate Action & Strategic Importance: Improve partnership between Medicaid, vocational rehabilitation (VR), providers, advocates, and schools to improve employment outcomes for individuals with autism.</td></tr>
<tr><td colspan="2">Future Steps Supporting Recommendation:
1. Update State of Kansas policies to ensure that children can get the employment support under the waiver if they have an individualized education program (IEP) with a school or an individualized plan for employment (IPE) with pre-employment transition services (Pre-ETS) and VR transition services if the IEP and IPE do not address that service.
2. Improve family employment education targeted to transition-age youth and young adults with autism by including supported education in the supported employment services to provide post-secondary opportunities for young adults after high school and streamlining employment protocols between payers, providers, and individuals.
3. Develop innovative payment methodologies to providers linked to employment outcomes to incentivize employment for individuals with autism.</td></tr>
<tr><td>Action Lead:
Vocational rehabilitation (VR), Employment First Commission, and Legislature</td><td>Key Collaborators:
Existing service providers in VR, Kansas Council on Developmental Disabilities (KCDD), University of Kansas, Governor's Commission on Employment, Employment First Commission, Kansas Department of Commerce, Kansas State Department of Education (KSDE), Disability Right Center of Kansas (DRC), and Kansas Department for Aging and Disability Services (KDADS)</td></tr>
<tr><td colspan="2">Outcome Measures:
• Increase in employment for youth with autism.</td></tr>
</table>

Services Recommendation 2.3: *Centralized Reference Resource & Systems Navigator*

Rationale: The Task Team discussed the importance of ensuring that autism-related resources are easily accessible for families by providing a centralized resource library for families to access information about autism-related services, providers, and programs. The centralized reference resource should be a user-friendly resource navigation tool for families to access continuously updated and maintained autism-related information. Autism Resource Connection App (*Appendix E,* page E-4) is an example of a centralized resource that was developed by the Kansas Technical Assistance System Network (TASN) and funded by the Kansas State

Department of Education (KSDE). The Autism Resource Connection App allows families in Kansas and Nebraska to locate services and resources related to autism in their communities. Although the resource app is available, the resources on the app are not consistently maintained and relies heavily on providers to submit information to be uploaded on the app, which potentially leaves families with outdated or missing resources. Therefore, with this recommendation, the Task Team recommends the State of Kansas be responsible for providing a centralized reference resource that is continuously maintained and easily navigated for families seeking resources.

Recommendation 2.3: The State of Kansas shall provide a single reference resource for families seeking resources for autism-related services and treatment by exploring innovative technology strategies to address the current barriers and issues within waivers and creating a centralized, user-friendly resource webpage that will serve as a resource navigation tool for families to easily access services across the lifespan and credentialed and trained providers based on region and accepted insurance.
Action Steps: ***2022-2023 Immediate Action:*** Ensure that the online resource provides a user-friendly interactivity component for families to access resources based on geographic location, county, and ZIP code, such as available providers across managed care organizations (MCOs), to close gaps and address barriers to services through the study of 'system needs' in real-time which would improve coordination of direct services. ***Strategic Importance:*** Contract with and fund community developmental disabilities organizations (CDDOs) to provide information for this centralized reference resource.
Future Steps Supporting Recommendation: 1. Create a roadmap for navigating the transition to the workforce, which includes vocational rehabilitation, school transition services, etc. 2. Ensure that statewide services, such as community mental health centers (CMHCs), community developmental disability organizations (CDDOs), vocational rehabilitation (VR), certified community behavioral health clinics (CCBHCs), and other services, are consistent in applications to reduce silos and fragmented services. 3. Utilize the American Rescue Plan Act (ARPA) State Fiscal Recovery Funds to support and maintain the centralized resource webpage using modern technology, such as logic and smart capabilities. 4. Create a team of systems navigator positions who will be accessible to families and assist the families in navigating through the system and processes. 5. Develop a system of referral and care that is accessible and easy to navigate by any medical providers in Kansas. 6. Provide updated links to other resources or autism-related sites. 7. Institute a program that identifies homeless adults with autism and provides housing for these individuals and assists with getting supplemental security income (SSI)/social security disability insurance (SSDI) to help provide funding of the staff and facilities while also seeking grants and scholarships elsewhere. 8. Assign a staff member dedicated to continuously gathering information and updating the online resource. 9. Mitigate any conflicts of interest.

Action Lead: Legislature	**Key Collaborators**: Kansas Department of Health and Environment (KDHE), Kansas Department for Aging and Disability Services (KDADS), managed care organizations (MCOs), parents of people with autism, family members, people with autism, Kansas Council on Developmental Disabilities (KCDD), Kansas Department for Children and Families (DCF), and Kansas State Department of Education (KSDE)
Outcome Measures: • Increase number of families being serviced based on what services the families need or want. • Receiving stakeholder feedback via survey. • The age at first access to services by type of services is younger.	

Services Recommendation 2.4: *Continuum of Care*

Rationale: The Task Team members discussed the importance of ensuring people with autism are receiving high-quality services across the continuum of care. Services may include *prevention services* to provide wellness checks and identify ways to help people work through potential crisis, *24/7 crisis telephone services* to provide information, referral, and action plan development, and *mobile crisis outreach services* to provide any services on-site as needed. Other services include *in-home crisis services* that will assist people to become stabilized in their home and *crisis residential services* that provide very short-term, highly supportive, and supervised residential settings. The Task Team discussed that children with autism should be served in their communities and emphasized that the intent of the recommendation should not increase the number of children in out-of-home placements. In addition, the Task Team members discussed Charting the LifeCourse (*Appendix E*, Page E-1), which provides a framework and tools for individuals with autism and their families to develop a vision for a good life throughout their lifespan. The framework also is applicable for programs, services, and organizations to drive transformational changes in practices and policies.

Recommendation 2.4: The State of Kansas shall improve the continuum of care by developing specialized service delivery programs modeled after evidence-based practices from other states, such as prevention service programs, crisis telephone services, mobile crisis outreach services, in-home crisis services, etc.
Action Steps: ***2022-2023 Immediate Action & Strategic Importance:*** Ensure all community mental health centers (CMHCs) and certified community behavioral health clinics (CCBHCs) have staff qualified to provide support (e.g., the array of outpatient services including functional assessments, etc.) for children and adults with autism and intellectual or developmental disability (I/DD), and introduce high-fidelity wraparound teams or health homes for adults and all multi-system involved children (e.g., crossover youth) before they are removed from the home. *Transitions:* ***2022-2023 Immediate Action & Strategic Importance***: Explore an array of evidence-based step-down options for discharge from a psychiatric residential treatment facility (PRTF) or acute care that ensures readiness for all youth including foster care youth with autism to transition back to home, community, school, intensive outpatient program, professional resource homes, etc.
Future Steps Supporting Recommendation: 1. Clarify that personal care under Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) is available for children who have personal care needs using the same authorization mechanism as the waiver. 2. Consider implementing reserved slots in the autism waiver for children in foster care or children at risk of out-of-home placement on their waivers. 3. Implement Charting the LifeCourse and a single person-centered service and support plan with a single comprehensive community care manager rather than having multiple care managers, targeted case managers (TCMs), coordinators and service/support plans. 4. Create an at-home parental education plan to provide parent-directed care while the child is unable to attend specific services. 5. Introduce CCBHCs as an additional resource for behavioral health services. 6. Allow for group billing for supportive home care (SHC) as respite and targeted therapeutic interventions. 7. Engage in collaborations with the juvenile justice system to address service needs related to autism spectrum disorder (ASD) characteristics. 8. Ensure that the waiver should retain the .217 special income group children’s eligibility and that state plan services are delivered to all waiver children. 9. Implement the “Three Buckets of Support Strategies” from the National Association of State Directors of Developmental Disabilities Services (NASDDS) for children with autism and their families. 10. Create a statewide plan with vocational rehabilitation, education, and waiver leaders to collaborate with youth individuals. *Transitions* 1. Introduce services in the state plan and on waivers to transition children out of PTRFs including transition coordination and participant-directed goods and services. 2. Comply with EPSDT and ensure that there are behavior supports available for kids during puberty under the state plan by reinstituting the EPSDT expanded state plan service exceptions process under 1905(r)(5) of the Social Security Act. 3. Identify and utilize funding sources to implement more continuum of care services including a pilot step-down program for high intensity individuals as they transition back to community settings. 4. Ensure state plan services are available to support children as they transition out of PRTFs.

5. Modify SHC definition and policies to ensure better access for children who transition to the I/DD waiver.	
Action Lead: Kansas Department for Aging and Disability Services (KDADS) and Kansas Department for Children and Families (DCF)	**Key Collaborators:** Community mental health centers (CMHCs), psychiatric residential treatment facilities (PRTFs), case management providers (CMPs), child placement agencies, managed care organizations (MCOs), and advocacy groups
Outcome Measures: • Service navigation and coordination are at full capacity and efficient. • There is a reduction in waitlists. • Decreases in the length of stay in psychiatric residential treatment facilities.	

Services Recommendation 2.5: *Early Intervention*

Rationale: Task Team members discussed the importance of ensuring that families and providers are aware of early intervention programs and services that are available so that families can collaborate with early childhood partners to create pathways for services. The Missouri First Steps (*Appendix E*, page E-2) is an example of an early intervention voluntary program implemented in Missouri to provide resources and coordinate services for families. In addition, the Task Team members discussed the importance of recognizing the signs and diagnosing autism in children as early as possible by developing and training an early intervention team of professional services providers who will work in collaboration with schools and other providers in rural areas. This early intervention team would work with schools to help recognize the signs of autism and help navigate the child's family to providers for a complete diagnosis. In 2021, diagnosis is currently provided by licensed psychologists with a PhD or PsyD, developmental pediatricians, pediatricians with autism diagnostic experience, psychiatrists, and neurologists. Therefore, the Task Team recommends children with new autism diagnosis and their families have access to autism services early, especially in rural areas and through the utilization of telehealth.

Recommendation 2.5: The State of Kansas will work with early childhood partners, such as Birth to 3 programs and tiny-k, to create a pathway for families to access active treatment services such as applied behavior analysis (ABA) and other evidence-based practices (EBP) for their child that exhibits a need for services in order to decrease the wait for services, reach children at a younger age, and potentially decrease the number of children that go on to receive a full diagnosis of autism by the end of year 5.	
Action Steps: ***2022-2023 Immediate Action***: Add an ABA therapy and services coaching model for parents and children with autism. ***Strategic Importance***: Create informational campaigns for providers to be aware of all programs that are available in the communities where the child lives to ensure that they can start services early.	
Future Steps Supporting Recommendation: 1. Require tiny-k to screen and administer modified checklist for autism in toddlers (M-CHAT) to all children aged 15 to 30 months and refer to the diagnostic team. 2. Develop and train a statewide funded program focused on identification, diagnosis, treatment/services, care management, and self-directed care throughout the life of the person. 3. Establish statewide early intervention (EI) autism diagnostic teams by recognizing and providing training for professional service providers including board certified behavior analysts (BCBAs), licensed psychologists, licensed master's level psychologists (LMLPs), speech-language pathologists, occupational therapists, physical therapists, neurologists, and mental health providers.	
Action Lead: Kansas Department of Health and Environment (KDHE) Bureau of Family Health	**Key Collaborators:** Tiny-k Early Intervention Program, Kansas State Department of Education (KSDE), Kansas Behavioral Sciences Regulatory Board (BSRB), Kansas Department for Children and Families (DCF), applied behavioral analysis (ABA) service providers, and physicians (i.e., pediatricians, family physicians, etc.)
Outcome Measures: • The age of autism diagnosis for children is younger. • The age at first access to services for children with autism is younger.	

Tier Three Recommendations

The Task Team adopted the following four recommendations in Tier 3:

Workforce Recommendation 1.5: *ASD Interagency Workgroup*

Rationale: The Task Team members discussed the importance of ongoing collaboration with key stakeholders to continue coordinating and concentrating efforts to improve autism services in Kansas. By creating an interagency workgroup on autism spectrum disorder (ASD), key collaborators, such as state agencies, advocates, family members, and community-based providers, would be able to continuously convene, reassess, and develop new recommendations to improve autism services in Kansas. In 2007, the Legislature created a Kansas Autism Task Force (*Appendix E*, page E-3) to study and conduct hearings on the issues related to the needs of and services available for people with autism and provide

recommendations for legislative changes to address those needs. The Task Team recommends the ASD interagency workgroup is similarly structured to the 2007 Kansas Autism Task Force; however, the charge would be reflective to address current issues related to autism services in Kansas.

<table>
<tr><td colspan="2">Recommendation 1.5: The State of Kansas will create an interagency workgroup on autism spectrum disorder (ASD) comprised of state agency leaders, self-advocates, family members, and community-based providers to coordinate and concentrate efforts to move policy into action.
(Charge: Specifically, this group would identify current services, identify gaps, and create an online navigation guide to assist families in determining the resources available to meet their specific needs. This interagency workgroup would work in the following areas: identify and diagnose at the first suspected signs of ASD; provide access to high-quality services regardless of geographic location; recognize and respond to the life-long needs of persons with ASD; incorporate families into all plans of service; engage and educate the community; create the navigation guide in order to connect individuals and their families with community resources; and create capacity within current systems to provide coordinated comprehensive services. By using the collective impact approach, agencies will create a shared vision, create a common agenda, develop a shared system of measurement and accountability, engage in mutually reinforcing activities, create an efficient communication system and identify a backbone organization.)</td></tr>
<tr><td>Action Lead:
Legislature</td><td>Key Collaborators:
Kansas Department of Health and Environment (KDHE), Kansas Department for Aging and Disability Services (KDADS), Kansas Department for Children and Families (DCF), Kansas State Department of Education (KSDE), Kansas Department of Labor (KDOL), Kansas Department of Transportation (KDOT), self-advocates, family members, and community-based providers, regulatory agencies, and managed care organizations (MCOs)</td></tr>
<tr><td colspan="2">Outcome Measures:
1. Request the Kansas Behavioral Sciences Regulatory Board (BSRB) to report data regarding language and cultural fluency on all licensed providers to the ASD interagency workgroup.
2. Conduct annual survey of people with autism around access to services.
3. Coordinated state effort (at agency level) to address the needs of individuals with autism and their families.</td></tr>
</table>

Services Recommendation 2.6: *Autism Registry* [Strategic Importance]

Rationale: The Task Team discussed the importance of continuous research and data collection to better understand autism in Kansas and to provide a pathway for services and supports for families by creating a statewide autism registry, which would collect data, such as diagnosis received, services provided, and treatments delivered. There are a few states, such as Utah, New Jersey and New Hampshire, where statewide autism registries are implemented. For a brief overview of these examples, please see *Appendix F* (page F-1).

Recommendation 2.6: The State of Kansas shall create an interconnected health care system by creating an autism registry that allows for better tracking of services, diagnosis, and treatments by leveraging technology and best practices for data storage and aggregation.	
Action Lead: Kansas Department of Health and Environment (KDHE)	**Key Collaborators:** Kansas State Department of Education (KSDE), Children's Mercy, University of Kansas Medical Center, Wesley Medical Center, community developmental disability organizations (CDDOs), tiny-k Early Intervention Program, vocational rehabilitation (VR)
Outcome Measures: • Established a statewide autism registry.	

Services Recommendation 2.7: *Foster Care Autism Support Positions*

Rationale: The Task Team discussed the importance of focusing on special populations such as children with autism in foster care homes and addressing their needs. Youth with complex needs, such as autism, intellectual or development disability (I/DD), and other co-morbid conditions need significant supports from staffs, biological parents, and foster parents. To provide support and understand how to meet their needs, the Task Team discussed that enhanced resources are essential for staff, biological parents, and foster parents so that they are fully aware of services and providers that are available, understand how to obtain necessary resources at the right time as youths are transitioning and re-integrating into their homes, and ensure that youths' needs are met under their care.

Recommendation 2.7: The State of Kansas will enhance resources to Kansas Department for Children and Families (DCF) case management providers. The resources could include additional training and coaching for staff, parents, and foster parents regarding transitions, including re-integration, and supporting youth with complex needs including autism, intellectual or developmental disability (I/DD), and other co-morbid conditions.	
Action Steps: ***2022-2023 Immediate Action & Strategic Importance:*** Ensure right-time training and navigation resources are available to appropriate child welfare staff, foster parents, kinship parents, and biological parents related to autism interventions and resources.	
Future Steps Supporting Recommendation: 1. Create an informational campaign to ensure child welfare staff, foster parents, kinship parents, and biological parents are aware of autism training including autism-related waivers and navigation resources in order to ensure they access resources when needed.	
Action Lead: Kansas Department for Children and Families (DCF)	**Key Collaborators:** Kansas Department for Aging and Disability Services (KDADS), case management providers (CMPs), Kansas Department of Health and Environment (KDHE), managed care organizations (MCOs), community developmental disability organizations

	(CDDOs), community mental health centers (CMHCs), and Kansas State Department of Education (KSDE).
Outcome Measures: • Reduction in number of children returning to psychiatric residential treatment facilities. • Increase in number of children in foster care accessing autism supports. • Reduction in number of children with autism going into or returning to foster care.	

Services Recommendation 2.8: *Smart Home Technology* [Strategic Importance]

Rationale: The Task Team discussed the importance of integrating innovative technology strategies, such as smart home technology, to provide support and improve quality of life for people with autism. Technology integration into home settings could assist families to ensure a safe and well-regulated home for both children and adults with autism. In addition, the Task Team discussed that incorporating smart home technology could potentially increase existing capacity to provide support for people with autism living independently or semi-independently, which would address staffing shortages for assistance by reducing direct and in-person staffing needs with remote monitoring and other home-technology automation. For example, Living Arrangements for the Developmentally Disabled (LADD), a non-profit organization, launched an initiative to develop integrated housing and service models for adults with developmental disabilities throughout Cincinnati, Ohio, and documented a 65-percent reduction in staff time[1] as of August 2021. (To learn more about LADD's Forever, Home Initiative, see *Appendix E*, page E-4)

Recommendation 2.8: The State of Kansas shall explore the option to incorporate smart home technology into waiver services as a pilot program while complying with the new Centers for Medicare and Medicaid Services (CMS) remote monitoring requirements for privacy and the Health Insurance Portability and Accountability Act of 1996 (HIPAA) compliance in a manner that does not violate individual personal and civil rights.	
Action Lead: Kansas Department for Aging and Disability Services (KDADS), Kansas Department of Health and Environment (KDHE), and the Legislature	**Key Collaborators**: Interhab, managed care organizations (MCOs), community developmental disability organizations (CDDOs), Kansas Department for Children and Families (DCF), community mental health centers (CMHCs), advocacy groups, Kansas Infinitec (by Kansas Technical Assistance System Network [TASN])
Outcome Measures: • Approve a pilot program, which will include developed measures for the pilot program. • Increases numbers of individuals with autism using smart home technology.	

Appendix A. Membership of the Autism Task Team

INDIVIDUALS AND FAMILY MEMBERS		
Name	**Title**	**Organization**
Angela Chapes	Individual	
Brenda Jackson	Parent	
Kathy Keck	Parent	
Rickey Otano	Parent	
Stephanie West-Potter	Parent	

PROVIDERS		
Name	**Title**	**Organization**
Allyson Bell	Director of Autism Services	Heartspring
Sandy Crawford	Vice President of Pediatric Services	Capper Foundation
Michael Slogic	Assistant Professor and Pediatric Physician	University of Kansas Medical Center
Colin Thomasett	Chief Operating Officer	Family Service & Guidance Center

EDUCATION/RESEARCH		
Name	**Title**	**Organization**
Linda Heitzman-Powell	Director of Community Research	University of Kansas Medical Center
Sean Swindler	Director of Community Program Development and Evaluation, Kansas Center for Autism Research and Training (K-CART)	University of Kansas Medical Center and family member

CONTRACTOR REPRESENTATIVES		
Name	**Title**	**Organization**
Matt Arnet	Clinical Director of Outpatient Services	KVC Health Systems
Nanette Perrin	Senior Director of Kansas Pathways	Sunflower Health Plan

(Continued) **Membership of Autism Task Team**

ADVOCACY ORGANIZATION REPRESENTATIVES		
Name	**Title**	**Organization**
Mike Burgess	Director of Policy and Outreach	Disability Rights Center
Matt Fletcher	Executive Director	Interhab
Sean Gatewood	Co-Administrator	KanCare Advocates Network (KAN)
Steve Gieber	Executive Director	Kansas Council on Developmental Disabilities
Rachel Marsh	Chief Executive Officer	Children's Alliance of Kansas

STATE AGENCIES		
Name	**Title**	**Organization**
Matthew Beery	Home and Community-Based Services (HCBS) and Autism Waiver Program Manager	Kansas Department for Aging and Disability Services (KDADS)
Megan Bradshaw	Program Consultant II	Kansas Department of Corrections (KDOC)
Janis DeBoer	Deputy Secretary of Programs	Kansas Department for Aging and Disability Services (KDADS)
Lee Stickle	Kansas Technical Assistance System Network (TASN) Autism and Tertiary Behavior Support (ATBS) Director	KDHE Kansas Technical Assistance System Network (TASN)
Michele Heydon	HCBS Director	Kansas Department for Aging and Disability Services (KDADS)
Brutus Segun	Policy and Program Oversight Manager	Kansas Department for Aging and Disability Services (KDADS)
Fran Seymour-Hunter	Interagency Liaison	Kansas Department of Health and Environment (KDHE)
Brenda Soto	Director of Medicaid and Children's Mental Health	Kansas Department for Children and Families (DCF)

Appendix B. SWOT Analysis Chart

SWOT Analysis
Autism Task Team
August 31, 2021

Topics	Strengths	Weaknesses	Opportunities	Threats
Key Themes	• Excellent resources in some parts of the state • Quality when services available • Agency openness to change • Competitive Medicaid rates	• Workforce size and training • Complex system / lack of info / no single point of entry • Services not available across the lifespan • Waiting lists • Coordination with foster care • Transitions difficult	• Single point of entry • Maintain waiver for special income group • Expand number of providers training • Coordination with other systems / sectors • Incentivize services in rural areas • Provide clear information from diagnosis to service • More family voice	• Budget • Red tape • Workforce shortage • Challenge for those with dual diagnosis • Distinct programs/silos
WORKFORCE	• Provider collaboration • Network of dedicated providers • Training programs available through K-CART and others • Expert providers and specialists • Excellent resources: KU Med, Schiefelbusch Clinic, PBI, CDDOs • We are nationally known for ABA training programs at KU	• Provider shortage /lack of providers • Inability to train enough providers to provide service • Inability to find providers • Lack of consistency • Costs to receive training are too high, meaning we lack a well-trained highly qualified workforce • Lack of training on not only behaviors but communication with a person who is nonverbal • Lack of a career path for autism professionals	• Increase training for families, practitioners, etc. • Require CMHCs to serve kids with ASD appropriately • Autism navigation specialists • Increase the number of providers trained to provide autism early intervention services through paying for training, paying incentives to serve rural areas, etc. • Decrease the paperwork that providers have to do to prove that they are providing ABA services	• Cherry-picking across systems, finding reasons to not serve the most challenging individuals • Allowing providers to set up barriers so they don't have to serve the most difficult populations or behavioral health challenges • Workforce shortages • "Brain Drain" from rural Kansas continues unless we provide incentives to serve these areas

Topics	Strengths	Weaknesses	Opportunities	Threats
WORKFORCE (continued)	• Clarification of training expectations opened up more BCBAs coming into network	• Lack of behavioral health expertise available for adults with ASD or adults served in HCBS system • Lack of well trained, knowledgeable navigators of the system	• Improve technology availability to address workforce challenges while protecting privacy • Increase types of training available to providers and families, i.e., learning to communicate with individuals with limited verbal skills, crisis management, etc.	• Lack of innovation (i.e., technology supports) • Credentialling and enrollment • Not enough trained workers in this field • Individual enrollment of providers and not working under a BCBA when providing ABA services • High turnover • Outsourcing qualified providers (losing them to other states)
SERVICES	• When ABA is provided and accessed it works as intended, but the lack of access means this only happens for a very few • Some innovative providers (i.e., Heartspring) • Have services up to age 21 in Medicaid • Kansans with good health insurance in some areas of the state have good access to services. • Kansans with good health insurance in urban areas or those who are wealthy can	• We are not meeting our obligations to provide medically necessary services under EPSDT • Lack of crisis support for families who have kids with autism who are in crisis • Lack of consistency • Poor transition services for kids with ASD • Expectation of day services being the only option for after high school • Poor consistency between CDDOs so kids in Johnson County are eligible for the waiver when other places in the state the same kid would.	• Provide more guidance to schools on how to best support youth on autism spectrum • Improved coordination between systems: I/DD, MH and foster care • Re-evaluate the termination of waiver services to ensure continuity of care • Require CMHCs to serve kids with ASD appropriately • Centralize autism state plan access under a single point of entry and coordination of provider network • Included options for choice based on the individuals needs from independent to	• Cherry-picking across systems, finding reasons to not serve the most challenging individuals • Silos • Lack of interaction of vocational rehabilitation, Medicaid and waivers • Need to listen to families in designing services

Topics	Strengths	Weaknesses	Opportunities	Threats
SERVICES (continued)	sometimes find adequate services • Emphasis on quality services and national standards • Person-centered services including many providers using LifeCourse	• Long waiting lists to get into KU Med and ABA providers • Wait time and red tape for diagnosis • Expectations of individuals going into residential care • Services not available for adults • No specific services for children with autism or continuity of care for those that are in foster care • Service array, such as opening group services clients with Medicaid • Lack of mental health resources for children with autism • Lack of behavioral health expertise available for adults with ASD or adults served in HCBS system • Poor coordination between systems, I/DD, mental health and foster care • Lack of technology first options • Having to fight to get waiver services • Narrowing definitions of personal care on HCBS waivers that don't service kids/adults with autism • Most children are aging off the waitlist for waiver, rather than receiving the service	more restrictive as wanted/needed • Establish data tracking so we know who is diagnosed what services they access and when they can't find services • Add a crisis program for I/DD and autism like START • Include more family input on helpful supports and services • CMHCs are expanding to specialize in supporting members with autism in a different way • If autism waiver stays, ensure that the process to enroll for services allows for self-direction. • Implement Charting the Life Course and raise expectations for children to have more meaningful lives • Clean up and streamline the credentialing and enrollment process for Medicaid AND waiver • Develop a process from suspicion of autism to diagnosis and potential services • Provide clear information regarding the availability of autism services through the state plan to all members with autism through EPSDT	

Topics	Strengths	Weaknesses	Opportunities	Threats
SERVICES (continued)			• Continue collaboration with the new 988 program to ensure clear crisis support when individuals with autism or their families reach out • Consolidate the processes for families to get diagnosis, find a provider, and the provider to access funding to cover those services • Improve case management so that families don't have 3-4 care managers and assessors	
FUNDING	• Waiver for kids • With the rate increase, as a provider, we have been able to increase our Medicaid participation up to almost 50% of our population. • Competitive Medicaid rate	• Limited waiver spots • Rates, while improved, do not allow for a margin adequate for providers to reinvest in programs and capacity • Costs to receive training are too high, meaning we lack a well-trained highly qualified work force • Lack of rate increases for supported employment	• Increasing funding for services • The waiver expanded to serve the population in the state • Paying for training, paying incentives to serve rural areas, etc. • Incentivizing rural Kansas • Increase the remaining waiver services to a sustainable rate	• Limited budget / funding (especially in 'out years') • Lack of funding or adequate infrastructure to allow new providers to take off • MCOs have an incentive to keep network small and inadequate and hard to access as they don't want to pay for more services... and we have zero enforcement mechanisms in current MCO contract

Topics	Strengths	Weaknesses	Opportunities	Threats
SUBPOPULATIONS	• Pockets of innovation (i.e. dual diagnosis strategizing in Sedgwick County	• Lack of crisis support for families who have kids with autism who are in crisis • Waiting list for I/DD waiver • Expectation of day services being the only option after high school • Families in rural areas and even some urban areas have almost NO ACCESS to autism services • Services not available for adults • Severe problem behavior is not a priority, focus has been on EIBI, which leaves out families who need services at other stages of life • Lack of training for foster care families and providers • No specific services for children with autism or continuity of care for those that are in foster care • Rural Kansas has to make do with what can be "fit in" rather than having well-trained providers knowledgeable on the barriers experienced by being rural • Narrowing definitions of personal care on HCBS waivers that don't service kids/adults with autism	• Being gender responsive • Improved coordination between systems: I/DD, MH and foster care • Include options for choice based on the individual needs from independent to more restrictive as wanted/needed • Add a crisis program for I/DD and autism like START • Provide training for foster families and free training for providers serving these families • Incentivizing rural Kansas • Maintain the 1915(c) for special income group children (i.e., .217 group)	• Foster care contractors and current practices • Lack of training among some foster families

Topics	Strengths	Weaknesses	Opportunities	Threats
ACCESS / OTHER	• State agency focus on improving outcomes • Willingness to review and make improvement with multiple stakeholder input • Recognizing there are problems to be looked at and improved	• Complexity of the system • Lack of confidence that kids with autism can have meaningful lives and employment • Poor information to families • Complicated enrollment system • Expectations of individuals going into residential care • Having to be an "expert" to get services for your child • Lack of well-trained, knowledgeable navigators of the system • Having to fight to get waiver services • Most children are aging off the waitlist for waiver, rather than receiving the service	• Provide more guidance to schools on how to best support youth on autism spectrum • Centralize autism state plan access under a single point of entry and coordination of provider network • STEPS employment pilot with KDHE • Be more family focused as opposed to provider centric • Establish data tracking so we know who is diagnosed, what services they access, and when they can't find services • Include more family input on what helpful supports and services are • Implement Charting the Life Course and raise expectations for children to have more meaningful lives • Clean up and streamline the credentialing and enrollment process for Medicaid AND waiver • Develop a process from suspicion of autism to diagnosis and potential services • Provide clear information regarding the availability of autism services through the state plan to all members with autism through EPSDT.	• Attitudinal barriers • Silos • Inertia of the status quo • Not using the information from the review to actually change the system

ACCESS / OTHER (continued)			• Work with education system and other systems to remove the myths − day services are the option for all children with autism, residential services look like X, employment will adversely affect your Medicaid • Create an Autism Registry for the State of Kansas to better inform and track families who have an ASD diagnosis • Track when families cannot receive adequate state plan services • Consolidate the processes for families to get diagnosis, find a provider, and the provider to access funding to cover those services	

Appendix C. Recommendation Rubric

Autism Task Team Recommendation Rubric, 2021

<table>
<tr><td colspan="2">Recommendation:</td></tr>
<tr><td colspan="2">Action Steps:

2022-2023 Immediate Action:
Strategic Importance:</td></tr>
<tr><td colspan="2">Rationale:</td></tr>
<tr><td>Ease of Implementation (Score 1-10):</td><td>Potential for High Impact (Score 1-10):</td></tr>
<tr><td>Consider:
☐Program Change, (Easiest)
☐Pilot Program,
☐Program Overhaul,
☐New Program, (Most difficult)

Will cost be a barrier to implementation? ☐Yes ☐ No

What is a potential funding source (e.g., State General Funds; Consensus Caseloads; American Rescue Plan Act funds)?

Does the recommendation include strategies for continuity? (How does it consider sustainability?)

Which of the following mechanisms may affect the achievability of the recommendation?
☐ Legislative session
☐ Federal approval process
☐ Regulatory process
☐ Contracts
☐ Agency budget development
☐ Grant cycles
☐ Systems (e.g., IT)

Can this be implemented by families and people with autism.
☐Yes ☐ No</td><td>Consider:
Will it benefit a large proportion of people with autism?
☐Yes ☐ No

Does it have a family focus? ☐Yes ☐ No

Will it significantly impact special populations?
☐Foster care
☐Rural communities
☐Urban communities
☐Limited English Proficient (LEP) persons
☐Low-income individuals
☐Children
☐Juvenile justice
☐Others? (List here)

Does it serve those who have been disproportionately impacted by the issue? (Does it address inequities?)

Could the recommendation produce savings in other areas?</td></tr>
<tr><td colspan="2">Relevance Check:
(1) How does this recommendation contribute to the CMS 1915(c) autism waiver renewal process?
(2) Does the recommendation align with the Task Team's vision? "Ensuring families have direct and clear access to information and a robust service network that adequately covers all areas of the state for people with autism across their lifespan."]</td></tr>
<tr><td>Action Lead:</td><td>Key Collaborators (include families and people with autism). [Who should be included as decisions are made about how to implement this recommendation?]</td></tr>
<tr><td colspan="2">Intensity of Consensus:
[Is there group consensus that this recommendation provides meaningful input to the agency and policymakers? Does a wide cross-section of stakeholders feel that this recommendation would be mutually beneficial? To be addressed during final review.]</td></tr>
<tr><td colspan="2">Outcome Measures:</td></tr>
<tr><td colspan="2">Future Steps Supporting Recommendation:</td></tr>
</table>

Appendix D. Considerations for Future Action Steps

The following items below are for the Intellectual or Developmental Disability (I/DD) Modernization Task Force to consider when it explores a children's I/DD and community living support waiver:

- Increase access for adults with autism to a community support waiver so they can access supported employment, personal care, assistive technology, and participant directed goods and services.
- Add "goods and services" to the autism home and community-based services (HCBS) waiver that will be a self-directed budget to pay for services that are specific to the daily support and/or care-giving role for the person with autism.
  - Context: This would be a self-directed budget to pay for services that are specific to the daily support and/or care-giving role for the person with autism, such as respite, behavioral support and interventions, home modifications, and health/ wellness management. Other examples may include transportation, adaptive equipment, caregiver supports and training.
- Ensure that community developmental disabilities organizations (CDDOs) and community mental health centers (CMHCs) support and serve a single children's waiver.

Appendix E. Additional Background Summaries

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act (IDEA)[2] ensures that free appropriate public education, special education, and related services, such as employment and independent living assistance, are available to children up to age 21 with disabilities that is tailored to their individual needs. The IDEA also ensures that the rights of children with disabilities and their families are protected under the law. In addition, the IDEA governs how states and public agencies provide early intervention, special education, and related services. Part A provides a foundation of the IDEA, defines the terms used, and creates the Office of Special Education Programs (OSEP), which is responsible for administering the terms. Part B provides education guidelines for school children age 3 to 21 years and authorizes grants annually to states to support special education and related services. Part C recognizes the need for identifying and reaching very young children from birth to the age of 2 years. Under Part C, states are awarded grants annually to support early intervention services, which the families of infants and children with disabilities are entitled to. Part D describes the national activities that are needed to improve the education of children with disabilities. Under Part D, the IDEA authorizes discretionary grants awarded through a competitive process for state education agencies, institutions of higher education, and other nonprofit organizations to support research, demonstrations, technical assistance and dissemination, technology development, personnel preparation and development, and parent training and education centers. The grants awarded under Part D are meant to improve the education of children with disabilities.

Charting the LifeCourse Nexus

Charting the LifeCourse[3] provides a framework and tools for individuals with disabilities and their families at any age or stage of life to develop a vision for a good life by thinking about what they need to know and do, identifying how to find and develop support, and discovering what is needed to live their lives as they envision. The framework is designed to reflect the needs of the people to drive changes for individuals with developmental disabilities and their families. However, the framework is applicable for all people at every stage of life and can be used to drive transformational change in practices, policies, organizations and communities. The LifeCourse framework adheres to the following eight key principles that will support an individual's "good life:"

- Focusing on all people;
- Recognizing the person within the context of their family;
- Trajectory of life experiences across the lifespan;
- Achieving life outcomes;
- Holistic focus across life domains;
- Supporting the three buckets of need;
- Integrated services and support across the LifeCourse; and
- Transformational policy and systems change.

Utilizing the LifeCourse framework encourages individuals, families and professionals to reframe the conversation beyond the healthy living, safety and security of individuals with disability by integrating discussions around other life domains, such as daily life and employment, community living, social and spirituality, and advocacy and engagement, that can impact the person's progress towards the life that they envision. The framework includes foundational tools[4] that provide guidance on planning, problem-solving and goal setting. Although these tools are provided for individuals and families, they are applicable outside the family setting. For example, the Life Trajectory worksheet allows professionals to consider life outcomes, as opposed to service outcomes, at each stage of life to examine practices or facilitate policy discussions. Charting the LifeCourse provides a framework and tools for individuals, families and professionals to engage in a different conversation surrounding the topic of disabilities and how to support those who are impacted.

Missouri First Steps

Missouri First Steps[5] is an early intervention system for infant and toddlers (birth to age 3 years) with delayed development or diagnosed conditions associated with developmental disabilities. This is a voluntary program that provides families resources to help their children be successful by coordinating services and assistance to young children with special needs and their families. First Steps is governed by federal and state rules and regulations, including Part C of the IDEA (see summary of IDEA above) and the Missouri State Plan. The Department of Elementary and Secondary Education (DESE) is the lead state agency that implements the program.

For parents and guardians interested in First Steps, there are resources for parents to learn how to make referrals, what their parental rights are, and how to build their Early Intervention Teams (EIT). The First Steps program also includes resources to support providers in locating guidance and information within the program. Examples of resources for providers include information on

evidence-based practices, practice manuals, access to module training and child data system, and policies and procedures regarding enrollment, EIT, individualized family service plan (IFSP), progress notes, billing, and mileage. In addition, the program includes other resources about the program's system point of entry and guidance for transitioning children from the program to Early Childhood Special Education.

Kansas Autism Task Force

The Kansas Autism Task Force[6] was created by the 2007 Kansas State Legislature (KSA 46-1208d[7]) to study and conduct hearings on issues related to the needs of and services available for people with autism and provide recommendations for legislative changes to address those needs. The Task Force was comprised of 20 appointed members, which included members of the legislature, service providers, providers with autism diagnosis experiences, parents of a child with autism, educators with specialization in autism, and representatives of health insurance companies. In addition, the secretaries of the Kansas Department of Health and Environment and the Kansas Department for Social and Rehabilitation Services (now the Kansas Department for Children and Families), the Commissioner of Education, and the chief administrative officer of the Easter Seals Capper Foundation (now Capper Foundation) served as ex officio members.

The Task Force provided eleven recommendations to the Legislative Educational Planning Committee[8], which included: 1) making training in the use of autism screening tools for primary care providers widely available, 2) making awareness training for tiny-k and school district personnel in the characteristics of ASD widely available, 3) increasing the use of telemedicine in diagnostic assessments in rural areas, 4) producing a Best Practices in Autism Intervention for Kansas Handbook that identifies best practices for individuals with ASD and provides comprehensive guidelines for the implementation of evidence-based interventions, 5) ensuring that trained professionals providing services to Kansans with ASD implement the interventions that are recommended as "Best Practice," 6) approving 2007 House Bill 2327 to provide financial incentives for students pursuing an applied behavioral science degree with an emphasis in autism spectrum disorders, 7) creating a specific funding mechanism in the tiny-k program to support the local providers who must provide high-cost intensive support services when they are identified in a child's ISP, 8) increasing (not reducing) the ability of local school districts to access state education funds to support the high-cost, intensive services of children with ASD identified in their IEPs, 9) expanding autism waiver funding in fiscal year 2009 to serve 100 children, 10) introducing a state health insurance mandate specific to ASD, and 11)

implementing the recommendation of the Joint House/Senate Budget Committee in November, 2006 to fully fund the developmental disability waitlist and raise rates substantially over a three-year period.

Autism Resource Connection (ARC) App

The Autism Resource Connection [9] is a mobile application developed by Kansas Technical Assistance System Network (TASN) that allows families in Kansas and Nebraska to locate autism-related services and resources in their communities by searching according to their ZIP code and the type of services that they need. Services categories include:

- Medical
- Early Intervention (Ages 0-3)
- School (Ages 3-21)
- Community Based Services
- Transition/Adults Services
- Mental Health

Users are able to assign ratings to each service and resource and designate favorites. This app is available for Apple IOS and Android.

Forever, Home Campaign

In October 2020, Living Arrangements for the Developmentally Disabled (LADD),[10] a nonprofit organization, launched a housing initiative for adults with developmental disabilities called Forever, Home, to use integrated housing and technology supports in Cincinnati, Ohio. The initiative aims to increase long-term independence for people with developmental disabilities while improving their quality of life and well-being. Forever, Home is built on the following three core components:

- **Building or remodeling 6-8 homes for adults with developmental disabilities** located in desirable, walkable neighborhoods close to amenities like grocery stores, shopping centers, and public transportation; 3-4 people will live in each home.

- **Developing a Technology Training Pilot** by equipping people and homes with technology and providing training on the technology to provide increased safety and self-sufficiency.

- **Provide comprehensive skills-based training**, such as learning to prepare meals, maintain health, and connect people with supported employment and other opportunities for community engagement.

The core of the Forever, Home innovative approach to care is two technology-based pilots[11] with Smart Supports and Training Service Model. Smart Supports is a pilot that will integrate advanced software with individual and home-based technology, such as remote monitoring and smart appliances, to reduce direct and in-person staffing needs and labor costs. Training Service Model is a pilot that equips people with technology like clothing and stabilizing hand sensors and trains them how to use it to remain safe outside of their home. Training would include focuses on healthy eating, exercise, and other skill developments that are a part of daily activities as well. Both pilots intend to decrease cost for support, increase service efficiencies, and support safe, independent living for people with disabilities.

Appendix F. Examples of Statewide Autism Registries in Other States

New Hampshire

The New Hampshire Department of Health and Human Services[12] established the online autism registry for providers to register their findings. In 2008, the New Hampshire Legislature approved He-M 501, a rule establishing and implementing a state autism registry, which required all health care and other providers who were qualified to make an autism spectrum disorder (ASD) diagnosis to record their findings when a new case of ASD is diagnosed in a New Hampshire resident. The registry intended to improve current knowledge and understanding of ASD and allowed the conducting of thorough and complete epidemiologic surveys of the disorder. The collected data would be analyzed to facilitate planning for services for children and adults with ASD and their families by tracking patterns in diagnostic assessment, which helps public health officials to determine how well New Hampshire is doing in meeting the important goals of universal screening and early identification.

New Jersey

The New Jersey Autism Registry[13] is a statewide registry of children diagnosed with autism spectrum disorder (ASD) and was created to better understand ASD in New Jersey and to link families to available services and supports. The child's health care provider would complete the registration by providing information such as name, date of birth, current address, parent's name, parent's date of birth, and the child's diagnosis.

Information in the registry is kept private. Families who choose to register anonymously would not be linked to special child health case management services, which are county-based coordinated service providers with years of experience and knowledge of the resources available to families. State law requires licensed health care providers to report any child diagnosed with autism to the autism registry. A child must be:

- A resident of New Jersey
- Under the age of 22
- Have one of these diagnoses:
    - Autism Spectrum Disorder (ASD);
    - Autistic Disorder;
    - Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS); or

- Asperger's Disorder/Syndrome.

Information about the child is sent to the special child health case management unit within the child's family county of residence. These case managers are available to serve families by providing them with coordinated, family-centered resources. This service is free and is available to the registered child from birth through the age of 21.

Utah

In 2002, the Utah Registry of Autism and Developmental Disabilities (URADD)[14] was established as a joint effort between the Utah Department of Health and the University of Utah Department of Psychiatry. The URADD's goal is to determine the number and characteristics of persons in Utah with autism spectrum disorder (ASD) and other developmental disabilities (DD). URADD uses a passive, population-based system to identify persons with ASD based on a community medical diagnosis of ASD and/or an autism special education eligibility.

The information gathered by URADD is used to:

- Inform public policy decisions;
- Plan for ASD and DD-related services;
- Improve community awareness of ASD and DD;
- Increase community access to ASD and DD screening tools;
- Lower the age at which a child is first identified with ASD or DD; and
- Study the causes of and outcomes related to ASD.

Appendix G. Endnotes

1. LADD Launches First-of-Its-Kind Smart Living Pilot to Increase Independence, Support More People with Disabilities. *LADD INC.* Published September 9, 2021. https://laddinc.org/news/ladd-launches-first-of-its-kind-smart-living-pilot/

2. About IDEA. *Individuals with Disabilities Education Act*. Accessed December 14, 2021. https://sites.ed.gov/idea/about-idea/

3. Framework. *LifeCourse Nexus*. Published 2020. Accessed December 14, 2021. http://www.lifecoursetools.com/lifecourse-library/lifecourse-framework/

4. Foundational Tools. *LifeCourse Nexus*. Published 2020. Accessed December 14, 2021. https://www.lifecoursetools.com/lifecourse-library/foundational-tools/

5. First Steps. *Missouri Department of Elementary and Secondary Education*. Accessed December 14, 2021. https://dese.mo.gov/childhood/early-intervention/first-steps

6. Preliminary Report to the Legislative Educational Planning Committee. *Kansas Autism Task Force.* Published December 2007. Accessed December 14, 2021. https://www.aucd.org/docs/ncbddd/rtoi/KS_state%20of%20the%20state.pdf

7. Kansas Autism Task Force; Membership, Powers and Duties; Reports and Recommendations to LEPC. K.S.A. 46-1208d *JUSTIA US Law.* Accessed December 14, 2021. https://law.justia.com/codes/kansas/2009/chapter46/statutes_19851.html

8. Preliminary Report to the Legislative Educational Planning Committee. *Kansas Autism Task Force.* Published December 2007. Accessed December 14, 2021. https://www.aucd.org/docs/ncbddd/rtoi/KS_state%20of%20the%20state.pdf

9. Autism Resource Connection App. *Kansas Technical Assistance System Network*. Accessed December 14, 2021. https://www.ksdetasn.org/atbs/autism-resource-connection-app

10. Forever, Home. *LADD Inc*. Accessed December 14, 2021. https://laddinc.org/donate/forever-home/

11. Lyons M. Ladd Launches Integrated Housing Initiative for Adults with Developmental Disabilities. *LADD Inc.* 2018. Accessed December 14, 2021. https://laddinc.org/wp-content/uploads/2018/12/Forever-Home-Press-Release.pdf

12. Autism Spectrum Registry. *New Hampshire Department of Health and Humans Services*. Accessed December 14, 2021. https://www.dhhs.nh.gov/dcbcs/bds/registry.htm

13. The New Jersey Autism Registry. *State of New Jersey Department of Health*. Updated June 4, 2020. Accessed December 14, 2021. https://www.nj.gov/health/fhs/autism/public/registry/

14. Utah Registry of Autism and Developmental Disabilities. *University of Utah School of Medicine*. Accessed December 14, 2021. https://medicine.utah.edu/psychiatry/research/labs/uradd/