Jim Pillen, Governor

December 15, 2023

The Honorable Ben Hansen
Members of the Health & Human Services Committee
State Capitol Room 1117
Lincoln, NE 68509

Subject: Independent Evaluation of the Family Support Program

Dear Chairman Hansen:

Pursuant to Neb. Rev. Stat. § 83-111, the Department of Health and Human Services collaborated with CBIZ Optumas, a private, nonprofit organization with expertise in developmental disabilities for an independent evaluation of the family support program set forth in § 68-1530. The evaluation completed by CBIZ Optumas is attached for your review.

Sincerely,

Tony Green, Director
Division of Developmental Disabilities

Attachment

Nebraska Department of Health and Human Services

Deliverable 2.0 Division of Developmental Disabilities System Evaluation for LB376

November 9, 2023

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Glossary

1. Code of Federal Regulations (CFR) – The official, legal publication, of the rules published in the *Federal Register* by the federal government.

2. Budget authority – The flexibility offered under a 1915(c) waiver program that allows individuals and families to have more discretion to use funding provided by the program to better meet their needs. Budget authority options can include but are not limited to: paying providers.

3. Employer authority – The ability, under a 1915(c) waiver, for individuals and families to exercise more flexibility related to providers and provider qualifications. Employer authority may include: provider qualifications, hiring and discharging decisions, and determining staff duties.

4. Federal financial participation – The federal government's share of a state's expenditures under the Medicaid program.

5. Homegrown assessment – An assessment developed by a state entity. Homegrown assessments are generally not validated and tested for reliability.

6. Home and community-based services (HCBS) – Services provided in a community setting, instead of an institutional setting. HCBS includes the services provided by a 1915(c) waiver.

7. Medicaid eligibility category – The category by which an individual qualifies for a state's Medicaid program. There are many Medicaid eligibility categories.

8. Medicaid state plan program (Medicaid or Medicaid program) – The optional state and federal program that provides health insurance to people with disabilities and individuals who have low incomes.

9. Medicaid 1915(c) HCBS waiver (1915(c) waiver) – Optional programs that are allowed under the Medicaid program. 1915(c) waivers offer services, in addition to the Medicaid program services, to people with disabilities or who are aging.

10. Person-centered service plan – A plan developed by the individual, their family, service coordinators, and providers that details the services offered to help support the individual meet their goals. A person-centered plan includes all services provided to the individual, including Medicaid program and 1915(c) waiver services.

11. Self-direction – Self-direction under a 1915(c) waiver includes both budget and employer authorities. A state has to seek permission from CMS to allow self-direction opportunities under a 1915(c) waiver.

12. Standardized assessment – An assessment that is tested and validated and produces results that are generalizable across a population of people with similar characteristics. Standardized assessments are not generally developed and produced by a state entity.

13. Waiver year – The 12 month period in which a 1915(c) waiver program operates. Generally, states seek permission from CMS to operate a 1915(c) program in five-year cycles.

14. 1915(c) waiver application – The document approved by CMS that includes details about a 1915(c) waiver program.

15. 1915(c) waiver renewal – The waiver application submitted to continue a waiver program after the completion of a five-year cycle.

16. 1915(c) waiver amendment – The waiver application submitted to make changes to a waiver program during the current five-year cycle.

Acronyms

1. AAA – Area Agency on Aging.

2. AD – Aged and Disabled Waiver Program.

3. ADL – Activities of Daily Living.

4. ADRC – Aging and Disability Resource Center.

5. ASAM – American Society of Addiction Medicine.

6. ASD – Autism Spectrum Disorder.

7. BSDC – Beatrice State Developmental Center.

8. CALS – Culturally and Linguistically Appropriate Services.

9. CANS – Child and Adolescent Needs and Strengths Assessment.

10. CDD – Comprehensive Developmental Disabilities Waiver Program.

11. CFS – Children and Family Services.
12. CHIP – Children's Health Insurance Program.
13. CMS – Centers for Medicare and Medicaid Services.
14. DAC – Disabled Adult Children.
15. DBH – Divisions of Behavioral Health.
16. DD – Developmental Disabilities.
17. DDAD – Development Disabilities Adult Day Services Waiver Program.
18. DDD – Division of Developmental Disabilities within the Nebraska DHHS.
19. DHHS – Nebraska Department of Health and Human Services.
20. DI – Developmental Index.
21. DSP – Direct Support Provider.
22. ECF CHOICES – Tennessee Employment and Community First CHOICES
23. EPSDT – Early and Periodic Screening, Diagnostic, and Treatment.
24. FPL – Federal Poverty Level.
25. HCBS – Home and Community-based Services.
26. ICF/IID – Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities.
27. I/DD – Intellectual and Developmental Disability.
28. IEP – Individualized Education Plan.
29. LOC – Level of Care.
30. MACPAC – Medicaid and CHIP Payment Access Commission.
31. MCO – Managed Care Organization.
32. MDT – Multidisciplinary Evaluation Team.

33. MIWD – Medicaid Insurance for Workers with Disabilities.
34. MLTC – Medicaid Long-Term Care, a Division within the Nebraska DHHS.
35. MMI – Munroe-Meyer Institute, part of the University of Nebraska Medical Center.
36. NAC – Nebraska Administrative Code.
37. NCBVI – Nebraska Commission for the Blind and Visually Impaired.
38. NF – Nursing facility.
39. PCSP – Person-centered service plan.
40. PERS – Personal Emergency Response System.
41. PY – Program year.
42. SLD – Specific Learning Disability.
43. SRT – State Review Team.
44. SSA – Social Security Administration.
45. SSI – Supplemental Security Income.
46. SUD – Substance Use Disorder.
47. TBI – Traumatic Brain Injury.
48. UCEDD – University Center for Excellence in Developmental Disabilities.
49. VR – Vocational Rehabilitation Services, a program within the Nebraska Department of Education.

Executive Summary

The Nebraska Department of Health and Human Services (DHHS) offers programs and services through one of five divisions to address a variety of public needs. The Division of Developmental Disabilities (DDD) is responsible for offering programs and services to individuals with disabilities, including disabilities related to: developmental or intellectual conditions and diagnoses, physical or medical complexities, and aging. DDD, along with other state entities and community partners, is a central component to the state's developmental disability (DD) service system.

In 2022, the Nebraska Legislature passed Legislative Bill 376 (LB376) in response to stakeholder concerns regarding the state of Nebraska's DD service system. Preceding the passage of LB376, stakeholders voiced concerns including, but not limited to, the following:

- Eligibility and access to services provided through the DD service system.
- Lack of supports and services dedicated to assisting families caring for a loved one with a developmental disability.
- Prior authorization processes and denial of services.
- Resources and education for families and individuals to better navigate the DD service system.
- Cross-system coordination to improve partnerships between DHHS divisions, other state entities, schools, and community partners.
- Limited direct service provider (DSP) workforce capacity and availability.

In response to these concerns, LB376 was passed with short-term and long-term goals in mind. The short-term goal is to provide assistance to families. LB376 accomplishes this short-term goal by requiring DHHS to apply for a Medicaid-funded 1915(c) waiver program primarily focused on providing supports to families caring for a child with a developmental disability. The long-term goal is to review the DD service system for "potential areas for improvement with an emphasis on maximizing impact, effectiveness, and cost-efficiencies."[1]

The long-term goal of LB376 required DHHS to contract with a nationally recognized consultant to conduct an evaluation of the DD service system in Nebraska, with the intent to "examine how the state can better service all Nebraskans with a variety of disabilities."[2] CBIZ Optumas (Optumas) and their sub-contract Myers and Stauffer LC (Myers and Stauffer) were selected via competitive bid to conduct the DD system evaluation, as required by LB376.

[1] Legislative Bill 376. (2022). Accessed 6 September, 2023. Page 3.

[2] Legislative Bill 376. (2022). Accessed 6 September, 2023. Page 7.

Collectively referred to as “the Team” throughout this report, Optumas and Myers and Stauffer conducted an extensive review to understand the current state of Nebraska’s DD service system. This review included conducting a comparative analysis between Nebraska’s DD service system and nine peer state service systems, to highlight the similarities and differences between service systems. The review of peer state DD service systems, coupled with stakeholder feedback from Nebraska’s individuals, families, providers and advocacy organizations, and national best practices, identified several opportunities for improvement for Nebraska’s DD service system.

The Team submits the following findings and recommendations to DHHS and the Nebraska Legislature, subsequent to the conclusion of the Nebraska DD service system evaluation.

Primary Findings

- DDD is an important contributor of programs and services for individuals served by Nebraska’s DD service system, but so too are other Divisions within DHHS, other state entities, and community partners.
- Nebraska is one of only seven states nationwide that applies Social Security Income (SSI) requirements when making Medicaid Program eligibility decisions. The majority of states operate a 1634 agreement with the Social Security Administration.
- Nebraska is one of only eight states that does not apply special income levels to eligibility determinations for the Medicaid program.
- The Katie Beckett Medicaid program eligibility category is limited in Nebraska to only children meeting a hospital level of care (LOC). Evidence from peer states indicates Katie Beckett eligibility is often broader than hospital LOC for states allowing for this eligibility category, and as such, opens the opportunity to serve more children in need of assistance
- Service access inequities exist between the current 1915(c) waiver programs operated by DDD.
- The DD registry prevents timely access for some individuals to 1915(c) waiver services, and was noted by stakeholders as a major concern with Nebraska’s current DD service system.
- Six peer states currently operate a waitlist to receive DD services through a 1915(c) waiver.
- A robust DD service system includes a range of services (both community and institutional-based) to meet the needs of individuals across the acuity spectrum.

- While opportunities to self-direct services exist in Nebraska, there are policies that could be supported to expand self-direction in all 1915(c) waiver programs.
- Integrated, competitive employment opportunities for individuals with disabilities are not well supported, as evidenced by Nebraska Vocational Rehabilitation (VR) outcomes data and the lack of employment and technology first initiatives in the State.
- Allowances for payment under a 1915(c) waiver to legally responsible individuals vary widely across states and programs.
- Stakeholders report not having access to consistent and reliable information regarding the DD service system, including but not limited to: available services; eligibility and enrollment requirements; prior authorizations from Medicaid managed care organizations (MCOs); and care coordination.
- Stakeholder feedback suggests that local school districts are not providing information to individuals and families on the importance of the DD service system.

Recommendations

Based on research from reviewing Nebraska and peer state DD service systems, listening to and learning from stakeholders, and best practice research, opportunities for improvement were identified. The opportunities for improvement as identified through the Team's DD system evaluation and research were paired with recommendations, as noted in *Table 1: Opportunities for Improvement and Recommendations*.

TABLE 1: OPPORTUNITIES FOR IMPROVEMENT AND RECOMMENDATIONS

Opportunities for Improvement	Recommendations
Streamlined access to 1915(c) waiver services and other Medicaid-funded programs.	No Wrong Door Initiatives and technology updates to provide greater access to information for families and individuals.
Improved navigation of services and programs.	Reorganization and divisional name change, so all individuals with disabilities are represented in the name of the division.
Expanded access to the Medicaid program.	• Complete an analysis of transitioning from a SSI to 1634 State. • Evaluate application of special income level rules in Nebraska's Medicaid program. • Evaluate expanding Nebraska Medicaid's Katie Beckett eligibility.

Opportunities for Improvement	Recommendations
Elimination of length of waiting period for 1915(c) services.	Eliminate the Nebraska DD registry so that immediate access to services is available for individuals in need. Along with eliminating the registry, DDD should consider implementing a "future need" tracking system that distinguishes between a need for immediate access to 1915(c) services from individuals who may have a need for services at a future date.
Expanded access to 1915(c) waiver services.	Align Nebraska's DD definition with the federal definition, to expand access to services provided by DDD.
Consistency between 1915(c) waiver programs.	Streamline needs assessments and assessors across waiver programs to ensure equitability.
More choice and options to serve individuals with DD.	Expand the service array to improve services across the DD system.
Provide services in a manner that bridges the divide between rural and urban areas; provide services to individuals who require sensory accommodations.	Allow telehealth as a mode of service delivery, to help address provider capacity concerns and improve services to individuals in need of accommodations.
Highlight the importance of employment choices and technology.	Support employment and technology first initiatives to promote competitive and integrate employment opportunities.
Encourage career growth for DSPs.	Build a more robust DSP workforce to ensure the sustainability of all DD services in the future.
Strengthen ADRC system.	Standardize services and quality across ADRCs to promote equitable access to services across the state.
Provide current information on the provider workforce for individuals, families, and service coordinators.	Maintain a list of active providers, so individuals and families have accurate and up-to-date information.
Eliminate system navigation difficulties for individuals and families.	Improve cross-system coordination to eliminate duplication and administrative burdens for individuals and families.
Promote equitable, consistent, and evidence-based Medicaid program service utilization practices.	Review managed care prior authorization process to ensure appropriate policies are in place when reviewing access to Medicaid state plan services.

Opportunities for Improvement	Recommendations
Develop the workforce to mitigate workforce challenges; promote increased choice to individuals and families receiving services from 1915(c) waivers.	Increase self-direction opportunities in all 1915(c) waivers to support flexibility for individuals and families in decisions regarding provision of care.
Mitigate challenges experienced by families and individuals when a service and/or program eligibility is denied.	Review, revise, and monitor grievance and hearing processes to promote transparency and provide resources to individuals and families.
Address knowledge gaps experienced by individuals and families served by the DD service system.	Provide standardized education and resources to individuals and families in accessible ways across the DD system to improve navigation of the system.
Have schools and school districts take a more active role in the DD service system.	Leverage schools to be a “first point of contact” with individuals and families as individuals and families often rely on schools as sources of information.
Encourage consistency and applied understanding of policies for DHHS staff.	Train service coordinators and assessors on all waivers, services, and options to ensure consistent and accurate information is provided to the public.
Provide meaningful ways for individuals and families to engage policymakers.	Continued work with stakeholders and partners to build a service system: representing different viewpoints; serves various of needs; and that is a reflection of stakeholder and partner feedback.
Determine funding strategies to support the needs and interests of individuals and families.	Combine American Rescue Plan Act funding with long-term investments to support 1915(c) program modifications.

The recommendations presented herein are intended to build upon the current successes and strengths of Nebraska’s DD service system, while addressing unmet needs and gaps for individuals engaged with the DD service system. To the extent feasible, implementing these recommendations in the relative near-term allows Nebraska to make positive systemic impacts, in tandem with already planned activities to address stakeholder needs.

Acknowledgments

The Team would like to thank all stakeholders who participated in the DD Service System Evaluation process for their time, willingness to share feedback on personal experiences, and commitment to improving services and programs for Nebraskans with DD.

In addition, the Team would like to acknowledge the Governor's DD Advisory Committee for their role in providing oversight of and feedback related to the DD Service System Evaluation. The DD Advisory Committee was instrumental in promoting awareness of the DD Service System Evaluation to the public, and their partnership in coordinating efforts for stakeholder engagement was instrumental to the success of DD Service System Evaluation.

Introduction

Historically, the Department of Health and Human Services (DHHS) has operated two Medicaid Home and Community-Based Services (HCBS) waiver programs for individuals with an intellectual and/or developmental disability. Qualifying individuals must meet the same LOC criteria for services provided in an Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities (ICF/IID). These waivers, the Comprehensive Developmental Disabilities Waiver Program (CDD) and Developmental Disabilities Adult Day Services Waiver Program (DDAD), serve individuals across the lifespan and provide habilitative supports to individuals in their community. DHHS is currently operating a registry for individuals waiting to receive services through one of these two ICF/IID 1915(c) waivers.

Due, in part, to the existing developmental disability (DD) registry, access to services supporting individuals with a DD are at times, difficult to obtain for individuals and families. Medicaid eligibility, coordinated case management and referrals, and a lack of individual and family education coalesce to create access barriers to services. As a result of activism from individuals, families, and advocacy organizations, the Nebraska Legislature passed Legislative Bill (LB) 376 which codified an evaluation of Nebraska's service system for individuals with a DD.

Legislative Bill 376 and Intent of Evaluation

LB376 was passed on April 13, 2022, and signed by Governor Pete Ricketts on April 20, 2022. There are two main objectives codified in LB376: submission of a 1915(c) waiver to Centers for Medicare and Medicaid Services (CMS) and an evaluation of the DD service system in Nebraska. This report is focused on the latter objective but will consider information about the new Family Supports Waiver. The Family Support Waiver is expected to be approved by CMS in 2023 and implemented in calendar year 2024 by Nebraska DHHS.

Section 8 of LB376 stipulates the following:

> "The Department of Health and Human Services shall engage a nationally recognized consultant to provide an evaluation of the state's developmental disabilities system in order to examine how the State of Nebraska can better serve all Nebraskans with a variety of developmental disabilities…The evaluation shall analyze the array of services and programs existing in Nebraska for persons with developmental disabilities and address potential areas for improvement with an emphasis on maximizing impact, effectiveness, and cost efficiencies. The evaluation shall consider: (a) Services offered and provided by the state through the medicaid state plan or by current medicaid waivers; (b) services offered by other states through medicaid state plans, medicaid waivers, or other

> mechanisms; and (c) any other areas which may be beneficial to the state in the assessment of its developmental disability services."[3]

In addition to specifying the scope of the DD services evaluation, LB376 also requires DHHS to contract with an independent, nationally-recognized contractor to perform the evaluation. The Optumas and Myers and Stauffer Team (the Team) was selected through a competitive bid process to perform the evaluation of Nebraska's DD services system.

The Optumas and Myers and Stauffer Team

Optumas and Myers and Stauffer have considerable expertise in HCBS, national and state-specific policy, rate development, and stakeholder engagement. Both firms have extensive experience working with Nebraska, particularly DHHS, and bring to the table subject-matter experts who are familiar with DHHS' existing 1915(c) waiver programs, data resources, staff, and external stakeholders.

Throughout the Nebraska DD System Evaluation, the Team strived to approach the review of services, programs, and considerations from a perspective of maximizing access to services, reducing costs to the State, and improving the service experience for individuals and families.[4] The DD System Evaluation was conducted in collaboration with the many individuals, families, guardians, advocacy organizations, providers, and State staff who all play a role in Nebraska's DD service system. The Team's evaluation could not have been accomplished without the participation of these stakeholders, particularly individuals and families.

Voices of Individuals and Families

The voices of individuals and families (including those individuals and families who are members of one of Nebraska's four federally-recognized tribes), were critical to providing representative input on the Team's evaluation of Nebraska's DD service system. Individuals and families bring a unique perspective to this evaluation because they are intimately familiar with areas the State may leverage to improve access and quality of services received. Other stakeholders such as providers and advocacy organizations are also integrally involved in the Nebraska DD service system. However, if individuals and families do not recognize the system as capable of effectively meeting their needs, the DD service system will not fulfill its critical role in helping individuals, and by extension, their families, maintain safe, healthy, independent lifestyles in their community of choice. It is for this reason that the voices of individuals and families were intentionally sought out and included in the Team's evaluation.

As a result of LB376, DHHS contracted with the Team to complete a system-wide evaluation of the services available and provided to individuals with DD. This encompasses all services provided by state and federal funds as well as private provider capacity. This investigation mostly

[3] Require application for and implementation of federal approval for services and supports for children with developmental disabilities and their families and require evaluations and reports. Legislative Bill 376. (2022).

[4] Throughout this report, we refer to biological and adoptive families, guardians, and all other persons caring for individual with DD as "family."

considered services provided within DHHS but also included an overview of entities outside of DHHS to represent a snapshot of the entire service array available. Given the scope of this report and the quantity of information and stakeholder feedback contained herein, the evaluation is sectioned into four components. *Figure 1: Nebraska DD System Evaluation Report Components* illustrates the process used by the Team to complete their analysis of the current DD service system. It is the Team's intent for the components of the evaluation to build upon each other, starting with a review of Nebraska's service system.

FIGURE 1: NEBRASKA DD SYSTEM EVALUATION REPORT COMPONENTS

The first component of this report is an overview of services currently available in Nebraska for individuals with disabilities and their caregivers. After completing a review of Nebraska's current DD service system, the Team conducted research on nine peer states and their respective DD service systems as compared to Nebraska's. The Team then collected stakeholder feedback through virtual sessions, email, and surveys. This feedback was reviewed, compiled into themes, and analyzed. Through the analysis of Nebraska's current DD system, comparison to peer states, stakeholder feedback, and best practice research, several recommendations for suggested system improvements were identified.

Background

Federal and State Medicaid Programs

The Medicaid program was signed into law in 1965 with the express purpose of providing needed health care coverage for low-income individuals. The program is funded jointly by the federal government and states. Over the years, Medicaid has become a critical safety net within the country's health insurance landscape and covers a number of programs and services, such as long-term care services and supports that are not typically covered by Medicare and commercial insurance payers. Although administered by CMS, each state has considerable flexibility to set its own Medicaid program guidelines for eligibility and services within broader parameters set by the federal government. Generally, Medicaid enrollment is offered to seniors, individuals with disabilities, and individuals and families who are low-income. In addition, recent estimates from CMS indicate that more than half of children across the whole country are enrolled in Medicaid and Medicaid's "sister program," the Children's Health Insurance Program (CHIP).[5]

Medicaid-funded services include those that are mandated by the federal government and those that are optional and funded by states under their Medicaid state plans.[6] *Appendix I: Mandatory and Optional Medicaid Program Services* lists all the mandatory and optional services that are coverable under a state's Medicaid program. Along with mandatory and optional program services, the federal government requires states to follow Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) guidelines. EPSDT requires states to provide comprehensive, medically-necessary services to children under age 21, regardless of whether the service is covered in a state's Medicaid plan.[7]

One of the optional services listed are ICFs/IID. ICFs/IID are facilities that have at least four beds that provide active treatment to individuals with intellectual disabilities or other related conditions.[8] As states offer more choice in where and how individuals receive long-term services and supports, a shift can be seen from institutional services, like ICFs/IID to HCBS, which includes 1915(c) waivers.[9]

[5] Centers for Medicare & Medicaid. *Delivering Services in School-Based Settings: A Comprehensive Guide to Medicaid Services and Administrative Claiming*. (May 2023). Accessed 5 June, 2023. Page 6.
[6] Medicaid.gov. *Mandatory &Optional Medicaid Benefits*. Accessed 12 July, 2023.
[7] Medicaid.gov. *Early and Periodic Screening, Diagnostic, and Treatment*. Accessed 12 July, 2023.
[8] Centers for Medicare & Medicaid. *Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID).* (December 2021). Accessed July 7, 2023.
[9] O'Malley Watts, Molly. MaryBeth Musumeci, and Priya Chidambaram. *Medicaid Home and Community-Based Services Enrollment and Spending.* (February 2020). Accessed 24 June, 2023.

1915(c) Home and Community-based Waiver Programs

Within broad federal guidelines, states are given the authority to develop Medicaid HCBS waiver programs to meet the needs of people who prefer to receive long-term care services and supports in their home or other community setting rather than in a traditional institution. These Medicaid waiver programs are also referred to as 1915(c) waivers, in reference to their specific section in the Social Security law.

1915(c) waiver applications are submitted to CMS for review and approval. States submit applications to CMS that outline the design of the program and demonstrate all necessary requirements states must meet to operate a 1915(c) waiver. States can offer a variety of services under a waiver program, though all services must be approved by CMS. Programs can provide a combination of services that address a medical need (such as services related to wound care or feeding tubes) and non-medical services typically designed to provide habilitation or relief to caregivers. The services offered by a 1915(c) waiver are tailored to meet the needs of a "target group" or cohort of individuals whose needs can be categorized into those related to aging, physical or medical disability, intellectual or developmental disability, and mental illness.[10] To receive 1915(c) waiver services, individuals must first be enrolled in a state's Medicaid state plan program, which provides them with access to Medicaid state plan services. States must specify in their application to CMS the maximum number of individuals the waiver can serve in a year. This limit is known as "slot capacity" or simply "slots."

Medicaid 1915(c) Waivers

Medicaid 1915(c) waivers provide HCBS and supports to individuals who would otherwise receive services in a facility.

The Kaiser Family Foundation estimates that over 1.8 million individuals received services through a Medicaid 1915(c) waiver in 2018 and the majority of Medicaid HCBS spending was for 1915(c) programs.[+]

[+]O'Malley Watts, Molly, et. al. "Medicaid Home and Community-Based Services Enrollment and Spending." (Feb. 2020). Accessed 22 May, 2023. https://files.kff.org/attachment/Issue-Brief-Medicaid-Home-and-Community-Based-Services-Enrollment-and-Spending.

Figure 2: Access to Medicaid State Plan and 1915(c) Waiver Services, illustrates the relationship between Medicaid state plan services and 1915(c) waiver services. Individuals who are enrolled on a 1915(c) waiver are able to access services from both programs.

[10] Centers for Medicare & Medicaid. *Application for a §1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria.* (January 2019). Accessed 30 May, 2023. Page 353.

FIGURE 2: ACCESS TO MEDICAID STATE PLAN AND 1915(c) WAIVER SERVICES

Medicaid program

State and federal funded health insurance for low-income individuals or people with disabilities.

Medicaid State Plan Services

Services provided to all individuals enrolled in the Medicaid program.

1915(c) Waiver Services

Services only available to individuals enrolled in a 1915(c) waiver program. Enrolled individuals have access to Medicaid State Plan and 1915(c) Waiver Services.

To access a 1915(c) waiver, individuals must demonstrate the same LOC as is required to receive services in a facility, such as an ICF/IID or nursing facility (NF).

In addition to specifying the number of individuals to be served through the 1915(c) waiver, waiver program services in the aggregate must be less than or equal to the cost of providing services in an equivalent institution. There are a number of other program requirements that states must demonstrate to CMS to operate a 1915(c) waiver, including but not limited to:

- Ensuring the protection of the individuals' health and welfare.
- Providing adequate and reasonable provider standards to meet the needs of the target population.
- Providing services in a manner that follows an individualized and person-centered plan of care.[11]

The Nebraska DHHS currently operates four distinct 1915(c) waiver programs. Program design elements for each of the four waivers are described in more detail in the following sections.

[11] Centers for Medicare & Medicaid. *Application for a §1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria*. (January 2019). Accessed 30 May, 2023. Pages 28-31.

Nebraska's Developmental Disability Service System Review

Similar to other states, the DD service system in Nebraska is comprised of multiple, public-serving state agencies, facility- and community-based providers (who are both for- and non-profit), and numerous informal supports. All these entities deliver services and supports to individuals with disabilities and their families. These services are intended to promote health and wellness, develop and grow skills, and foster personal independence.

This section of the report provides an overview of programs and services delivered through Nebraska's DD service system. This section is organized first, by the programs and services administered by DHHS, then, by programs and services offered by other state of Nebraska agencies, and finally, by other organizations.

Department of Health and Human Services: Programs and Services

Nebraska Revised Statute 81-101 allows for the creation of state agencies to assist the Governor of Nebraska in "execution and administration of the laws." DHHS is one of 12 state agencies specified for this purpose[12] and is comprised of five divisions,[13] responsible for operating and overseeing critical health care programs for Nebraskans. This includes the Divisions of Behavioral Health (DBH), Children and Family Services (CFS), DDD, Medicaid and Long-term Care (MLTC), and Public Health, all of which are integral to how individuals and families receive services to meet health care needs—specifically, needs related to developmental disabilities.

Appendix II: Available Nebraska Disability Programming and Service Charts and *Appendix III: Nebraska Service Definitions* provide a summary of the Team's review of available programs and services, along with applicable service definitions provided by DHHS. Both appendices collectively identify services available to individuals with disabilities and their families.

Division of Developmental Disabilities: Current 1915(c) Waivers

Aged, Adults, and Children with Disabilities

Nebraska's Aged and Disabled (AD) waiver program was first approved by CMS in 1991[14] and is structured to provide services to two target groups who meet a NF LOC: individuals, ages 65 or older, and individuals with physical disabilities, ages 0-64.[15] The NF LOC is assessed using different criteria based on the age of the individual being assessed. *Table 2: Nebraska Nursing Facility Level of Care Comparisons* summarizes the differences between the two age groups.[16]

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[12] Nebraska Revised Statute 81-101. "Executive department; civil administration vested in Governor; departments created." Accessed 22 May, 2023.
[13] Nebraska Revised Statute 81-3113. "Department of Health and Human Services created; divisions." Accessed 22 May, 2023.
[14] Medicaid.gov. Accessed 26 May, 2023.
[15] Aged, Adults, and Children with Disabilities 1915(c) Waiver Application. (July 2022). Accessed 26 May, 2023. Pages 4 and 25.
[16] Aged, Adults, and Children with Disabilities 1915(c) Waiver Application. (July 2022). Accessed 26 May, 2023. Page 39.

TABLE 2: NEBRASKA NURSING FACILITY LEVEL OF CARE COMPARISONS

	Adults	Children
Age Group	18 and older	0-17
Assessment Tool	interRAI Home Care Assessment (interRAI-HC)	interRAI Pediatric Home Care Assessment (interRAI PEDS-HC)
NF LOC Criteria	Individuals must meet at least one of the following criteria: • A limitation in at least three activities of daily living (ADL) and one or more risk factors. • A limitation in at least three ADLs and one or more medical conditions or treatments. • A limitation in at least three ADLs and one or more areas of cognitive limitation. • A limitation in at least one ADL, at least one risk factor, and at least one area of cognitive limitation.	• Children age 0-47 months must have needs related to a minimum of one defined medical condition or treatment, as specified in 471 Nebraska Administrative Code (NAC) Chapter 43. • Children age 48 months through 17 years can be met in one of three ways: ○ At least one medical condition or treatment need. ○ Limitations in at least six ADLs. ○ Limitations in at least four ADLs and the presence of at least two other considerations.

According to the AD waiver application approved by CMS on July 1, 2022, the AD waiver can serve up to the following number of individuals in each waiver year:

- Waiver Year 1: 7,770.
- Waiver Year Two: 8,000.
- Waiver Year Three: 8,300.
- Waiver Year Four: 8,600.

- Waiver Year Five: 8,900.[17]

There are no limitations on the number of individuals served during a waiver year[18], and currently, Nebraska's registry does not apply to the AD waiver. This means that once an individual is found eligible for enrollment on the AD waiver, there is no wait to begin the enrollment process.

The AD waiver currently offers 15 services under its benefit package, although some services are only available to individuals of certain ages. For example, although the AD waiver application does not specify an age requirement to receive adult day health services, adult day health cannot be provided during the school hours set by a school district.[19] Therefore, most children are excluded from receiving adult day health. Another such service is extra care for children with disabilities, which provides assistance to meet the costs of childcare associated with a child's medical or disability-related needs; however, this service is available only to individuals from birth through 17 years of age.[20] A full list of services provided under the AD waiver is located in *Appendix I.*

Additional information relative to service provisioning, service limitations, and budgets under the AD waiver can be found in *Table 3: AD 1915(c) Waiver Additional Information.*

[17] Aged, Adults, and Children with Disabilities 1915(c) Waiver Application. (July 2022). Accessed 26 May, 2023. Pages 28-29.
[18] Aged, Adults, and Children with Disabilities 1915(c) Waiver Application. (July 2022). Accessed 26 May, 2023. Pages 28-29.
[19] Aged, Adults, and Children with Disabilities 1915(c) Waiver Application. (July 2022). Accessed 26 May, 2023. Page 52.
[20] Aged, Adults, and Children with Disabilities 1915(c) Waiver Application. (July 2022). Accessed 26 May, 2023. Page 76.

TABLE 3: AD 1915(C) WAIVER ADDITIONAL INFORMATION

Topic	Specifications
Service Provisioning	• Allows for agency or independent providers of service.[21] • Legally responsible individuals to include a parent (biological or adoptive) or a minor child or the guardian of a minor child who is obligated to provide care are prohibited from receiving payment for services.[22] • At least one waiver service is required to be received per month, or monthly monitoring is required when at least one service is not received monthly.[23]
Service Coordination	• Ages birth to three: Early Development Network. • Ages three through 17: Local DHHS offices. • Ages 18 and older: Area Agencies on Aging or the League of Human Dignity.[24]
Service Limitations	• Unless otherwise specified within a service definition, there are no additional limitations placed on the amount of waiver services an individual can receive.[25]
Budgets	• Participant-direction opportunities, including the ability to manage a budget, are not afforded.[26]

Comprehensive Developmental Disabilities Services

The CDD waiver serves individuals from birth throughout their lifespan who have a DD and meet an ICF/IID LOC. Individuals seeking enrollment on the CDD waiver must also meet the definition of developmental disabilities as prescribed in the Nebraska Developmental Disabilities Services Act (NRS 83-1205).[27] *Appendix IV: Comparison between State and Federal Developmental Disability Definitions* highlights the differences in the ways Nebraska and the federal government define DD. Substantive differences in definitions are **bolded** and underlined.

The federal government does define the term "developmental disabilities" within the Code of Federal Regulation (CFR). As shown in *Appendix IV*, Nebraska's definition of developmental

[21] Aged, Adults, and Children with Disabilities 1915(c) Waiver Application. (July 2022). Accessed 26 May, 2023. Pages 51-97.
[22] Aged, Adults, and Children with Disabilities 1915(c) Waiver Application. (July 2022). Accessed 26 May, 2023. Page 101.
[23] Aged, Adults, and Children with Disabilities 1915(c) Waiver Application. (July 2022). Accessed 26 May, 2023. Page 38.
[24] Department of Health and Human Services. *Services on the Aged and Disabled Waiver*. Accessed 9 July, 2023.
[25] Aged, Adults, and Children with Disabilities 1915(c) Waiver Application. (July 2022). Accessed 26 May, 2023. Page 116.
[26] Aged, Adults, and Children with Disabilities 1915(c) Waiver Application. (July 2022). Accessed 26 May, 2023. Page 143.
[27] Nebraska Administrative Code 403, Chapter 2 *Application, Eligibility, Funding, Waitlist and Appeals*. (July 2018). Accessed 1 June, 2023.

disabilities is more restrictive than the federal definition, which impacts access to services provided through the CDD waiver program. This is primarily due to the requirement that individuals have substantial functional limitations in all areas of adaptive functioning, rather than three or more areas established in the federal disability criteria.

Figure 3: Nebraska ICF/IID Level of Care Criteria presents a summary of the LOC criteria an individual must meet per regulation.[28] It should be noted that unlike the AD waiver, the ICF/IID LOC criteria applies to all age groups. ICF/IID LOC is determined by completion of the Developmental Index (DI), a homegrown assessment developed by the State. [29]

FIGURE 3: NEBRASKA ICF/IID LEVEL OF CARE CRITERIA

ICF/IID Level Of Care Criteria
1. The individual has a diagnosis of an intellectual disability or a related condition, which has been confirmed by prior diagnostic evaluations, standardized tests, and sources independent of the ICF/IID. 2. The individual can benefit from active treatment as defined in 42 CFR 483.440(a) and 471 NAC 31-002. In addition, the following criteria apply: a. The individual has a related condition and the independent qualified intellectual disabilities professional assessment identifies the related condition has resulted in substantial functional limitations in three or more of the following areas of major life skills: self-care, receptive and expressive language, learning, mobility, self-direction, or capacity for independent living. These substantial functional limitations indicate the individual needs a combination of individually planned and coordinated special interdisciplinary care, a continuous active treatment program, treatment, and other services that are lifelong or of extended duration. b. A Medicaid-eligible individual has a dual diagnosis of DD, or a related condition, and a mental illness. The DD or related condition has been verified as the primary diagnosis by both an independent qualified intellectual disabilities professional and a mental health professional whose scope of practice allows the diagnosis of mental illness: i. Historically there is evidence of missed developmental stages, due to DD or a related condition. ii. There is remission in the mental illness and it does not interfere with intellectual functioning and participation in training programs.

[28] Nebraska Administrative Code Title 471, Chapter 31. "Services in an Intermediate Care Facility for Individuals with Developmental Disabilities (ICF/DD)." (December 2021). Accessed July 7, 2023. Page 11.
[29] Comprehensive Developmental Disabilities 1915(c) Waiver Application. (March 2022). Accessed 1 June, 2023. Pages 3, 26, and 41.

ICF/IID Level Of Care Criteria
iii. The diagnosis of DD or a related condition takes iv. precedence over the diagnosis of mental illness. c. When the individual does not have substantial functional limitations in self-care skills, the individual must have substantial functional limitations in at least the life skill area for capacity for independent living, along with two other life skill areas.[30]

As approved by CMS on March 1, 2022, the CDD waiver program has the following number of slots approved per waiver year:

- Waiver Year One: 4,300.
- Waiver Year Two: 4,500.
- Waiver Year Three: 4,500.
- Waiver Year Four: 4,500.
- Waiver Year Five: 4,500.[31]

Nebraska does limit the number of participants served during a waiver year, as specified in the waiver application. The limit that applies in each year equals the maximum number of slots in each of the waiver years.[32] DHHS operates a registry for individuals seeking to enroll in the CDD waiver.

The CDD waiver program currently offers 24 services. Person-centered service plans are developed by service coordinators employed by DDD, with the individual and others as selected by the individual.[33] It is important to note that some services are available only to certain age categories. Examples of this are the prevocational and child day habilitation services.[34] A full list of services can be found in *Appendix II*. Residential habilitation services under the CDD waiver allow for individuals to receive continuous habilitation support to assist with developing and retaining skills related to ADLs. All residential habilitation service delivery options also allow the service provider to deliver services overnight.[35] There are three allowable residential habilitation service delivery options:

[30] Nebraska Administrative Code 471, Chapter 31 *Services in an Intermediate Care Facility for Individuals with Developmental Disabilities (ICF/DD)*. (December 2021). Accessed 1 June, 2023.
[31] Comprehensive Developmental Disabilities 1915(c) Waiver Application. (March 2022). Accessed 1 June, 2023. Page 25.
[32] Comprehensive Developmental Disabilities 1915(c) Waiver Application. (March 2022). Accessed 1 June, 2023. Page 26.
[33] Nebraska Department of Health and Human Services. *Services on the Developmental Disability Waivers*. Accessed 9 July, 2023.
[34] Comprehensive Developmental Disabilities 1915(c) Waiver Application. (March 2022). Accessed 1 June, 2023. Pages 49, 52, and 82.
[35] Comprehensive Developmental Disabilities 1915(c) Waiver Application. (March 2022). Accessed 3 June, 2023. Page 56.

- Continuous home: Services and supports delivered in a provider-owned, leased, operated, or controlled residential setting and provided by agency provider shift-staff not living in the setting.

- Host home: Services and supports provided in a private home, owned or leased as the sole residence by an individual, couple, or family who is an employee of a provider agency authorized to provide services. The employee must be chosen by the waiver-enrolled individual.

- Shared living: Services and supports delivered in a private home, owned or leased by an individual, couple, or family chosen by the participant and who is an independent contractor of a provider agency. The contractor and the waiver-enrolled individual live together in the residence.[36]

Additionally, the following CDD waiver services allow for participant-direction opportunities, including budget authority. This means that program participants are empowered to hire the caregiver of their choice to provide personal care assistance and help with other daily living activities, such as mobility and preparation and cleanup of meals. These services are:

- Supported employment-individual.
- Child day habilitation.
- Homemaker.
- Independent living.
- Environmental modification assessment.
- Assistive technology.
- Supported family living.
- Consultative assessment (employer authority only).[37]

Participants must receive at least one waiver service within a period of 90 days to be considered eligible for the waiver. Requests to continue waiver enrollment past the 90 day period are subject

[36] Developmental Disabilities Day Services Waiver for Adults 1915(c) Waiver Application. (March 2022). Accessed 3 June 2023. Page 55.
[37] Comprehensive Developmental Disabilities 1915(c) Waiver Application. (March 2022). Accessed 1 June, 2023. Page 208.

to review and approval by DDD.[38] In addition, the CDD waiver prohibits payments to legally-appointed guardians and responsible relatives of a waiver participant, including the parent of a minor child or a spouse. As defined in the CDD waiver, a "guardian" applies to all individuals under guardianship, regardless of age.[39]

Developmental Disabilities Day Services Waiver for Adults

Along with the CDD waiver, the DDAD waiver program also provides supports to eligible individuals meeting the same developmental disability criteria and ICF/LOC, although it is tailored specifically to individuals beginning at age 21 and through their lifespan. Like the CDD waiver, service coordination is provided by employees of DDD.[40] A registry is in place and active for the DDAD waiver.

As approved by CMS in March 2022, the DDAD waiver may serve up to 1,055 individuals per each of the five waiver years. Nebraska limits the number of individuals that can be served at any point in a waiver year to 900.[41]

The DDAD waiver covers 18 services, some of which include:

- Adult day: Health and social activities that take place within the community designed to foster social interactions and independence.
- Community integration: Habilitative activities designed to foster independence, community networking, and personal choice.
- Prevocational services: Habilitative services focused on developing non-job specific skills of individuals to support building future paid employment capacity in an integrated community setting.
- Supported family living: Individually-tailored, intermittent teaching, and supports provided within a private family home owned by a relative, to assist with the acquisition, retention, and/or improvement in skills related to living in the community during times in which the individual is awake.

[38] Comprehensive Developmental Disabilities 1915(c) Waiver Application. (March 2022). Accessed 1 June, 2023. Pages 160 and 40.
[39] Comprehensive Developmental Disabilities 1915(c) Waiver Application. (March 2022). Accessed 1 June, 2023. Pages 49, 52, and 82.
[40] Nebraska Department of Health and Human Services. *Services on the Developmental Disability Waivers.* Accessed 9 July, 2023.
[41] Developmental Disabilities Day Services Waiver for Adults 1915(c) Waiver Application. (March 2022). Accessed 3 June 2023. Pages 25 and 26.

- Transitional: Payment of initial household expenses that are non-recurring and support individuals during transition from an institution to a private residence.[42]

The DDAD waiver program does not provide the opportunity for individuals to receive services in a residence not owned by a relative.[43] Despite limitations on where individuals may receive services, individuals enrolled on the DDAD program are offered employer and budget authority options for 12 services.[44]

Traumatic Brain Injury

Nebraska's Traumatic Brain Injury (TBI) waiver application defines a TBI as:

> *Non-degenerative, non-congenital insult to the brain from an external mechanical force, possibly leading to permanent or temporary impairment of cognitive, physical, and psychosocial functions, with an associated diminished or altered state of consciousness. [TBI] does not apply to brain injuries induced or caused by birth trauma.*[45]

To enroll in the TBI waiver program, individuals must meet the NF LOC criteria and have a documented diagnosis of TBI. The program is available to individuals who are between the ages of 18-64 years old.[46] NF LOC criteria is assessed using the same instrument (interRAI-HC) as that used for adults enrolling on the AD waiver. *Table 4: Comparison of LOC Criteria between the AD and TBI Waiver* demonstrates the differences in adult waiver criteria.

[42] Developmental Disabilities Day Services Waiver for Adults 1915(c) Waiver Application. (March 2022). Accessed 3 June 2023. Pages 64, 72, 49, 110, and 115.
[43] Developmental Disabilities Day Services Waiver for Adults 1915(c) Waiver Application. (March 2022). Accessed 3 June 2023. Pages 110-112.
[44] With the exception of the Consultative Assessment services on the DDAD waiver, all other services offer both employer and budget authority options. Consultative Assessment only allows for employer authority.
[45] Traumatic Brain Injury 1915(c) Waiver Application. (July 2022). Accessed 3 June, 2023. Page 4.
[46] Traumatic Brain Injury 1915(c) Waiver Application. (July 2022). Accessed 3 June, 2023. Page 28.

Table 4: Comparison of LOC Criteria between the AD and TBI Waiver

	AD	TBI
NF LOC Criteria	Individuals must meet at least one of the following criteria: • A limitation in at least three ADLs and one or more risk factors. • A limitation in at least three ADLs and one or more medical conditions or treatments. • A limitation in at least three ADLs and one or more areas of cognitive limitation. • A limitation in at least one ADL, at least one risk factor, and at least one area of cognitive limitation.	Individuals must meet at least one of the following criteria: • A limitation in at least three ADLs, one or more risk factors, and a medical diagnosis of TBI. • A limitation in at least three ADLs, one or more medical conditions or treatments, and a medical diagnosis of TBI. • A limitation in at least three ADLs, one or more areas of cognitive limitation, and a medical diagnosis of TBI. • A limitation in at least one ADL, at least one risk factor, at least one area of cognitive limitation, and a medical diagnosis of TBI.

Only one service is covered under the TBI benefit package: assisted living services. Service coordination is provided by the League of Human Dignity.[47] The TBI waiver has slot capacity to serve up to 40 participants in a waiver year. Nebraska does not limit the number of participants the TBI waiver serves at any point during a waiver year. Despite the limited nature of the TBI waiver, there is no wait to receive services provided by the TBI waiver.

Division of Developmental Disabilities: Registry

Purpose and Operationalization of the Registry

Nebraska is one of many states that operate a registry for services provided through 1915(c) Medicaid waiver programs. Nebraska's registry is partially in place because of limited funding to support all requests for enrollment in the CDD or DDAD 1915(c) waiver programs. The registry is also used to note a future need for waiver services that other programs or services (Medicaid state plan services or another 1915(c) waiver) will not be able to support.[48] No other 1915(c) Medicaid waiver programs in Nebraska operate with a registry, which means that there is currently no wait to receive services provided by the AD or TBI waivers.[49] In other words, there is sufficient waiver program availability to enroll all those who qualify; however, some individuals already enrolled on the AD waiver may be on the registry for enrollment to either DD waiver.

Nebraska Registry: CDD and DDAD 1915(c) Waivers

Nebraska maintains a registry (or waitlist) for the CDD and DDAD 1915(c) programs. There is no registry for enrollment on the AD or TBI waivers.

As of June 2023, DDD estimates that individuals will spend 5.5 years waiting for enrollment on the CDD waiver. Enrollment on the DDAD waiver occurs after an individual turns 21 and is fully transitioned out of school services.

It is standard operating procedure that prior to placement, DDD staff hold a discussion with individuals and their families about the services offered through the CDD and DDAD waivers and the current wait time for those services. Also, prior to placement, the individual is assigned a waiver services specialist who works with the individual and family while eligibility for placement on the registry is determined. The waiver

[47] Department of Health and Human Services. *Services on the Traumatic Brain Injury Waiver*. Accessed 9 July, 2023.
[48] 9/7/23 email received from Kristen Smith, Deputy Director of Eligibility, Policy, and Quality to Jackie George, Myers and Stauffer.
[49] Department of Health and Human Services. "Eligibility for Medicaid HCBS Waiver Services: Comprehensive Developmental Disabilities (CDD) and Developmental Disabilities Adult Day (DDAD) Waivers." Accessed 30 May, 2023.

services specialist is available to provide information on the application for services, the Medicaid and 1915(c) waiver program eligibility process, and other questions related to the registry.[50]

Individuals waiting to receive services through either the CDD or DDAD 1915(c) waiver programs are placed on the registry after determination through the DI assessment that they meet the ICF/IID LOC criteria. The next step in the process to determine registry placement is completion of an eligibility worksheet filled out by staff in DDD's Eligibility & Enrollment unit. Additionally, Eligibility & Enrollment unit clinical staff may also use a *Vineland 3*, *Adaptive Behavior Assessment System or Gilliam Autism Rating Scale* assessment if there is a lack of medical documentation for the individual.[51] DDD staff indicated an individual can be placed on the registry, even if they are not enrolled or eligible for Medicaid at the time of placement;[52] however, all individuals are waiver-eligible at the time of placement on the registry.[53]

DDD manages the registry placement process consistently for all age groups, levels of disability, and service needs. Registry placement is based on date of application, which is documented on the eligibility worksheet and maintained by DDD.[54]

Once an individual is placed on the registry, DDD communicates to individuals and families on the following schedule:[55]

- When an individual is found newly eligible for either the CDD or DDAD waivers.
- When an individual turns 10 or 18 for verification that they still meet the definition of developmental disabilities.
- For an annual LOC redetermination (applicable when an individual is already enrolled in another waiver but is still on the registry for CDD or DDAD).
- During the period in which the individual is between 18 to 21 years old to remind them to enroll in SSI and Medicaid, for the purposes of future enrollment on the DDAD waiver.

[50] 5/31/23 email received from Kathy Arens, DHHS Program Specialist, Developmental Disabilities Home and Community-Based Services to Jackie George, Myers and Stauffer.
[51] 5/31/23 email received from Kathy Arens, DHHS Program Specialist, Developmental Disabilities Home and Community-Based Services to Jackie George, Myers and Stauffer.
[52] 5/31/23 email received from Kathy Arens, DHHS Program Specialist, Developmental Disabilities Home and Community-Based Services to Jackie George, Myers and Stauffer.
[53] 7/12/23 conversation with Jennifer Clark, Deputy Director of Community Services.
[54] 5/31/23 email received from Kathy Arens, DHHS Program Specialist, Developmental Disabilities Home and Community-Based Services to Jackie George, Myers and Stauffer.
[55] 5/31/23 email received from Kathy Arens, DHHS Program Specialist, Developmental Disabilities Home and Community-Based Services to Jackie George, Myers and Stauffer.

Additional information provided to families prior to and immediately following placement on the waitlist includes:

- Advisement on non-Medicaid funded programs, such as Lifespan Respite and PASS.[56]
- Contact information for family resources.

Despite this information being provided immediately following placement on the registry, DDD discontinued the practice of sending written communication to individuals and families about their registry status in approximately 2015. The above contact schedule is the only communication families receive while on the registry.

Funding for a slot on the CDD or DDAD 1915(c) waiver is codified in Nebraska regulations at NRS §83-1216. The regulation specifies the six priorities for funding by which individuals are enrolled on the CDD or DDAD 1915(c) waivers from the registry. Priority for funding is as follows, when responding to the needs of individuals who:

- Are in immediate crisis because of caregiver death, homelessness, or a threat to the life and safety of the person.
- Have resided in an institutional setting for a period of at least 12 consecutive months and are requesting HCBS.
- Are wards of DHHS or placed under the supervision of the Office of Probation Administration by the Nebraska court system and are turning 19 years of age with no other alternatives to support residential services necessary to pursue economic self-sufficiency.
- Are transitioning from the education system upon attaining 21 years of age to maintain skills and receive the day services necessary to pursue economic self-sufficiency.
- Are a dependent of a member of the armed forces of the United States who is a legal resident of Nebraska as a result of a military assignment.
- Do not meet any other priority category. Enrollment on a 1915(c) Medicaid waiver from the registry for this priority funding category is based on the date of application.[57]

[56] PASS refers to Plan to Achieve Self-Support, which is a plan of action submitted to the Social Security Administration to achieve self-support by getting a particular kind of job or starting a business. If approved, the money used for the plan's expenses will not be counted in the SSI eligibility determination.

[57] Nebraska Revised Statute 83-1216. Department; duties; services; legislative intent; priorities. Accessed 30 May, 2023.

Division of Developmental Disabilities: Programs and Services under Development

Family Supports Waiver

In addition to the DD system evaluation, LB376 directs DHHS to develop a 1915(c) Family Supports waiver program to serve individuals with DD. The new waiver is tentatively scheduled for implementation in 2024, with final program design dependent on approval from CMS.

As such, information included in this report draws from LB376 language and information presented by DDD to stakeholders over the past year. *Figure 4: Family Supports Waiver Regulatory and Stakeholder Outreach Activities* outlines the regulatory and stakeholder activities DDD completed during 2023, in relation to implementation of the Family Support Waiver.[58] It is important to note that approval of the Family Support Waiver is subject to CMS approval.

FIGURE 4: FAMILY SUPPORTS WAIVER REGULATORY AND STAKEHOLDER OUTREACH ACTIVITIES

Date	Activity
October 2022	Family Supports Waiver Engagement Survey.
November 2022	Stakeholder Listening Sessions.
April - May 2023	Listing Sessions as part of Family Support Waiver Listening Tour.
July 2023	Public Hearing on Family Support Waiver Regulations (403 NAC).
July - August 2023	30-day Public Comment Period.

Core elements of the Family Supports waiver include:

- Creating a pathway for Medicaid eligibility by only considering a child's income and assets.

[58] Nebraska Department of Health and Human Services. "LB376 – Family Support Waiver- Milestone Timeline." Accessed July 7, 2023.

- Serving children birth through 21 years of age who meet eligibility for DD services, in addition to meeting ICF/IID LOC.
- An initial slot capacity of 850 in the first five years of the program.
- Specifying funding priorities to determine order of enrollment.
- Allowing for participant-direction of services.
- Offering an annual budget per individual of $10,000 for waiver services; this amount is in addition to services provided through the Medicaid State Plan program.[59]

There are a number of services DDD is reviewing for inclusion in the Family Supports waiver. Based on feedback from stakeholders, some of the services being considered for inclusion are: child day habilitation; home modifications; respite; supported family living; and vehicle modifications. These services already exist in other 1915(c) Medicaid waivers operated by DDD. In addition to these services, DDD is considering the development of new services for the Family Supports waiver including: family caregiver training, family and peer mentoring, and participant-directed goods and services.[60]

It is important to reiterate that the Family Supports waiver application is under development as of the date of this report, and the information contained herein is subject to change based on feedback from Nebraska's stakeholders and CMS.

Changes to the TBI Waiver

Nebraska's 1915(c) TBI Medicaid waiver program is due for renewal, with CMS approval expected by October 1, 2023.[61] Within the renewal, DDD is proposing some changes to the administrative and operational aspects of the program. These proposed changes include but are not limited to the following:

- Updating performance metric information.
- Removing the maximum age limit, currently set at age 64, for individuals served on the waiver.

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[59] Nebraska Department of Health and Human Services: Division of Developmental Disabilities. "Family Support Waiver Tour." Accessed 30 May, 2023. Pages 8-9.
[60] Nebraska Department of Health and Human Services: Division of Developmental Disabilities. *Family Support Waiver Tour*. Accessed 30 May, 2023. Pages 10-11.
[61] Division of Developmental Disabilities. *TBI Waiver Renewal Public Comment Period. Presentation dates: April 13, 18, and 21, 2023.* (April 2023). Accessed 30 May, 2023. Page 7.

- Increasing the number of individuals who can be served in each program year from 40 to 370.
- Adding community inclusion, employment, personal care, respite, and caregiver training services.
- Addressing the ability of relatives and legal guardians to receive payment for providing waiver services.62

Medicaid and Long-Term Care: Medicaid Program

The Division of MLTC within DHHS administers Nebraska's Medicaid program, which serves low-income children and adults, the aged, and individuals with disabilities, who meet the State's specific eligibility categories. Sometimes referred to as "Heritage Health," Medicaid is a significant payer of health services in Nebraska. The Division's appropriated budget of approximately $3 billion dollars paid for services for approximately 15 percent of Nebraskans, who were Medicaid beneficiaries in state fiscal year 21. Approximately 92,000 providers are enrolled with Nebraska Medicaid.[63]

Medicaid Expansion in Nebraska

Expansion of Medicaid benefits to individuals ages 19-64 earning up to 138% of the FPL began in October 2020.

Between October 1, 2020, and September 30, 2021, receipt of services such as dental, vision, and over-the-counter medications were subject to specific criteria for individuals qualifying for Medicaid under expansion policies. Beginning October 1, 2021, all individuals eligible for Medicaid through expansion were automatically eligible to receive these benefits. [+]

+Department of Health and Human Services. *Medicaid Expansion in Nebraska*. https://dhhs.ne.gov/Pages/Medicaid-Expansion.aspx. Accessed 6 June, 2023.

In addition to administration of the Medicaid State Plan program, MLTC is also responsible for making certain Medicaid eligibility and disability determinations. In the absence of a disability determination from the Social Security Administration, MLTC's State Review Team (SRT) review applications and render disability determinations. For certain eligibility pathways, a disability determination is needed to qualify for the Medicaid program in Nebraska.[64]

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[62] Division of Developmental Disabilities. *TBI Waiver Renewal Public Comment Period. Presentation dates: April 13, 18, and 21, 2023.* (April 2023). Accessed 30 May, 2023. Pages 13-20.

[63] Nebraska Department of Health and Human Services. *Nebraska Medicaid Annual Report – State Fiscal Year 2021.* (December 2021). Accessed July 7, 2023. Page 4.

[64] Nebraska Department of Health and Human Services. *Medicaid Disability Reviews.* Accessed 6 June, 2023.

On October 1, 2020, the Nebraska Legislature expanded Medicaid eligibility under the authority of the Affordable Care Act of 2010. The Nebraska Medicaid program now covers individuals who may or may not have a disability, who:

- Earn no more than 138% of the federal poverty level (FPL) annually.
- Are between 19 and 64 years of age.
- Are a resident of Nebraska.[65]

Medicaid eligibility varies from state to state, and there are various pathways in which an individual may qualify for Medicaid. Medicaid expansion, the Disabled Adult Children (DAC), Katie Beckett, and Medicaid Insurance for Workers with Disabilities (MIWD) eligibility categories have expanded opportunities for developmentally disabled and other individuals to qualify for the Medicaid program in Nebraska.

Medicaid Program Eligibility Determinations

There are three ways Medicaid program eligibility determinations can be made. See *Table 5: Eligibility Determination Options below* for details on the type of eligibility determination options available to states, and the differences between each option. Currently, Nebraska uses the SSI state option for determining Medicaid eligibility.

TABLE 5: ELIGIBILITY DETERMINATION OPTIONS

Eligibility Determination Option	Details
SSI State	• In SSI states, a state Medicaid program may make their own Medicaid determinations or ask that determinations are completed by the Social Security Administration (SSA).[66] • Individuals are required to submit information to the state for a separate eligibility determination.

[65] Nebraska Department of Health and Human Services. *Heritage Health Adult Toolkit*. Accessed 6 June, 2023.
[66] Social Security Administration. *Policy for States and State Choices*. (October 2017). Accessed 11 July, 2023.

Eligibility Determination Option	Details
209(b) State	• States may chose eligibility criteria related to income and assets, disability, or both, that are more restrictive than SSI program criteria, but criteria cannot be more restrictive than the criteria in effect in January 1972.[67]
1634 State	• States enter into an agreement with the SSA that allows SSA to make Medicaid eligibility determinations for individuals receiving SSI or federally-administered state supplementary payments.[68] • The determination process for SSI automatically qualifies an individual for the state's Medicaid program.

Nebraska is one of seven states[69] that use SSI eligibility criteria for Medicaid determinations. Nebraska utilizes the SRT within MLTC to make disability determinations when a determination has not been made by the Social Security Administration.[70]

When making income determinations for the Medicaid program, states also have the option to consider individual's income under "special income level." The special income level allows for individuals to have up to 300% of the SSI benefit rate. This option applies to individuals who require at least 30 days of HCBS or institutional care.[71] As of 2022, Nebraska is one of eight states that does not allow for determinations under the special income limit.[72]

Medicaid Program Eligibility Categories: Disabled Adult Children, Katie Beckett, and Medicaid Insurance for Workers with Disabilities

The Nebraska Medicaid program offers numerous eligibility categories for enrollment into the program. For the purposes of the DD services system review, the Team focused on three eligibility categories—DAC, Katie Beckett, and MIWD—because of the direct impact these eligibility categories have on individuals with disabilities. Full Medicaid State Plan benefits are available to individuals who qualify for the Medicaid program under one of these three eligibility categories.

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[67] Medicaid and Chip Payment and Access Commission (MACPAC). *MACStats: Medicaid and CHIP Data Book 2022*. (2022). Accessed 11 July, 2023. Page 3.
[68] Social Security Administration. *Policy for States and State Choices*. (October 2017). Accessed 11 July, 2023.
[69] The Commonwealth of the Northern Mariana Islands also use the SSI eligibility criteria for Medicaid.
[70] Nebraska Department of Health and Human Services. *Medicaid Disability Reviews*. Accessed 11 July, 2023.
[71] MACPAC. *MACStats: Medicaid and CHIP Data Book 2022*. (2022). Accessed 11 July, 2023. Page 3.
[72] MACPAC. *MACStats: Medicaid and CHIP Data Book 2022*. (2022). Accessed 11 July, 2023. Page 3.

DAC recipients may also be known as childhood disability beneficiaries. Individuals qualifying for Medicaid under DAC requirements must meet all of the following:

- No longer in receipt of SSI after November 10, 1986, due to receipt or increase in Social Security Title II benefits because of the retirement, death, or disability of a parent.
- Age 18 or older.
- Determined to be blind or have a diagnosed disability before the age of 22.
- Would continue to be eligible for SSI if they were not receiving the Title II DAC benefit.[73]

The Katie Beckett eligibility category (also referred to as the Katie Beckett Program) under Nebraska's Medicaid State Plan qualifies children under the age of 19 for Medicaid coverage in certain circumstances. Under the Katie Beckett eligibility category, the income and resources of a parent or guardian are not reviewed; only a child's income and resources are considered to determine Medicaid eligibility for the child.[74] Children must also:

- Meet the age criteria (under age 19).
- Not be eligible for the SSI program or eligible for Medicaid based on parental income.
- Live in the home of a parent or legal guardian.
- Be found to meet a hospital LOC.
- Not incur in-home service costs that would exceed the costs Medicaid would pay if the child received care in a hospital setting.[75]

For the Katie Beckett Program, hospital LOC is met if the child needs one or more of the following:

- A ventilator at least 10 hours per day.

[73] Nebraska Administrative Code. Title 477, Chapter 27. *Eligibility for the Aged, Blind, and Disabled; Medically Needy; Qualified Disabled Working Individuals; Medicaid Insurance for the Workers with Disabilities; Breast and Cervical Cancer; Emergency Medical Services Assistance; and Katie Beckett*. (September 2021). Accessed 6 June, 2023.
[74] Nebraska Department of Health and Human Services. *Katie Beckett Program*. Accessed 6 June, 2023.
[75] Nebraska Administrative Code. Title 477, Chapter 27. *Eligibility for the Aged, Blind, and Disabled; Medically Needy; Qualified Disabled Working Individuals; Medicaid Insurance for the Workers with Disabilities; Breast and Cervical Cancer; Emergency Medical Services Assistance; and Katie Beckett.* (September 2021). Accessed 6 June, 2023.

- Regular bronchial tree suctioning of a tracheostomy.
- Intravenous therapy involving central lines for daily fluids or nutrition at least 10 hours per day.
- Continuous assessment and medical intervention to prevent life-threatening situations.[76]

The MIWD eligibility category allows individuals with a disability, as determined by the SSA or MLTC's SRT, to earn income while working and not be subject to more stringent Medicaid program income limitations. There are two categories of MIWD in which an individual may qualify: the "Basic Coverage Group" or the "Medical Improvement Group." The differences in the Basic Coverage and Medical Improvement Groups are outlined in *Table 6: Comparison of MIWD Coverage Groups*. Both coverage groups are defined by the federal "Ticket to Work and Work Incentives Improvement Act" of 1999.

TABLE 6: COMPARISON OF MIWD COVERAGE GROUPS

	Basic Coverage	Medical Improvement Coverage
Age	At least 16 but less than 65 years old.	At least 16 but less than 65 years old.
Disability	Disabled per SSA or SRT.	Must meet the definition of a medically-improved disability but no longer meet the medical criteria for disability as defined by the SSA or SRT.
Earned Income	Must have earned income, including income from self-employment.	Must have earned income, including income from self-employment.
Income Limit	Combined countable earned/unearned income is more than 100% but less than 250% of the FPL.	Combined countable earned/unearned income is more than 100% but less than 250% of the FPL.
Resource Limit	Countable resources are no more than $4,000 (individual) or $6,000 for a couple.[77]	Countable resources are no more than $4,000 (individual) or $6,000 for a couple.[78]

[76] Nebraska Department of Health and Human Services. *Katie Beckett Program*. Accessed 6 June, 2023.
[77] Nebraska Administrative Code. Title 477, Chapter 27. *Eligibility for the Aged, Blind, and Disabled; Medically Needy; Qualified Disabled Working Individuals; Medicaid Insurance for the Workers with Disabilities; Breast and Cervical Cancer; Emergency Medical Services Assistance; and Katie Beckett*. (September 2021). Accessed 6 June, 2023.
[78] Nebraska Administrative Code. Title 477, Chapter 27. *Eligibility for the Aged, Blind, and Disabled; Medically Needy; Qualified Disabled Working Individuals; Medicaid Insurance for the Workers with Disabilities; Breast and Cervical Cancer; Emergency Medical Services Assistance; and Katie Beckett.* (September 2021). Accessed 6 June, 2023.

Once an individual qualifies for the Nebraska Medicaid program under an eligibility category, an individual generally has full access to the services offered by Nebraska Medicaid.

Medicaid Services

In addition to the mandatory Medicaid services, the Nebraska Medicaid program offers numerous optional services. A*ppendix I: Mandatory and Optional Medicaid Program Services* provides a list of all mandatory and optional services under federal requirements for state Medicaid programs.

With very few exceptions, individuals enrolled in the Nebraska Medicaid program receive services through one of three MCOs. Nebraska's MCOs are responsible for coordinating the services offered under the Medicaid State Plan program. As of the date of this report, MLTC contracts with Healthy Blue, Nebraska Total Care, and UnitedHealthcare as the State-designated MCOs.[79]

During stakeholder engagement, a number of key groups identified the following Medicaid covered services as the most often used and important services to individuals with DD:

- Behavioral health services.
- Case management.
- Dental.
- Durable medical equipment and supplies.
- Hospital stays.
- ICFs/IID.
- Pharmacy.
- Physician services.
- Therapies, including occupational, physical, and speech language pathology.

Though all of these Medicaid State Plan services were noted as important for individuals served in the DD service system, ICF/IID services were noted as playing a particularly critical role for

[79] Nebraska Department of Health and Human Services. *Heritage Health*. Accessed June 6, 2023.

individuals with complex behavioral health concerns. Federally, states are required to provide a choice to individuals for where they receive services.[80] In lieu of receiving services through an HCBS 1915(c) waiver, individuals have the choice to receive services in a setting like an ICF/IID. As noted in the *Stakeholder Engagement* section of this report, ICFs/IID help support people who struggle to live independently and safely outside this setting.

Beatrice State Developmental Center (BSDC) is the only state and federally funded ICF/IID in the state of Nebraska. BSDC provides specialized psychological, medical, and developmental supports to people with IDD. BSDC offers residential settings to about 90 adults who require specialized support in cottages on a campus-like setting. Supports provided include residential, vocational, and other community-based services and supports to individuals across the acuity continuum.[81]

A further discussion of all of the above noted services is found in the *Stakeholder Engagement* section of this report.

Division of Children and Family Services: Economic Assistance and Health Care Programs

Services and programs provided by the Division CFS fill an important gap for those who cannot qualify for the Medicaid program, regardless of the presence of a DD. The Team reviewed a number of programs and services offered by CFS and lists below those programs that further supplement services available to individuals with developmental, physical, or medical disabilities:

- Aid to the Aged, Blind, or Disabled.
- Disabled Children's Program.
- Disabled Persons and Family Support Program.
- Genetically Handicapped Persons Program;
- Lifespan Respite.
- Medically Handicapped Children's Program.
- Social Services Aged & Disabled Adults Program.

The above-mentioned programs are available to eligible individuals; eligibility for each program is distinct, though some may have similar criteria. An example of CFS programs with similar eligibility criteria are Disabled Children's Program and Medically Handicapped Children's

[80] Code of Federal Regulations. *§441.301 Contents of request for a waiver*. Accessed 13 September, 2023.
[81] Nebraska Department of Health and Human Services. *Beatrice State Developmental Center*. Accessed 14 August, 2023.

Program. *Appendix VI: Eligibility for Disabled Children's Program and Medically Handicapped Children's Program* illustrates the unique characteristics of each programs' eligibility requirements, while also highlighting some similarities. In the case of both programs, an individual must be a resident of Nebraska to qualify.

Though eligibility criteria do differ by program, CFS provides an important service safety net to individuals and families who may not meet Nebraska Medicaid program requirements. For a full list of CFS programs, please reference *Appendix II;* program definitions can be found *in Appendix III.*

Division of Behavioral Health: Crisis, Mental Health, and Treatment Services.

DBH administers and provides funding and oversight for a community-based prevention, treatment, and recovery support system. DBH is critically important to serving individuals with DD who may not qualify for, or who may need, services that are unallowable under the Medicaid program. DBH contracts with six Regional Behavioral Health Authorities which are responsible for providing behavioral health services to individuals in their communities. In addition, the Regional Behavioral Health Authorities support provider network initiatives and oversee providers contracted to provide services.[82]

As identified in *Appendices II and III*, DBH covers numerous services under the following broad categories:

- Mental Health Prescriptions Program (LB95).
- Crisis/emergency services.
- Treatment services (hospital/outpatient).
- Rehabilitative services.
- Substance use disorder (SUD) services.

These services are enumerated in DBH's continuum of care manual (Manual), published on DBH's website.[83] In addition to services outlined by DBH in the Manual, Regional Behavioral Health Authorities may also provide region-specific services, depending on the needs and

Co-Occurring Diagnoses

Individuals with intellectual disabilities have an increased risk of developing a psychiatric disorder because of interactions between biological, psychological, and social factors.

National estimates of the prevalence of mental illness in the population with an intellectual disability range from 39-50%+

+Fletcher, Dr. Robert J. and Lynda Gargan. *Emerging Best Practices for People with an Intellectual/Developmental Disability Co-Occurring with Serious Mental Illness.* https://nasmhpd.org/sites/default/files/TAC-Emerging%20Best%20Practices%20for%20People%20with%20an%20Intellectual%20orDevelopmental%20Disability%20Co-Occurring%20with%20Mental%20Illness.pdf. Accessed 6 June, 2023.

[82] Nebraska Department of Health and Human Services. *Behavioral Health*. Accessed 6 June, 2023.

[83] Division of Behavioral Health. *Nebraska Continuum of Care Manual for Mental Health and Substance Use Disorders*. (July 2022). Accessed 6 June, 2023.

resources available to the community. Region-specific services may be found on each of the Regional Behavioral Health Authorities websites.

Estimates of co-occurring mental illness range from 39-50 percent for individuals with intellectual and developmental disabilities.[84] As such, the importance of DBH and the Regional Behavioral Health Authorities cannot be overstated for people with DD. DBH and their partners provide a wide variety of services to address behavioral health needs, but these services may be accessed through different pathways, often depending on whether the service may be reimbursed through the Medicaid program. Integration of behavioral health services between Divisions and payers is not seamless, leading to challenges in accessing services.

Services Offered Outside of the Nebraska Department of Health and Human Services

Aged and Disabled Resource Centers, State and Regional Partners

Aging and Disability Resource Centers (ADRCs) were first introduced through a partnership between the Administration for Community Living, CMS, and the Veteran's Health Administration as a part of their No Wrong Door system initiative created to support state efforts to improve access to long-term services and supports for older adults and individuals with disabilities. No Wrong Door systems are intended to ensure that no matter where in the system an individual initiates services, they can easily find their way to the appropriate services.[85]

The goal of an ADRC is to establish, in every community, trusted and easily accessible sources of information to connect individuals to needed services. ADRCs are intended to build on already established state resources for aging and disability. Area Agencies on Aging (AAA) are local supports for the aging population, and nationally, nearly two-thirds of AAAs perform ADRC services in their local communities. Services are available to all individuals regardless of income level. [86]

Nebraska started the ADRC as a pilot project in 2016, and made it permanent in 2018. The ADRC is available to all Nebraskans, ages 60 and older, people with disabilities of all ages, and their families, caregivers and advocates. ADRCs offer information, referrals, and support for individuals who are seeking assistance in accessing community services and long-term care options. Legislative Bill 856 passed in April 2022, authorized funding of participating disability partners

[84] Fletcher, Dr. Robert J. and Lynda Gargan. *Emerging Best Practices for People with an Intellectual/Developmental Disability Co-Occurring with Serious Mental Illness*. Accessed 6 June, 2023.
[85] Administration for Community Living. *Aging and Disability Resource Centers Program / No Wrong Door System*. (January 2022). Accessed 23 June, 2023.
[86] USA Aging. *Aging and Disability Resource Centers*. Accessed 23 June, 2023.

through the State Unit on Aging. [87] In FY 2022, the ADRCs recorded 11,241 total contacts statewide, which can consist of a brief call or in-person discussion.[88]

The local AAA can provide ADRC services but requires partnership with organizations that serve the disability community.[89] ADRCs are joined by statewide and regional partners. Statewide partners include: [90]

- Brain Injury Alliance Nebraska.
- Easterseals Nebraska.
- League of Human Dignity.
- Munroe Meyer Institute.

Nebraska is divided into eight regional AAAs. The following are the regional partner agencies:[91]

- Blue Rivers Area Agency on Aging (southeast corner).
- Eastern Nebraska Office on Aging (eastern).
- Aging Partners Area Agency on Aging (southeast).
- Midland Area Agency on Aging (eastern south central).
- Northeast Nebraska Area Agency on Aging (northcentral to northeast).
- South Central Agency on Aging (south central).
- West Central Nebraska Area Agency on Aging (west central to south west).
- Aging Office of Western Nebraska (west and northwest).

Figure 5: Nebraska ARDC Landscape displays a map of Nebraska and the regional partner agency coverage areas.

[87] Nebraska Department of Health and Human Services. *Aging & Disability Resource Center Report*. (December 2022). Accessed 12 June, 2023. Page 4.
[88] Nebraska Department of Health and Human Services. *Aging & Disability Resource Center Report*. (December 2022). Accessed 12 June, 2023. Page 10.
[89]Nebraska Department of Health and Human Services. *Aging and Disability Resource Center*. Accessed 12, June 2023.
[90] Nebraska Department of Health and Human Services. *Nebraska Aging and Disability Resource Centers & Area Agencies on Aging*. Accessed 12 June, 2023.
[91] Nebraska Aging and Disability Resource Center. *State and Regional Partners*. Accessed 12 June, 2023.

FIGURE 5: NEBRASKA ARDC LANDSCAPE[92]

Nebraska Aging and Disability Resource Centers (ADRCs) & Area Agencies on Aging (AAAs)

844-843-6364 http://ADRCNebraska.org/ (routes to 2-1-1)

Resources

● **Brain Injury Alliance**
402-423-2463
844-423-2463
https://biane.org
P.O. Box 22147
Lincoln, NE 68542
Staff are available to meet in-person in the Omaha, Grand Island, and North Platte areas.

▲ **Easterseals Nebraska**
402-462-3031
800-471-6425
https://www.easterseals.com/ne/
Omaha, Geneva, Lincoln, Petersburg, Hastings, Bertrand, Doniphan, Sidney, York, Fort Calhoun, Fremont, Blue Hill

■ **Munroe Meyer Institute**
402-559-6418
800-656-3937
https://unmc.edu/mmi/
6902 Pine ST
Omaha, NE 68106

✚ **League of Human Dignity**
https://leagueofhumandignity.com/
Omaha Office
402-595-1256
800-843-5784

Lincoln Office
402-441-7871
800-508-4758

Kearney Office
308-224-3665
877-544-3296

North Platte Office
308-532-4911
877-870-4911

Scottsbluff Office
308-632-0470
877-298-1380

Norfolk Office
402-371-4475
800-843-5785

0 25 50 Miles N

1-844-843-6364
Press # for local office:
1 BIA-NE
2 Easterseals
3 LHD
4 MMI
5 for Aging Offices:
1 Scottsbluff
2 Lincoln
3 Beatrice
4 Omaha
5 Hastings
6 Norfolk
7 Kearney
8 North Platte

Western Nebraska
Northeast Nebraska
South Central Nebraska
West Central Nebraska
Midland
Aging Partners
Eastern Nebraska
Blue Rivers

SCOTTSBLUFF, SIDNEY, NORTH PLATTE, NORFOLK, PETERSBURG, FREMONT, FORT CALHOUN, OMAHA, KEARNEY, BERTRAND, DONIPHAN, HASTINGS, BLUE HILL, YORK, GENEVA, LINCOLN, BEATRICE

★ Aging Office of Western Nebraska AAA & ADRC
308-635-0851, 800-682-5140
www.aown.org
1517 Broadway, Suite 122
Scottsbluff, NE 69361

★ Northeast Nebraska AAA & ADRC
402-370-3454, 800-672-8368
www.nenaaa.com
119 W Norfolk AVE
Norfolk, NE 68701

★ Eastern Nebraska Office on Aging & ADRC
402-444-6536, 888-554-2711
www.enoa.org
4780 South 131 ST
Omaha, NE 68137

★ West Central Nebraska AAA
308-535-8195, 800-662-2961
www.wcnaaa.org
115 North Vine
North Platte, NE 69101

★ South Central Nebraska AAA & ADRC
308-234-1851, 800-658-4320
www.agingkearney.org
620 East 25th ST, Suite 12
Kearney, NE 68847

★ Midland AAA & ADRC
402-463-4565, 800-955-9714
www.midlandareaagencyonaging.org
2727 West 2nd ST, Suite 440
Hastings, NE 68901

★ Aging Partners AAA & ADRC
402-441-7070, 800-247-0938
https://www.lincoln.ne.gov/City/Departments/Aging-Partners
600 S. 70th ST, BLDG 2
Lincoln, NE 68510

★ Blue Rivers AAA & ADRC
402-223-1376, 888-989-9417
www.braaa.org
103 Eastside Boulevard
Beatrice, NE 68310

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Good Life. Great Mission.
DEPT. OF HEALTH AND HUMAN SERVICES
RESOURCES UPDATED: MARCH 2023

Throughout the state, available services vary by region but are also offered by some of the statewide partners. *Table 7: ADRC Services Available through AAA and Statewide Partners FY 2022* summarizes services provided by each statewide partner.

[92] Nebraska Department of Health and Human Services. *Nebraska Aging and Disability Resource Centers & Area Agencies on Aging*. Accessed 8 July, 2023.

Table 7: ADRC Services Available through AAA and Statewide Partners FY 2022[93]

AAA and Statewide Partners	ADRC Services
Aging Office of Western Nebraska	• Information and referral. • Options counseling.
Aging Partners Area Agency on Aging	• Benefits analysis. • Information and referral. • Options counseling.
Blue Rivers Area Agency on Aging	• Information and referral. • Options counseling.
Brain Injury Alliance Nebraska	• Information and referral. • Options counseling.
Eastern Nebraska Office on Aging	• Information and referral. • Options counseling.
Easterseals Nebraska	• Benefits analysis. • Information and referral. • Options counseling. • Transitional options counseling.
League of Human Dignity	• Benefits analysis. • Information and referral. • Mobility training. • Options counseling. • Transitional options counseling.
Midland Area Agency on Aging	• Benefits analysis. • Information and referral. • Options counseling.
Munroe-Meyer Institute (MMI)	• Information and referral. • Options counseling. • Transitional options counseling.
Northeast Nebraska Area Agency on Aging	• Information and referral. • Options counseling.
South Central Agency on Aging	• Benefits analysis. • Information and referral. • Options counseling.
West Central Nebraska Area Agency on Aging	• No ADRC services provided.

[93] Nebraska Department of Health and Human Services. *Aging & Disability Resource Center Report*. (December 2022). Accessed 12 June, 2023. Page 7.

Figure 6: Number of ADRC Services Provided Statewide shows how many services were provided by service type in FY 2021 and 2022.

FIGURE 6: NUMBER OF ADRC SERVICES PROVIDED STATEWIDE[94]

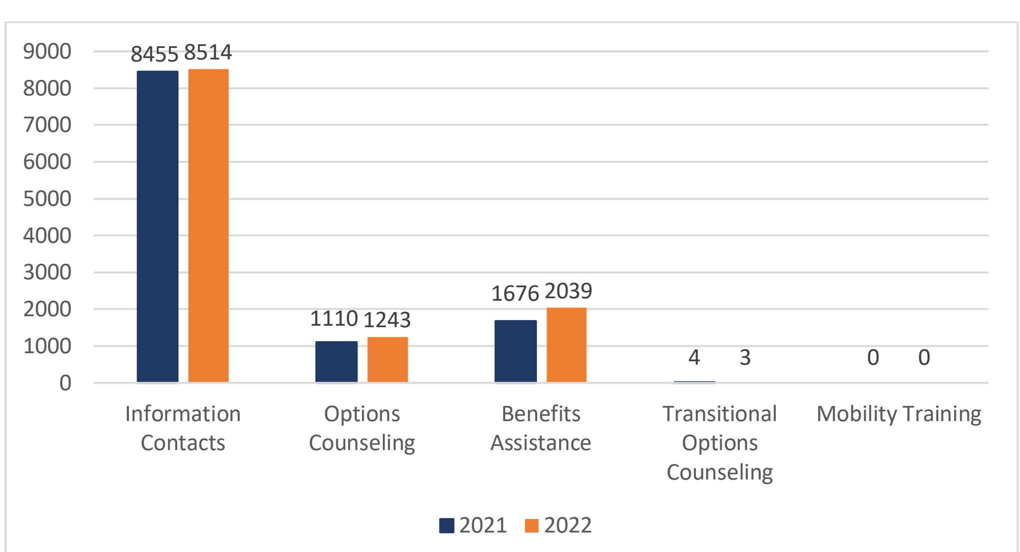


Figure 7: Total ADRC Contacts in FY 2022 by Agency shows how many of the total contacts were provided by each regional and statewide agency in Nebraska.

[94] Nebraska Department of Health and Human Services. *Aging & Disability Resource Center Report*. (December 2022). Accessed 12 June, 2023. Page 10.

FIGURE 7: TOTAL ADRC CONTACTS IN FY 2022 BY AGENCY[95]

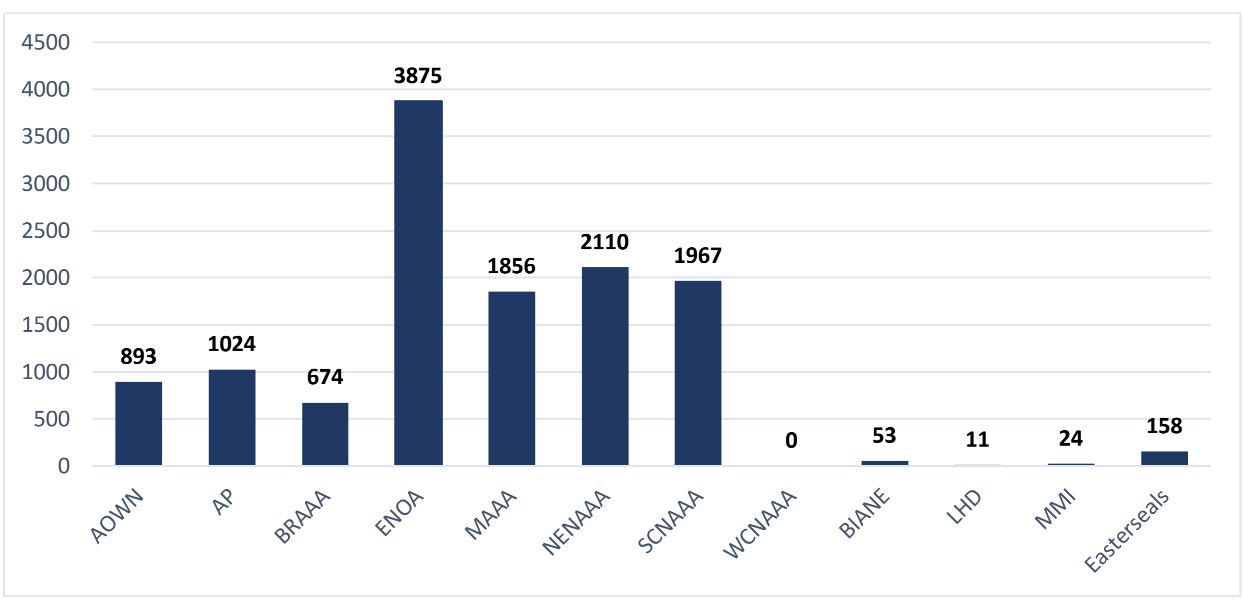
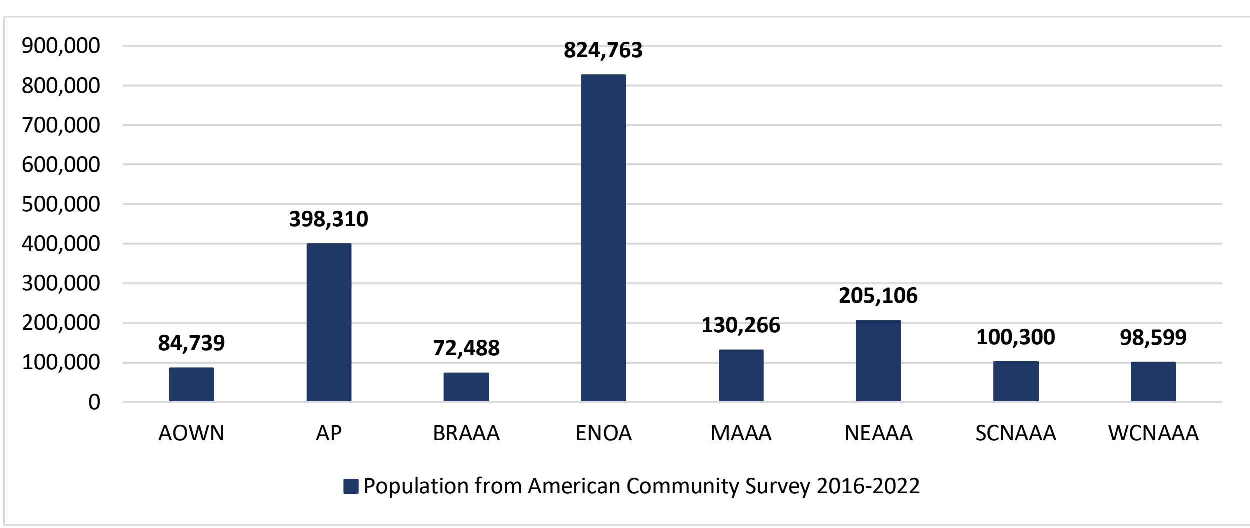


Figure 8: Nebraska Population by ADRC Region is an illustration of the population breakdown per ADRC regional coverage area.

FIGURE 8: NEBRASKA POPULATION BY ADRC REGION[96]



[95] Nebraska Department of Health and Human Services. Aging & Disability Resource Center Report. (December 2022). Accessed 12 June, 2023. Page 14.
[96] Nebraska Department of Health and Human Services. Aging & Disability Resource Center Report. (December 2022). Accessed 12 June, 2023. Page 6.

A review of the ADRC Report from December 2022 reveals that while all counties are covered by a regional agency, different regions have different services available. Considering the above information as a collective representation of the state of the ADRCs in Nebraska, the data demonstrates that service coverage and outreach efforts are limited in certain areas of the state. For example, the region covered by West Central Nebraska Area Agency on Aging (WCNAAA) offers zero services and had zero contacts for the entire region in FY 2022. ADRC coverage and service limitations adversely impact consumers with disabilities, who may be reliant on ADRC services.

Nebraska Commission for the Blind and Visually Impaired

The Nebraska Commission for the Blind and Visually Impaired (NCBVI) is the state agency responsible for providing vocational rehabilitation services to individuals who are blind or have a visual impairment. NCBVI offers a number of programs and services that support individuals in achieving full participation in the community.[97] Programs and services are provided at no cost to qualifying individuals.[98]

There are three types of services and five types of programs administered by NCBVI, which are described in *Table 8: Program and Service Descriptions: Nebraska Commission for the Blind and* Visually-Impaired*.*

[97] Nebraska Commission for the Blind And Visually Impaired. *Annual Report for Calendar Year 2022*. Accessed 27 June, 2023. Page 3.
[98] Nebraska Commission for the Blind and Visually Impaired. *Vocational Rehabilitation*. Accessed 27 June, 2023.

TABLE 8: PROGRAM AND SERVICE DESCRIPTIONS: NEBRASKA COMMISSION FOR THE BLIND AND VISUALLY-IMPAIRED

Description of NCBVI Programs and Services
VR: The VR program works with blind and visually-impaired individuals in preparation to enter, maintain, or advance in full-time or, if appropriate, part-time competitive employment in the integrated labor market.[99]
Older Adults with Vision Loss: NCBVI offers specialized services and programs for individuals who are 55 and older to promote maintaining independence.[100]
Independent Living: There are two types of independent living for individuals 0-13 years of age and those who are 14-54 years of age. Independent living for children is focused on providing training and support to the child, family, and schools. For adults, independent living is focused on teaching individuals skills needed for daily living activities.[101]
The Nebraska Center for the Blind: The Nebraska Center for the Blind is a blindness rehabilitation training facility for adults who are blind living in Nebraska. The Nebraska Center for the Blind utilizes the "Structured Discovery" approach to training students in the alternative skills of blindness, which is the leading cognitive-based training methodology in the field of blindness rehabilitation.[102]
Technology services: NCBVI Technology Services provide technology services to blind and visually-impaired consumers across the state.[103]
Deaf-blindness services: Deaf-blindness services are provided through the Nebraska Individuals with Deaf-Blindness Project, an affiliate of the Helen Keller National Center for Deaf-Blind Youth Adults. The Project helps support individual's ability to live independently, living in their communities of choice, along with vocational goals.[104]
Employer services: NCBVI works to match Nebraskans receiving services and supports from NCBVI with employers seeking to fill positions. NCBVI offers employers a number of services, including but not limited to staff consultations and employer training.[105]

NCBVI also supports the Nebraska Business Enterprises program, which implements federal legislation, targeting vendors who are blind by providing needed rehabilitation and employment opportunities. Nebraska Business Enterprises supports vendor-owners who are blind with vending machine contracts across the state, including Interstate rest areas.[106]

In 2022, NCBVI served the following individuals:

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[99] Nebraska Commission for the Blind and Visually Impaired. *Annual Report for Calendar Year 2022*. Accessed 27 June, 2023. Page 4.
[100] NCBVI. *Older Adults with Vision Loss*. Accessed 27 June, 2023.
[101] NCBVI. *Older Adults with Vision Loss*. Accessed 27 June, 2023.
[102] Nebraska Commission For The Blind And Visually Impaired. *Annual Report for Calendar Year 2022*. Accessed 27 June, 2023. Page 10.
[103] Nebraska Commission for the Blind and Visually Impaired. *Annual Report for Calendar Year 2022*. Accessed 27 June, 2023. Page 10.
[104] NCBVI. *Deaf-Blind Services*. Accessed 27 June, 2023.
[105] NCBVI. *Employer Services*. Accessed 28 June, 2023.
[106] NCBVI. *Nebraska Business Enterprises*. Accessed 27 June, 2023.

- Approximately 470 individuals in the NCBVI VR program, 191 of which have at least one other disability in addition to blindness or visual impairment.
- 214 youth between the ages of 14-24, in transition services under the NCBVI VR program;
- 91 individuals received Independent Living Services.
- 524 individuals were enrolled in the Older Individuals who are Blind program.[107]

Despite serving several hundred people in 2022, NCBVI does operate a waiting list for services, based on order of selection, which is a federally-mandated method required of VR agencies when funding is limited. Federal and state regulations require NCBVI to serve individuals with the most significant disabilities first. [108] As such, NCBVI has created three priority categories as part of their order of selection process that are presented in *Table 9: Order of Selection Priority Categories.* Items in *Table 9* that are **bolded** indicate the differences between Categories A and B.

[107] Nebraska Commission For The Blind And Visually Impaired. *Annual Report for Calendar Year 2022*. Pages 5-16.
[108] Nebraska Commission For The Blind And Visually Impaired. *Order of Selection Frequently Asked Questions*. Accessed 6 June, 2023. Pages 1-2.

TABLE 9: ORDER OF SELECTION PRIORITY CATEGORIES

Priority Group	Priority Group Criteria
Priority Category A (most significant disability)	• Has a severe visual impairment or combination of visual, physical, or mental impairment that profoundly limits functional limitations in terms of an employment outcome in five or more of the following functional areas: mobility, communication, self-care, self-direction, work skills, interpersonal skills, or work tolerance. • Is expected to require **at least four** VR services for **at least 12 months**. • Meets the definition contained in "List of physical or mental disabilities."
Priority Category B (significant disability)	• Has a severe visual impairment or combination of visual, physical, or mental impairment that seriously limits functional limitations in terms of an employment outcome in three or four of the following functional areas: mobility, communication, self-care, self-direction, work skills, interpersonal skills, or work tolerance. • Is expected to require **at least three** VR services for **at least six months**. • Meets the definition contained in "List of physical or mental disabilities."
Priority Category C (all other eligible individuals with a disability)	• Does not meet the definition of Individual with a Most Significant Disability or the definition of Individual with a Significant Disability.[109]

NCBVI must provide information and referral services to individuals placed on the waiting list, as well as contact information for their local Workforce Center.

NCBVI provides a variety of services and supports to individuals who are blind or have a visual impairment.

[109] Nebraska Commission For The Blind And Visually Impaired. *Order of Selection Frequently Asked Questions*. Accessed 6 June, 2023.

Munroe-Meyer Institute

The MMI is part of the University of Nebraska Medical Center providing research, education, and key diagnostic services and a wide variety of other therapeutic and supportive services to individuals and their families. For over a century, MMI has cared for children and individuals with disabilities who have complex heath care needs and their families.[110] It serves as a source of disability-related information to scientists, care providers, clinicians, families, and community leaders across the region and beyond and acts as both provider and advocate at the local, state, federal, and international levels to promote best practices, policies, and/or laws.[111]

Since 1968, MMI was designated as a University Center for Excellence in Developmental Disabilities (UCEDD) through the U.S. Department of Health and Human Services. The UCEDD program at MMI provides a liaison between the university and the community. It promotes independence, self-determination, and inclusion for individuals with developmental and intellectual disabilities.[112] In addition to MMI's designation as a UCEDD, MMI also operates a Leadership Education in Neurodevelopmental Disabilities Program, which supports interdisciplinary training for graduate students, post-doctoral interns, and other professionals focused on evidence-based practices.[113]

Munroe-Meyer's Footprint

The MMI has 35 provider locations across Nebraska, with 17 outside of Omaha.

In 2022, Munroe-Meyer served individuals in 74 of Nebraska's 93 counties, and provided over 90,000 services.*

*Munroe-Meyer Institute. *The Munroe-Meyer Institute's Statewide Impact 2022 Annual Report. Accessed 8 July, 2023. Page 29.*

MMI has programs in patient care, family resources, training, and research in areas that support individuals with developmental and other disabilities along with their families and caregivers. MMI uses an interdisciplinary team approach that includes parents, teachers, therapists, and community service providers to offer a comprehensive service program. MMI specializes in over 50 types of clinical services and provides patient care at over 40 locations across Nebraska. *Table 10: UCEDD Services Overview* provides a description of the categories of services provided by MMI.[114]

[110] The Munroe-Meyer Institute. *History*. Accessed 7 July, 2023.
[111] University of Nebraska Medical Center. *Munroe-Meyer Institute About Us, Leadership & Mission*. Accessed June 11, 2023.
[112] University of Nebraska Medical Center. *Munroe-Meyer Institute, UCEDD*. Accessed 11 June, 2023.
[113] Munroe-Meyer Institute. *Leadership Education in Neurodevelopmental Disabilities Program*. Accessed 8 July, 2023.
[114] University of Nebraska Medical Center, Munroe-Meyer Institute. *UCEDD*. Accessed 16, June 2023.

TABLE 10: UCEDD SERVICES OVERVIEW

Service Category	Description
Community information and training	• DD information sessions. • DD topic training. • Paid disability advocacy and leadership traineeship (two individuals annually).
Leadership, advocacy, and support	Assist with access to disability-specific organizations: • Advocacy. • Support and leadership opportunities. • Civil and legal resources.
Lifespan resources	Care coordination to find resources specific to families that have a child with disabilities.
Policy and systems change activities	• Staff serve on national and state public policy and planning committees. • Disability-related task force, policy, and legislative activities.
Programs and supports	Help with access to disability-specific organizations: • Advocacy. • Support and leadership opportunities. • Civil and legal resources.

Within the categories of services noted in *Table 8*, there are numerous programs available through MMI, including the following:

- Assistive technology.
- Autism diagnostic services.
- Care coordination.
- Dental treatment.
- Genetic medicine.
- Occupational therapy.
- Pediatric feeding disorder services.
- Physical therapy.
- Psychology.

- Recreational therapy.
- Speech-language pathology.[115]

Referrals for services are generally sent to MMI's individual and family resource coordinators by schools, physician's offices, and families themselves. Once a referral occurs and an individual is found eligible, MMI services may be covered through a variety of insurance options, including Medicaid, employer, and private-pay insurance.[116]

Birth to 21 Educational Services

The Nebraska Department of Education, Office of Special Education oversees guidance for educational service provision for individuals with disabilities from birth until age 21. Birth to 21 educational services in Nebraska include early intervention services provided through Nebraska's Early Development Network (ages 0-3) and school-based services (ages 3-21). Early intervention and school-based services play a critical role for individuals with DD and health care needs in connecting individuals and families to vital services.[117]

The Nebraska Early Development Network is composed of 29 regions that offer service coordination and other services such as educational, social, transition, and medical services[118] Nebraska's early intervention developmental delay eligibility criteria are covered in Title 92 of Nebraska Administrative Code, Chapter 52. 006.04.[119] Eligibility for free and public education early intervention services is established when the school district or approved cooperative determines that the infant or toddler is experiencing a developmental delay[120] or any of the other disabilities described in regulation.[121] For a child with a developmental delay to qualify for early intervention services, the child must have one of the following:

- Diagnosis related to a physical or mental condition that is likely to result in a substantial developmental delay; or

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[115] Munroe-Meyer Institute. *Programs and Services*. Accessed 8 July, 2023.
[116] MMI Clinical Directors Meeting. 28 June, 2023.
[117] Nebraska Early Development Network. *The Nebraska Early Development Network*. Accessed 22 June, 2023.
[118] Nebraska Early Development Network. *What is Early Development Network Service Coordination?* (May 2015). Accessed 22 June, 2023.
[119] Nebraska Department of Education. *Title 92, Nebraska Administrative Code, Chapter 52*. (July 2014). Accessed 22 June, 2023. Page 16.
[120] 92 NAC 52-006.04A
[121] Nebraska Administrative Code. Title 92 Chapter 51. *Regulations and Standards for Special Education Programs*. Accessed 8 July, 2023.

- Significant developmental delay related to: cognitive development; physical development, including vision and hearing; communication development; social or emotional development; or adaptive development.[122]

Similar to an individualized family service plan offered from birth to three, children who meet criteria for a school-age eligibility category are offered an IEP. The individualized family service plan and IEP detail current ability levels and needs, goals, placements, direct and related services, accommodations, and modifications necessary to guarantee the individual access to free and public education.[123] *Figure 9: Nebraska School-Age Special Education Eligibility Categories* illustrates the types of diagnoses and conditions that qualify a child or youth for special education services. *Appendix VII: Nebraska School-Age Eligibility Categories and State Definition* includes additional details on the criteria for each of the eligibility categories listed in *Figure 9*.

FIGURE 9: NEBRASKA SCHOOL-AGE SPECIAL EDUCATION ELIGIBILITY CATEGORIES[124]

Autism
Deaf-Blindness
Deaf or Hard of Hearing
Developmental Delay
Emotional Disturbance
Intellectual Disability
Multiple Disabilities
Orthopedic Impairment
Other Health Impairment
Specific Learning Disabilities
Speech-Language Impairment
Traumatic Brain Injury
Visual Impairment

School-age services are provided for a limited time and are offered with the goal that students exit services in a manner that successfully prepares them for community-integrated employment in adulthood. A key component necessary for successful post-secondary outcomes is transition planning. IEPs for individuals between the ages of 14 and 21 are required to include transition

[122] Nebraska Department of Education. *Title 92, Nebraska Administrative Code, Chapter 52*. (July 2014). Accessed 22 June, 2023. Page 16.
[123] U.S. Department of Education. *Individuals with Disabilities Education Act*. Accessed 9 June, 2023.
[124] Nebraska Department of Education. *Special Education Eligibility Guidelines*. Accessed 9 June, 2023.

planning for the student's adult life, which includes both current and post-secondary needs. Transition planning into the workforce is important for young individuals with disabilities because they are more than twice as likely to experience poverty than their peers without disabilities.[125] Review of the data from Nebraska's Post-School Outcomes Project reveals school-aged individuals with intellectual disability and multiple disabilities were significantly less likely than all other eligibility groups to have enrolled in higher education or other post-secondary education or training programs or be competitively employed within one year of leaving high school. *Figure 10: Post-School Outcomes for Individuals by Special Education Eligibility Category* compares post-secondary school outcomes by special education eligibility category.

[125] Nebraska Department of Education, Office of Special Education. *Transition Planning.* January 2022. Accessed 9 June, 2023. Page 5.

FIGURE 10: POST-SCHOOL OUTCOMES FOR INDIVIDUALS BY SPECIAL EDUCATION ELIGIBILITY CATEGORY[126]

Category	Enrolled in Higher Education	Enrolled in Higher Education or Competitively Employed	Enrolled in Higher Education or Post-Secondary Education or Training Program, or Competitively Employed
Autism	29.5%	46.7%	64.8%
Emotional Disturbance	28.6%	54.8%	71.4%
Hearing Impaired	46.7%	73.3%	86.7%
Intellectual Disability	1.3%	21.1%	57.9%
Multiple Impairment	0.0%	0.0%	9.1%
Orthopedic Impairment	28.6%	28.6%	42.9%
Other Health Impairment	35.2%	64.2%	74.2%
Specific Learning Disability	39.4%	74.7%	86.3%
Speech-Language Impairment	34.3%	71.4%	85.7%
Traumatic Brain Injury	0.0%	40.0%	60.0%
Visual Impairment	80.0%	80.0%	100.0%

Vocational Rehabilitation Services

Nebraska VR Services is an employment program within the Nebraska Department of Education for people who have disabilities. In addition to the administrative offices located in Lincoln, VR has 12 service offices, collectively responsible for providing services to 12 regions of the state.[127]

[126] Nebraska Department of Education. *Nebraska Post-School Outcomes - Measuring Outcomes for Youth with Disabilities*. (January 2023). Accessed 9 June, 2023. Pages 6 and 9.

[127] Nebraska Vocational Rehabilitation. *How to Reach Us?* Accessed 29 June, 2023.

Like the Medicaid program, VR is jointly funded by the federal government and the states. VR serves people with all types of disabilities, with the exception of individuals who are blind or visually-impaired and receive services through NCBVI.[128]

VR serves approximately 6,000 individuals per year. It is estimated that in 2022, over 1,800 Nebraskans were successful entering the workforce with the assistance of VR.[129] To qualify for VR services, an individual must meet the following eligibility criteria:

- Diagnosis of a disability, including a physical, mental, emotional, or learning disability.
- Demonstration that the disability interferes with the ability to retain employment or may cause challenges in preparing for and finding future employment.
- Evidence that VR services will be beneficial for an individual in obtaining and retaining employment.[130]

Table 11: Primary Disability Type Served by Vocational Rehabilitation provides a breakdown of data published by the United States Department of Education in 2022, on the number of individuals served by Nebraska VR within disability groups.[131] *Appendix VIII: Populations Served by Vocational Rehabilitation* provides additional details regarding the number of individuals served with specific disabilities.

TABLE 11: PRIMARY DISABILITY TYPE SERVED BY VOCATIONAL REHABILITATION

Primary Disability Type by Group	PY 17 Number of Participants	PY 17 Percent	PY 18 Number of Participants	PY 18 Percent	PY 19 Number of Participants	PY 19 Percent
Visual	-	0%	-	0%	-	0%
Auditory/ Communicative	470	8.3%	259	8.6%	174	8.5%
Physical	1,138	20.1%	635	21.1%	422	20.7%
Cognitive	1,975	34.9%	1,192	39.6%	932	45.6%
Psychological/ Psychosocial	2,072	36.6%	921	30.6%	515	25.2%

Similar to the services provided by NCBVI, VR services are dedicated to helping people with disabilities prepare for, find, or keep employment. Individuals who choose to participate in VR

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[128] Nebraska Department of Education. *Nebraska Vocational Rehabilitation – Who We Are*. Accessed 29 June, 2023.
[129] Nebraska Department of Education. *Nebraska Vocational Rehabilitation – Who We Are*. Accessed 29 June, 2023.
[130] Nebraska Department of Education. *Nebraska Vocational Rehabilitation – Who We Are*. Accessed 29 June, 2023.
[131] United States Department of Education. *Federal Fiscal Year 2021 Report On The Review Of Nebraska Vocational Rehabilitation*. Accessed 6 June, 2023. Page 48.

will have access to services that are person-centered and delivered based on information included in the individual's individualized plan for employment. Generally, the individualized plan for employment will include the following:

- Employment goal(s) of an individual, including when the individual would like to reach their goals.
- All the services an individual needs to attain their employment goal(s).
- The responsible party for providing services (unlike NCBVI, some individuals may hold responsibility for partially paying for VR services).
- The party responsible for paying for services.[132]

There are a variety of items and services that VR can purchase. According to the State Rehabilitation Council's 2021-2022 annual report, VR funding was used to support some of the following items and services:

- Pre-employment transition services.
- Supported employment.
- Occupational/vocational training.
- Transportation.
- Benefits counseling.
- College and graduate school.
- Job placement assistance.[133]

When funding is limited and VR services cannot be provided to all individuals who qualify, VR operates under an Order of Selection Policy.[134] Individuals are placed in one of three priority groups, which are designed to consider limitations in functional areas and the amount of services an individual is likely to require. Specific information for each of the priority groups is listed below.

[132] United States Department of Education. Federal Fiscal Year 2021 Report On The Review Of Nebraska Vocational Rehabilitation. Accessed 6 June, 2023. Page 48.
[133] Nebraska State Rehabilitation Council. *Report of the Nebraska State Rehabilitation Council*. (2022). Accessed 11 July, 2023. Page 5.
[134] Nebraska Department of Education. *Nebraska Vocational Rehabilitation – Order of Selection Fact Sheet*. Accessed 6 June, 2023.

- Priority Group 1 Criteria: An eligible individual with severe physical or mental impairments resulting in a serious limitation of two or more functional areas and who requires multiple services over an extended period of time. Individuals in Priority Group 1 are selected for services before all other eligible persons if, and when, sufficient funds become available.

- Priority Group 2 Criteria: An eligible individual with severe physical or mental impairments resulting in a serious limitation of one functional area and who requires multiple services over an extended period of time. Individuals who receive SSDI or SSI automatically qualify for Priority Group 2 and are assessed to determine whether they qualify for Priority Group 1.

- Priority Group 3 Criteria: This group includes all other eligible individuals who have a limitation in at least one of the seven functional areas.[135]

According to the Nebraska VR website, there is currently no wait list for any of the priority groups. In May 2021, Nebraska VR submitted an amendment for the VR services portion of the Combined State Plan for Nebraska's Workforce System Program [136] with the intent to open its Priority Group 1 – Individuals with the Most Significant Disabilities. Rehabilitative Services Administration (RSA) reviewed and approved the amendment request. This allowed Nebraska VR to remove all individuals from Priority Group 1 and 2 waitlists and close the Priority Group 3 category. Although Priority Group 3 is officially closed, any individuals who fall into Priority Group 3 criteria are added to the list and removed within one week. [137]

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[135] Nebraska Department of Education. *Nebraska Vocational Rehabilitation – Order of Selection Fact Sheet*. Accessed 6 June, 2023.
[136] Nebraska Department of Education. *Nebraska Vocational Rehabilitation – Combined State Plan for Nebraska's Workforce System Program Years 2020-2023.* Accessed 11 July, 2023.
[137] Nebraska Department of Education. Nebraska Vocational Rehabilitation - Welcome to Nebraska VR, Order of Selection Accessed 6 June, 2023.

Peer State Service System Reviews

Peer states included in this research were chosen because of their demographic similarities, DD service system programming, existence of Medicaid MCOs, and input from the Governor's DD Advisory Committee. *Appendix IX: Peer State Summary Information* provides a snapshot of the criteria the Team considered when choosing the nine peer states.

For the purposes of our evaluation, the Team reviewed information from:

- Colorado
- Kansas
- Missouri
- Ohio
- Oklahoma
- Pennsylvania
- South Dakota
- Tennessee
- Wisconsin

The following section includes detailed review of the peer state DD service systems. The Team used this review to conduct a comparative analysis of key components of the Nebraska state DD system. This analysis was used to inform our observations on the strengths and weakness of Nebraska's service system.

Peer State Programs and Services

Due to flexibilities inherent within the Medicaid program, each of the nine peer states is unique in the way they deliver programs and services to individuals with intellectual and developmental disabilities (I/DD), just as they are unique in the way their health and human service systems are designed and operated. Like Nebraska, some states operate under an umbrella type agency like DHHS, where responsibilities are shared, while other states have separate departments or agencies dedicated to administration and operation of specific DD programs, the Medicaid program, and other support services.

The programs and services included in the review of peer states were:

- 1915(c) waivers.
- Medicaid programs (including the disability determination process, eligibility categories, and service requirements and coverage).
- Services and supports that are part of the DD service system but are not funded by federal Medicaid dollars.

To assist in providing a complete landscape of peer state programs and services, detailed information is presented in the following section.

Peer State 1915(c) Waivers: Overview

Across the nine peer states, there are 56 approved 1915(c) waiver programs. The Team reviewed all 56 as part of the DD service system evaluation. The review identified some key differences in target population characteristics and operating authorities. Some waiver programs are targeted to specific age ranges (children and adults), while others are open to all ages. We also found evidence of 1915(c) waiver programs that incorporate more than one LOC.

Also of note, some peer states operate their waiver programs solely under the 1915(c) authority, while others operate their 1915(c) waiver programs in conjunction with managed care authorities approved under 1915(b) waivers. States use the combined authorities primarily to mandate enrollment into managed care, employ cost savings to furnish additional services, and limit choice in providers for certain covered services.

Tennessee is the only state in which enrollment to a 1915(c) waiver is closed. Tennessee still operates three 1915(c) ICF/IID waivers, including the Comprehensive Aggregate Cap Waiver, the Statewide Waiver Program, and the Self-Determination Waiver Program; however, the State is no longer enrolling new individuals to these programs.[138] Instead, all new individuals who are seeking HCBS DD services are referred to the Employment and Community First Choices managed care program.

Tennessee has taken steps to integrate DD services into the state Medicaid agency's (known as TennCare) managed care program. As part of this integration, all individuals who otherwise would have sought services under one of the state's 1915(c) waivers may be eligible to enroll in the Employment and Community First CHOICES Program.[139] The Employment and Community First CHOICES Program is discussed in more detail in the *Peer State Medicaid Programs* section below.

Appendix X: Peer State 1915(c) Waivers lists all the 1915(c) waiver programs reviewed for this evaluation. Waiver applications, effective dates, and sources referenced in this report are

[138] Tennessee Division of TennCare. 1915(c) HCBS waivers. Accessed 24 June, 2023.
[139] Tennessee Division of TennCare. Frequently Asked Questions. Accessed 24 June, 2023.

Peer State Assessment Tools

Peer states use a wide variety of assessment tools to determine eligibility for 1915(c) waiver programs. Tools are homegrown, standardized instruments, or a combination. In addition, states use customized, state-specific versions of standardized assessments for some of their 1915(c) programs.

identified in *Appendix XI: Peer State Waiver Application References*. Unless otherwise noted, information contained herein can be found within these applications.

Eligibility and Enrollment

The eligibility and enrollment processes for 1915(c) waiver programs employed by the nine peer are not drastically dissimilar from those in Nebraska. Depending on 1915(c) program design, the states that limit 1915(c) waiver program enrollment to certain age and target groups also use a wide variety of LOC assessment tools, including those that are homegrown, to determine eligibility.

One of the most important factors for determining 1915(c) waiver program eligibility and enrollment is an individual's LOC. As discussed previously, the LOC criteria for 1915(c) waivers is the same as the criteria required to receive care in the comparable nursing facility or ICF/IID institutional setting. The only CMS requirement is that states use a valid tool for determining LOC. Furthermore, states have the flexibility to use a different instrument to determine LOC for 1915(c) waiver program and facility placement, but they must demonstrate that the outcome of the LOC determination for the 1915(c) waiver is reliable, valid, and comparable to an outcome for institutional care.[140] Nebraska uses both a homegrown (i.e., the DI) and standardized assessment tools (interRAI HC, interRAI HC-PEDS) to determine LOC. The same is true for all nine peer states. *Appendix XI: Assessment Tools Used by Peer States* summarizes the Team's findings based on a review of publicly available information.

Peer State Assessment Tool Findings

- **Colorado, Kansas, and Wisconsin are in the process of using, or use, a unified LOC screening across all waivers. Additional assessments are used to supplement the LOC information for person-centered planning.**
- **Kansas worked with interRAI to build their unified screening tool called the Medicaid Functional Eligibility Instrument.**
- **Using a unified screening tool allows for individuals to move between waivers more easily.**

[140] Centers for Medicare & Medicaid. *Application for a §1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria*. (January 2019). Accessed 30 May, 2023. Page 105.

In the case of ICF/IID LOC 1915(c) waivers, Nebraska and the peer states require individuals to meet state-specific DD definitions. *Appendix XII: Peer State DD Definitions* presents a summary of each state's definition for DD. It is important to note that while no peer state definition exactly matches the federal definition provided in *Appendix VII,* seven peer states only require substantial limitations in three or more major life functioning areas. This contrasts with Nebraska, which requires a substantial limitation in all areas of adaptive functioning as defined in the Nebraska Revised Statutes.

Neither Colorado nor Wisconsin define the number of major life functioning areas that require a demonstrated substantial limitation. Similarly, the DD definitions in both states are broad in comparison to Nebraska and the other peer states, which likely allows for more individuals to be found to meet the definition of a DD.

States also define "severe, chronic disability" differently, which, in some cases, allows for a wider interpretation. For example, the Kansas definition of DD refers to either an intellectual disability or a severe chronic disability that is "attributable to a mental or physical impairment, a combination of mental and physical impairments or a condition which has received a dual diagnosis of intellectual disability and mental illness…"[141]

Some 1915(c) waiver programs require individuals to meet additional criteria beyond that required by CMS. One such example is the Colorado Children's Habilitation Residential Program 1915(c) waiver program, which serves individuals from birth through age 20 who have an ID or DD. To be eligible for waiver program services, not only are individuals required to meet Colorado's definition of DD and LOC, but they must also be determined to be at risk of placement in an ICF/IID and at risk of or in need of out of home placement.[142]

Another such program is the OhioRISE 1915(c) waiver, which serves individuals from birth through age 20 who have a serious emotional disturbance. Like Colorado's Children's Habilitation Residential Program, the OhioRISE program requires individuals to meet additional criteria beyond LOC and federal requirements. These criteria include the following:

> "Documented functional impairment and behaviors that substantially interfere with, or limit, the youth's role or functioning in family, school, or community activities which result in recommended institutionalization and potential relinquishment of custody to the child welfare system. In addition to assessing the individual's inpatient psychiatric level of care, the CANS assessment must show at least one of the following additional functional impairments and behaviors to be eligible for waiver enrollment:
>
> - The youth's persistent physical abuse or violence that results in physical injury or emotional distress to caregivers, family members, others in the home and

[141] Kansas Legislative Sessions. Statute Chapter 39, Article 18. *Developmental Disabilities Reform*. (2021). Accessed 16 June, 2023.
[142] HCBS – Children's Habilitation Residential Program. 1915(c) waiver Application. (January 2023). Accessed 22 June, 2023. Page 37.

community; or physical destruction of property that impacts the youth's housing stability.

- The youth's history of suicidal ideation with intent, or history of suicide attempts, within the past six months.
- The youth's sexually problematic behavior(s) that creates a safety risk for themselves or others without a high level of direct supervision.
- The youth's suspension or expulsion from school; or withdrawal from school, daycare, or preschool program as the result of the youth's actions/intensive behaviors.
- Law enforcement or child welfare contact involvement due to the youth's intensive behaviors.
- The youth has a history of victimization or exploitation, including human trafficking within the past 12 months, and re-victimization may be imminent. This may include physical or sexual abuse, sexual exploitation, or violent crime."[143]

As demonstrated, eligibility and enrollment processes vary among state 1915(c) waiver programs. Though the peer states operationalize eligibility and enrollment differently than Nebraska, the most significant key point is how states define DD. In most cases, states do not rely on the exact federal language for DD, and instead, use broader definitions than those established in Nebraska.

Clearly, definitions of DD can serve as barriers to accessing needed services and supports through 1915(c) programs, which may be further exacerbated by the presence of registries and waitlists.

Waitlists

Unlike Nebraska, the nine peer states commonly use the term "waitlist" instead of "registry." Throughout this section, we refer to a list of individuals who have signed up and are waiting for services as "waitlist." Of the peer states, six were determined to have a waitlist for DD services for at least one 1915(c) program, while South Dakota, Tennessee, and Wisconsin do not. As explained previously, Tennessee does not have a waitlist for 1915(c) services because it closed enrollment to the state's three ICF/IID LOC waivers and redirects new applicants to an MCO.[144]

[143] OhioRISE waiver. 1915(c) waiver Application. (July 2022). Accessed 22 June, 2023. Page 33.
[144] Tennessee Division of TennCare. *1915(c) HCBS waivers*. Accessed 24 June, 2023.

Our Team reviewed publicly available information to determine how the peer states describe their 1915(c) waiver program waitlists for services. *Table 12: Peer State Waitlists Descriptions* provides further information on their waitlist descriptions.

TABLE 12: PEER STATE WAITLISTS DESCRIPTIONS

State	Waitlist Description
Colorado	• There is one waitlist for individuals who are eligible for the HCBS-I/DD waiver. • The waitlist is active when the total slot capacity for enrollment or the total legislative appropriation is met.[145]
Kansas	• An individual who meets program and functional eligibility for the I/DD waiver is placed on the waitlist. • If an individual is not already enrolled in the Medicaid program, they will need to apply for Medicaid eligibility.[146]
Missouri	• The waitlist includes all individuals who qualify for services provided by the Division of Developmental Disabilities under the Department of Mental Health, but have not yet received services. • Individuals are assigned to a category on the waitlist, based on age, LOC eligibility, eligibility for Missouri's Medicaid program (HealthNet), and need for waiver services.[147]
Ohio	• Individuals waiting to receive services through the Individual Options, Level 1, or Self-Empowered Life Funding (SELF) waivers and who are determined to have a current need are placed on the waitlist. Individuals are asked if they currently receive Medicaid State Plan services, but no information is gathered on Medicaid eligibility.[148]
Oklahoma	• When an individual on the waitlist is next for review, Oklahoma's contractor makes phone contact with the

[145] Colorado Code of Regulations. 10 CCR 2505-10 8.500 *Home and Community-Based Services for Individuals with Intellectual or Developmental Disabilities (HCBS-DD) waiver.* (June 2023). Accessed 12 July, 2023. Pages 15-16.
[146] Kansas Department of Aging and Disability Services. *Intellectual/DD (I/DD) waiver Program; Frequently Asked Questions.* Accessed 12 July, 2023.
[147] Missouri Code of State Regulations. *Department of Mental Health. Division 45-Division of Developmental Disabilities, Chapter 2- Eligibility for Services*. (March 2023). Accessed 18 July, 2023. Page 6.
[148] Ohio Administrative Code 5123-9-04 *Home and community-based services waivers- waiting list*. (November 2018). Accessed 26 June, 2023. Page 4.

State	Waitlist Description
	individual to review 1915(c) services and confirm eligibility.[149]
Pennsylvania	• The waitlist is made up of individuals who are eligible to receive services through an HCBS waiver, but due to insufficient slots, are waiting to be enrolled on a waiver. • Individuals are categorized based on assessed needs from the Prioritization of Urgency of Need for Services tool.[150]

Waiting Lists for HCBS

The Kaiser Family Foundation estimates that approximately 37 states operated a waiting list for HCBS services in 2021. Of those waiting for services, most are individuals with an ID or DD.*

*Burns, Alice. Molly O'Malley Watts, and Meghana Ammula. "A Look at Waiting lists for Home and Community-Based Services from 2016 to 2021." (November 2022). https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-home-and-community-based-services-from-2016-to-2021/. Accessed 24 June, 2023.

Appendix XIII: Peer State Waitlist Comparison provides further information on peer state waitlists. In summary, half of the peer states with a waiting list for 1915(c) services screen individuals for eligibility while waiting for services.[151] Transition of individuals from a waiting list to full enrollment in a 1915(c) waiver occurs based on priority or on a first come, first served basis.[152] Peer states vary in the goals of their waitlist management approach, which may include:

- Complete elimination of their waitlists.
- Expanding slot capacity to gradually increase enrollment into 1915(c) waivers.
- Reducing waitlist rolls through assessment of needs prior to placement on a waitlist.

In most instances, states rely on additional funding from their legislative bodies to increase waiver program enrollment. Moreover, states are working with a variety of stakeholders including individuals, families, Councils on Developmental Disabilities, and UCEDDs to examine ways in which waitlists can be eliminated or the waiting times shortened. *Figure 11: Peer State Profiles: Waitlists* highlights four peer state approaches to address their waitlists. The information contained in *Figure 11* summarizes recent efforts by Colorado, Kansas, Ohio, and Oklahoma to

[149] Oklahoma Human Services, DD Services. *Wait List Process*. Accessed 18 July, 2023. Page 1.
[150] Pennsylvania Department of Human Services. *Annual Waiting List Report: Office of Developmental Programs (ODP)*. (2022). Accessed 18 July, 2023. Page 4.
[151] Kaiser Family Foundation. *Medicaid HCBS waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility*. 2021. Accessed 20 April, 2023.
[152] Medicaid and Chip Payment and Access Commission. *Compendium of Medicaid Home-and Community-Based Services waiver Waiting List Administration*. (2020). Accessed 20 April, 2022.

remove people from waiting lists, eliminate waiting lists, or research possible solutions to address their waiting lists. Additional details on Ohio and Oklahoma's waitlist changes follow in *Figure 11*.

FIGURE 11: PEER STATE PROFILES: WAITLISTS

State	Waitlist Description
	Colorado • State estimates project 3,000 individuals are waiting for services on the HCBS DD waiver. • The state legislature authorized one-time funding for 667 new slots in Senate Bill 21-205, passed in May 2021.[153]
	Kansas • Approximately 4,500 individuals with an intellectual or DD are on a waitlist for services.[154] • A Medicaid Wait List Study is being conducted to make recommendations to the Kansas Department for Aging and Disability Services on how to best reduce waitlists.[155]
	Ohio • Approximately 2,000 individuals are waiting for services on one of Ohio's three ICF/IID LOC waivers. • In collaboration with stakeholders, the Ohio Department of Developmental Disabilities codified changes to its administrative code in 2018, and now requires individuals to be assessed for immediate or current needs.
	Oklahoma • 2,100 individuals are on the waitlist to receive services through one of Oklahoma's 1915(c) waivers.[156] • The State is working to eliminate the waitlist by March 2024. Estimates indicate it will cost the State approximately $21.3 million to end the waitlist for individuals who were waiting as of May 1, 2022.[157]

Ohio chose to address waitlist concerns by implementing an assessment tool and codifying rules which change how the waiting list is administered. These changes took place in 2018, after

[153]Colorado Department of Health Care Policy & Finance. *HCPF DD Strategic Plan Report*. (November 2022). Accessed 16 August, 2023.
[154] Kaiser Family Foundation. *Medicaid HCBS Waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility*. (2021). Accessed 16 August, 2023.
[155] The University of Kansas. *Institute for Health and Disability Policy Studies*. Accessed 16 August, 2023.
[156] Oklahoma Department of Human Services. *The Waitlist*. Accessed 16 August, 2023.
[157] Oklahoma Department of Human Services. *State Leaders Announce Budget Agreement to End Wait List for Developmental Disability Services*. (May 2022). Accessed 16 August, 2023.

several years of research by the State, in collaboration with community partners. In 2014, the Ohio Colleges of Medicine Government Resource Center worked with the Ohio Developmental Disabilities Council and representatives from the Departments of Developmental Disabilities and Medicaid to release findings related to Ohio's waitlist. Results of the waitlist study suggested that at the time of the study, approximately 41,000 individuals were waiting for services, and the median wait time for services was 6.4 years.[158] This study, along with stakeholder input and collaboration, was the basis for the Department of Developmental Disabilities to change processes related to administration of the waiting list in 2018.

Changes were codified in Ohio Administrative Code, as was a waitlist assessment which is now used to determine unmet needs of individuals prior to placement on the waitlist. Individuals are assessed to determine if there exists an immediate or current need. Immediate needs are defined by Ohio as a "situation that creates a substantial harm to an individual, caregiver, or another person if action is not taken within thirty calendar days to reduce the risk."[159] A current need is defined in the Ohio Administrative Code as "an unmet need for home and community-based services within twelve months, as determined by a county board based upon assessment of the individual using the waiting list assessment tool."[160]

Ohio's waitlist assessment tool not only determines if an individual has an immediate or current need but reviews available resources which may help to address the need, outside of enrollment on a 1915(c) waiver. These services, known as "community-based alternative services," include different programs, services, and supports that may or may not be funded by Medicaid.[161] The waitlist assessment tool does not, however, make a LOC determination. The LOC criteria and assessment tool are defined in Ohio regulation separately from the waitlist.[162]

Ohio places individuals on the waitlist only if they meet the following criteria; of which, the first three criteria under the definition of DD in Ohio include mental or physical impairment or a combination of the two, other than an impairment caused solely by mental illness; the condition manifested before the age of 22; the condition is likely to continue indefinitely; and the condition is assessed to have a current need that cannot be met by community-based alternative services in the county where they reside. This includes situations in which an individual has a current need, despite being enrolled on any one of Ohio's 1915(c) waivers.[163]

[158] Ohio Colleges of Medicine Government Resource Center. *What Are We Waiting For? waiver Supported Services Needed by Individuals and their Caregivers*. (February 2014). Accessed 24 June, 2023. Page 9.
[159] Ohio Administrative Code 5123-9-04 *Home and community-based services waivers- waiting list*. (November 2018). Accessed 26 June, 2023. Page 2.
[160] Ohio Administrative Code 5123-9-04 *Home and community-based services waivers- waiting list*. (November 2018). Accessed 26 June, 2023. Page 1.
[161] Ohio Administrative Code 5123-9-04 *Home and community-based services waivers- waiting list*. (November 2018). Accessed 26 June, 2023. Page 1.
[162] Ohio Administrative Code 5123-8-01 *Developmental disabilities level of care*. (November 2020). Accessed 12 July, 2023. Page 1.
[163] Ohio Administrative Code 5123-9-04 *Home and community-based services waivers- waiting list*. (November 2018). Accessed 26 June, 2023. Page 1.

A copy of the waitlist assessment used in Ohio is found in *Appendix XV: Ohio's Assessment for Immediate and Current Needs.*

> **Waiting in Oklahoma: Previous Wait Times for 1915(c) Services**
>
> **Prior to the investment made by Oklahoma's Governor and state legislators, the Oklahoma Department of Human Services estimated individuals spent 13 years waiting to be enrolled in a 1915(c) waiver. That is more than double the estimated waitlist time in Nebraska.***
>
> *** Oklahoma Human Services. State Leaders Announce Budget Agreement to End Wait List for DD Services. (May 2022). Accessed 26 June, 2023.**

By reviewing the needs of individuals prior to placement on the waitlist, Ohio addresses their needs sooner and reserves ICF/IID waiver placement as a true last resort for individuals whose needs cannot be met in another way. Though Ohio has not eliminated their waitlist, the method by which the State administers its waitlist saves limited Medicaid funding and waiver slots for only those who are in most need of 1915(c) waiver services and establishes a more reliable predictor of additional funding requirements. In addition, Ohio can provide more immediate relief through the promotion of non-waiver community-based alternative services to individuals who otherwise would have unmet needs in the community.

Instead of making changes to the administration of the waiting list, Oklahoma is moving toward the total elimination of its waitlist. In May 2022, Oklahoma's Governor signed a budget agreement to provide funds to end the state's waitlist. Along with an increase in provider rates, the budget agreement appropriated a total of $32.5 million to end the waitlist for 1915(c) services.[164] Oklahoma engaged a contractor to contact individuals on the waitlist to assist in obtaining documents used to make eligibility determinations. Individuals have been split into cohorts based on the date an application for services was first submitted.

Depending on the application date, Oklahoma has assigned specific timeframes for how quickly an individual's application will be processed. It is estimated that all applications for individuals on the waitlist as of May 1, 2022 will be processed by March 2024.[165] Information was not publicly available for how quickly the applications of individuals who applied for services after May 1, 2022 will be processed.[166]

1915(c) Services Offered by Peer States

CMS does not limit the number of services a state can offer under a 1915(c) waiver, and depending on the design and target population, states may choose to offer a wide range of different services to help meet the needs of individuals enrolled. *Table 13: Peer State 1915(c)*

[164] Oklahoma Human Services. *DD Services Waitlist*. Accessed 26 June, 2023.
[165] Oklahoma Human Services. *DD Services Waitlist*. Accessed 26 June, 2023.
[166] Oklahoma Human Services: DD Services (DDS). *Wait List Elimination Timeline*. Accessed 26 June, 2023.

Service Examples provides an illustration of the types of services found across the waiver programs available in peer states. Examples were chosen to illustrate the wide variety of services among programs.

TABLE 13: PEER STATE 1915(C) SERVICE EXAMPLES

State	Waiver Example and Information	Service Examples
Colorado	**Children's HCBS** • LOC: Hospital and NF • Number of Services: 2	Case Management, In-Home Support Services[167]
Kansas	**I/DD** • LOC: ICF/IID • Number of Services: 11	Assistive Services, Enhanced Care Service, Overnight Respite, Residential Supports Specialized Medical Care, Wellness Monitoring[168]
Missouri	**Structured Family Caregiving** • LOC: NF • Number of Services: 1	Structured Family Caregiving[169]
Ohio	**Level 1** • LOC: ICF/IID • Number of Services: 23	Community Respite, Career Planning, Functional Behavioral Assessment, Home Delivered Meals, Residential Respite, Waiver Nursing Delegation[170]
Oklahoma	**Homeward Bound** • LOC: ICF/IID • Number of Services: 26	Agency Companion, Dental, Family Counseling, Psychological, Specialized Foster Care[171]
Pennsylvania	**Adult Autism** • LOC: ICF/IID • Number of Services: 18	Community Transition Services, Family Support, Specialized Skill Development, Therapies, Temporary Supplemental Services[172]
South Dakota	**Home and Community-Based Options and Person Centered Excellence (HOPE)** • LOC: NF	Adult Day Services, Assisted Living, Chore Services, Community Living Home,

[167] Colorado's Children's Home and Community Based Services (CHCBS) waiver Application. (July 2023). Accessed 13 July, 2023. Pages 2 and 49.
[168] Kansas HCBS-I/DD waiver Application. (July 2021). Accessed 13 July, 2023. Pages 4 and 58.
[169] Missouri Structured Family Caregiving Application. (July 2023). Accessed 13 July, 2023. Page 4 and 43.
[170] Ohio Level 1 waiver Application. (July 2022). Accessed 13 July, 2023. Pages 5 and 57.
[171] Oklahoma Homeward Bound waiver Application. (July 2023). Accessed 8 September, 2023. Pages 4 and 56-57.
[172] Pennsylvania Adult Autism waiver Application. (January 2023). Accessed 13 July, 2023. Pages 4 and 57.

State	Waiver Example and Information	Service Examples
	• Number of Services: 19	Residential Respite Care, Structured Family Caregiving[173]
Tennessee	**Comprehensive Aggregate Cap HCBS** • LOC: ICF/IID • Number of Services: 28	Behavioral Respite Services, Family Model Residential Supports, Intermittent Employment and Community Integration Wrap-Around Supports, Residential Habilitation, Transitional Case Management[174]
Wisconsin	**Include, Respect, I Self-Direct (IRIS)** • LOC: NF and ICF/IID • Number of Services: 32	Community Transportation, Consultative Clinical and Therapeutic Services for Caregivers, Consumer Education and Training, Residential Services (1-2 Bed AFH), Training Services for Unpaid Caregivers[175]

As seen in *Table 13,* services offered under 1915(c) waivers vary somewhat among peer states. It is important to note that peer states may offer the same services as the examples in *Table 2*, but under a different name. Although CMS offers guidance on service names for consistency, states nevertheless have flexibility to name services as they choose.[176]

Due to variability in names, it is important to review service definitions to determine true similarities and differences between services. Although the name may be the same from state to state, the service components may differ. For example, in-home residential supports are described as Residential Services, Residential Habilitation, Community Living Home, and In-Home Support Services. While they may all provide in-home supports to enable independent living, the details of each similar service can be different. Additionally, a review of service definitions provides further information regarding variances among states regarding limitations in where a service can be provided and to whom. *Appendix XVI: Peer State Service Examples - Description* provides additional details for the services listed in *Table 13*.

Self-Direction and Legally Responsible Individuals

Self-direction opportunities in peer state 1915(c) waivers vary by program. All offer at least one type of self-direction opportunity, which is briefly described as follows:

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[173] South Dakota HOPE waiver Application. (October 2021). Accessed 15 July, 2023. Pages 51-52.
[174] Tennessee Comprehensive Aggregate Cap HCBS waiver Application. (January 2020) Accessed 13 July, 2023. Pages 4 and 53-54.
[175] Wisconsin IRIS waiver Application. (January 2021). Accessed 15 July, 2023. Pages 57-58.
[176] Centers for Medicare & Medicaid. *Application for a §1915(c) Home and Community-Based waiver: Instructions, Technical Guide and Review Criteria*. (January 2019). Accessed 30 May, 2023. Page 149.

- **Budget Authority Only:** Ohio
- **Employer Authority Only:** Colorado, Kansas, Ohio, Missouri, Pennsylvania, and South Dakota
- **Both Self-Direction Opportunities:** Colorado, Missouri, Ohio, Oklahoma, Pennsylvania, South Dakota, Tennessee, and Wisconsin

Appendix XVII: Peer State Self-Direction Opportunities summarizes the self-direction opportunities that are offered under the 1915(c) waivers in the peer states.

In the same way that budget limitations vary, so too do provider requirements and limitations within peer state 1915(c) waiver programs. This includes payments to legally responsible individuals, relatives, and legal guardians. Within a 1915(c) waiver application, states have the option to select if they make payment for services to individuals who meet a state's definition of legally responsible individual, relative, or legal guardian. States can make the following selections within a waiver application:

- Provision of personal care or similar services by legally responsible individuals.
- Payment for waiver services (other than personal care) furnished by relatives and legal guardians.[177]

CMS notes that although these items are similar, they are intentionally distinct. The expectations between personal care and other waiver services' scopes and qualifications are different, to ensure states are considering the additional requirements necessary for the safe provision of personal care or similar services. For example, other waiver services furnished by relatives or legal guardians can include mileage reimbursement for transportation or respite care. Expectations around these types of services are less than what is needed to provide personal care or similar services. In both instances, however, legally responsible individuals, relatives, and legal guardians who are paid for providing services:

> "[M]ust meet the provider qualifications that apply to a service and there must be a properly executed provider agreement. In addition, other requirements such as the proper documentation and monitoring of the provision of services also apply."[178]

[177] Centers for Medicare & Medicaid. *Application for a §1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria*. (January 2019). Accessed 30 May, 2023. Page 119.
[178] Centers for Medicare & Medicaid. *Application for a §1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria*. (January 2019). Accessed 30 May, 2023. Page 119.

It is important to note when legally responsible individuals are allowed to provide personal care or similar services under a waiver program, CMS requires a state to specify:

> "The method for determining that the amount of personal care or similar services provided by legally responsible individuals is "extraordinary care," exceeding the ordinary care that would be provided to a person without a disability of the same age… By extraordinary, CMS means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and avoid institutionalization."[179]

State definitions of legally responsible individuals and guardians differ and may be defined by program. *Appendix XVIII: State Definitions of Legally Responsible Individuals and Guardians* presents definitions of these terms taken from state 1915(c) waiver applications, statute, and guidance documents.

State limitations on payments to legally responsible individuals as providers changed drastically in response to how they managed the COVID-19 emergency. The Medicaid and CHIP Payment and Access Commission (MACPAC) estimates that 32 states submitted requests to temporarily allow payment for services provided by family caregivers and legally responsible adults. This number does not include states who had already received CMS approval for these payments.[180] With the exception of Tennessee, all other peer states included in this report requested this flexibility for at least one of their 1915(c) waivers.[181] *Appendix XIX: Peer State Payments to Legally Responsible Individuals* demonstrates payments peer states allow in their approved 1915(c) waivers to legally responsible individuals, guardians, and other relatives.

The Team reviewed the most recently available waiver applications to determine the 1915(c) programs approved by CMS to allow for payments to legally responsible individuals. In addition to the summary information in *Appendix XIX*, the following information shown in *Figure 12: Peer State Profiles: Legally Responsible Individuals as Providers*, highlights how three peer states handle payments to legally responsible individuals.

[179] Centers for Medicare & Medicaid. *Application for a §1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria*. (January 2019). Accessed 30 May, 2023. Page 119-120.
[180] MACPAC. *1915(c) HCBS waiver Appendix K modifications*. Accessed 15 July, 2023.
[181] MACPAC. *1915(c) HCBS waiver Appendix K modifications*. Accessed 15 July, 2023.

FIGURE 12: PEER STATE PROFILES: LEGALLY RESPONSIBLE INDIVIDUALS AS PROVIDERS

State	Legally Responsible Individual Descriptions
KANSAS	**Kansas HCBS/I/DD Waiver** • Parents of minor children, guardians, and durable powers of attorney may be paid to provide personal care services in certain circumstances. • Probate courts must rule that no conflict of interest concerns exist for payment to parents of minors, guardians, and durable powers of attorney to occur.
	Pennsylvania Person/Family Directed Support Waiver • Legally responsible individuals are people who have obligations under law to care for another person including parents of minors (under 18) and legally assigned relative caregivers of minors. • Personal care delivered under the In-Home and Community Support service is the only type of personal care that can be provided by legally responsible individuals. • Other waiver services may be provided by relatives and legal guardians.
SOUTH DAKOTA THE MOUNT RUSHMORE STATE	**South Dakota Family Support 360 Waiver** • South Dakota does not pay parents of minors (under 18) or spouses of individuals for services provided under the Family Support 360 waiver. • Payment may be made to parents or legal guardians of an adult participant (over 18) for provider Personal Care 1, respite, supported employment, and companion care. These providers must be employees under the Agency with Choice model.
WISCONSIN 1848	**Wisconsin Family Care Waiver** • In certain circumstances, relatives (defined by the State as any relative of the individual) or legal guardians may be paid to provide personal care, supportive home care, specialized transportation, certified one to two bed adult family home services, education, respite, skilled nursing, and supported employment services. • Spouses may be paid to provide personal care or supportive home care only when services exceed normal spousal responsibilities.

Limits on Amount of Waiver Services

Depending on the 1915(c) program, peer states limit the amount that may be spent on waiver services during a specific timeframe in a variety of ways. A few examples include:

- **Colorado:** The Children's Extensive Support waiver program limits expenditures to $10,000 over five years. Home accessibility adaptations, vehicle modifications, and assistive technology cannot in combination exceed $10,000, though the limit can be exceeded on a case-by-case basis.[182]

- **Ohio:** Annual service limitations for adult day support, vocational habilitation, individual employment support, group employment support, and career planning offered under the Individual Options waiver.[183]

- **Ohio:** The SELF waiver has a maximum budget for individuals based on age. Individuals under the age of 22 are limited to a total of $30,000, and individuals aged 22 and older are limited to a total of $45,000 per year. Budgets apply to all waiver services covered under SELF.[184]

Examples of peer state 1915(c) waivers that do not impose any type of waiver service limitations include:

- **Colorado:** Developmental Disabilities.[185]

- **Kansas:** Intellectual/Developmentally Disabled.[186]

- **Missouri:** Children with Developmental Disabilities.[187]

- **Oklahoma:** ADvantage waiver.[188]

- **Tennessee:** Statewide Home and Community-Based Services.[189]

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[182] Children's Extensive Support waiver Application. (July 2023). Accessed 14 July, 2023. Page 119.
[183] Ohio Individual Options waiver Application. (July 2022). Accessed 13 July, 2023. Page 173.
[184] Ohio SELF waiver Application. (July 2022). Accessed 13 July, 2023. Page 154.
[185] Colorado Developmental Disabilities waiver Application. (July 2023). Accessed 14 July, 2023. Page 151.
[186] Kansas HCBS-I/DD waiver Application. (July 2021). Accessed 13 July, 2023. Page 116.
[187] Missouri Children with Developmental Disabilities waiver Application. (July 2023). Page 152.
[188] Oklahoma ADvantage waiver Application. (July 2021). Accessed 14 July, 2023. Page 132.
[189] Tennessee Statewide Home and Community Based Services waiver Application. (July 2020). Accessed 14 July, 2023. Page 238.

- **Wisconsin:** Family Care.[190]

Peer State 1915(c) Family Support Program Examples

The Team reviewed two peer state 1915(c) programs that were identified as "family support programs" to determine: program designs, eligibility criteria, funding mechanisms, and services provided. The two programs are from South Dakota and Wisconsin.

South Dakota's Family Support 360 program[191] is available to support individuals from birth through their lifespan.[192] The Family Support 360 Waiver offers a total of 11 services, including, but not limited to: two types of personal care, companion care, respite, and specialized therapies.[193] The personal care services differ in that one is designed to supplement personal care offered through the Medicaid State Plan (Personal Care 2), and the other (Personal Care 1) is offered by different provider types and does not require a physician's order.[194] Companion care is similar to personal care in that it is a non-medical service dedicated to skill development that may be provided as hands-on assistance or prompting. Companion care is also used to help an individual with integrated socialization, role modeling, and independent living skills.[195]

The respite service offered under the Family Support 360 Waiver is provided in several locations including:

- A private home or place of residence.
- Foster home.
- Hospital.
- ICF/IID.
- Group home.
- Another community residential facility that is not a private residence.[196]

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[190] Wisconsin Family Care waiver Application. (January 2020). Accessed 15 July, 2023. Page 172.
[191] South Dakota Family Support 360 Waiver. (June 2022). Accessed 19 July, 2023. Page 2.
[192] South Dakota Family Support 360 Waiver. (June 2022). Accessed 19 July, 2023. Page 30.
[193] South Dakota Family Support 360 Waiver. (June 2022). Accessed 19 July, 2023. Pages 55-56.
[194] South Dakota Family Support 360 Waiver. (June 2022). Accessed 19 July, 2023. Pages 57 and 71.
[195] South Dakota Family Support 360 Waiver. (June 2022). Accessed 19 July, 2023. Pages 74.
[196] South Dakota Family Support 360 Waiver. (June 2022). Accessed 19 July, 2023. Pages 61.

The Family Support 360 Waiver specialized therapies include art, music, and hippotherapy/therapeutic horseback riding. Specialized therapy providers must be state or national board certified therapists.

Wisconsin's Family Care 1915(c) waiver program serves both individuals who meet ICF/IID LOC criteria and individuals who meet NF LOC criteria.[197] The waiver specifies age minimums and maximums, depending upon the target group to which an individual qualifies. For individuals who are within the "aged, or disabled, or both" target group, the following age requirements apply:

- Aged: Minimum age is 65. There is no maximum age limit.
- Disabled (physical): Minimum age is 18; maximum age is 64.
- Disabled (other): Minimum age is 18; maximum age is 64.

For individuals qualifying under the "intellectual disability or DD, or both" target group, the below age requirements are in place:

- DD: The minimum age is 18. There is no maximum age limit.
- Intellectual disability: The minimum age is 18. There is no maximum age limit.[198]

The Family Care 1915(c) waiver offers 32 services. There are specific services that provide dedicated support to families, in addition to supports that help individuals live independently in the community. These include:

- Consumer education and training.
- Daily living skills training.
- Day habilitation services.
- Housing counseling.
- Training services for unpaid caregivers.[199]

[197] Wisconsin Family Care Waiver. (January 2020). Accessed 19 July, 2023. Pages 2-3.
[198] Wisconsin Family Care Waiver. (January 2020). Accessed 19 July, 2023. Page 30.
[199] Wisconsin Family Care waiver Application. (January 2020). Accessed 15 July, 2023. Pages 2-3 and 60-61.

Consumer education and training is designed to help individuals develop self-advocacy and self-determination skills by deepening an understanding of their civil rights, decisions, and actions that are within their control and their responsibilities. Consumer education and training is provided to individuals enrolled on the Family Care 1915(c) waiver, along with caregivers and legal representatives.[200] Daily living skills training is centered on education and skills development for an individual. Skills are targeted toward ADLs and achieving/maintaining independence and participation in community living. Like consumer education and training, daily living skills training may involve natural supports for the individual enrolled on the waiver.[201] In addition to the training provided through consumer education and training and daily living skills, training services for unpaid caregivers is focused on providing support to caregivers who do not receive payment for care provided. This service includes:

- Instruction on treatment protocols, including use of equipment.
- Services included in the person-centered plan.
- Guidance to support the individual successfully in the community.[202]

Training services for unpaid caregivers may include online or in-person training, conferences, or resource materials on specific disabilities or illnesses. Also included in the scope of training services for unpaid caregivers are registration costs and fees for formal instruction related to needs identified in the person-centered plan.[203]

Day habilitation services are provided outside of the individual's place of residence and help with the acquisition and retention of skills enhancing social development and in the performance of ADLs. Day habilitation services may also be used to support and provide activities to individuals who choose to retire from employment.[204] Housing counseling services support individuals who are seeking community housing. Housing counseling is used to "promote [individual] choice and control, increase access to affordable housing, and promote community inclusion."[205] Housing counseling may be accessed more than once, and can be accessed at any time.[206]

Peer State Medicaid Programs

Medicaid programs, just like the 1915(c) waivers, have a wide range of options and flexibility available, including with respect to coverage and payment of services. Upon review of available peer state Medicaid program information, the Team determined that the most important

[200] Wisconsin Family Care waiver Application. (January 2020). Accessed 15 July, 2023. Page 108.
[201] Wisconsin Family Care waiver Application. (January 2020). Accessed 15 July, 2023. Page 68.
[202] Wisconsin Family Care waiver Application. (January 2020). Accessed 15 July, 2023. Page 144.
[203] Wisconsin Family Care waiver Application. (January 2020). Accessed 15 July, 2023. Page 144.
[204] Wisconsin Family Care waiver Application. (January 2020). Accessed 15 July, 2023. Page 71.
[205] Wisconsin Family Care waiver Application. (January 2020). Accessed 15 July, 2023. Page 119.
[206] Wisconsin Family Care waiver Application. (January 2020). Accessed 15 July, 2023. Page 119.

program components relate to eligibility determination requirements and process, including flexibility with income rules and Medicaid aid categories related to disabilities.

Figure 13: Peer State Profiles: Medicaid Program Summaries provides an overview of each peer state's Medicaid program, including the total number of individuals enrolled and identification of some key optional Medicaid state plan services that we believe are relevant to the LB376 system evaluation. It is important to clarify that *Figure 13* does not represent all situations in which coverage of optional services is allowed in each state.

FIGURE 13: PEER STATE PROFILES: MEDICAID PROGRAM SUMMARIES

State	Medicaid Program Summaries[207]
	Colorado • Number of Medicaid and CHIP enrollees (March 2023): 1,726,651. • Examples of covered optional services: dental, pharmacy, occupational therapy, physical therapy, speech, telemedicine.[208]
	Kansas • Number of Medicaid and CHIP enrollees (March 2023): 506,906. • Examples of covered optional services: dental, pharmacy.[209]
	Missouri • Number of Medicaid and CHIP enrollees (March 2023): 1,486,826. • Examples of covered optional services: dental, occupational therapy, physical therapy, speech, pharmacy, private duty nursing.[210]
	Ohio • Number of Medicaid and CHIP enrollees (March 2023): 3,421,792. • Examples of covered optional services: dental, occupational therapy, physical therapy, speech, pharmacy, private duty nursing.[211]
	Oklahoma • Number of Medicaid and CHIP enrollees (March 2023): 1,326,908. • Examples of covered optional services: dental, occupational therapy, physical therapy, speech, personal care, pharmacy.[212]

[207] All enrollment numbers were accessed on July 22, 2023 from *Medicaid.gov: April 2023 Medicaid & CHIP Enrollment Data Highlights*.
[208] Health First Colorado. *Health First Colorado Benefits & Services*. Accessed 22 July, 2023.
[209] KanCare. *Benefits & Services*. Accessed 22 July, 2023.
[210] Missouri Department of Social Services. *MO HealthNet Benefit Tables*. Accessed 22 July, 2023.
[211] Ohio Department of Medicaid. *Services*. Accessed 22 July, 2023.
[212] Oklahoma Health Care Authority. *SoonerCare Benefits Guide*. Accessed 22 July, 2023.

State	Medicaid Program Summaries[207]
	Pennsylvania • Number of Medicaid and CHIP enrollees (March 2023): 3,713,633. • Examples of covered optional services: unable to determine.[213]
	South Dakota • Number of Medicaid and CHIP enrollees (March 2023): 146,957. • Examples of covered optional services: dental, health homes, occupational therapy, physical therapy, speech, personal care, pharmacy.[214]
	Tennessee • Number of Medicaid and CHIP enrollees (March 2023): 1,805,245. • Examples of covered optional services: dental, occupational therapy, physical therapy, speech, pharmacy, private duty nursing.[215]
	Wisconsin • Number of Medicaid and CHIP enrollees (March 2023): 1,439,080. • Examples of covered optional services: dental, occupational therapy, physical therapy, speech, pharmacy.[216]

Peer State Medicaid Eligibility Determinations and Categories

Table 14: Peer State Medicaid Eligibility Determinations summarizes the way in which each peer state determines Medicaid eligibility. The majority of the nine peer states (Colorado, Ohio, Pennsylvania, South Dakota, Tennessee, and Wisconsin) determine Medicaid eligibility under the 1634 authority of the Social Security Act. Missouri is the single peer state that relies on the more restrictive 209(b) option to determine Medicaid eligibility. Kansas and Oklahoma rely on the SSI option when making Medicaid eligibility determinations.[217]

[213] Pennsylvania Department of Human Services. Health Care/Medical Assistance. Accessed 22 July, 2023.
[214] South Dakota Department of Social Services. South Dakota Medicaid Recipient Handbook. Accessed 22 July, 2023.
[215] Wisconsin Department of Health Services. BadgerCare Plus: Covered Services and Copays. Accessed 22 July, 2023.
[216] TennCare. TennCare Benefit Packages. (March 2023). Accessed 22 July, 2023.
[217] MACPAC. MACStats: Medicaid and CHIP Data Book. (2022). Accessed 20 July, 2023. Pages 103-104.

TABLE 14: PEER STATE MEDICAID ELIGIBILITY DETERMINATIONS

State	209(b)	SSI	1634
Colorado			Yes
Kansas		Yes	
Missouri	Yes		
Ohio			Yes
Oklahoma		Yes	
Pennsylvania			Yes
South Dakota			Yes
Tennessee			Yes
Wisconsin			Yes

In addition to a review Medicaid eligibility, the Team also reviewed peer state uptake of the Special Income Rule and found that all peer states have adopted special income limits as of 2022. Except for Missouri, all other peer states allow individuals to enroll in the Medicaid program up to 223 percent of the FPL, if they are in an institution or receive services through an HCBS waiver. Two-hundred twenty-three percent of the FPL is the highest a state could allow under special income levels in 2022.[218]

Table 15: Peer State Special Income Levels summarizes the income limits that each state allows under the special income levels.

[218] MACPAC. *MACStats: Medicaid and CHIP Data Book*. (2022). Accessed 20 July, 2023. Page 105.

TABLE 15: PEER STATE SPECIAL INCOME LEVELS

State	Special Income Levels for Institutions[219]	Special Income Levels for HCBS[220]	FPL Income Limits for Institutions/HCBS[221]
Colorado	Yes	Yes	223%
Kansas	Yes	Yes	223%
Missouri	Unable to determine	Unable to determine[222]	130%
Ohio	Yes	Yes	223%
Oklahoma	Yes	Yes	223%
Pennsylvania	Yes	Yes	223%
South Dakota	Yes	Yes	223%
Tennessee	Yes	Yes	223%
Wisconsin	Yes	Yes	223%

Further Medicaid program review found that four of the nine peer states offer a Medicaid eligibility pathway through the Katie Beckett authority. Peer states that do not offer Katie Beckett as a Medicaid eligibility category may, however, offer "Katie Beckett-like" income and eligibility standards under a 1915(c) waiver.[223] Eight of nine peer states allow for a pathway to Medicaid eligibility through MIWD, while Tennessee does not.[224]

Table 16: Peer State Medicaid Eligibility Categories summarizes the availability of Katie Beckett Medicaid program and MIWD eligibility. Although the DAC eligibility pathway was explored previously, peer state information regarding DAC was not readily available through public resources.

[219] Kaiser Family Foundation. *Medicaid Eligibility for Long-Term Care Through the Special Income Rule*. (July 2022). Accessed 20 July, 2023.
[220] Kaiser Family Foundation. *Medicaid Eligibility for Long-Term Care Through the Special Income Rule*. (2022). Accessed 20 July, 2023.
[221] MACPAC. *MACStats: Medicaid and CHIP Data Book*. (2022). Accessed 20 July, 2023. Pages 1-3.
[222] Information obtained from the Kaiser Family Foundation's article titled *Medicaid Eligibility for Long-Term Care Through the Special Income Rule*, was published in July 2022. Information contained in this article was used for the purposes of distinguishing special income levels for institutions and HCBS. This article does not include Missouri as allowing for special income levels, though the MACPAC article titled *MACStats: Medicaid and CHIP Data Book* published in December 2022 does include Missouri as a special income level state. Therefore, the Team is recognizing the Missouri special income level as 130% FPL as indicated by MACPAC, but is not able to confirm if this flexibility applies to institutions, HCBS, or both.
[223] Kaiser Family Foundation. *State Adoption of Major Optional Pathways to Full Medicaid Eligibility Based on Old Age or Disability*. (2022). Accessed 21 July, 2023.
[224] Musumeci, MaryBeth, Molly O'Mallery Watts, Meghana Ammula, and Alice Burns. *Medicaid Financial Eligibility in Pathways Based on Old Age or Disability in 2022: Findings from a 50-State Survey*. (July 2022). Accessed 20 July, 2023.

TABLE 16: PEER STATE MEDICAID ELIGIBILITY CATEGORIES

State	Katie Beckett	MIWD
Colorado	Yes	Yes
Kansas	Yes	Yes
Missouri	Yes	Yes
Ohio	No	Yes
Oklahoma	Yes	Yes
Pennsylvania	No	Yes
South Dakota	Yes	Yes
Tennessee	Yes	No
Wisconsin	Yes[225]	Yes[226]

Based on publicly available Medicaid program information, the Team was able to confirm Katie Beckett Medicaid eligibility categories in seven of nine peer states. Of those, Katie Beckett eligibility is available to individuals who meet any one of several program LOC criteria. A summary of the LOC criteria is as follows:

- Oklahoma requires an individual to meet an ICF/IID, NF, or acute medical hospital LOC criteria to qualify.[227]
- South Dakota's Katie Beckett eligibility pathway (referred to as the Disabled Children's Program) allows for hospital, NF or ICF LOC criteria.[228]
- Tennessee appears to be more flexibility and determines eligibility according to multiple LOC criteria that are defined in the states Katie Beckett Level of Care Guide. This includes medical diagnosis, medical or behavioral needs, and other circumstances, such as involvement in child welfare agencies.[229]
- Wisconsin requires a LOC determination to be made for their Katie Beckett eligibility category using the Children's Programs Eligibility and Function Screen. This screener

[225] Musumeci, MaryBeth, Molly O'Mallery Watts, Meghana Ammula, and Alice Burns. *Medicaid Financial Eligibility in Pathways Based on Old Age or Disability in 2022: Findings from a 50-State Survey*. (July 2022). Accessed 20 July, 2023.
[226] Musumeci, MaryBeth, Molly O'Mallery Watts, Meghana Ammula, and Alice Burns. *Medicaid Financial Eligibility in Pathways Based on Old Age or Disability in 2022: Findings from a 50-State Survey*. (July 2022). Accessed 20 July, 2023.
[227] Oklahoma Department of Human Services. *TEFRA Packet*. Accessed 28 July, 2023. Page 7.
[228] South Dakota Department of Social Services. *South Dakota Medicaid Coverage Groups*. Accessed 28 July, 2023.
[229] Division of TennCare. *Katie Beckett Parts A and B: Level of Care Criteria for Children*. (April 2021). Accessed 28 July, 2023.

assesses for physical, developmental, and social/emotional disabilities.[230, 231] No further information regarding LOC requirements was obtained by the Team.

Although Colorado is noted as having a Katie Beckett program,[232] the State neither refers to the program as "Katie Beckett eligibility" nor uses institutional or other LOC criteria to determine eligibility. The Health First Colorado Buy-In Program for Children with Disabilities provides Medicaid benefits for children under age 19 with a qualifying disability whose family income is at or below 300 percent of the FPL.[233] However, unlike Katie Beckett eligibility as established federally, Colorado does not require children to meet an institutional LOC threshold. Instead, Colorado enrolls children who meet all other eligibility criteria so long as they have a qualifying disability. A qualifying disability includes:

- Having a physical or mental impairment (or combination of impairments) that causes severe functional limitations.
- The impairment is expected to last at least 12 months or will lead to death.
- The child not working a job that entails conducting substantial work.[234]

Eligible families enrolled in the Colorado Buy-In Program for Children with Disabilities are required to pay a monthly premium, based on the family's adjusted income.[235]

The Team was unable to identify publicly available information for eligibility under the Kansas and Missouri's Katie Beckett programs.

Peer State Medicaid Program Services

Due to the considerable scope and amount of variability between State Medicaid program services, it is not feasible to include a full evaluation of Medicaid-covered services available on a national scale within the Nebraska DD service system review. States have the flexibility to determine the amount and scope of all services but are required to adhere to EPSDT standards

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[230] Wisconsin Department of Health Services. *Katie Beckett Medicaid: How to Apply*. Accessed 28 July, 2023.
[231] Wisconsin Department of Health Services. *Children's Programs Eligibility and Functional Screen*. Accessed 28 July, 2023. Page 2.
[232] Musumeci, MaryBeth, Molly O'Mallery Watts, Meghana Ammula, and Alice Burns. *Medicaid Financial Eligibility in Pathways Based on Old Age or Disability in 2022: Findings from a 50-State Survey*. (July 2022). Accessed 20 July, 2023.
[233] Colorado Department of Health Care Policy & Financing. *Health First Colorado Buy-In Program for Children with Disabilities. Eligibility and Enrollment FAQ*. (March 2022). Accessed 28 July, 2023. Page 1.
[234] Colorado Department of Health Care Policy & Financing. *Health First Colorado Buy-In Program for Children with Disabilities. Eligibility and Enrollment FAQ*. (March 2022). Accessed 28 July, 2023. Page 1.
[235] Colorado Department of Health Care Policy & Financing. *Health First Colorado Buy-In Program for Children with Disabilities. Eligibility and Enrollment FAQ*. (March 2022). Accessed 28 July, 2023. Page 1.

for individuals under 21. Because of this, there is variability in even the same services covered by states.

Despite the wide variety in how states cover Medicaid services, it should be noted that all state Medicaid programs are required to provide all mandatory services as detailed in *Appendix I.* Though optional services are subject to inclusion in a state's Medicaid State Plan, the Team was able to identify examples of optional services that most peer states are covering. These examples include:

- Dental services.[236, 237]
- ICF/IID services.[238]
- Physical/Occupational/Speech Therapy.[239]

Given the complexity of state Medicaid programs, the Team identified several states and services to demonstrate representative examples of Medicaid-covered services. ICF/IID services are optional and covered by all nine peer states.

Peer state ICF/IID resources are located in *Appendix XX: Peer State ICFs/IID References*. It is important to note that the Team confirmed several peer state examples of state-owned ICFs/IID including: Kansas,[240] Missouri,[241] Ohio,[242] and Oklahoma.[243]

Dental services was widely discussed among stakeholders, details of which are found in the stakeholder feedback section of this report. It is for this reason that the Team reviewed this service, to demonstrate the variability in how states are covering this optional service.

As is the case for all optional services, dental service coverage varies considerably among states. The following example illustrates some of those differences in three peer states.

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[236] National Academy for State Health Policy. *State Medicaid Coverage of Dental Services for General Adult and Pregnant Populations*. (October 2022). Accessed 10 August, 2023.
[237] Although Tennessee is noted as not having an adult dental program in above National Academy for State Health Policy source from 2022, Tennessee as of 2023 is covering adult dental services for certain populations of adults. This is further detailed within this section of the report.
[238] CMS. *Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID)*. Accessed 10 August, 2023.
[239] Kaiser Family Foundation. *Medicaid Benefits: Home Health Services – Physical Therapy, Occupational Therapy, and/or Speech Pathology Audiology*. (2018). Accessed 10 August, 2023.
[240] Kansas Department of Aging and Disability Services. *Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IID)*. Accessed 20 September, 2023.
[241] Missouri ICFIID Directory Report. (August 2023). Accessed 20 September, 2023.
[242] Ohio Department of Developmental Disabilities. *Developmental Centers*. Accessed 20 September, 2023.
[243] Oklahoma Health Care Authority. *317:35-9-4. Services in Intermediate Care Facility for Individuals with Intellectual Disabilities (public and private).* (September 2017). Accessed 20 September, 2023.

- Colorado:
  - Services include cleanings, root canals, fillings, crowns, and partial dentures.
  - No co-payments are required.
  - No annual benefit limit for adults or children.[244]
- Oklahoma:
  - Services include preventive care, full and partial dentures, and extractions for individuals 19 and over. Children have complete dental coverage.
  - Co-payments apply to certain individuals covered by Medicaid, for non-emergency care.
  - Annual service limits were unable to be determined.[245]
- Tennessee:
  - Offers 12 different benefit packages based primarily on age, receipt of Medicare benefits, and long-term services and supports. [246]
  - Services include all preventive, diagnostic, and treatment services that are medically necessary for individuals under 21 years of age. For individuals over 21, covered services include but are not limited to: preventive cleanings, fluoride treatments, fillings, crowns, and complete and partial dentures for individuals over 21 years of age.[247]
  - Dental services are covered for all individuals, regardless of within which benefit package an individual is enrolled.[248]

As demonstrated in these examples, there is wide variation in dental service coverage. Such types of variation can be seen across state Medicaid programs and mandatory and optional services.

Despite the limitations of our review in Medicaid program services across the peer states, the Team did, however, identify several innovative optional programs and services in its limited review. *Figures 14* through *16* provide examples of the unique innovative programs and services found in Ohio, South Dakota, and Tennessee.

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[244] Health First Colorado. *Health First Colorado Benefits & Services.* Accessed 22 July, 2023.
[245] Oklahoma Health Care Authority. *Comparison Chart of SoonerCare Benefits and Copay Amounts.* Accessed 22 July, 2023.
[246] TennCare. *TennCare Benefit Packages*. (March 2023). Accessed 22 July, 2023.
[247] Rules of the Tennessee Department of Finance and Administration Bureau of TennCare. *Chapter 1200-13-13 TennCare Medicaid.* (January 2023). Accessed 22 July, 2023. Page 37.
[248] TennCare. *TennCare Benefit Packages*. (March 2023). Accessed 22 July, 2023.

FIGURE 14: PEER STATE PROFILES: CHILD/YOUTH PREPAID INPATIENT HEALTH PLAN IN OHIO

OhioRISE Prepaid Inpatient Health Plan

The focus of OhioRISE is to keep children and youth with multi-system needs together with their families. There are two components of the OhioRISE program: Medicaid State Plan services and services offered through a 1915(c) waiver. Children and youth may be eligible for services provided through the State Plan component of OhioRISE, regardless of their enrollment on the 1915(c) waiver if they:

- Are eligible for Ohio Medicaid.
- Are between the ages of 0 and 21.
- Require significant behavioral health treatments as determined by the Ohio Child and Adolescent Needs and Strengths assessment.

Eligibility requirements for the 1915(c) waiver include:

- Meeting the State Plan component of OhioRISE eligibility requirements.
- Having an inpatient psychiatric LOC.
- Receiving a diagnosis of a serious emotional disturbance.
- Having documented functional limitations.
- Requiring at least one OhioRISE 1915(c) waiver service.
- Having waiver needs that are less than or equal to the service cost limit of $15,000.

OhioRISE benefits are managed through the State's prepaid inpatient health plan vendor. Benefits included under the State Plan portion of OhioRISE include:

  - Care coordination.
  - Improved intensive home-based treatment.
  - In-state psychiatric residential treatment facilities.
  - Behavioral health respite.
  - Primary flex funds.
  - Mobile response and stabilization services.

OhioRISE 1915(c) waiver services include:

  - Out-of-home respite.
  - Transitional services and supports.
  - Secondary flex funds.

When a child qualifies for OhioRISE, they have access to all the OhioRISE Medicaid State Plan services, OhioRISE 1915(c) waiver services (if enrolled), and all other Ohio Medicaid State Plan services.[249]

[249] Ohio Medicaid Managed Care. *About OhioRISE*. Accessed 22 July, 2023.

FIGURE 15: PEER STATE PROFILES: A MODEL OF CARE FOR INDIVIDUALS WITH CHRONIC DISEASE

South Dakota Health Homes

As of July 2022, South Dakota is one of 19 states[250] along with the District of Columbia that have a state plan amendment approved to cover health homes. Health homes help to improve care coordination and care management for individuals enrolled in Medicaid programs who have complex needs. Health homes integrate physical and behavioral health care, including long-term services and supports.

The South Dakota Health Home program is dedicated to providing enhanced health care services to individuals with chronic conditions and serious mental illness.[251] The health home program in South Dakota supports enhanced health care services and helps individuals connect to other services that may be needed in the community. The South Dakota health home model makes connections between an individual's doctors, counselors, and other team members to make sure that an individual meets their health goals. South Dakota's health home services include:

- Providing education to individuals.
- Scheduling appointments for screenings (like cancer screens) when they are needed.
- Building a team dedicated to helping individuals meet their health goals.
- Providing referrals to different providers and specialists.
- Explaining test results.
- Preventing readmissions to hospitals or emergency rooms.

Individuals may qualify for the health home program if they are:

- Enrolled in South Dakota's Medicaid program.
- Diagnosed with a chronic disease like asthma, chronic obstructive pulmonary disease, diabetes and pre-diabetes, heart disease, hypertension, obesity, substance use disorder, mental health conditions, tobacco use, cancer, hypocholesteremia, depression, and musculoskeletal and neck/back disorders.[252]

[250] Kansas, Missouri, Tennessee, and Wisconsin also cover health homes for people with chronic conditions, serious mental illness, HIV/AIDS, and substance use disorders (Centers for Medicare & Medicaid. Medicaid Health Homes: An Overview).
[251] Centers for Medicare & Medicaid Services. *Medicaid Health Homes: An Overview*. (March 2022). Accessed 22 July, 2023. Page 2.
[252] South Dakota Department of Social Services. *Health Home Your Care Connection*. Accessed 22 July, 2023.

FIGURE 16: PEER STATE PROFILES: TENNESSEE'S ALTERNATIVE TO 1915(C) WAIVERS

Tennessee Employment and Community First CHOICES (ECF CHOICES)

Individuals who previously would have sought enrollment on a 1915(c) waiver now receive services through ECF CHOICES,[253] an 1115 demonstration waiver.[254] The program is for all ages who have an I/DD, including people with significant disabilities, who qualify for Tennessee's Medicaid program.[255] Individuals do not need to be employed to be enrolled, but must be open to exploring employment options. Benefits include residential supports, up to 24 hours per day, and include assistance with activities of daily living. Benefits are dependent on which benefit group an individual is enrolled.[256] There are five benefit groups under ECF CHOICES:

- Essential Family Supports: Services for families caring for an individual under the age of 21, in their home who has an I/DD. This does not include foster families. Adults aged 21 and older with an I/DD living at home with their families may also qualify for this benefit group.
- Essential Supports for Employment and Independent Living: Services for adults over 21 years of age who have an I/DD, but do not meet the nursing facility LOC. People between the ages of 18 and 21 may qualify if they cannot live at home with their family, as can individuals who meet the nursing facility LOC but cannot enroll in the Comprehensive Supports for Employment and Community Living group.
- Comprehensive Supports for Employment and Community Living: Services are only for adults over the age of 21 who qualify to get care in a nursing facility.
- Intensive Behavioral Supports: For children under 21 who live with their family and have an I/DD and a severe behavioral support need and is at risk of placement outside the home.
- Comprehensive Behavioral Supports for Employment and Community Living: For adults who are moving into the community who have an I/DD and severe behavioral support need.[257]

Providers of residential supports are paid more for supporting people who need more hours of care or have medical/behavioral needs. Some services can be provided through participant-direction options.[258]

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[253] Division of TennCare. *Employment and Community First Choices*. Accessed 22 July, 2023.
[254] Centers for Medicare & Medicaid. *TennCare II Section 1115 Demonstration Fact Sheet*. (February 2016). Accessed 30 July, 2023. Page 2.
[255] Division of TennCare. *Who qualifies for Employment and Community First CHOICES?* Accessed 22 July, 2023.
[256] Division of TennCare. *Frequently Asked Questions*. Accessed 22 July, 2023.
[257] Division of TennCare. *Employment and Community First CHOICES Benefit Groups*. Accessed 22 July, 2023.
[258] Division of TennCare. *Frequently Asked Questions*. Accessed 22 July, 2023.

Other Peer State Programs Supporting Persons with Developmental Disabilities

Beyond 1915(c) waivers and Medicaid programs, the nine peer states offer a wide variety of services and supports for individuals with developmental disabilities. The following sections briefly present information on the following programs and services:

- Non-Medicaid funded family support programs.
- Other non-Medicaid funded programs.
- Services offered by state UCEDDs.
- Employment and technology first initiatives.

Non-Medicaid Funded Family Support Programs

Colorado, South Dakota, and Tennessee offer three family support programs that are outside of their 1915(c) waivers. These programs are funded through state general funds, and as a result, offer more flexibility in program design than what would be allowed under a Medicaid-funded program.

All three programs are based on similar eligibility criteria and offer similar services. *Table 17: Colorado, South Dakota, and Tennessee Family Support Programs* provides a summary of program information for each of these states' family support programs.

TABLE 17: COLORADO, SOUTH DAKOTA, AND TENNESSEE FAMILY SUPPORT PROGRAMS

State and Program Name	Eligibility Criteria	Services
Colorado – Family Support Services	• Any individual with an I/DD or developmental delay living with their family.[259]	Examples of services include: • Assistive technology • Environmental engineering • Medical and dental items • Parent and sibling support • Professional services • Respite • Transportation[260]
South Dakota – Strengthening Families Program	• Individuals with a diagnosis of a DD or required long-term assistance for ages 0 to 3.	Services may include but are not limited to: • Incontinence supplies

[259] Code of Colorado Regulations. *10 CCR 2505-10 8.613 Family Support Services Program (FSSP).* (June 2023). Accessed 20 July, 2023. Page 81.
[260] Colorado Department of Health Care Policy & Financing. *Family Support Services Program (FSSP)*. Accessed 20 July, 2023.

State and Program Name	Eligibility Criteria	Services
	• Individuals must live in a family home. • Individuals must not already receive services through the CHOICES or Family Support 360 waivers.[261]	• Medication copays • Nutritional supplements • Recreational opportunities • Adaptive equipment • Housing modifications • Travel expenses for medical care • Vehicle modifications[262]
Tennessee – Family Support Program	• Individuals must meet the following criteria: ○ Live with a family, as defined by Tennessee regulations. ○ Have a severe or DD, as defined by regulation. ○ Must not be in receipt of supportive living, community-based day services, Employment and Community First Choice, Katie Beckett, or CHOICES.[263]	Services may include but are not limited to: • Respite • Day care services • Home modifications • Equipment and supplies • Personal assistance • Transportation • Homemaker services • Housing costs • Health-related needs • Nursing • Counseling[264]

Other Non-Medicaid Funded Developmental Disability Programs

The Team reviewed several other programs and services that help to support individuals with DD and their families in the nine peer states, which include special programs dedicated to serving individuals with medical or genetic complexities that are available outside of the Medicaid program. Lastly, the Team found examples of programs and services that would be of benefit to all individuals, including those with disabilities. Though these programs and services are not operated specifically to address individuals with an I/DD, the benefits provided by these programs help to support general health and welfare of a broader patient population. *Appendix XXI: Peer State Non-Medicaid Funded Program Examples* provides details of the Team's findings

[261] Department of Human Services. *Strengthening Families Program*. Accessed 19 July, 2023.
[262] Department of Human Services. *Strengthening Families Program*. Accessed 19 July, 2023.
[263] Department of Intellectual & Developmental Disabilities. *Tennessee Family Support Guidelines*. (July 2023). Accessed 20 July, 2023. Page 1.
[264] Department of Intellectual & Developmental Disabilities. *Family Support Program*. Accessed 20 July, 2023.

from reviewing the programs and services operated by peer states outside of their Medicaid programs.

Aging and Disability Resource Centers

The Team reviewed peer state services delivered by ADRCs. ADRC services provided in peer states are located in *Appendix XXII: Peer State Aging and Disability Resource Center Services.* It is important to note that states operationalize and refer to their ADRC networks differently. For example, Missouri uses their AAA network to operationalize their ADRC system. Noted differences in naming conventions are listed in the references column of *Appendix XXII*.

University Centers for Excellence in Developmental Disabilities

The Team reviewed all the designated UCEDDs in each peer state. The selected UCEDDs cover a variety of programs and services supporting individuals with DD and their families. They all share similar characteristics with respect to research activities, provisioning of certain services and supports, and initiatives (such as peer-to-peer or family-to-family programs). However, despite their similarities the peer state UCEDDs also have clear distinctions. For example, the UCEDD at the University of Kansas offers several programs, such as assistive technology supports, training for childhood special education staff, and a disability and health program.[265] In comparison, Temple University's Institute on Disabilities in Pennsylvania offers programs that support self-advocacy training, employment, and media, arts, and culture.[266]

The variety of services and programs offered by peer state UCEDDs reflects the needs of the communities they serve. So long as UCEDDs meet their core functions of providing "pre-service preparation, services, research, and information dissemination,"[267] UCEDDs have flexibility in how they implement specific programs and services. A full list of the programs and services provided by the peer state UCEDDs is in *Appendix XXIII: Peer State UCEDD Programs and Services*.

Vocational Rehabilitation

The Team reviewed publicly available employment outcomes reported by peer state VR agencies under the Workforce Innovation and Opportunities Act. Participants served in a program year (defined by Workforce Innovation and Opportunities Act as July through June), employment rates, and median earnings[268] were identified, which we deemed was relevant to Nebraska's DD system evaluation.

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[265] Kansas University Center on Developmental Disabilities. *Service and Outreach*. Accessed 24 July, 2023.
[266] Temple University, Institute on Disabilities. *Programs and Services*. Accessed 24 July, 2023.
[267] Association of University Centers on Disabilities. *About UCEDD*. Accessed 24 July, 2023.
[268] In addition to disabilities, states report employment outcomes for individuals who experience or who are low levels of literacy or cultural barriers; ex-offenders; homeless; long-term unemployed; migrant and seasonal farmworkers; single parents; individuals who have exhausted Temporary Assistance to Needy Family Funds; displaced homemakers; and youth in foster care or aged out of the system.

Figure 17: Peer State Employment Outcomes, Program Year 2021 provides a summary of information reported to the Rehabilitation Services Administration by the peer states, combined with state census data to determine the percentage of the population with disabilities served by the VR program.[269] Program Year 2021 was the most current year for which data was available at the time of the DD system evaluation.

FIGURE 17: PEER STATE EMPLOYMENT OUTCOMES, PROGRAM YEAR 2021

State	Total Population [270]	Total Individuals Served with a Disability	Percentage of Population with a Disability Served	Percentage of Population with a Disability	Employment Rate for Individuals with a Disability	Median Earnings for Individuals with Disabilities
Colorado	5,812,069	8,889	0.15%	11.2%	52.1%	$5,205
Kansas	2,934,582	6,609	0.23%	13.4%	44.7%	$3,105
Missouri	6,168,187	16,332	0.27%	14.8%	61.5%	$4,384
Nebraska	1,963,692	3,184	0.16%	12.7%	61.6%	$4,180
Ohio	11,780,017	25,878	0.22%	14.2%	58.1%	$3,262
Oklahoma	3,986,639	8,189	0.21%	17.2%	50.8%	$4,923
Pennsylvania	12,964,056	35,373	0.28%	13.8%	61.4%	$5,161
South Dakota	895,376	3,362	0.38%	12.4%	57.8%	$3,492
Tennessee	6,975,218	10,126	0.15%	14.9%	51.9%	$5,169
Wisconsin	5,895,908	18,680	0.32%	11.9%	54.0%	$3,302

Peer states ranged from .15 percent to .38 percent in percentage of population served by VR for individuals with disabilities. Peer states ranged widely in overall population. To create a more equal comparison, the percentage of the population served with a disability was derived by dividing the total number of individuals served with a disability by the state's total population. Also included in the state breakdown is the employment rate, which ranged from 44.7 percent to 61.6 percent for individuals with disabilities. The median earnings for individuals with disabilities ranged from $3,105 to $5,205 per program year.

Nebraska falls at the low end of the range (.16 percent) for percentage of the population with a disability served by VR. Individuals in Nebraska with a disability that receive VR services have an employment rate of 61.6 percent, which is higher than all the peer states even though they serve a much smaller percentage of the population than most. With respect to population, Kansas and

[269] Rehabilitation Services Administration. *WIOA Annual Reports*. Accessed 27 July, 2023.
[270] US Census Bureau. 2021 Census Data by Disability Characteristics. Accessed 28 July, 2023.

South Dakota are the most similar in size to Nebraska, but both serve a higher percentage of individuals with disabilities through their VR program.

While the statistics listed in *Figure 17* represent the quantity of VR services being offered by each state, it does not necessarily reflect the quality of integrated employment opportunities and services for individuals with disabilities.

Employment and Technology First Initiatives

States can implement specific policies and programs to promote community inclusion, self-direction, and independence for individuals with disabilities. "Employment First" is one such initiative, which emphasizes the importance of integrated employment in the community for individuals with disabilities. Some states achieve this through passing legislation, while other states elect to use other non-legislative actions such as policies or executive orders. Additionally, some states elect to set these policies specifically for individuals with I/DD, while others set policies for cross-disability populations. Currently, Nebraska does not have any Employment First policies in place.[271] *Table 18: Employment First States* reflects which states currently have Employment First policies in place, the method in which they were implemented and for which populations they cover. As indicated, Nebraska has not implemented any Employment First policies to date.[272]

[271] State Employment Leadership Network. Employment First Resource List. (June, 2023). Accessed 27 July, 2023. Pages 1-2.
[272] State Employment Leadership Network. Employment First Resource List. (June, 2023). Accessed 27 July, 2023. Pages 1-2.

TABLE 18: EMPLOYMENT FIRST STATES

State	Employment First[273]	Employment First Legislation Passed	Employment First Policy Directive, Executive Order, or Other Non-Legislative Action	Cross-Disability Policies	I/DD-Specific Policies
Colorado	X	X		X	
Kansas	X	X		X	
Missouri	X	X	X	X	
Nebraska					
Ohio	X	X			X
Oklahoma	X	X	X	X	
Pennsylvania	X	X	X	X	
South Dakota					
Tennessee	X		X		X

Figure 18: Peer State Profile: Colorado's Employment First Policies and *Figure 19: Peer State Profile: Missouri's Employment First Policies* provide snapshots of implementation of Employment First initiatives by two of the nine peer states.

[273] State Employment Leadership Network. Employment First Resource List. (June, 2023). Accessed 27 July, 2023. Pages 1-2.

FIGURE 18: PEER STATE PROFILE: COLORADO'S EMPLOYMENT FIRST POLICIES

Colorado's Employment First Profile

In Colorado, Employment First policies and practices are designed to expand employment opportunities for individuals with disabilities, including individuals with more complex disabilities who previously may not have been considered for competitive integrated employment. In Senate Bill 16-077 "Employment First for persons with Disabilities" Colorado designated the State Rehabilitation Council the lead agency, coordinating a cross-system committee with the Department of Labor and Employment, Education, Higher Education, Healthcare Policy & Financing, and Human Services. While they have been implementing new Employment First policies, workforce shortages have impacted the effectiveness of implementation.[274]

FIGURE 19: PEER STATE PROFILE: MISSOURI'S EMPLOYMENT FIRST POLICIES

Missouri's Employment First Profile

Missouri has had an Employment First policy in place since 2011 for individuals with an I/DD. In May, 2023, Missouri passed the Missouri Employment First Act Senate Bills 45 and 90, which guarantee integrated employment practices to individuals with disabilities regardless of disability type. The Division of Developmental Disabilities through the Missouri Department of Mental Health oversees implementation and provides resources and coordination of services related to the Employment First initiative.[275]

With self-direction and independence goals like those of the Employment First initiative, some states have adopted a "Technology First" initiative. Technology First requires systems to consider technology options available to support individuals with disabilities to increase autonomy, self-direction, and community engagement, while reducing reliance on caregivers.

Shifting reliance from caregivers for activities individuals can do themselves with the appropriate supports can assist in alleviating workforce limitations, reduce costs, and improve quality of life outcomes overall for individuals with disabilities.[276]

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[274] Colorado Division of Vocational Rehabilitation. 2022 Annual Report. (December, 2022). Accessed 27 July, 2023. Page 16.
[275] Missouri Department of Mental Health. Promoting Employment. Accessed 27 July, 2023.
[276] University of Kansas. State of the States in Intellectual and Developmental Disabilities. Accessed 27 July, 2023.

Table 19: Technology First States identifies which of the selected peer states have Technology First initiatives either through legislation or through other non-legislative actions. As shown in the table, Nebraska currently does not have any Technology First initiatives in place.

TABLE 19: TECHNOLOGY FIRST STATES

State	Technology First[277]	Technology First Legislation
Nebraska		
Colorado	X	
Kansas		
Missouri	X	X
Ohio	X	X
Oklahoma	X	
Pennsylvania	X	
South Dakota		
Tennessee	X	
Wisconsin	X	

Figure 20: Peer State Profile: Ohio's Technology First Initiative and *Figure 21: Peer State Profile: Missouri's Technology First Profile* provide an overview of two of the peer states, and how they adopted Technology First policies to increased self-determination and independence for individuals with disabilities.

[277] University of Kansas. State of the States in Intellectual and Developmental Disabilities. Accessed 27 July, 2023.

FIGURE 20: PEER STATE PROFILE: OHIO'S TECHNOLOGY FIRST INITIATIVE

Ohio's Technology First Profile

Ohio's Technology First rule was implemented on April 21, 2022 specifically to increase access to technology for individuals with developmental disabilities and their families and to build on the program implemented in 2018 under executive order.[278] The purpose of the program is to improve independence, technology use, and personal freedom to improve individuals with disabilities' quality of life.[279] Ohio's supportive technology-based services include services such as Assistive Technology and Remote Support. Assistive Technology refers to items that provide personalized support for daily tasks, while Remote Support is a two-way communication support solution that allows them to communicate with providers in real time when they need them remotely. Ohio requires that each person-centered plan will clearly delineate the technology solutions explored and document them, including the ability to increase capacity of technology use, and strategies to improve knowledge, skills, and comfort of individuals and the staff that works with them. These should be considered for the purposes of:

- **Enhancing personal freedoms.**
- **Increasing the ability to communicate effectively.**
- **Establishing meaningful relationships.**
- **Enabling tasks to maintain employment.**
- **Increasing independence with daily tasks.[280]**

Ohio offers a variety of assistive technology options under their Individual Options, Level One, and SELF waivers.[281]

[278] Ohio Department of Developmental Disabilities. 5123-2-01 Technology First Rule. Accessed 27 July, 2023.
[279] Ohio Department of Developmental Disabilities. Technology First. Accessed 27 July, 2023.
[280] Ohio Department of Developmental Disabilities. 5123-2-01 Technology First Rule. Accessed 27 July, 2023. Pages 2-3.
[281] Ohio Department of Developmental Disabilities. Assistive Technology. Accessed 27 July, 2023.

FIGURE 21: PEER STATE PROFILE: MISSOURI'S TECHNOLOGY FIRST PROFILE

Missouri's Technology First Profile

Missouri's Department of Developmental Disabilities, as a part of the Missouri Department of Mental Health, oversees the Technology First initiative. Missouri's Technology First initiative prioritizes the practice of considering technology before direct support professionals. Examples of technologies offered through their DD waivers include dispensing devices, phone applications, door and window sensors, environmental controls or systems, communication systems, or remote staff support.[282]

Comparative Summary of Nebraska and Peer State DD System Findings

After reviewing information from Nebraska and the nine peer states selected for this evaluation, the Team presents here a comparative summary of relevant findings in the key similarities and differences in the respective DD service systems. While Nebraska's DD service system shares many characteristics with the peer states, those are also notable differences in state demographics, governance structures, and programs offered. Some of those differences create gaps and challenges in meeting the needs of individuals with an I/DD in Nebraska.

Recommendations identified through these findings are discussed in the section of this report titled *Recommendations for Nebraska's DD Service System.*

Analysis of Developmental Disability Service Systems

The following analysis of DD service systems is divided into the following topics:

- 1915(c) programs.
- Medicaid eligibility determinations.
- Innovative Medicaid-funded service options.
- Non-Medicaid funded programs and services.

[282] Missouri Department of Mental Health. *Technology First*. Accessed 27 July, 2023.

Nebraska and Peer State 1915(c) Programs: Design and Services

There are seven major points of analysis the Team focused on during the review of Nebraska and peer state 1915(c) programs. These seven points involve the following topics:

- Definition of DD.
- Registry and waitlist management practices.
- LOC assessment tools, including use of single assessment tools for all 1915(c) programs.
- Services offered through state 1915(c) waiver programs.
- Variation in how services are delivered and by whom.
- Self-direction opportunities.
- Prioritization of Employment First and Technology First initiatives across disabilities.

Definition of Developmental Disability

State definitions of DD, while similar in certain characteristics, are not uniform. Moreover, no state definition reviewed is an exact match to the federal definition. In stark contrast, however, is the difference in number of areas of major life functioning that an individual with developmental disabilities must meet to qualify for services under the definitions. Peer states that do not use diagnosis as the only criterion to determine a DD most closely align with the federal requirement of meeting three areas of major life functioning. Nebraska is neither aligned with the federal definition nor aligned with the peer states criteria for determining a DD.

Registry and Waitlist Management

Regarding registry and waitlist management practices, the Team found that Nebraska is not unique in the level and scope of capacity and funding limitations that impede its ability to serve everyone in need of services. Nebraska is also similar to some peer states in the way individuals are placed on the registry. Along with Nebraska, Colorado, Kansas, and Missouri were determined to confirm program eligibility prior to placement on waitlists in those respective states.[283] However, Nebraska does not formally determine appropriateness of waiver services or community services in lieu of waiver services to address immediate needs. In addition, because Nebraska's registry includes both eligible individuals who are actively waiting to receive services

[283] Kaiser Family Foundation. *Medicaid HCBS waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility*. (2021). Accessed 20 April, 2023.

and who are seeking future services, it is difficult to determine who has an immediate need for waiver enrollment.

Additionally, although individuals are referred to case management and to community services at the time of placement on the registry, Nebraska does not redirect those whose needs may be best met with services and supports other than 1915(c) waiver services. As a result, the registry process becomes overloaded, and DHHS has no way to ensure limited 1915(c) waiver slots are dedicated to those who qualify and are most in need. In contrast, Ohio's use of a current and immediate needs assessment process is used to evaluate 1915(c) service needs. The assessment will redirect individuals to other, non-waiver services when applicable, which helps to minimize wait time for waiver program placement.

Level of Care Assessment Tools for 1915(c) Programs

The nine peer states conduct LOC assessments using a variety of different tools based on the population characteristics served through each 1915(c) waiver program. Some peer states use a unified LOC screening tool, whereas other states use different LOC assessments for different populations. Colorado and Kansas are examples of states using the same assessment tool across at least two waiver programs. Missouri, Ohio, and Pennsylvania are examples of peer states that are using different assessment tools across at least two 1915(c) programs.

Nebraska is like most peer states in use of a mix of homegrown and standardized assessment tools. Nebraska utilizes the interRAI Home Care, interRAI Pediatric-Home Care, and Inventory for Client and Agency Planning assessments, all of which are standardized tools. Nebraska also uses the homegrown DI to perform assessments for the Comprehensive Developmental Disabilities and the DD Adult Day waivers. When compared to the peer states that use only homegrown assessment tools, Nebraska has made great progress in adopting a primary best practice in rendering LOC determinations, which is further explored in the *Best Practice* section of this report.

Services Offered between 1915(c) Programs

Nebraska and peer state 1915(c) waiver programs were found to be similar in the number and type of services offered based on the target population of the waiver. Service similarities were prevalent across 1915(c) waivers with the same LOC criteria. Examples of these programs include but are not limited to:

- **Colorado:** Persons with Developmental Disabilities and Supported Living Services waivers.
- **Missouri:** DD Comprehensive and Partnership for Hope waivers.
- **Ohio:** Level One and SELF waivers.

- **Oklahoma:** Community and Homeward Bound waivers.

As highlighted in the review of Nebraska's Comprehensive Developmental Disabilities and the DD Adult Day waivers, these waivers offer some of the same services including Adult Day; Assistive Technology, Home and Vehicle Modifications, and Prevocational Services. However, there are some distinct differences between the services offered between the two programs. This creates an inequity in where individuals can choose to live, while receiving needed intermittent supports.

Variation in Service Delivery

The services offered in Nebraska and the peer review states have a wide variation in how and by whom those services are delivered. Respite care, for example, is a service offered in Nebraska's 1915(c) programs, but provider requirements and location of services to be delivered are limited when compared to peer states. Consider, for instance, respite examples from Kansas, Missouri, Ohio, South Dakota, and Tennessee as summarized in *Appendix XXIV: Peer State Respite Services*. Each of these respite services provide some level of relief to primary caregivers, are unique, and allow for flexibility in the location in which the service is provided.

In addition to the differences in how states define services, they must also define legally responsible individuals in terms of service delivery. The definition of legally responsible individuals may also include family caregivers. While peer states use different definitions of legally responsible individuals, many 1915(c) waiver programs the Team reviewed do allow at least some services to be provided by legally responsible individuals in certain circumstances. *Appendix XIX* includes the details of the 1915(c) programs the Team reviewed that allow for payment to legally responsible individuals, in addition to payments to relatives and legal guardians.

Nebraska does not make payments to any legally responsible individuals, as defined by the State. Legal guardians are not included in the State's definition of legally responsible individuals. Legal guardians of adults and other non-legally responsible relatives under the AD waiver are eligible to receive payment for the provision of services; however, under the CDD and DDAD waiver, legal guardians of adults are not eligible to provide services to individuals, though non-legally responsible individuals can. Nebraska's use of legal guardians is different than several examples from peer states (Colorado,[284] Kansas,[285] Ohio,[286] Oklahoma,[287] and South Dakota[288]) which

[284] Colorado Developmental Disabilities waiver Application. (July 2023). Accessed 14 July, 2023. Page 137.
[285] Kansas HCBS-I/DD waiver Application. (July 2021). Accessed 13 July, 2023. Page 105.
[286] Ohio Individual Options waiver Application. (July 2022). Accessed 13 July, 2023. Page 155.
[287] Oklahoma Homeward Bound waiver Application. (July 2023). Accessed 8 September, 2023. Page 146.
[288] South Dakota Family Support 360 Waiver. (June 2022). Accessed 19 July, 2023. Page 91.

allow legal guardians of adults enrolled in an ICF/IID LOC waiver to be paid providers, in certain circumstances.

Self-Direction Opportunities

In the same sense as how and who can provide services, self-direction opportunities varied across the peer state waiver programs reviewed. Generally, the Team found that at least one aspect of self-direction in ICF/IID LOC waivers. This was the case in Nebraska and across the peer states. However, peer states were more generous in their self-direction allowances within non-ICF/IID LOC waivers, than what is currently allowed in Nebraska.

Employment First and Technology First Initiatives

Most peer states are Employment First states who cover a cross-disability population and have Technology First policies in place. Currently, Nebraska has not adopted the recognized Employment First or Technology First policies to promote independence, self-determination, and community inclusion for any population. Nebraska offers VR services, Assistive Technology, and several different types of employment-related services through some of their waivers, but the State has not adopted policies that encourage community integration with employment and uniform technology practices around technology consideration could bolster the current VR and supported employment services available.

Medicaid Eligibility Determinations: Similarities and Differences between Nebraska and Peer States

Medicaid eligibility categories and criteria are driven by state-specific policy objectives and legislative priorities. There was some differentiation in how peer states determine eligibility for the Medicaid program. The most significant of these are the following:

- Nebraska is one of only eight states (including Kansas) that establishes eligibility through the SSI authority. Most other states nationwide, including six of the peer states, establish eligibility through 1634 criteria.[289]

- Nebraska is also only one of eight states not using special income level rules to determine eligibility for long-term services and supports, including 1915(c) waivers and facility-based services. All peer states reviewed allow for special income levels.[290]

[289] Social Security Administration. *Policy for States and State Choices*. (October 2017). Accessed 11 July, 2023.
[290] Medicaid and Chip Payment and Access Commission. *MACStats: Medicaid and CHIP Data Book 2022*. (2022). Accessed 11 July, 2023. Page 3.

- Katie Beckett eligibility is allowable in some peer states but is limited in Nebraska in terms of only covering hospital LOC. States with Medicaid program and Katie Beckett eligibility allow for multiple LOCs to meet eligibility criteria.

- MIWD is common and was identified as an allowable eligibility category in Nebraska and the peer states.

Medicaid eligibility is critical to how individuals access services that make up the DD service system. Without a pathway to Medicaid eligibility, individuals are often left with filling critical service needs on their own, and sometimes without the assistance and benefit of coordination and oversight of services.

Medicaid-Funded Service Innovations

The Medicaid Program provides states with a certain amount of flexibility in terms of optional services and administration of eligibility and benefits. Such flexibilities are important to consider when comparing and analyzing similarities and differences between Nebraska's DD and peer state DD systems. When considering which flexibilities would best enhance Nebraska's current DD system, the Team identified the following guiding questions:

- Are there opportunities to support individuals by adding new Medicaid services?

- Can a different service delivery model address any identified gaps in eligibility or services for individuals with developmental disabilities and other co-morbidities?

- If DHHS' divisions were restructured, would this improve Medicaid-funded service access or enhance program and service efficacy for individuals with developmental disabilities and other co-morbidities?

- Could providing extended State Plan services to vulnerable populations enrolled in 1915(c) waivers help to enhance services to select populations?

Our review of Nebraska's Medicaid program services suggests a wide variety of services and supports to address both acute and long-term needs. Such services and supports relative to individuals with a DD include the following:

- Behavioral health services (relative to people with co-occurring diagnoses).

- Case management.

- Dental.

- Durable medical equipment and supplies.
- Hospital stays.
- ICFs/IID.
- Pharmacy.
- Physician services.
- Therapies, including occupational, physical, and speech language pathology.

Many of these same services are covered by the peer states included in this report. Nebraska is covering all mandatory and many optional Medicaid State Plan services. However, our review of some of the innovative services covered by peer state Medicaid programs suggests there may be opportunities for Nebraska to expand Medicaid-funded services offered to individuals with a DD.

As stated previously, recommendations for innovations within Nebraska's Medicaid program are explored in the section of this report titled *Recommendations for Nebraska's DD Service System*. These recommendations are informed by the following programs, services, and benefit administration examples found in the Team's peer state review.

Health Homes

South Dakota's health homes were highlighted as an innovative practice, but other peer states (Kansas, Missouri, Tennessee, and Wisconsin) also cover health homes for people multiple chronic conditions, including I/DD.[291] Nebraska is not currently offering health homes to any population, and exploring health homes as an option may help to provide improved coordination of care for individuals.

Prepaid Inpatient Health Plans and 1115 Demonstration Waivers

Ohio and Tennessee are restructuring their services and programs to better coordinate and provide care to individuals with complex needs. In Ohio, youth with a behavioral health and multi-system need are receiving behavioral health and all other services to address their co-morbid diagnosis through the OhioRISE prepaid inpatient health plan. The program is tailored to provide services to children who require only Medicaid State Plan services, 1915(c) and Medicaid State

[291] Centers for Medicare & Medicaid Services. *Medicaid Health Homes: An Overview*. (March 2022). Accessed 22 July, 2023. Page 2.

Plan services, and care through a psychiatric residential treatment facility.[292] The ECF CHOICES program in Tennessee, while similar in certain respects to a 1915(c) waiver,[293] allows for additional flexibilities because of the program's authorization under an 1115 waiver. Benefits are managed through one of the state's MCOs, which also coordinate Medicaid State Plan services for these same individuals.[294] Nebraska does have an approved 1115 waiver; however, this program's primary focus is on substance use disorder and other behavioral health conditions.[295]

Combined Developmental Disability and Behavioral Health Programs

Not only do the examples found in the abovementioned peer states allow for better coordination of services, but state governance structures also help to promote this as well. Wisconsin's Division of Care and Treatment Services under the Department of Health Services serves and supports individuals with I/DD and behavioral health conditions.[296] Though Missouri's Developmental Disabilities Division is separate from the Division of Behavioral Health – Substance Use and Mental Illness, both Divisions fall under the purview of the Department of Mental Health.[297] Nebraska's DDD and DBH are both under the purview of DHHS, but further exploration of a combined DD and behavioral health Division may be useful when considering how to better coordinate care.

Extended State Plan Services

All peer states provided extended state plan services in at least one of their approved 1915(c) waivers. 1915(c) waivers cannot offer the same services or scope of services as offered under the Medicaid program. However, 1915(c) waivers can cover Medicaid program services that are broader in scope than what is allowed under a State Plan. For example, private duty nursing services are an optional Medicaid State Plan service. If a state only allows for 20 hours of private duty nursing in a month for adults under its Medicaid State Plan, a 1915(c) waiver could cover up to 40 hours a month of private duty nursing.

Nebraska is not currently offering any extended State Plan services in any of the state's four waiver programs. By offering extended State Plan services to individuals enrolled on a 1915(c) waiver, states are providing additional benefits to individuals who typically require a large amount of supports to remain safe and independent in the community.

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[292] Ohio Medicaid Managed Care. *About OhioRISE.* Accessed 22 July, 2023.
[293] ECF Choices provides services in the community and not an institution, with the goal of the program being to promote individual independence to the greatest extent possible.
[294] Division of TennCare. *Employment and Community First Choices.* Accessed 22 July, 2023.
[295] Nebraska Department of Health and Human Services. *Substance Use Disorder Demonstration*. Accessed 30 July, 2023.
[296] Wisconsin Department of Health Services. *Division of Care and Treatment Services*. Accessed 30 July, 2023.
[297] Missouri Department of Mental Health. *About the Department of Mental Health*. Accessed 30 July, 2023.

Other Non-Medicaid Funded Programming Findings

In addition to innovations identified in peer states under Medicaid programs, the Team notes several observations regarding other programs and services. They include the following:

- Non-Medicaid funded programming in Nebraska is similar or even more than what is offered in peer states. Services provided by CFS, such as the Disabled Children's Program or the Medically Handicapped Children's Program are similar in scope and services to other peer state programs. The CFS programs and services are available to fill gaps in needs, especially for individuals who are on the registry or may not be eligible for Medicaid.

- Nebraska currently offers VR services to a relatively small percentage of the population with disabilities, as compared to the peer states the Team reviewed. Additionally, Nebraska is currently not utilizing employment or technology first initiatives like the peer states highlighted in the peer state profiles, whereas most peer states are prioritizing employment and technology first initiatives.

- UCEDD services vary, but across Nebraska and all peer states, UCEDDs are providing core sets of services and support DD service systems.

Observations

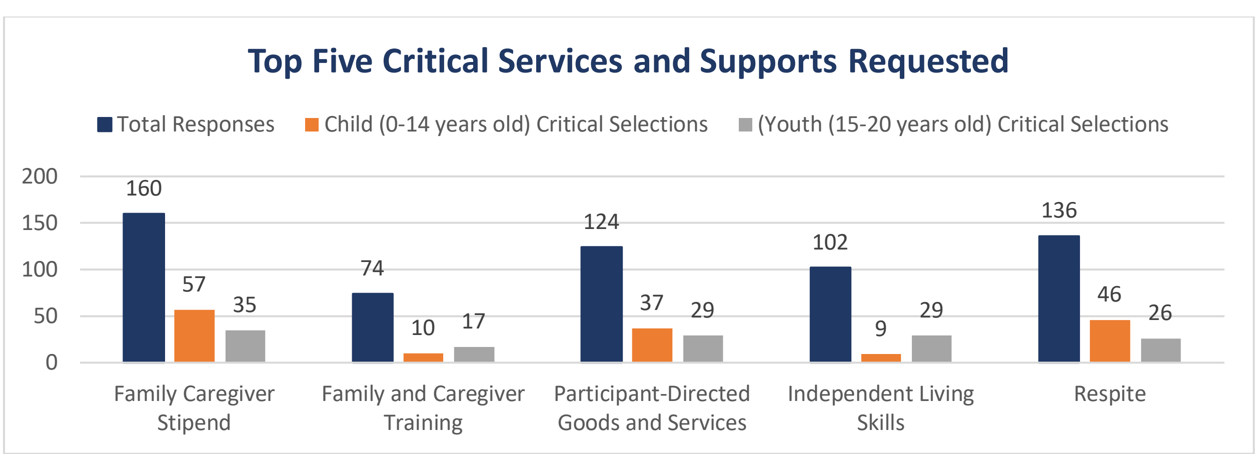
Based on the Team's review of Nebraska and peer state DD service systems, it is clear each state varies in the type and scope of Medicaid program structure, services, and supports available to meet the specific needs of individuals with an I/DD and other special needs and high-risk populations. There are both similarities and differences between Nebraska's DD service system and those of the nine peer states. These differences can be used to draw certain lessons learned, identify best practices, and suggest opportunities for positive change. Nebraska may want to consider providing services; however, only so much can be learned from peer state examples because of each state's unique characteristics. For this reason, Nebraska decision makers will need to consider the voices of individuals, families, advocates, and providers when deciding how to improve upon the service delivery system existing in the state today.

Stakeholder Engagement

Previous Stakeholder Engagement Conducted by DHHS

Between October and November 2022, DHHS DDD conducted a Family Support Waiver Engagement Survey and two listening sessions to gather feedback from stakeholders. Feedback was focused on services and supports requested by family members, for inclusion in the new Family Support Waiver being developed by DDD per the requirements in LB376. *Figure 22: Top Five Critical Requested Services and Supports* illustrates responses received by DHHS from participants regarding the services and supports family members would like to see included in the Family Support Waiver.

FIGURE 22: TOP FIVE CRITICAL REQUESTED SERVICES AND SUPPORTS



Much of the information previously collected by DDD helped to determine which services to consider including in the new Family Support Waiver. While important, this information only tells a partial story of individual and families' needs, and the waiver services which may be implemented to better support population needs. Individuals and families use and access DD-related services offered by other divisions of DHHS, other state agencies and departments, and outside entities. These other programs and services should be considered when evaluating the availability of DD services necessary to support Nebraskans. Therefore, it is important to understand the consumer experience with accessing and receiving services, beyond simply understanding what DD services are offered by the DHHS DDD.

Reviewing these data, along with other information collected from DDD's previous stakeholder engagement efforts, was critical to informing how to collect meaningful and different feedback from many of the same stakeholders the Team engaged with as part of the DDD System Evaluation for LB376.

Stakeholder Engagement: Planning for LB376-Related Sessions

The Team's stakeholder engagement strategy for the DD System Evaluation was focused on capturing input from as many stakeholders as possible, while incorporating previously received feedback and applying it to understand opportunities to further enhance service access. Though all members of the public were encouraged to attend virtual listening sessions (discussed in further detail below), the Team was especially interested in seeking feedback from individuals and families who:

- Are new to the DD service system.
- Have not traditionally participated in conversations with the State.
- Have limited experience in stakeholder engagement opportunities.

Using this strategy for stakeholder engagement as a guiding principle to help shape listening sessions with stakeholders, the Team's goal was to present new insights and findings to DHHS to support needed DD system improvements. This goal included highlighting opportunities to implement national best practices in Nebraska's DD service system. National best practices help to support consistency and equitable access to services for individuals with disabilities and their families.

The next section outlines the Team's communication plan for gathering the stakeholder feedback for the DD System Evaluation per LB376.

Communication Plan for System Evaluation

The intent of the listening sessions the Team facilitated was not to duplicate information already provided by stakeholders to DDD regarding requested services and supports. Rather, the stakeholder listening sessions conducted for the DDD System Evaluation Project were focused on:

- Understanding how individuals access services.
- Interactions with Medicaid MCOs or other state agencies.
- Experiences with the DDD registry.
- Feedback on Medicaid eligibility determinations.
- Important changes stakeholders would like to see within the next one to five years.

Targeted Stakeholders

The Team's goal in conducting stakeholder outreach was to include as many stakeholder groups as possible, to get a wide range of feedback on the DD service system. The Team, with input from DDD and the Governor's Developmental Disability Advisory Committee (the Committee) identified the stakeholders included within *Table 20: Target Stakeholder Lists* or which listening sessions were scheduled. After input from DDD and the Committee, it was decided that advocacy organizations would be invited to participate in individual and family listening sessions.

TABLE 20: TARGET STAKEHOLDER LISTS

<table>
<tr><th colspan="2">Target Stakeholders</th></tr>
<tr><td><u>Individuals and Families</u>
Individuals to the extent feasible and appropriate.
Nebraska families caring for a disabled family member or child with a disability.
Legal guardians.
Other individuals caring for an individual with a disability.</td><td><u>Advocates</u>
The Arc of Nebraska
Munroe-Meyer Institute (MMI) at University of Nebraska Medical Center</td></tr>
<tr><td><u>Tribal Members</u>
Tribal members, including individuals, families, and leadership from the following federally recognized tribes and nations located in Nebraska:
Omaha Tribe of Nebraska
Ponca Tribe of Nebraska
Santee Sioux Nation
Winnebago Tribe of Nebraska</td><td><u>State Entity Representatives</u>
Nebraska DD Advisory Committee
Nebraska DD Council
Olmstead Advisory Committee
Olmstead Steering Committee
Nebraska Commission for the Blind and Visually Impaired
Early Development Network
Department of Education, Vocational Rehabilitation
Other state agencies providing DD services</td></tr>
<tr><td><u>Providers</u>
Members of the Nebraska Association of Service Providers
Area Agencies on Aging
League of Human Dignity</td><td></td></tr>
</table>

Flyer Notification, Tribal Postcard, and Listening Session Sign-Up Form

To notify the target list of stakeholders regarding the opportunity to provide feedback in listening sessions, the Team created a flyer notification to be published and distributed via:

- Posting to the DD Advisory Committee webpage.
- Posting to the DHHS DDD Family Support Waiver LB376 homepage.
- Having advocacy organizations assist in communicating about the opportunity.
- Requesting families share the information with other families, friends, and advocates using social media platforms.
- Leveraging other community organizations (e.g., churches, YMCAs, etc.) to distribute the flyer to members of their organization.

With input from DDD and the Committee, the Team modified the draft flyer, the final flyer was shared with the Committee during the April 12, 2023 DD Advisory Committee public meeting, and the final version and link to the sign-up survey was posted live on the DHHS website on April 17, 2023. The flyer notification was used to alert stakeholders about the feedback opportunity and to sign up for one of the sessions. Included on the flyer notification were a hyperlink, uniform resource locator, and quick response code for stakeholders to access the electronic listening sign-up form, housed on the Myers and Stauffer Qualtrics platform. The flyer notification information was also modified for the purposes of distributing a postcard-sized handout to tribal members during a Tribal Health Listening Session in South Sioux City, Nebraska that was attended by DHHS staff. The tribal postcard included all the same information as the flyer notification posted on the DDD webpage, including the URL and quick response code.

The listening session sign-up form provided background information about the DDD System Evaluation being conducted by the Team, in compliance with LB376. The purpose of providing context was to ensure all potential stakeholders were aware of the DDD System Evaluation and the importance of the evaluation on the potential future of the DD service system. After contextual information, the survey asked potential stakeholders to answer a series of questions about:

- What type of stakeholder they are (i.e., individual, family member, legal guardian, tribal member, advocacy organization, provider, or state agency or committee staff).
- Access to DD services.
- Language or accommodation preferences.

- Preferred dates and times for a stakeholder listening session.

Skip logic was built into the sign-up survey to direct prospective stakeholders to the appropriate set of listening sessions, based on how they identified (individual, family member, legal guardian, tribal member, advocacy organization, provider, and state agency or committee staff).

The listening session sign-up form provided information to assist the Team in finalizing the schedule of listening sessions and plan for additional communication supports such as language interpreters. In addition, the listening session sign-up form also afforded the opportunity for a prospective stakeholder to request a separate, electronic feedback questionnaire, in lieu of or in addition to, participation in a virtual listening session. The feedback questionnaire is discussed in more detail below.

Prior to the Session Sign-up Survey, the Team initially proposed holding:

- Three 90-minute individual, parent, family, guardian, and advocacy organization sessions.
- Four 90-minute tribal member sessions (one session per federally recognized tribe).
- One 90-minute provider session.
- One 90-minute state agency staff session.

After Session Sign-up Survey registrations were received, session requests were analyzed. As a result, the Team scheduled and confirmed participant registrations for:

- Seven 90-minute individual, parent, family, guardian, and advocacy organization sessions.
- Two 90-minute provider sessions.
- Two 90-minute state agency staff sessions.
- One open listening session (for anyone interested in providing feedback).
- One session with the University of Nebraska Medical Center, MMI parent care provider team. The Team participated and gathered feedback from a large group at a MMI's provider staff meeting, per their request.
- One session with the University of Nebraska Medical Center, MMI directors and financial staff to gather MMI-specific leadership concerns and areas for overall DD system improvement.

- No tribal-specific sessions were needed. Of note, a few Native American individuals and providers did participate in the individual, parent, family, guardian, and advocacy organization sessions.

Based on the Team's previous experience with virtual stakeholder engagement and the ability to facilitate meaningful dialog where all participants have enough time to provide their feedback, sessions were limited to 30 participants. The separate online feedback questionnaire was also used to solicit information from stakeholders in instances where all sessions were filled, or they were unable to attend a virtual listening session. Information regarding the listening session schedules and participant counts is outlined in *Table 21: Final Session Dates, Times, and Participants*. Feedback and questions about the project were also accepted through the project email.

TABLE 21: FINAL SESSION DATES, TIMES, AND PARTICIPANTS

Focus Group	Session Date and Times	Scheduled	Attended
Individuals, Families, Guardians, Advocacy Organizations	5/16/23 9:00 AM 5/16/23 12:00 PM 5/16/23 5:30 PM 5/17/23 9:00 AM 5/17/23 12:00 PM 5/19/23 12:00 PM 5/19/23 5:30 PM	8 7 8 7 7 8 7	4 2 3 6 4 5 2
State and Committee Staff	5/23/23 9:00 AM 5/23/23 3:00 PM	8 2	5 2
Providers	6/01/23 9:00 AM 6/13/23 9:00 AM 6/13/23 3:00 PM	19 7 7	19 6 7
Open Listening Session	6/15/23 12:00 PM	60	29
MMI Clinical Directors	6/28/23 10:00 AM	22	22
Total	14 held	177	116

The final flyer, DDD webpage posting, tribal postcard, and screenshots of the listening session sign-up form are in *Appendix XXV: Listening Session Communications.*

Feedback Online Questionnaire Survey

In addition to the stakeholder listening sessions, the Team developed another Qualtrics survey to gather individuals' written feedback that followed the same logic and questions used in the stakeholder listening session slide presentations. The online questionnaire was available for listening session stakeholders to provide additional feedback and to also gather feedback from those not able to attend a listening session or who were more comfortable providing feedback

Email Feedback

The team received 48 stakeholder emails with feedback for consideration through June 30, 2023.

in written format. The online feedback questionnaire was available publicly from May 24, 2023 to July 5, 2023. The link was posted on the Nebraska DHHS LB376 information page and was also shared during the listening sessions.

The online feedback questionnaire gathered a significant amount of written feedback from a wide range of Nebraska DD stakeholders. Two-hundred forty-one responses were recorded from the Qualtrics Feedback Questionnaire with a 99 percent response quality.

*Appendix XXVI: Feedback Online Survey Question*s lists the questions incorporated into the electronic outreach survey.

Project Email Feedback

Many stakeholders provided feedback in written format to the project email NE_DDSystemEval@mslc.com. Use of the email was promulgated with assistance from the DD community partners involved with the evaluation as they shared the email address and the survey information to a wide audience of their professional and personal contacts. The Team responded to each email and recorded the information in an email log. The Team reviewed the content of these emails for inclusion in the themes heard throughout all the various feedback formats.

Summary of Stakeholder Feedback: LB376-Related Sessions

A summary table of all feedback received from the virtual stakeholder sessions, electronic survey responses, and email responses is in *Appendix XXVII: Stakeholder Feedback Summary.* The information contained in *Appendix XXVII* summarizes the feedback received from stakeholders and is not directly associated with any one participant or entity. It is important to note that the Team heard a wide variety of feedback concerning topics of general and situational-specific concern. While all feedback collected is provided in *Appendix XXVII*, the major themes that were drawn from stakeholders are highlighted below. Some feedback may appear to contradict other feedback; this summarized feedback is reflective of what was collected from individuals' lived experiences but does not necessarily reflect the views of the Team or known best practices for individuals with disabilities.

Major Stakeholder Feedback Themes

Upon review of the stakeholder feedback, a reoccurring concern was identified. Currently, there are many barriers to accessing quality health care and services in Nebraska for individuals and their families with DDs. Barriers to accessing care can be caused by many things, such as:

technology, environment, transportation, economic, systemic, communication, and equity to name a few. It is through the barrier lens that the Team distilled the feedback into themes.

The following themes related to barriers arose multiple times throughout the stakeholder process. These themes are not necessarily related to how often stakeholders discussed these issues. Rather, the themes identified by the Team were informed by how impactful these issues are to individuals and families, and if these issues cause barriers to full engagement with the DD service system. Themes identified include:

- Cumbersome process to apply for and maintain services for individuals and families.
- Impacts of access barriers on individuals and families.
- Technology.
- Service system limitations.
- Communication.
- Waiver eligibility.
- Cross-system limitations.
- MCO denials.
- Equity.

Cumbersome Process to Apply and Maintain Services for Individual and Families

It is important to design systems in such a way that they are accessible to all or provide reliable supports to help everyone navigate the process successfully. It is important to consider that some barriers may be a small inconvenience for some, but present an insurmountable barrier for other individuals, depending on their abilities and support systems. Additionally, enough small inconveniences add up. At some point, putting enough barriers in the way of accessing critical health care services leads to frustration and abandonment of necessary services. Individuals with disabilities and their families often must bear the burden of navigating complex systems to receive the services they need just to live their lives safely each day. *Figure 23: Stakeholder Feedback: Cumbersome Process to Apply and Maintain Services* contains a list of summarized feedback that present access barriers for individuals and their families.

FIGURE 23: STAKEHOLDER FEEDBACK: CUMBERSOME PROCESS TO APPLY AND MAINTAIN SERVICES

Stakeholder Feedback: Cumbersome Process to Apply for and Maintain Services
• Unclear application process. • No easy entry point into the system. • Navigating denials for needed equipment and services. • Loss of services due to being unable to find qualified providers. • Inconsistent information provided by people from the same state agencies. • Passed from one team member to another without answers. • Grievance process is hard to understand and no resolution when complaints are made. • Insensitive process requirements, asking the same or inappropriate questions for conditions that do not change. • Coordination was easier when there was a single point of contact between assessment and service coordination. • The name of the DDD is confusing for individuals without DDs who receive services through them. • Disconnected programs make it tough for families to navigate. • Different requirements and re-assessments lead to a loss of needed services from ages 12 to 18.

Impact of Access Barriers on Individuals and Families

When health and social services systems are not accessible, individuals and families are impacted in other ways. Families frequently reported a loss of employment and homes due to lack of appropriate childcare and respite options for their loved ones with disabilities. For families with children, summer childcare was reported as the most difficult to obtain. Families reported that finding care for individuals aged 13 to 21 after they age out of child programs, or the ability to go to child day care centers was hard to find and pay for, because it is not covered in the AD waiver. Some reported that the supports offered are often not enough to meet their needs, and the reliance on unpaid family caregivers impacts the caregiver's mental and physical health. Also noted was the frequency of assessments and their invasive nature contributes to caregiver grief and loss of hope.

Sometimes, the barriers listed above cause families to abandon services they qualify for because they are either too difficult to access or too ineffective. Also, when critical services are denied, families reported that they often must pay out of pocket and put themselves at risk for bankruptcy and economic hardship while waiting for services. This was frequently mentioned when discussing the Developmental Disability Registry and denials for services, equipment, or medications through MCOs.

Technology

One theme that was identified as a significant barrier to helping individuals and families access appropriate services was the State's and provider's knowledge and use of technology. *Figure 24: Stakeholder Feedback: Technology Barriers* displays a list of summarized stakeholder feedback received regarding technology barriers.

FIGURE 24: STAKEHOLDER FEEDBACK: TECHNOLOGY BARRIERS

Stakeholder Feedback: Technology Barriers
• The DHHS website is difficult to navigate for families. • Therap, Maximus, and Tellus are challenging to access. • Providers need training in how to use assistive technology, communication devices, smart TVs, and smartphones. • Assistive technology is not consistently used. • Telehealth and other virtual services should be an option for individuals and their families when appropriate. • Improved payment processing to providers is needed.

Service System Limitations

Accessing the necessary services in your area was frequently mentioned during stakeholder engagement. Service system limitations were reported throughout the stakeholder engagement process. It should be noted that available services can vary significantly by location in the state. Feedback about service system barriers is included in *Figure 25: Stakeholder Feedback: Service System Barriers*.

FIGURE 25: STAKEHOLDER FEEDBACK: SERVICE SYSTEM BARRIERS

Stakeholder Feedback: Service System Barriers
• Provider options are limited, and of those available, many are not accepting Medicaid or new Medicaid members. • The enrollment and management process for independent providers is difficult. • There are reimbursement discrepancies between waiver providers. • Service coordinators are unprepared and unhelpful in accessing the right services. • Person-centered planning is not happening. Once planning is completed, nothing comes of it. • Slow service coordination response times. • No follow-up from service coordinators. • Lack of consistency from service coordinators.

Stakeholder Feedback: Service System Barriers
• There are very limited services available for individuals with lower acuity needs who do not meet LOC for waivers. • Limited services are available for individuals with autism to support them to be more independent. • Lack of providers of all types, including dentistry and behavioral health services, particularly in western Nebraska. • Limited supports for individuals with complex medical needs. • Challenge of accessing independent providers. • Limited location of services. • Reimbursement rates from Medicaid are significantly lower than other payers, resulting in less provider options. • Providers cannot afford to provide services at the current rates. • Services are not provided in a timely manner. • Mixed feelings on the quality of services received by community and facility-based providers. • Concerns about the quality of services; staff perceived as untrained. • Mixed responses on the quality and helpfulness of VR and employment services. • Stricter standards and more transparency for all types of providers for safety purposes. • State definition of DD differs from the federal and creates many service gaps and barriers. • No childcare support for parents so they can work to support their families. • No transportation to work for older individuals with disabilities. • Limited service availability in the areas of recreational activities, educational activities, and respite. • Services are unavailable for medically complex children, and Katie Beckett is very difficult to access. • There are gaps in services for individuals who struggle with executive functioning. • Katie Beckett: Only a few kids meet the hospital LOC to be eligible for the program. Then if kids are eligible, they still run into barriers with nursing shortages. • Services have improved since the AD moved to DDD, but interactions with Medicaid continues to be difficult to navigate. • Lack of streamlined referral system. • Money earmarked for individuals with disabilities is not getting to the individuals who need it; money is being returned to the federal government instead of being used for those who need it. • Housing. • Dental care is limited, with most providers not accepting Medicaid.

Stakeholder Feedback: Service System Barriers
• Inadequate provider network. • MCOs deny needed services, medications, and equipment without a way to appeal. • Very limited accessible transportation is available for individuals with complex medical needs. • VR and supported employment do not include transportation. • There are limitations to transportation of individuals under the age of 19, they need an adult. • Long travel times in some parts of the state. • Telehealth is not always an option. • Bus routes are not an option, even in the city. • Delays in medical care occur due to limited transportation. • The vehicle modification process is unnecessarily burdensome. • Independent providers need to be educated on transportation pay. • Not all services are offered in all areas. • Have to travel out of county or state for some services. • Funding is not enough to cover transportation costs. • Transportation provided by Medicaid is unreliable, late, or leaves individuals stranded. • Would like to be able to have Uber covered by Medicaid. • Need transportation for day services. • Nearest programs or events are one to four hours away. • Rural, after-hours transportation is unavailable and needed. • Depending on income or resources, providers pay for gas out of pocket or ask the family to cover gas.

Communication

Stakeholders reported limitations in accessible communication in numerous areas throughout the feedback sessions. Providing inadequate communication about how to access critical programs and services limits the efficacy of their intended purpose. *Figure 26: Stakeholder Feedback: Communication Barriers* contains summarized feedback from stakeholders related to their experience with communication about programs and services for individuals with disabilities:

FIGURE 26: STAKEHOLDER FEEDBACK: COMMUNICATION BARRIERS

Stakeholder Feedback: Communication Barriers
• Limitations in accessing services without language barriers, but worse for individuals who do not speak English. • The DHHS website is difficult to navigate for families. • Not easy to understand what services are available, sometimes they refuse services when waiver services are offered. • Cultural barriers exist in immigrant and minority communities whose primary language may not be English (Karen and Spanish noted). • Information is not understandable. • Providers use the wrong terminology and are uninformed on the process. • Terminology and acronyms used are not well known by all families such as LOC and ADL. • Limited communications are received from DDD. • Nothing is provided in writing. • Service coordination in other languages is not adequate. • Families are not informed of all the VR options available. • Perception that staff do not understand well enough to provide information to the public. • Programs are available but hard to find out about them without knowing someone in the system. • Schools are not informed about what services are offered through DDD and the information they provide is inconsistent. • The division name is confusing for individuals without DDs. • MCOs do not always inform individuals about services they provide. • Communication is limited; hard to understand to navigate the process. • Ask for feedback in accessible language. • Families need more training about the options available. • There is a lack of education to parents of school-age children about services. • Decisions are made without stakeholder input. • Funding is taken away from a population who cannot always effectively advocate for themselves.

Waiver Eligibility Barriers

During the sessions, stakeholders reported the following feedback about the waiver eligibility process. *Figure 27: Stakeholder Feedback: Waiver Eligibility Barriers* includes summarized feedback pertaining to the eligibility and enrollment process for waivers.

FIGURE 27: STAKEHOLDER FEEDBACK: WAIVER ELIGIBILITY BARRIERS

Stakeholder Feedback: Waiver Eligibility Barriers
• Unclear application process which makes it difficult for families to navigate. • Individuals and families are passed between multiple staff in multiple divisions who all provide differing and conflicting information. • Individuals are unenrolled due to cumbersome administrative processes. • The assessment process is too invasive, asks inappropriate questions for some populations. • All the waiver programs are disconnected making it tough for families to navigate. • Many individuals and families expressed frustration over the amount of time before services were received. • Many families stated frustration with the complexities of applying for, qualifying for, and receiving services. • Somewhat disconnected eligibility and enrollment, and service coordination, processes. • Lack of a streamlined referral system. • Lack of automatic access to waivers for progressive diagnoses in which proactive care can improve quality of life for the duration of their life. • Lack of staff who understand the whole process, no synergy between waivers to help people access the appropriate services. • Lack of equitable access in the process based on how well you understand the system. • Long wait times for waiver services due to length of time spent on registry. • Removed from waitlist due to inability to pay for service coordination. Occurred multiple times. • Other states have better waiver services or no waiting lists. • Limited follow-up and support in accessing other non-DHHS services and programs for individuals placed on the registry. • Lack of education about what the waitlist is and what waiver services offer, once a slot is open. • No updates, communication, or services while on the registry. • The registry should not exist, it violates people with disabilities rights and puts vulnerable people at unnecessary risk. • Most people wait more than five years on the registry for services. • Had to pay for services out of pocket while waiting for registry. • Should provide additional education on what the waivers provide and who qualifies. • Unless you know to get on the registry early, you likely will not have waiver services until adulthood, after school transition services end.

Cross-System Limitations

A theme that arose through review of the stakeholder feedback is that DHHS does not coordinate well with outside entities. Also noted was that even within DHHS, the divisions do not work together well. *Figure 28: Stakeholder Feedback: Cross-System Limitations* covers summarized feedback received related to the state of current cross-system coordination.

FIGURE 28: STAKEHOLDER FEEDBACK: CROSS-SYSTEM LIMITATIONS

Stakeholder Feedback: Cross-System Limitations
• **Many individuals reported being unaware of the availability of case/care management through an MCO.** • **School-based services are limited, and this is a particularly prevalent issue for transition-age students.** • **Children with disabilities (especially behaviors) are not afforded a full educational day like neurotypical peers, or the amount of services in accordance with an IEP.** • **Sometimes parents of children with disabilities are encouraged to sign away their rights to school services up to the age of 21.** • **Lack of coordination between DHHS and other state-level departments like the Department of Education.** • **Many siloed processes in place.** • **Limited coordination of programs between DDD, CFS, and Medicaid.** • **Lack of a streamlined referral system.** • **More transparency is needed in the decision-making process.** • **Limited access to waiver services because of the registry.** • **Decisions made without stakeholder input.** • **Schools are not informed about what services are offered through DD and what they provide for information is inconsistent.** • **Families are not informed on all VR options available.** • **Perception is that staff are not highly trained, leading to misinformation to the public.** • **Having the department labeled DDD is confusing and frustrating to individuals with other disabilities.** • **Children are ending up in foster care due to lack of support from DDD.** • **Differences in what waiver services are accessible for children and adults.** • **Katie Beckett is small and limited. People do not know it is available and the requirements to qualify are too high for most people to qualify.** • **Perception that leadership of DDD is open to building relationships with stakeholders and attempt to address problems for families and individuals.** • **Perception that DHHS is under-resourced, particularly with service coordinators and front-line staff.**

Stakeholder Feedback: Cross-System Limitations
• When DDD staff have tried to assist families to get special equipment (such as a wheelchair) who are solely on Medicaid, it is incredibly difficult to get anything through. They look at how much things cost, not how a family is impacted. • Use of MCOs limits an individual's ability to appeal denials for needed services, medications, and equipment. • The period of school transition to adulthood was reported as putting strain on families because of a lack of clarity around future available services and supports. • Supports provided are inadequate for the individual's needs.

MCO Denials

Another theme that was gathered through the stakeholder process was that the use of MCOs made it more difficult to access certain services, medications, and equipment. The use of MCOs also made it difficult to appeal when denials were made.

Figure 29: Stakeholder Feedback: MCO Denials displays summarized feedback related to MCO performance and denials of services.

FIGURE 29: STAKEHOLDER FEEDBACK: MCO DENIALS

Stakeholder Feedback: MCO Denials
• Mixed feedback based on specific MCO case manager. • Case managers have been able to provide guidance to families as they try to navigate a complicated, confusing medical system. The system seems to always be changing, which complicates a family's ability to navigate the system. Each manage Medicaid system seems to have different requirements that are always evolving. • When trying to assist families to get special equipment (such as a wheelchair) who are solely on Medicaid, it is incredibly difficult to get anything through. They look at how much things cost, not how a family is impacted. • Reported situations where the MCO would not approve needed adaptive equipment. This would be necessary to live and function equipment that they would not approve. Then there is no recourse for them not approving. • MCOs do not care about the individual. They think about the bottom line. Money. • Some authorizations do not come easily. Reported need to work to overcome barriers to help with funding and necessary services individuals. • Depending on which MCO they have depends on what benefits they will end up receiving support from different doctors and other entities. • Some do not cover what is needed for the people we support. They are kind to work with, but often have their own hands tied and cannot get access to the necessary care or items they need.

Stakeholder Feedback: MCO Denials
• **Perception that Medicaid MCOs cut services, or they get limited because the State does not give them enough money to operate on or to make a profit.** • **Billing is a nightmare. Care coordinators are not feet on the ground, and telephone assistance can lead to frustration and distress.** • **Managed care is devastating. Attractive to the State so it can stay in budget, but at what cost? It complicates accessibility for health care and passes cost on to the person. Having to ensure you pick just the right managed care health insurance to cover what you need does not benefit anyone but the State. There is zero benefit for the person despite the bells and whistles that are sometimes offered if you choose their plan like gym memberships or benefit cards. Keep it simple and spend the money on accessible care that is easy for all involved.** • **A lot of dental offices no longer want to use MCOs, and the people who work at the MCO offices change so often that you cannot build a rapport with anyone.** • **Nebraska Total Care is intentionally denying needed medical equipment to pad their bottom line.**

Equity

For individuals and their families with disabilities who speak a primary language other than English, the other barriers mentioned are compounded by communication barriers. For individuals and their families with limited financial means, denials of services, lack of childcare, or waiting lists for services like the registry, place them at higher risk for economic instability.

Stakeholder Requested Services and Supports

The following list is compiled from stakeholder feedback on requested services and supports stakeholders believe would improve the current DD service system in Nebraska. *Figure 30: Stakeholder Feedback: Requested Services and Supports* contains a summary of stakeholder-requested changes to the current services and supports provided by the state of Nebraska to individuals with disabilities.

FIGURE 30: STAKEHOLDER FEEDBACK: REQUESTED SERVICES AND SUPPORTS

Stakeholder Feedback: Requested Services and Supports
Specialty Care
• **Offer medically trained staff/nursing services.** • **More providers for respite and mental health and are experienced with DD and ID.** • **Genetic testing.** • **Physical therapy, occupational therapy, and speech therapy.** • **Applied behavior analysis.**

Stakeholder Feedback: Requested Services and Supports
• Nursing care. • More comprehensive developmental programs as alternatives to medication. • In-home care. • Better vision coverage. • Qualified knowledgeable, enthusiastic, creative providers. • In-home care for individuals with behavioral needs. • Continued availability of ICF/IID services through BSDC. BSDC provides a safe environment for individuals served there, and the existence of BSDC is valued by families with loved ones living there. • Programs designed to support individuals on the autism spectrum beyond what is provided in schools. • After school programs or care. • To have enough providers to actually receive the approved services. • Higher pay for providers. • Supports so youth can stay in home instead of moving to a group home. • Discontinue the registry. • More residential care other than nursing homes, like roommate or supported housing. • Access to nursing care for respite. • More dental providers.
Employment, Integration, and Recreation Activities
• Employment building skills. • Independent living skills. • Supported decision-making. • Coverage for gyms for exercising in the winter. • Transportation and transportation for medically complex individuals. • Recreational activities. • Socialization. • Companionship. • Better community-integrated employment services, and better transition supports from school to adult services. • Peer programs. • Summer camps. • After hours services to allow individuals to attend community functions. • More transitional training.
Assistive Devices and Supplies
• Safety equipment. • Durable medical equipment.

Stakeholder Feedback: Requested Services and Supports
• Pull-ups and gloves. • Over the counter medications and thickeners.
Family Supports
• Assistance for all ages. • Flexibility for funds. • Financial support. • Help with SSI. • Better customer service and processes. • More communication about the waivers for the public. • Paid parent caregivers. • List of providers willing to work with families. • Family counseling services. • Additional support in the summer for children/families. • Support for aging caregivers to support community transition. • Allow parental shared living providers to maintain their guardianship. • Allow both parents to be paid providers. • Weekend assistance. • Support for families on the registry. • Rent and additional assistance encouraging community access. • Transition support. • Nutritional supports and home-delivered meals.
Other
• Homeless services. • Consistency for program requirements, stop changing requirements so frequently.

Stakeholder Vision for Future Services

One of the prompt questions asked of all stakeholders was about their vision of future services for ID. Below, are some examples of the feedback received. Selected excerpts related to stakeholders' vision for future services is in *Figure 31: Stakeholder Feedback: Vision for Future Services.* For more detailed examples of stakeholders' vision for future services, see *Appendix XXVIII: Stakeholder Vision for Future Services.*

FIGURE 31: STAKEHOLDER FEEDBACK: VISION FOR FUTURE SERVICES

Stakeholder Feedback: Vision for Future Services
• Emphasis on targeted case management, supported decision-making, and more real and genuine inclusion with the community.

Stakeholder Feedback: Vision for Future Services
• Eliminate the registry. • Increase expectation of employment and acceptance for people with DD. Less reliance on adult day care for people who are employment ready. • Better pay for providers and better working conditions to attract and retain caregivers. • A specific, detailed Olmstead Plan that is used as part of a continuous improvement process for state and private services. • Expansion of waivers to include new initiatives in service delivery and community inclusion. Major shift in service focus away from workshops towards competitive employment. All of these are achievable if we start planning and working towards them now. • Continued availability of ICF/IID services through BSDC. BSDC provides a safe environment for individuals served there, and the existence of BSDC is valued by families with loved ones living there. • No waitlist. Transitional programming meeting the needs of young adults aged 19 and beyond. Private/partner collaboration to meet the needs within the broader community context (e.g., intergenerational programming, etc.), transportation, respite for families, more residential services and jobs/experiences that are available to those with special needs in the broader community. • Would start designating funds to go toward younger children with needs, and not just ones who do not qualify for Medicaid based on income. • There would be flexible care so that parents do not have to choose between work and keeping their children safe. There would be client-centered care that is more focused on problem solving than barrier creation. • Allow telehealth as a mode of service delivery when proven to provide increased accessibility and the same or better quality of care for individuals. • That managed care would cover nursing hours for those who are deemed nursing facility LOC by AD waiver. We have not had respite or time away or a break for years. • Children with progressive diseases could be allowed on the waiver without waiting until they are so bad it costs more money. If we could have had help with medication earlier or physical therapy sooner, our son might still be able to walk. We paid for things out of pocket for a long time, but we could not afford the only medication at the time ($90,000 per year). Recently, our primary insurance has denied an infusion of medications that would stop the progression. It costs $300,000 per year. • In three to five years, there would be a list of providers and their availability. Perhaps people who want to be independent providers are on a list would check a box for the hours available, type of disabilities they will work with, etc. • Improvements to how interested individuals enroll as independent providers.

Stakeholder Feedback: Vision for Future Services
• **Parents need to be given information about services available and what steps they need to take before their child enters high school. There needs to be more collaboration between DHHS and the elementary schools. Parents are often overwhelmed by the process and put off applying for services. This causes a crisis when a parent or caregiver passes away, or a young adult needs housing due to other circumstances.** • **More accessible communication to families, including families whose primary language is not English.** • **Align DD definition with the federal definition.**

Stakeholder Suggested Critical Issues for Improvement

The following selected stakeholder feedback represents some of the feedback collected related to critical issues for improvement. Selected excerpts of stakeholder identified critical issues for improvement is in *Figure 32: Stakeholder Feedback: Critical Issues for Improvement.* For more detailed examples of stakeholders' vision for future services, see *Appendix XXIX: Stakeholder Reported Critical Issues for Improvement.*

FIGURE 32: STAKEHOLDER FEEDBACK: CRITICAL ISSUES FOR IMPROVEMENT

Stakeholder Feedback: Critical Issues for Improvement
• **Help people find solutions to their problems. When my payee calls to find out why my food stamps are less and less each month, they tell her that my income is too high or that it is not changing, but it does change and now I cannot even save $60.00 a month. I pay $640.00 in rent, and between utilities, spend down, food, clothing, and cleaning supplies, I am broke.** • **Better vision and dental.** • **Better pay and benefits to attract and retain qualified caregivers.** • **More services (day services and residential services) offered in regions that are NOT on the interstate.** • **Address the registry.** • **Better information provided to parents of school age youth on what services are, when they need to apply, and the different waiver options available after school. This should be done at IEP meetings routinely, so parents are not left scrambling or feeling lost.** • **The State should make a firm and lasting commitment to HCBS as to where we need to direct state resources and quit wasting state dollars on congregate settings.** • **Make employment supports more accessible. VR is not always willing to support individuals with disabilities based on complex needs, and DD will not approve employment supports until VR services have been exhausted. This ends up resulting in**

Stakeholder Feedback: Critical Issues for Improvement
barriers to supports and can cause stagnation or even regression for individuals who are trying to work toward independence by seeking gainful community employment. • **Provide more person-centered case management. DD service coordinators only work with DD systems. So, a person may have multiple separate case workers for separate services (VR, DD, MCO, special education, if applicable, etc.), but none that cooperate within different systems.** • **To not deny an individual with disabilities services because they are "not disabled enough." Provide affordable assisted living housing for the vast number of individuals living with autism spectrum disorder and other disabilities who can work and live semi-independent lives but not live completely independently.** • **Increase transition programming for all, regardless of waitlist status.** • **Increased coverage of medications.** • **Better Medicaid reimbursement for medical offices—primarily dental. It is very hard to find good, special needs-qualified offices that take Medicaid.** • **Less denials for needed items.** • **More clarity on who is eligible and the criteria.** • **After-hours transportation services that permit individuals to be part of their community.** • **Clarification on what each entity is, who they serve, and how to contact them would be a good place to start.** • **Families implore the State to help make this system better and make it so that those with progressive, life-ending diseases automatically qualify for waiver services.**

Summary and Analysis of Stakeholder Feedback

Given the quantity of feedback received from stakeholders, it is impractical to include every individual's feedback in this report. Most of the stakeholder feedback indicates that there are many barriers to accessing critical health and social services in Nebraska. These barriers are related to the themes discussed above.

After analyzing stakeholder feedback, the Team can conclude that there are several opportunities for improvement, and mitigation of barriers within the DD service system. Individuals and families are struggling to understand and navigate the DD service system, including processes related, but not limited to:

- Eligibility and enrollment.
- Service authorizations and access (both initial and continued).

- Which entity is responsible for the provision of care.

The struggle of individuals and families is likely a result of the complexity of the DD services, lack of clear communication to individuals and families, and the numerous entities involved in overseeing, providing, and paying for services and supports.

It should be noted that not all feedback received was negative. Stakeholders were overwhelmingly positive in their praise and appreciation for DDD staff, including the Division's leadership. Even when stakeholders voiced concerns regarding the consistency of information received from DDD staff, stakeholders acknowledged that DDD staff are "doing their best," are "overworked," and "provide and demonstrate good customer service."[298]

The feedback received from stakeholders is useful to inform recommendations for improvements to Nebraska's DD service system. Without stakeholder feedback, recommendations developed by the Team may not resonate with the individuals and families who are engaging in the DD service system. Considering the peer state research, stakeholder feedback, and application of best practices will result in high-quality and meaningful recommendations for Nebraska's DD service system.

[298] Stakeholder feedback is paraphrased and does not represent direct quotes from any one individual.

Best Practices

Best Practices: Why they Matter

Best practices are proven strategies to help with improvements to systems, policies, and processes. Best practices are generalizable to different populations or environments, which makes them ideal to implement across the multiple programs and services that comprise the Nebraska DD system. Our Team identified and reviewed several best practices to help inform our recommendations to improve DHHS' support of individuals with disabilities and their families. The best practices identified by the Team are categorized into the following main topics:

- Accessible communication and universal design.
- Communication with stakeholders.
- Culturally and linguistically appropriate services (CLAS).
- Support throughout the lifespan, with an emphasis on childhood.
- System improvements focused on understanding and eliminating barriers to enhance cross-system partnerships.

Identification of Best Practices

The following best practices are drawn from national resources, as well as the Team's experiences serving state clients in the areas of HCBS and behavioral health services.

Accessible Communication and Universal Design

Oxford University defines accessible communication as:

> "An umbrella term to describe communication that is clear, direct, easy to understand and that can be made available to multiple formats so that all users have equal access. It takes into consideration the various barriers to accessing information, and removes these or provides alternative formats for the communication to take place."[299]

Accessible communication is one of many parts of the Americans with Disabilities Act Title II regulations. Title II requires that governmental entities (like DHHS) communicate with individuals

[299] University of Oxford. *Accessible Communication. Guidance for communicating clearly and accessibly*. Accessed 1 August, 2023.

with disabilities in ways that are easily understood by these individuals.[300] This includes ensuring governments provide accommodations to individuals to support an inclusive environment.

Recognizing and providing different accessible and usable communication modalities to individuals with disabilities and their families supports their full participation in conversations with policy leaders and decision-makers and further promotes the idea of universal design.[301] Universal design is intended to benefit all people, regardless of age or disability, by making available simple easy to use products, communication materials, and physical environments.[302]

Some proven, best practice, accessible communication techniques for people served by DD systems include, but are not limited to:

- **Promote and use people-first language.** Person-first language was written into law in the Americans with Disabilities Act (1990) and the Individuals with Disabilities Education Act (1997). “Person-first language” puts the person before the disability, and describes what a person has, not who a person is. Person-first language uses phrases such as “person with a disability,” “individuals with disabilities,” and “children with disabilities,” as opposed to phrases that identify people based solely on their disability, such as “the disabled.” Adopting the use of person-first language promotes respect and dignity when communicating with individuals and helps reduce stigma.

- **Easy Read formatting.** Easy Read is a method of presenting information in a way that makes it easier for individuals with disabilities to understand written communication. Easy Read includes formatting styles (e.g., text font and size, bullet points, and spacing, etc.) and provides clear, concise information to explain and give context to readers.[303]

- **Improve public-facing resources, including websites.** It is important to consider people-first language and Easy Read formatting techniques when designing and maintaining public-facing resources, including websites. Moreover, creating simple, approachable, and user-friendly resources is a best practice that provides more value to all individuals who navigate DD and other state systems.

- **Ask for stakeholder feedback.** Stakeholders are invaluable in understanding how to make communication more accessible and how to better design service systems. The use of strategies like person-first language and Easy Read formatting requires buy-in and

[300] United States Department of Justice, Civil Rights Division. *ADA Requirements: Effective Communication.* (February 2020). Accessed 15 August, 2023.
[301] Centers for Disease Control and Prevention (CDC). *Disability and Health Inclusion Strategies.* Accessed 1 August, 2023.
[302] CDC. *Disability and Health Inclusion Strategies.* Accessed 1 August, 2023.
[303] Autistic Self Advocacy Network. *One Idea Per Line: A Guide to Making Easy Read Resources*. Accessed 3 August, 2023. Pages 7-10, 35.

support from stakeholders to achieve the success of accessible communications and universal design of service systems.

Stakeholder Communication

Considering stakeholder feedback in how to improve upon accessible communication and universal design is critical to ensure easy navigation and understanding of the DD system. Similarly, frequent, thoughtful, and meaningful stakeholder engagement is key to designing programs and services that will best meet the needs of individuals seeking support from the DD service system. It is important to include individuals with disabilities (including self-advocates), families, providers, and advocacy organizations.

Promote Culturally and Linguistically Appropriate Services

Inclusive and welcoming environments help to provide accessible platforms for stakeholders to engage in decision-making conversations. The design of physical environments are, however, only one way in which states provide accessibility. Providing accessible CLAS is an important factor for states to lessen disparities. The United States Department of Health and Human Services, Office of Minority Health implemented enhanced national CLAS standards in 2013, which are intended to advance health equity, improve quality, and help eliminate health care disparities by establishing a blueprint for individuals, as well as health and health care organizations to implement CLAS. These standards can be used by state health care offices to work toward health equity for all individuals[304] and inclusion of different groups in conversations around disability.

The National Committee for Quality Assurance published a toolkit of resources for state government use to improve the integration of CLAS in daily operations. The toolkit includes best practice resources dedicated to individuals, including individuals with disabilities, who are more likely to experience health care disparities.[305] The resources included in the toolkit include:

- Practical tools to guide the provision of CLAS.
- Training materials for leadership and state staff.
- Assessment and measurement tools.

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[304] National Committee for Quality Assurance. *A Practical Guide to Implementing the National CLAS Standards: For Racial, Ethnic and Linguistic Minorities, People with Disabilities and Sexual and Gender Minorities*. (December 2016). Accessed 4 August, 2023. Page 5.
[305] National Committee for Quality Assurance. *A Practical Guide to Implementing the National CLAS Standards: For Racial, Ethnic and Linguistic Minorities, People with Disabilities and Sexual and Gender Minorities*. (December 2016). Accessed 4 August, 2023. Page 5.

- Materials for individuals served by health care systems.
- Examples illustrating how to improve the provision of CLAS.[306]

Support throughout the Lifespan, with an Emphasis on Childhood

It is important to apply CLAS standards throughout all parts of a DD service system, especially practices that promote and support individuals with disabilities throughout their lifespan. Childhood, adulthood, and senior years provide different opportunities to support self-advocacy, choice, and inclusion.[307] The Team heard from Nebraska's stakeholders that there is not enough emphasis on early childhood and school-aged engagement of families and individuals in education about the DD service system.[308]

Schools are an important partner for families and individuals and can serve as a primary resource in providing education to families about the DD service system. Schools not only provide specialized supports to individuals with disabilities but are critical in helping to facilitate discussions regarding transition from the school environment to adulthood.

A best practice is to establish a formal and consistent process of collaboration between schools, teachers, and families to support student learning, secure needed services, and promote independence. Research suggests that when partnerships between the education system and parents is strong, parents "report less stress, greater family quality of life, and greater satisfaction with education and related services."[309] Furthermore, research has shown that when teachers and families collaborate, the following outcomes are likely to occur:

- Individuals are more likely to achieve their goals.
- Family knowledge about post-education activities increases, which can influence outcomes.
- Strategies, such as supporting positive behavior, are translated to the home and can increase positive outcomes.[310]

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[306] National Committee for Quality Assurance. *A Practical Guide to Implementing the National CLAS Standards: For Racial, Ethnic and Linguistic Minorities, People with Disabilities and Sexual and Gender Minorities.* (December 2016). Accessed 4 August, 2023. Page 7.
[307] Davis, Stephen and Sara Molina-Robinson. Social Innovations Journal. *Innovative Practices Supporting Individuals with Developmental and Intellectual Disabilities and Their Families Throughout the Lifespan*. (March 2017). Accessed 4 August, 2023.
[308] Davis, Stephen and Sara Molina-Robinson. Social Innovations Journal. *Innovative Practices Supporting Individuals with Developmental and Intellectual Disabilities and Their Families Throughout the Lifespan*. (March 2017). Accessed 4 August, 2023.
[309] McLeskey, J., Et. al. *High-leverage practices in special education.* (January 2017). Accessed 4 August, 2023. Page 8.
[310] McLeskey, J., Et. al. *High-leverage practices in special education.* (January 2017). Accessed 4 August, 2023. Page 8-9.

System Improvements: Understanding Barriers and Enhancing Cross-System Partnerships

To improve the functions of a DD service system, states must first identify barriers to effective operations and provisioning of services. Barriers can take a wide variety of forms, but are especially notable when considering:

- Proper service planning.
- Access to flexible services.
- Technical assistance.[311]

When individuals, families, and service providers do not understand where and how to access the appropriate services needed to support an individual, the result is often a negative outcome. This is even more likely for individuals who have co-occurring diagnoses, as services to address all their needs are often siloed and not well coordinated.

To improve these outcomes, best practice system improvements and mitigation of service access barriers can be made through:

- Improved knowledge of all service systems (including DD systems).
- Cooperative partnerships.
- Inclusion of stakeholders with experience in different practice areas (DD, behavioral health, special education, justice systems) in policy decisions.[312]

Cross-System Coordination Resources

The National Community of Practice for Supporting Families Across the Lifespan published several templates and tools for state policymakers to use when making improvements to cross-system coordination. The templates are used to support:

- Brainstorming discussions.
- Identification of grassroots initiatives.

[311] Fletcher, Dr. Robert J., and Lynda Gargan, Ph.D. *Emerging Best Practices for People with an Intellectual/Developmental Disability Co-Occurring with Serious Mental Illness*. Accessed 4 August, 2023. Page 41.
[312] Fletcher, Dr. Robert J., and Lynda Gargan, Ph.D. *Emerging Best Practices for People with an Intellectual/Developmental Disability Co-Occurring with Serious Mental Illness*. Accessed 4 August, 2023. Page 45-51.

- Cataloguing groups and initiatives within the state for use in identifying new stakeholder networks and opportunities to leverage existing programs.
- Interagency collaboration and partnerships to better support families.[313]

Employing these best practice strategies can have positive impacts on individuals with DD and their families in achieving greater inclusion and improving access to services available through Nebraska's DD service system.

Enhancing Partnerships with Nebraska's Tribes

In addition to incorporating cross-system resources into conversations with partners, special consideration is needed when engaging with tribal entities. There are specific requirements when communicating with tribal partners, especially during public comment periods for 1915(c) waiver applications and Medicaid state plan amendments.[314] Several federal government entities have produced best practices to building and maintaining successful partnerships between federal, state, and tribal governments. These best practices include, but are not limited to:

- Understand the demographic and political makeup of the tribe. This will ensure the inclusion of appropriate decision-makers within stakeholder meetings.[315]
- Listen, learn, and approach conversations with humility.
- Use concise and clear messaging to reach target tribal audiences.
- Share decision-making and leadership with tribal leaders to facilitate consensus-building.
- Utilize electronic communications when possible.[316]
- Communicate in a culturally mindful manner that is sensitive to the cultural diversity of the tribe.[317]

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[313] National Community of Practice for Supporting Families Across the Lifespan. *National CoP Resources*. Accessed 8 August, 2023.
[314] Centers for Medicare & Medicaid. *Application for a §1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria.* (January 2019). Accessed 30 May, 2023. Page 77.
[315] United States Department of the Interior, Bureau of Reclamation. *Working with Indian Governments: Consultation, Cultural Awareness, and Protocol Guidelines*. (July 2020). Accessed 3 August, 2023. Page 16.
[316] National Congress of American Indians. *Effective Tools for Communications and Leadership in Indian Country*. Accessed 3 August, 2023. Page 4.
[317] United States Department of the Interior, Bureau of Reclamation. *Working with Indian Governments: Consultation, Cultural Awareness, and Protocol Guidelines*. (July 2020). Accessed 3 August, 2023. Page 16.

Recommendations for Nebraska's Developmental Disability Service System

To identify and develop recommendations for Nebraska's DD service system, the Team considered primary concerns voiced by stakeholders, as well as research on the current state of Nebraska's DD service system, and peer state findings and best practices. *Table 22: Opportunities for Improvement and Recommendations* highlights opportunities for improvement as identified by stakeholders and through the Team's research. The table links these opportunities with recommendations on how to improve gaps and strengthen areas of weakness in Nebraska's DD service system.

TABLE 22: OPPORTUNITIES FOR IMPROVEMENT AND RECOMMENDATIONS

Opportunities for Improvement	Recommendations
Streamlined access to 1915(c) waiver services and other Medicaid-funded programs.	No Wrong Door Initiatives and technology updates to provide greater access to information for families and individuals.
Improved navigation of services and programs.	Reorganization and divisional name change, so all individuals with disabilities are represented in the name of the division.
Expanded access to the Medicaid program.	• Complete an analysis of transitioning from an SSI to 1634 State. • Evaluate application of special income level rules in Nebraska's Medicaid program. • Evaluate expanding Nebraska Medicaid's Katie Beckett eligibility.
Elimination of length of waiting period for 1915(c) services.	Eliminate the Nebraska DD registry so that immediate access to services is available for individuals in need. Along with eliminating the registry, DDD should consider implementing a "future need" tracking system that distinguishes between a need for immediate access to 1915(c) services from individuals who may have a need for services at a future date.
Expanded access to 1915(c) waiver services.	Align Nebraska's DD definition with the federal definition, to expand access to services provided by DDD.

Opportunities for Improvement	Recommendations
Consistency between 1915(c) waiver programs.	Streamline needs assessments and assessors across waiver programs to ensure equitability.
More choice and options to serve individuals with DD.	Expand the service array to improve services across the DD system.
Provide services in a manner that bridges the divide between rural and urban areas; provide services to individuals who require sensory accommodations.	Allow telehealth as a mode of service delivery, to help address provider capacity concerns and improve services to individuals in need of accommodations.
Highlight the importance of employment choices and technology.	Support employment and technology first initiatives to promote competitive and integrate employment opportunities.
Encourage career growth for DSPs.	Build a more robust DSP workforce to ensure the sustainability of all DD services in the future.
Strengthen ADRC system.	Standardize services and quality across ADRCs to promote equitable access to services across the state.
Provide current information on the provider workforce for individuals, families, and service coordinators.	Maintain a list of active providers, so individuals and families have accurate and up-to-date information.
Eliminate system navigation difficulties for individuals and families.	Improve cross-system coordination to eliminate duplication and administrative burdens for individuals and families.
Promote equitable, consistent, and evidence-based Medicaid program service utilization practices.	Review managed care prior authorization process to ensure appropriate policies are in place when reviewing access to Medicaid state plan services.
Develop the workforce to mitigate workforce challenges; promote increased choice to individuals and families receiving services from 1915(c) waivers.	Increase self-direction opportunities in all 1915(c) waivers to support flexibility for individuals and families in decisions regarding provision of care.
Mitigate challenges experienced by families and individuals when a service and/or program eligibility is denied.	Review, revise, and monitor grievance and hearing processes to promote transparency and provide resources to individuals and families.

Opportunities for Improvement	Recommendations
Address knowledge gaps experienced by individuals and families served by the DD service system.	Provide standardized education and resources to individuals and families in accessible ways across the DD system to improve navigation of the system.
Have schools and school districts take a more active role in the DD service system.	Leverage schools to be a "first point of contact" with individuals and families as individuals and families often rely on schools as sources of information.
Encourage consistency and applied understanding of policies for DHHS staff.	Train service coordinators and assessors on all waivers, services, and options to ensure consistent and accurate information is provided to the public.
Provide meaningful ways for individuals and families to engage policymakers.	Continued work with stakeholders and partners to build a service system: representing different viewpoints; serves various types of needs; and reflects stakeholder and partner feedback.
Determine funding strategies to support the needs and interests of individuals and families.	Combine American Rescue Plan Act funding with long-term investments to support 1915(c) program modifications.

Recommendations are organized by the following categories, which were informed by the Team's research and stakeholder feedback:

- Eligibility and access to services.
- Service coverage, design, and provisioning.
- Communication.
- Providers.
- Funding options.

Eligibility and Access to Services Recommendations

A considerable theme of stakeholder feedback revolved around barriers to accessing services prior to, or during, the initial eligibility or renewal process for individuals with DD. The Team used

stakeholder input and peer state and best practice research to develop several best practice recommendations to improve access to services. These include:

- No wrong door initiatives and technology updates.
- Reorganization and divisional name change.
- Transition Medicaid eligibility determination authority from SSI to 1634.
- Adopt special income level rules within Nebraska's Medicaid program.
- Expand Nebraska Medicaid's Katie Beckett eligibility.
- Develop a viable strategy to eliminate the Nebraska DD registry.
- Align Nebraska's DD definition with the federal definition.
- Streamline LOC assessments and assessor standards across Medicaid waiver programs.

Figure 33: Eligibility and Access to Services Recommendations reflects the abovementioned recommendations and where they impact access to services in the eligibility and enrollment processes.

FIGURE 33: ELIGIBILITY AND ACCESS TO SERVICES RECOMMENDATIONS

Pre-eligibility
- No wrong door and technology updates.
- Reorganization and Divisional name change.
- Transition Medicaid eligibility determination authority from SSI to 1634.
- Adopt special income level rules in Nebraska's Medicaid program.

Initial Eligibility
- Expand Nebraska Medicaid's Katie Beckett eligibility.
- Develop a viable strategy to eliminate the Nebraska DD registry.
- Align Nebraska's DD definition with the federal definition.

Eligibility and Renewals
- Streamline LOC assessments and assessor standards across waiver programs.

No Wrong Door Initiatives and Technology Updates

Throughout the stakeholder feedback process, concerns were repeatedly voiced about challenges in connecting with the right person to initiate the eligibility process. Stakeholders struggled to understand how to access services on the DHHS website and by phone. Stakeholders reported they were frequently passed around between staff and divisions, and often received different answers based on where they were referred. Websites that are not organized in a manner that is accessible to individuals with disabilities can act as a barrier to accessing services. This is contrary to Title II of the Americans with Disabilities Act, which requires that government entities present information through websites and telecommunications in a logical, accessible manner to ensure individuals with disabilities can access the services they need.[318]

Nebraska should consider the following to improve access to finding and accessing critical programs, services, and supports for individuals with disabilities:

[318] U.S. Department of Justice – Civil Rights Division. *Guidance on Web Accessibility and the ADA*. (March 2022). Accessed 8 August, 2023.

- DHHS should establish a "No Wrong Door" screening philosophy and process as the pathway to initial entry into the DD service delivery system. The initial screening may be designed to collect information that helps guide individuals and their caregivers to services for which they may qualify, regardless of where they enter the system.[319] Moreover, information captured in the screening can provide DDD with useful data and information to better understand access points and service needs and to identify areas and opportunities for further improvements.

- The DHHS website design should be enhanced to incorporate accessibility guidelines or universal design principles.[320]
  - Following systematic review of the website and stakeholder feedback, the website was found to be difficult to navigate due to a lack of a clear organizational structure. Information was not easily attainable due to the number of links one needs to navigate to find information about topics such as the registry, Medicaid eligibility, and services. In addition, language and terminology is difficult to understand, unless individuals have specialized and technical knowledge of the DHHS system and programs.
  - After reviewing website information from the waiver application process for 1915(c) for all four of the 1915(c) waiver programs, it was found that only Medicaid and DD services are initiated on ACCESS Nebraska. The AD waiver and TBI waiver require a form to be submitted, which is only found on a separate website. Nebraska should streamline all the waiver applications to be initiated on ACCESS Nebraska to eliminate barriers to initial access to waiver services.
  - The Team reviewed peer state health and human services-related websites to determine key design elements that should be incorporated. Peer state best practice examples from this research are found in *Appendix XXX: Peer State Websites Review.*

Responsible Entities and Rationale

To implement a "No Wrong Door" screening process, all divisions of DHHS must share a common vision and commit to participate and collaborate. However, DHHS can structure this initiative so the Division assigned with primary responsibility oversees implementation. The primary Division would have responsibility for:

[319] The Administration for Community Living. *No Wrong Door System of Access to LTSS for all Populations and Payers*. Accessed 8 August, 2023.
[320] The U.S. General Services Administration. *Universal Design and Accessibility*. Accessed 8 August, 2023.

- Ensuring implementation of the "No Wrong Door" screen follows DHHS' established timelines and procedures.

- Collaborating with the other divisions to determine what, if any, procedures or processes are already established to use as a foundation for the "No Wrong Door" screen.

- Developing a stakeholder engagement strategy. Though the primary division would hold responsibility for developing the stakeholder engagement strategy, the Team recommends that all divisions participate in stakeholder feedback opportunities to ensure the voices of individuals and families are incorporated into the development of the "No Wrong Door" screen.

Reorganization and Divisional Name Change

Stakeholder feedback indicated that individuals with disabilities, other than those that have developmental and intellectual disabilities as well as their families, did not have a clear understanding of how or why they receive services from DDD. This group includes individuals who have age-related disabilities, a TBI, or other physical disabilities. Stakeholders reported confusion and difficulty in finding contact information to arrange for services, likely exacerbated by misalignment between the name of the division and the population being served.

Other stakeholders reported that it was difficult to access services offered through other divisions (DBH, CFS, or MLTC) because DDD staff were uninformed about what other services are available and from which divisions. Stakeholders reported utilizing services that are available in DBH and CFS, in addition to the waiver services they receive through DDD. For this reason, it is important that all DHHS staff are informed about other Divisions' programs and services to best assist individuals whose needs are multi-systemic in nature.

In addition to stakeholder feedback, DHHS is either considering, or actively pursuing, expansion of community-based behavioral health services, including those that are dedicated to supporting individuals with serious mental illness. An example of this expansion is the requirement that DHHS adopt certified community behavioral health clinics, per LB276.[321] Expanding community-based services to support a variety of disabilities provides DHHS with an opportunity to consider combining DDD and DBH.

Based on stakeholder feedback and the future direction of community-based services, Nebraska could consider combining DDD and DBH to promote synergy between the two divisions. Combining divisions will allow DHHS to build upon both divisions' strengths in providing community-based services. Moreover, combining divisional staff will allow DHHS to improve

[321] Legislature of Nebraska. LB276. (2023). Accessed 11 September, 2023.

administrative efficiencies and help maximize staffing where there are position vacancies. If this reorganization occurs, the Division name should change to be more inclusive of the diverse population it serves. The Team offers the following example of names for DHHS' consideration:

- Division of Community-Based Supports
- Division of Aging and Disability Supports
- Division of Disability Services
- Division of Disability Supports
- Division of Behavioral Health and Disability Supports

Responsible Entities and Rationale

Responsibility for changing the organizational structure of DHHS, including divisional name changes, rests primarily with DHHS leadership and the Nebraska State Legislature.

- DHHS leadership, including the Chief Executive Officer, will need to determine if and how resources can best be combined to better serve individuals receiving services from multiple divisions.
- DHHS leadership will need to work with the Nebraska State Legislature to change NRS to remove references to the "Division of Developmental Disabilities" and the "Division of Behavioral Health" were appropriate.
- DHHS leadership will also need to identify staff responsible to amend NAC references to replace "Division of Developmental Disabilities" and the "Division of Behavioral Health" with the new division's name.

Complete an Analysis of Transitioning from an SSI to 1634 State

States that use the SSI eligibility criteria for Medicaid eligibility determinations either require the single state Medicaid agency or the SSA to make an eligibility determination. States known as SSI states make their own determinations for SSI recipients.[322] Currently, Nebraska is one of only seven states nationwide (including one peer state) to determine Medicaid eligibility using SSI

[322] Social Security Administration. Program Operations Manual System (POMS) SI 01715.010 Medicaid and the Supplemental Security Income (SSI) Program, A. 2. Accessed 29 August, 2023.

criteria. This means that individuals must submit information to the State for a separate eligibility determination.

In contrast, states that wish the SSA to make Medicaid eligibility determinations must have a "1634 agreement" in place between the single state Medicaid agency and the SSA.[323] 1634 agreements specify the State and SSA's responsibilities and requires the State to provide Medicaid coverage to recipients of federally-administered state supplementary payments such as SSI.[324] 1634 states are more likely than those who do not to have a streamlined application process as individuals who are SSI applicants and beneficiaries are automatically reviewed for Medicaid eligibility. However, the Team notes that SSA timeliness may cause delays in Medicaid eligibility determinations.

State Medicaid programs that have 1634 agreements with the SSA are referred to as 1634 states and rely on the federal eligibility determination process for SSI to automatically qualify an individual for Medicaid.[325] In other words, SSI recipients not already enrolled in full Aged, Blind, and Disabled Medicaid will be automatically enrolled without a separate Medicaid application. Most peer states and other states nationwide determine eligibility using 1634 agreements.[326]

In 1634 states, the SSA tells SSI-Medicaid-eligible individuals that they will hear from their State about Medicaid in the SSI award notice. Disability decisions are transmitted from the SSA to the MLTC SRT through an automatic interface known as the state data exchange. In the case of a denial, the SSA refers ineligible SSI claimants to the State, and the State will issue a Medicaid denial notice. The SSA also refers the records of SSI claimants who do not meet the Medicaid-only eligibility factors to the State (i.e., claimants who refuse to assign their rights to third-party medical payments, those who refuse to provide third-party liability information, or those who appear to have a Medicaid trust). The SSA does not determine Medicaid ineligibility, so 1634 states must make their own ineligibility determinations for Medicaid and are responsible for all Medicaid ineligibility notices.

One additional note of importance is that 1634 states are no longer required to operate a Medicaid spenddown program, in which aged, blind, and disabled individuals with incomes over the SSI limit spenddown amount of excess income on medical bills to qualify for Medicaid.[327] In a spenddown program, when the spenddown amount is met, any remaining medical bills each

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[323] Social Security Administration. Program POMS SI 01730.005 Social Security Administration/State Agreements under Section 1634. Accessed 29 August, 2023.
[324] Social Security Administration, Program Operations Manual System (POMS) SI 01715.010 Medicaid and the Supplemental Security Income (SSI) Program, A. 3. Accessed 29 August, 2023.
[325] MACStats: Medicaid and CHIP Data Book. Exhibit 37. Medicaid Income Eligibility Levels as a Percentage of the Federal Poverty Level for Individuals Age 65 and Older Persons with Disabilities by State. (2022). Accessed 29 August, 2023. Page 3.
[326] MACStats: Medicaid and CHIP Data Book. Exhibit 37. Medicaid Income Eligibility Levels as a Percentage of the Federal Poverty Level for Individuals Age 65 and Older Persons with Disabilities by State. (2022). Accessed 29 August, 2023. Pages 1-3.
[327] The Indiana Family and Social Services Administration. 2014 Disability Eligibility Changes (1634 Transition), Stakeholder Briefing, (January 2014). Accessed 29 August, 2023.

month are paid by Medicaid. It should be noted that although eliminating spenddown will reduce concerns related to Medicaid coverage gaps and inconsistent provider reimbursement, the elimination of spenddown may cause the loss of Medicaid coverage for certain individuals.

Given the above information, the Team recommends Nebraska complete an analysis on the impacts of transition from an SSI to a 1634 state, given peer state research and stakeholder feedback. This analysis should include:

- Evaluation of all impacted eligibility categories which may include:
  - SSI recipients not enrolled in Medicaid.
  - Individuals <=100% FPL not enrolled in full Medicaid.
  - Dual-eligibles 100%-185% FPL.
  - Duals > 185% FPL.
  - Non-duals>100% FPL.
  - Institutional and waiver beneficiaries, depending on the application of the special income levels in Nebraska.
- Review of how Medicaid spenddown will impact individuals who currently spenddown to qualify for Medicaid.
- Consideration of how the SRT processes may be impacted by moving to a 1634 state. This analysis will help to determine any adverse impacts to individuals if switching to a 1634 state.

In addition to an analysis of the impacts of changing to 1634 criteria, Nebraska will also need to conduct the following, should the State move forward with transitioning to a 1634 state:

- Sign a 1634 Agreement with the SSA to authorize the SSA to make Medicaid disability determinations using SSI disability criteria.

Responsible Entities

MLTC and DDD will need to coordinate efforts with the SSA and CMS to move from an SSI to 1634 criteria state. Specifically:

- MLTC will hold primary responsibility for engaging the SSA to enter into a 1634 agreement.

- MLTC will also be required to submit any required Medicaid SPAs to CMS to allow for the transition.

- MLTC will need to work with internal DHHS information technology and SSA staff to determine what changes, if any, would be needed to the MLTC eligibility system to process and maintain SSA disability determinations.

- DDD will need to review and amend all applicable appendices of 1915(c) waiver applications (e.g., B-4 and B-5) and submit amendments to CMS.

- Both MLTC and DDD will need to review all state regulations to determine needed updates because of transitioning to a 1634 criteria state.

Evaluate Application of Special Income Level Rules in Nebraska's Medicaid Program

States can elect the "special income rule" option to allow people with functional needs who require an institutional LOC to qualify for Medicaid LTSS with incomes up to 300 percent SSI (or approximately 223 percent FPL)[328]. States also can apply an asset limit under the special income rule, usually the SSI amount of $2,000 for an individual and $3,000 for a couple.[329]

States using the special income rule also have the option to apply it to individuals in institutions and or who receive HCBS under their state plans (§ 1902(a)(10)(A)(ii)(XXII) of the Act and 42 CFR 435.219). Aligning financial eligibility rules across long-term care settings is important to eliminating programmatic bias toward either HCBS or institutional care.

Nebraska is one of eight states nationwide that does not apply special income level rules to individuals receiving institutional or HCBS services. All the peer states reviewed allow for special income level rules for these populations.[330] Based on these findings, the Team recommends Nebraska evaluate impacts of adopting the Special Income Rule of 300 percent SSI for both institutional and HCBS Medicaid recipients. This evaluation should occur regardless of the decision to evaluate or transition to a 1634 state eligibility type.

Responsible Entities

The following entities will be responsible for overseeing the recommendation to evaluate the impacts of special income levels when determining Nebraska Medicaid Program eligibility.

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[328] (§ 1902(a)(10)(A)(ii)(V) of the Act, 42 CFR 435.236, 42 CFR 435.230(c)(2)(v))

[329] KFF, Medicaid Financial Eligibility in Pathways Based on Old Age or Disability in 2022: Findings from a 50-State Survey, MaryBeth Musumeci , Molly O'Malley Watts , Meghana Ammula , and Alice Burns, Published: Jul 11, 2022. https://www.kff.org/report-section/medicaid-financial-eligibility-in-pathways-based-on-old-age-or-disability-in-2022-findings-from-a-50-state-survey-appendix/.

[330] Medicaid and CHIP Payment and Access Commission. *MacStats: Medicaid and CHIP Data Book*. (2022). Accessed 20 July, 2023. Pages 103-104.

- MLTC will need to submit a SPA to CMS for approval, to include special income levels in eligibility determinations.
- MLTC and all DHHS fiscal, budget, and forecasting staff will need to determine the impact of allowing special income level consideration under the Medicaid State Plan.

Evaluate Expansion of Nebraska Medicaid's Katie Beckett Eligibility

Nebraska is one of only four states nationwide allowing for Katie Beckett eligibility through the Medicaid State Plan and 1915(c) waivers.[331] Allowing for Katie Beckett eligibility rules to apply in a variety of manners is a significant way in which Nebraska is providing a pathway for children with disabilities enrollment in the Medicaid program. However, Nebraska only allows for children meeting a hospital LOC to enroll in the Katie Beckett Medicaid eligibility pathway. The hospital LOC, as defined by Nebraska, is very specific to highly complex medical conditions. This limits the number of children with other, often severe developmental disabilities, from enrolling in the Medicaid program, and accessing needed supports and services. The Team's peer state research suggests that states are allowing multiple LOCs under their Medicaid State Plans, including ICF/IID LOC.

Based on the Team's findings, it is recommended Nebraska evaluate expanding Katie Beckett Medicaid Program eligibility to include at least ICF/IID LOC. The Team recommends for an evaluation to include the following:

- Analyzing potential enrollment on Medicaid through an expanded Katie Beckett eligibility category.
- Developing a cost impact analysis to determine budget impacts to the Medicaid Program.

In addition, development of state plan language and all applicable regulation amendments are required if DHHS were to adopt expanded Katie Beckett eligibility.

An evaluation of Katie Beckett eligibility is important, as this pathway can provide access to the Medicaid programs' comprehensive preventative, acute, and long-term services and supports. Katie Beckett allows children with disabilities to gain access to Medicaid program supports earlier in life, without regard to parental or household income. Medicaid program supports for children with disabilities help to support overall health and wellbeing. Furthermore, Medicaid coverage will help families with needs access services that may not be available through other forms of

[331] Musumeci, MaryBeth, Molly O'Malley Watts, Meghana Ammula, and Alice Burns. *Medicaid Financial Eligibility in Pathways Based on Old Age or Disability in 2022: Findings from a 50-State Survey*. (July 2022). Accessed 4 August, 2023.

insurance (e.g., employer-sponsored or private insurance) that may be too expensive to afford. This recommendation is supported by feedback gathered by stakeholders.

Responsible Entities

The following entities will be responsible for implementation of the recommendation to evaluate expansion of Medicaid Program Katie Beckett eligibility.

- MLTC, DDD, and all DHHS fiscal, budget, and forecasting staff will need to determine the impact of expanding allowable LOCs under the Katie Beckett eligibility pathway.
- MLTC is the primary entity responsible for amending the Nebraska Medicaid State Plan. To include additional LOCs under the Katie Beckett eligibility pathway, MLTC will need to submit an amendment to Section 2.2 A, Supplement 3, to CMS for approval.[332]
- MLTC and DDD will be required to coordinate efforts to notify stakeholders of this change, and to ensure the appropriate ICF/IID LOC is incorporated in the Medicaid State Plan and all applicable state regulations.

Eliminate the Nebraska DD Registry and Institute a Future Need Tracker

As indicated by stakeholder feedback, many individuals, families, advocates, and providers believe the registry to be one of the largest barriers to accessing timely, quality services for themselves or those they care for. Though information is provided on available services while waiting for enrollment on the CDD or DDAD waivers, the delay in access to 1915(c) program services (and by extension Medicaid state plan program services) caused by the registry has significant impacts on who, and how, DD services are accessed in Nebraska. Additionally, the registry often delays waiver services until after many individuals age out of school-age services, limiting the efficacy of transition planning for adulthood.

It is recommended that Nebraska consider eliminating the DD registry as an avenue to reduce accessibility barriers to SSA services for individuals with disabilities. DDD will need to consider and review options with DHHS leadership and other policymakers to determine a long-term, sustainable, funding strategy to have waiver slots available to individuals deemed eligible for enrollment on a 1915(c) waiver. Peer state research indicates that states are making strides to improve upon or eliminate their waitlists for individuals who need access to 1915(c) services immediately. Oklahoma is currently working toward complete elimination of its waitlist.[333] Eliminating the registry would remove a significant barrier to receiving timely waiver services for

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[332] Nebraska Medicaid State Plan. Supplement 3 to Section 2.2-A. *Method for Determining Cost Effectiveness of Caring for Certain Disabled Children at Home*. (July 1995). Accessed 13 August, 2023.
[333] Oklahoma Department of Human Services. *OKDHS Announces Timeline to End Wait List*. (July 2022). Accessed 8 August, 2023.

individuals in Nebraska with disabilities. In addition to providing more timely access to services, eliminating the registry would have the added benefit of allowing for better coordination with school districts for planning transitions to adulthood for individuals with IDD.

For individuals who are currently on the registry to express a need for services in the future, DDD should consider the following recommendations:

- Establish a definition of a future need to distinguish between individuals who are eligible and are able to accept 1915(c) services immediately (suggested to be defined as within 90 days) from those individuals who are likely to be eligible and may require 1915(c) services at a later date.
- For individuals with an immediate need, provide a waiver slot to address the immediate need.
- For individuals who may be eligible and need services in the future, track and monitor these individuals to ensure they are provided with resources to access other community and Medicaid-funded services.
- Establish policies, procedures, and an oversight strategy for the "future need" tracking system.

By eliminating the registry and implementing a "future need" tracking system, DDD will be poised to provide access to individuals currently in need, while offering supports to individuals who do not require immediate access to 1915(c) waiver services.

Responsible Entity

DDD holds primary responsibility for determining how to address and eliminate the registry. Along with DDD, coordination between multiple entities will be needed.

- DDD will need to complete a registry analysis to include a budgetary impact to determine a long-term funding proposal for eliminating the registry.
- Coordination between DDD and MLTC will be needed to determine the best pathway to enroll individuals from the registry into the Medicaid program and one of the DD waivers.
- A budgetary request from DDD will be made to the Nebraska State Legislature and the Governor's Office.

- With support from MLTC, DDD will work with stakeholders and individuals on the registry to notify them of the changes to the registry, and work to enroll individuals on a waiver program.

Align Nebraska's Developmental Disability Definition with the Federal Definition

The Team's review of peer state DD definitions found that no peer state is using the federal definition of DD. When compared to Nebraska's state DD definition, peer states are more closely aligned to the federal definition than Nebraska. Moreover, stakeholder feedback reflected concerns that Nebraska's definition of DD was more restrictive than the federal definition of DD. Stakeholders indicated that the misalignment causes unintended service gaps. This is especially apparent for individuals with lower acuity needs who do not meet Nebraska's definition of DD but do meet the federal definition. These individuals are left without services in place that would support them to live and participate in the community. This can also place individuals without community based LTSS at an elevated risk of longer institutional stays.[334]

The Team recommends Nebraska align the State's DD definition to the federal definition. *Appendix V* shows a side-by-side comparison of DD definitions. While variations were observed in the peer state definitions of DD, requiring a DD definition that is more restrictive than the federal definition impacts access to services for individuals with lower acuity needs. Supporting individuals with lower acuity needs can reduce the risk of needing high-acuity services and supports in the future, improving overall self-direction and quality of life.

Responsible Entities and Rationale

DDD will hold primary responsibility for amending the DD definition as codified in NRS 83-1205.[335] As with the statute and regulatory changes mentioned above, DD and DHHS will be required to work with the Nebraska State Legislature to amend NRS 83-1205. DDD will be responsible for coordinating this change with all other DHHS divisions (and any external partners like Nebraska VR), as applicable to determine the impacts of this change.

Streamline Needs Assessments and Assessors across Waivers

Stakeholders mentioned multiple barriers that exist when transitioning between waiver programs. Their perceptions were that assessors and service coordinators were not familiar with different waiver program options and could not provide useful feedback to individuals and families as they had to decide which waiver best fit their needs. Also, service providers changed when on different waivers. Additionally, different waivers required different LOC assessments.

[334] CMS. *Does Early Use of Community-Based Long-Term Services and Supports Lead to Less Use of Institutional Care?* Accessed 8 August, 2023.
[335] Nebraska Revised Statute 83-1205. *Developmental disability, defined*. (April 2016). Accessed 1 June, 2023.

Feedback was received about the inadequacy of the assessments currently in use for LOC and person-centered planning budgeting for both DD waivers.

DDD could consider reviewing current LOC assessment processes and tools to identify if there are opportunities to streamline processes between programs. As part of the process, DDD could identify if updates to assessment tools, or more efficient practices exist. An analysis of these processes may lead to outcomes that would help eliminate staffing knowledge and skills barriers and increase the staff capacity to provide guidance on all waivers. Peer states use a variety of LOC assessments, with some peer states using the interRAI for LOC and person-centered planning. In the last two years, Nebraska has implemented the interRAI HC and the interRAI PEDS-HC for use on the AD and TBI waivers. Nebraska may want to consider other versions of the interRAI (such as interRAI Intellectual Disabilities or interRAI Child Youth Mental Health – DD) that may be better suited for individuals with DDs for use in both LOC determinations and for the purposes of person-centered planning.[336]

Responsible Entity and Rationale

The Team recommends DDD follow the same procedures previously utilized when implementing the interRAI HC and interRAI PEDS HC, when considering any changes to streamline LOC assessment processes. The process used to move to the interRAI HC and interRAI PEDS-HC included:

- Concurrent analysis using the previous LOC tools and the new tools. This ensures no adverse impacts to LOC determinations when switching from old to new tools.
- Review of clinical assessment protocols as part of person-centered planning.
- Training for assessors in the Eligibility and Enrollment and Service Coordination Units.

Additionally, DDD would need to consider any changes needed to budget planning processes if implementing the interRAI Intellectual Disabilities or interRAI Child Youth Mental Health – DD as both assessments may be used to replace the current budget planning tool (the Inventory for Client and Agency Planning tool).

Services: Coverage, Design, and Provisioning Recommendations

Throughout the stakeholder process, feedback was received that indicated the current service array available to individuals with DD in Nebraska was not adequate. Service limitations included:

[336] interRAI. *Comprehensive Assessment Instruments*. Accessed 9 August, 2023.

- Available services were not robust enough to support individuals of varying ability levels.
- Not all services are available in all areas of the state.
- Limited assistive technology was in use across the state.
- VR and employment services were very limited.
- Provider shortages make it difficult to receive services they have been approved for.
- Cross-system coordination across divisions and departments was limited.
- Transportation limitations in all areas are limiting service access.
- MCOs are denying access to SSA services, medications, and equipment without offering the option to appeal.
- Person-centered planning practices in use is inconsistent.
- The quality of services varied significantly between providers.
- The grievance process is not easy for people to navigate.

Figure 34: Nebraska Service Access Limitations illustrates how access limitations impact the service array offered in the DD service system, specific service access, and the quality of services received.

FIGURE 34: NEBRASKA SERVICE ACCESS LIMITATIONS

Service Array

- The services available were not robust enough to support individuals of varying ability levels.
- Not all services are available in all areas of the state.
- Limited assistive technology is used across the state.
- VR and employment services were very limited.

Service Access

- Provider shortages make it difficult to receive services they have been approved for.
- Cross-system coordination across divisions and departments was limited.
- Transportation limitations in all areas are limiting service access.
- MCOs are denying necessary services, medications, and equipment without offering the option to appeal.

Service Quality

- The quality of services varied significantly between providers.
- Person-centered planning practices in use are inconsistent.
- The grievance process is not easy for people to navigate.

Given the abovementioned stakeholder feedback and the service system analysis and peer state review, the following service system changes are proposed as recommendations to improve overall access to quality services for individuals with DD:

- Expand the service array.

- Allow telehealth as a mode of service delivery.
- Support employment and technology first initiatives.
- Build direct support professional workforce.
- Unify the Service Coordinator and provider pool across waivers through ADRCs.
- Maintain a list of active providers.
- Improve cross-system coordination.
- Review managed care prior authorization processes.
- Increase self-direction opportunities in all 1915(c) waivers.
- Review, revise, and monitor grievance and hearing processes.

Expand the Service Array

Stakeholder feedback related to the current service array reflected that there are currently certain services unavailable to meet the needs of individuals with specific conditions. Additionally, stakeholder feedback also suggested that without maintaining an adequate array of services to meet the needs of individuals across a continuum of care, individuals with complex needs may not have access to services that allow them to lead healthy, independent lives in their communities of choice. Moreover, the Team's research suggests that while Nebraska is offering similar services to those available in peer states, there is always room to be innovative and expand services to ensure choice and meaningfully address individuals' needs.

Service arrays directly impact how individuals are served. Without a robust set of services to meet an individual's needs across a continuum, individuals and their families are placed in situations that increase safety concerns, and in some cases, the economic wellbeing of their families.

There are several different services that Nebraska currently offers that should be maintained as part of a continuum. Conversely, there are also services that are not yet part of Nebraska's service array that should be considered as options to offer. The following list of specific services address stakeholder feedback and findings from the Team's peer state review. This list of services demonstrates a need to maintain current service options or add new services to the DD system. Additional services that DHHS may want to consider including as part of the DD service system are noted in *Appendix XXXI: Considerations for Service Array Expansion.*

- The Team recommends broadening the available services and supports for individuals with progressive conditions, such as Duchenne muscular dystrophy. This recommendation is based on the following:
  - Progressive conditions require long-term supports that change as a condition worsens.
  - Improved supports and access to services dedicated to the treatment of progressive conditions can help to provide proactive treatment and improve quality of life for individuals.
  - Stakeholders mentioned the need to consider Duchenne, as well as other progressive conditions, as qualifiers for automatic eligibility and enrollment on a 1915(c) waiver program. This will allow access to services sooner when disease progression can be managed earlier.
  - Should DHHS consider a diagnosis, like Duchenne, as an immediate qualifier for 1915(c) services, consideration will need to be given to LOC and other eligibility policies.
- Individuals with complex medical or behavioral co-occurring diagnoses should be afforded additional supports and services to address both their DD and medical/behavioral health conditions. The Team proposes this recommendation due to:
  - The need to ensure proper coordination and service planning takes place to provide individuals with all services and supports to treat, prevent, and manage all chronic conditions.
  - Management of co-occurring diagnoses is important as the treatment of each disease may have impacts on other conditions. Communication between treatment teams helps to mitigate adverse impacts of treating multiple conditions in siloes.
  - Stakeholder feedback regarding the lack of specific and targeted services to treat complex medical and behavioral health conditions. Stakeholders indicated more support is needed to improve coordination and access to all needed services, including behavioral health services, regardless of payer source.
- Consideration should be given to expanding service qualifications for allowable providers of respite care. Based on the Team's research, the allowable providers of respite in Nebraska are limited when compared to peer states.

- The Team recommends DHHS consider expanding service providers of respite to at least the following: ICFs/IID, paid family caregivers (excluding those who are the primary caregiver), and licensed foster and group homes.
- Further feedback from stakeholders and the SSA to ensure the potential service providers mentioned above are aligned with the needs of families.
- Changes to policy or waiver amendments may be needed to expand service definitions and provider qualifications to align with this recommendation.

- Health homes for individuals with a DD diagnosis should be considered as a new service for the DD services system.
  - Five of the nine peer states the Team reviewed are covering health homes to promote and improve upon care coordination and specialized care needs of individuals with chronic conditions, including DD.
  - Consideration should be given to targeting certain sub-populations of individuals with DD, like children, to improve upon specific care needs of these sub-populations.
- The maintenance of ICFs/IID as an option for individuals with severe and complex DD conditions who choose to receive services in this manner should continue. The Team is including this recommendation for consideration based on the following:
  - ICFs/IID are a service option that should be available within the DD service system, as they provide high-level support for people with the highest acuity needs.
  - Providing a choice of where individuals receive services is an important aspect of long-term services and supports. ICFs/IID should be maintained as a choice for individuals who choose to call an ICF/IID "their community."
  - Promotion of ICFs/IID, and BSDC in particular, as a community for individuals who chose to live there will reduce stigma and fear around receiving services from these entities for individuals who require this LOC.
  - Stakeholder feedback on the importance that BSDC plays for them and their loved ones cannot be understated. Proper supports and funding to continue to have BSDC as a service option is critically important for those BSDC serves.

Responsible Entities and Rationale

The development of new services and the maintenance of existing services within the DD service system is the responsibility of all entities, regardless of funding source. All the services and

supports listed above may be funded through Medicaid, either as a State Plan service, or through a 1915(c) waiver. MLTC and DDD will need to consider how best to coordinate efforts to determine the best federal authorities to implement these services. Moreover, these two divisions should work across the DHHS structure to provide DBH, CFS, and DPH with information regarding services within the DD service system. Lastly, MLTC and DDD should coordinate efforts with external entities, such as VR, MMI, and schools to ensure education is provided to families and individuals on the availability of services in the DD service system.

Allow Telehealth as a Mode of Service Delivery

In addition to concerns regarding limited service availability, stakeholders also suggested that telehealth for certain services is not widely available. Nebraska expanded the use of telehealth during the COVID-19 pandemic, but as of March 2023, telehealth allowances were being reduced from what had been previously allowed prior to that date.[337] *Table 23: Telehealth Flexibilities under Nebraska Medicaid* outlines the services for which telehealth applies, as of the March 2023 Medicaid Provider Bulletin. It should be noted that some services continue to temporarily be available through telehealth, until at least December 2023.[338]

TABLE 23: TELEHEALTH FLEXIBILITIES UNDER NEBRASKA MEDICAID

Allowed Services Under Telehealth as of May 2023	Non-Allowed Services Under Telehealth as of May 2023
• Any service which includes hands-on care as part of its service definition. • Initial or recertification of home health and hospice assessments. • Pediatric feeding disorder outpatient therapy. • Telephonic codes. • Certain evaluation and management services. • Certain behavioral health services.	• Health check services. • Mental health and substance use. • Physical therapy and occupational therapy services. • Physician services. • Speech pathology and audiology services. • Visual care services. • Chiropractic services.

The use of telehealth is not always an appropriate option for every individual, but for some individuals, it may be a more accessible option than traveling long distances for appointments or going to appointments in unfamiliar, sensory-overwhelming spaces. Additionally, given stakeholder concerns about the provider workforce in Nebraska, telehealth is a method to

[337] Nebraska DHHS. *Provider Bulletin 23-08: Guidance on Telehealth*. (March 2023). Accessed 15 August, 2023.
[338] Nebraska DHHS. *Provider Bulletin 23-08: Guidance on Telehealth*. (March 2023). Accessed 15 August, 2023.

expand provider coverage across the state. Virtual telehealth coverage can help fill in service gaps, especially in rural areas of Nebraska. By offering telehealth as an option, it could reduce reliance on available transportation providers and reduce delays in accessing needed services in underserved communities.[339]

Nebraska could consider allowing and encouraging providers to offer some health care and social services virtually. While there are limitations to what can be offered through telehealth, utilizing it as an integral part of the overall service system can improve health outcomes for individuals from underserved communities in multiple disciplines. The barriers to accessing telehealth can differ from the barriers to accessing in-person care, but providers and agencies can design accessibility practices to support individuals with disabilities and other underserved groups.[340]

Responsible Entities and Rationale

Telehealth opportunities fall under the responsibility and purview of multiple entities. Medicaid allowances for telehealth are crucial to support services provided through this modality. Providers must have the ability to receive reimbursement through Medicaid for services delivered through telehealth. CMS and federal regulations are broad when allowing for the use of telehealth, and only in certain circumstances does CMS require a SPA for states to implement telehealth.[341] MLTC support for telehealth is critical, and the Team suggests that MLTC conduct enhanced stakeholder engagement regarding this issue, to ensure all opportunities to allow for telehealth are considered.

In addition to MLTC, the following entities also play a role in telehealth use in Nebraska:

- DDD should consider and solicit stakeholder feedback on increased opportunities to explore telehealth as a service modality for 1915(c) waiver services.
- MMI can continue to practice the use of telehealth within the parameters of current MLTC billing. In addition, MMI can remain an engaged stakeholder and advocate for the use of telehealth (where and when appropriate) as a method for reaching families in all parts of the state.

Support Employment and Technology First Initiatives

The Team's review of peer states indicated that the majority are supporting employment and technology first initiatives. Nebraska is either not currently considering or in the very early stages of exploring employment and technology first initiatives. These findings were supported by the

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[339] Department of Health and Human Services. *Health Equity in Telehealth*. Accessed 9 August, 2023.
[340] Department of Health and Human Services. *Telehealth for People with Disabilities*. Accessed 9 August, 2023.
[341] Medicaid.gov. *Telehealth*. Accessed 16 August, 2023.

stakeholder feedback the Team received regarding concerns surrounding supports for employment and technology.

Stakeholder feedback was received about the lack of available employment services in Nebraska. Additionally, the disparity in economic outcomes for individuals with IDD in Nebraska was noted in *Figure 10: Post-School Outcomes for Individuals by Special Education Eligibility Category* of this report. Investments in the employment services provided are needed to improve access for individuals with IID.

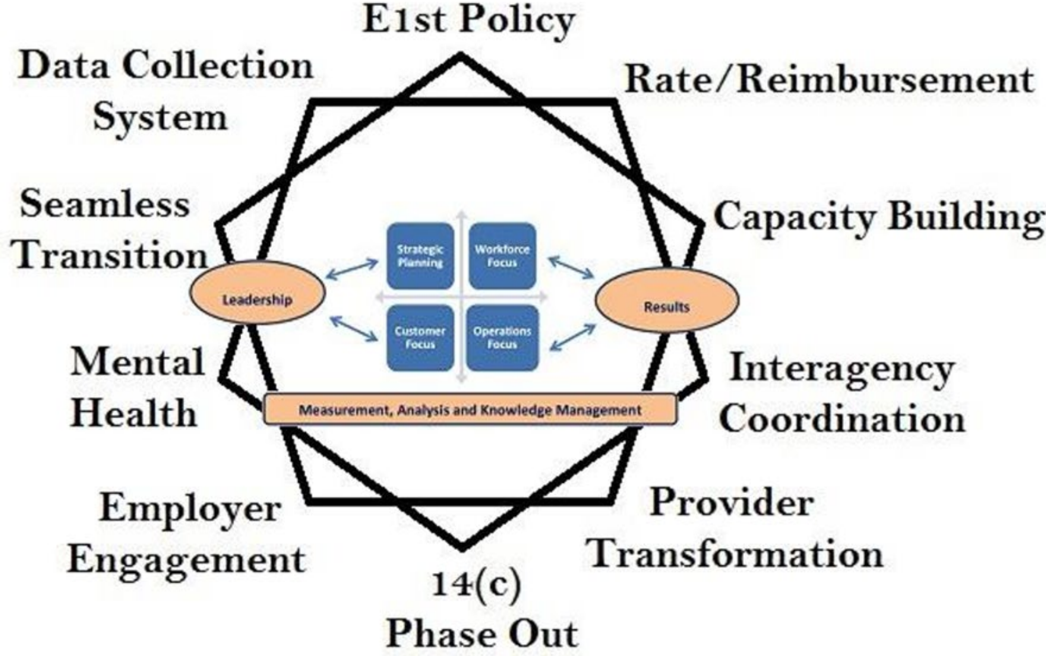
Currently, stakeholders reported that the consideration of assistive technology use is inconsistent, and even when assistive technology is available, providers are reportedly unfamiliar or unwilling to use it. Concerns arose related to the planning procedures that are included in the current ISP process, and that they are not person-centered. Assistive technology, when used correctly, can reduce an individual's reliance on direct support staff and offer more self-direction opportunities to individuals with disabilities.

Nebraska could consider utilizing employment first and technology first[342] initiatives as a framework to improve overall quality of life outcomes for individuals with disabilities. Nebraska could consider redesigning VR services using employment first and technology first principles to promote self-determination, independence, and community integration. Nebraska may want to consider building these principles into their waiver program policies and procedures regardless of whether the legislature requires it. However, if the Nebraska Legislature passed a bill requiring the adoption of employment and technology first policies for cross-disability populations, this could ensure these policies are not seen as optional provisions.

The United States Department of Labor has identified 10 critical areas to increase competitive integrated employment. *Figure 35: Employment First State Leadership Mentoring Program 10 Critical Areas* displays an organizational framework for promoting competitive integrated employment for individuals with disabilities.[343] Most of the peer states reviewed used one or both initiatives and applied them to a cross-disability population to ensure these practices were utilized across the board. These 10 areas may be helpful for Nebraska policymakers to review how to implement employment first initiatives using best practices.

[342] University of Kansas. *Technology First Systems Change Model*. Accessed 9 August, 2023.
[343] United States Department of Labor. *Employment First State Transformation Guide*. Accessed 16 August, 2023. Page 2.

FIGURE 35: EMPLOYMENT FIRST STATE LEADERSHIP MENTORING PROGRAM 10 CRITICAL AREAS



In addition to guidance provided by the Department of Labor on employment first, the National Association of State Directors of Developmental Disabilities Services published a report detailing promising practices for technology first initiatives. The report details four pillars that support a foundation for implementation of a technology first agenda for states. These four pillars are:

1. "Setting clear expectations as to the role of technology in the lives of people with intellectual/developmental disabilities and their families;

2. Identifying policies, practices, and information that both internal and external stakeholders need for technology adoption and use to be successful;

3. Identifying barriers, considerations, and solutions that advance the use of technology; and

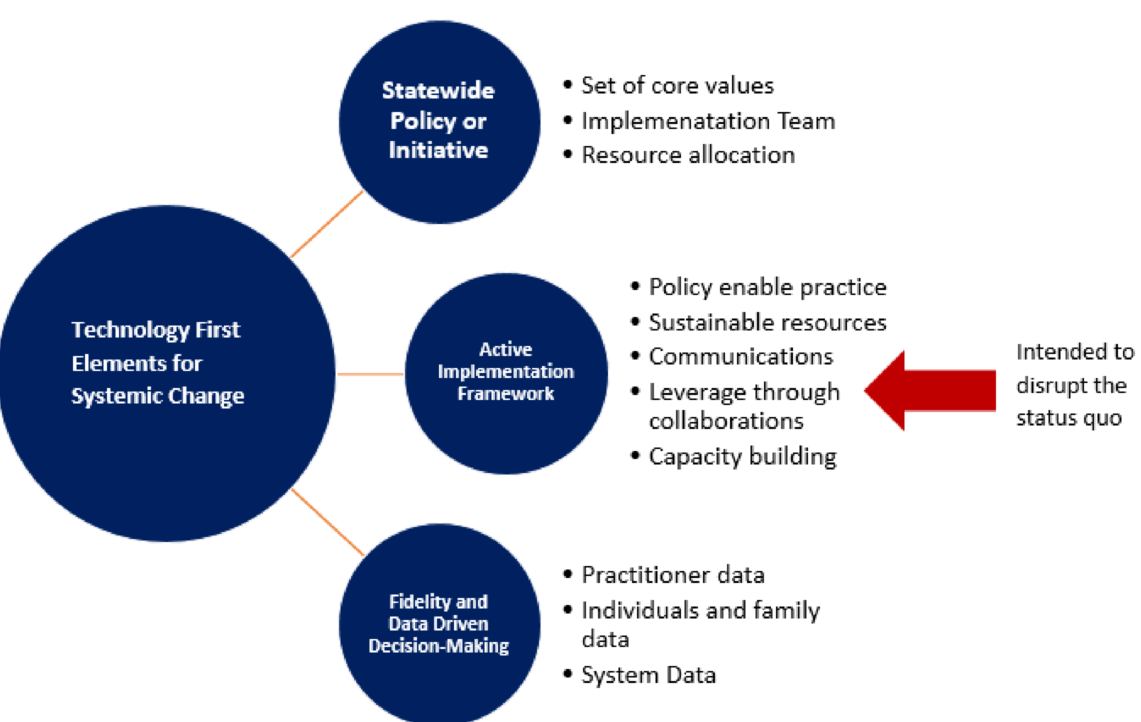
4. Building a nimble policy process, given the accelerated advancements in the use and types of apps and devices."[344]

These pillars are important for Nebraska to consider, should the State move toward supporting a technology first initiative. These pillars will help to guide policymakers and stakeholders in identifying and promoting positive practices to best incorporate technology within the DD service system.

If Nebraska moves toward implementing technology first, it is important to recognize that all individuals should have their person-centered service plan designed to promote independence as much as possible. Nebraska could refine the person-centered planning process to include the technology first elements of systemic change. *Figure 36: Technology First Elements for Systemic Change* is a graphic presentation if how to make systemic changes that promote technology first initiatives.[345]

[344] National Association of State Directors of Developmental Disabilities Services. *Technology for People with Intellectual/Developmental Disabilities and Their Families*. Accessed 16 August, 2023. Pages 2-3.
[345] University of Kansas. *Technology First Systems Change Model*. Accessed 9 August, 2023.

FIGURE 36: TECHNOLOGY FIRST ELEMENTS FOR SYSTEMIC CHANGE



It is best practice that any person-centered activity and planning opportunity consider available assistive technology options to promote self-direction regardless of the environment or task.

Responsible Entities and Rationale

Similarly to telehealth, the implementation of employment and technology first initiatives is not the sole responsibility of any one entity involved in Nebraska's DD service system. Implementation of these initiatives will require support and buy-in from all entities. For this reason, the Team recommends for the following entities to play a role in any future implementation of both initiatives:

- DDD can continue to support the modernization of services available under each of the four 1915(c) waivers. The inclusion of employment and technology services that help meet the needs of individuals will naturally promote Nebraska to move toward implementation and adoption of employment and technology first initiatives.

- Nebraska VR is a partner with DHHS and with DDD. Nebraska VR and DHHS should partner to support the adoption of employment and technology first initiatives. This will allow all individuals who express an interest in integrated competitive employment, and who may need technology to be successful in the workforce, to have the best outcomes possible.

- The Nebraska DD Council has supported the adoption of employment and technology first initiatives in recent years, as demonstrated, in part, by their work to sponsor research into supported employment outcomes.[346] The Team recommends for the Nebraska DD Council to continue to encourage policymakers to adopt employment and technology first initiatives. This should occur in accordance with their demonstrated commitment to inclusive and modern services for individuals with DD.

- Though employment and technology first initiatives can occur outside of an Executive Order or a legislative mandate, the support of Nebraska's legislative and executive bodies would further demonstrate a commitment by policymakers to provide opportunities and enhanced supports to individuals with DD.

Build a More Robust Direct Support Professionals Workforce

DSPs are the backbone of a healthy and well-functioning DD service system. Without a strong DSP workforce, individuals with DD and their families will struggle to receive needed services and supports. Stakeholders suggested that DSPs should be treated as professionals, and that more work is needed to support DSPs create a career serving individuals with DD and those who support them. There are several factors that Nebraska should consider to build, support, and maintain a robust DSP workforce.

After reviewing stakeholder feedback, the Team submits the following recommendations for consideration:

- Reimbursement rates should not be stagnant and must adapt with the economic environment of the state and federal climate. The Team recommends that DHHS should maintain a schedule to review reimbursement rates across all Medicaid-funded services, including those under 1915(c) waivers. This will allow Nebraska to remain competitive with surrounding states and will provide a reasonable living wage to the individuals who support some of the most vulnerable in the state.

[346] Moving to a Different Drum, LLC. *Necessity or Luxury? Supporting Nebraskans with Intellectual and Developmental Disabilities to Join the Workforce and Contribute to Nebraska's Economy.* (February 2023).

- Professionalizing DSPs will promote caretakers to see themselves in a long-term career, rather than just a short-term job. Career ladders help to support DSP skills and create a pathway for DSPs to see themselves in a professional career path. Additionally, career ladders can support increased benefits and pay as DSPs work their way up the ladder and can promote ongoing educational and competency-based training opportunities.[347]

- The National Alliance for Direct Support Professionals developed a national certification program for two years to encourage national recognition of DSP contributions. Instituting certification standards such as those developed by the National Alliance for Direct Support Professionals helps to enhance quality, oversight, and monitoring.[348] Additionally, evidence suggests that credentialing supports increased length of stay in the profession, which will help to support the workforce capacity in the state.[349] Should Nebraska move toward DSP certification, DSP oversight could fall within the purview of the Nebraska Board of Health. The Nebraska Board of Health holds rule and regulation authority and currently oversees professionals who are licensed, registered, or certified by DHHS.

Responsible Entities and Rationale

The Team has identified the following entities as holding responsibility for implementation of these suggested recommendations:

- Reimbursement reviews fall within the purview of MLTC and DDD. It is recommended for both divisions to work collaboratively to ensure an equitable and modern rate is provided to DSPs serving individuals with DD and their families.

- MLTC and DDD will need to coordinate efforts with DPH if the decision was made to move forward with DSP credentialing. DPH already certifies several different provider types, and DHHS could consider having DPH hold responsibility for certifying DSPs using already established processes. All divisions will need to coordinate efforts to ensure the provider certification process (which was noted as being of concern to stakeholders) is seamless, efficient, and easily understood by DSPs working to be enrolled in Medicaid and provide certification materials.

- Should Nebraska work to develop a new board dedicated to DSPs, it is likely DHHS will need to work with the Nebraska State Legislature to authorize such a board within NRS.

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[347] Barbara Kleist, JD. Institute on Community Integration, University of Minnesota. *Professionalizing DSPs and their Career Path*. Accessed 16 August, 2023. Page 13.
[348] National Alliance of Direct Support Professionals. *NADSP Certification*. Accessed 16 August, 2023.
[349] National Alliance of Direct Support Professionals. *NADSP Certification*. Accessed 16 August, 2023.

The new board would hold responsibility for oversight and quality assurance of DSPs in a manner similar to how Nebraska's medical and nursing boards currently provide oversight to medical professionals.

Standardize Services and Quality across ADRCs

During review of Nebraska's DD services system, the Team identified that there are significant differences in the services offered by the various ADRCs. For instance, one ADRC (the League of Human Dignity) offers five different services, but most other ADRCs only offer two or three services. The Team was unable to locate any services provided by West Central Nebraska Area AAA.[350] In addition to the differences in services offered by ADRCs across the state, very few transitional options counseling and mobility training services were provided in 2021 and 2022.[351]

The Team's findings suggest that the ADRCs are not providing equitable access to the same services across the state. The ADRC system is intended to provide local communities with a network to support the long-term service and support needs of their members. ADRCs are especially important for individuals who may not qualify for Medicaid or 1915(c) waiver services.

To help strengthen the ADRC system, consideration should be given to unifying services and quality across the ADRCs. This will allow a more uniform system across the state to ensure local communities are served and provided with the same resources, regardless of which part of the state an individual lives.

Responsible Entities and Rationale

ADRCs receive funding from the State Unit on Aging which is currently housed in MLTC. The State Unit on Aging is responsible for providing a legislative report on the performance of the ADRCs, annually. For this reason, the Statue Unit on Aging, with support from MLTC and DDD, should work with the ADRCs to unify, increase, and expand the availability of services and resources across all ADRCs.

To further support uniform service availability across the ADRC network, the State Unit on Aging and MLTC may want to consider putting forth an amendment to NRS 68-1116. Currently, 68-1116 states that "Each aging and disability resource center shall provide one or more" of the services listed in the statute.[352] The Team recommends for the State Unit on Aging and MLTC to amend

[350] Nebraska Department of Health and Human Services. *Aging & Disability Resource Center Report*. (December 2022). Accessed 12 June, 2023. Page 7.
[351] Nebraska Department of Health and Human Services. *Aging & Disability Resource Center Report*. (December 2022). Accessed 12 June, 2023. Page 10.
[352] Nebraska Revised Statute 68-1116. "Aging and disability resource centers; services." Accessed 17 August, 2023.

the NRS language to read "Each aging and disability resource center shall provide all of the following services."

Maintain a List of Active Providers

One of the areas of concern mentioned during stakeholder feedback sessions was that it is very difficult to find providers for individuals and families with disabilities. Often, individuals and caregivers noted having to call multiple providers when searching for available supports. In these instances, stakeholders report that referrals they were given were either not available or were no longer working in the field. Oftentimes, individuals reported spending a long time finding providers to fill approved services. Coupled with high provider turnover individuals reported having to go through this process frequently to limit service disruptions.

Nebraska could consider creating and maintaining a unified active provider list, organized by region and service provided. With the help of ADRCs, this list should be actively updated to reflect provider availability. Additionally, maintaining this list could allow Nebraska to proactively identify regions which have extreme provider shortages and create solutions to prevent service disruptions for individuals on waivers.

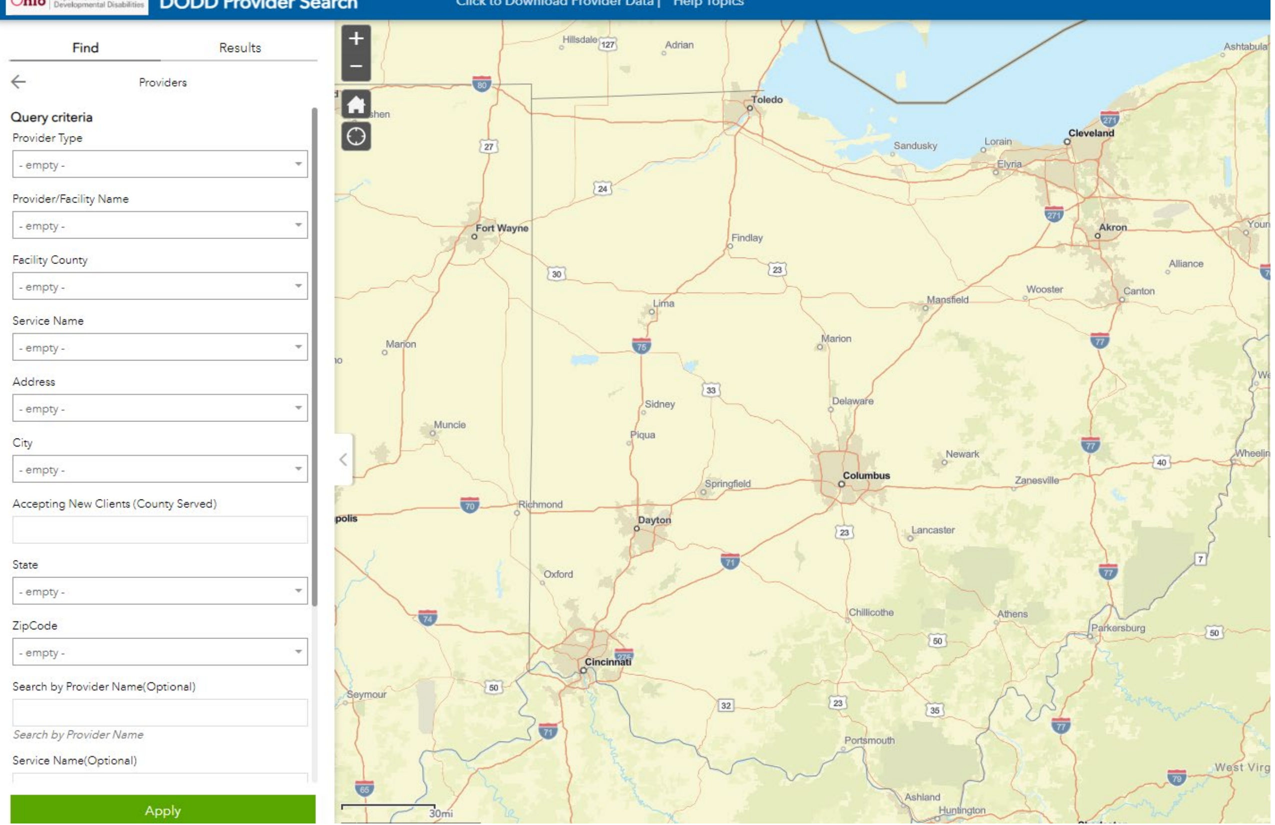
Responsible Entities and Rationale

Through collaborative efforts, MLTC and DDD can work together, and with their external partners, can create and maintain an active list of service providers working in the DD service system.

- MLTC and DDD can work with each ADRC to identify available providers in all regions of the state.
- DHHS could post an active provider registry on their website for families and individuals to use when searching for needed supports. This registry could list services and funding sources the providers accept. *Figure 37: Ohio Provider Search Tool*[353] demonstrates an example from a peer state provider search directory that may serve as a model for DHHS' consideration.

[353] Ohio Department of Developmental Disabilities. *DODD Provider Search*. Accessed 17 August, 2023.

FIGURE 37: OHIO PROVIDER SEARCH TOOL



- DHHS can work with external partners like VR, MMI, the Nebraska DD Council, and the Arc of Nebraska to coordinate efforts and share information regarding active providers in different regions of the state. This information could then be maintained in an active provider search directory.

Improve Cross-System Coordination

Limited cross-system coordination was noted during the stakeholder feedback sessions. One of the most frequently discussed topics was the lack of coordination between school districts and individuals receiving 1915(c) waiver services. Schools can serve as a major entry point into services, and much of the feedback received from stakeholders was that they were uninformed on what services individuals with disabilities could access and how to initiate the process. Additionally, schools complete many of the SSA assessments and documentation that assessors rely on to make determinations of eligibility for individuals with DD.

Stakeholders suggested that the lack of school resources dedicated to individuals with DD is having an impact on the way in which families are made aware of DD services. Many families of younger children reported not receiving many resources or referrals from schools for their children with DD. Moreover, multiple stakeholders mentioned that CDD and DDAD waiver access was not granted until after the individual aged out of school-age services. Stakeholders suggested that schools encourage individuals to graduate prior to turning 22 years of age. Early graduation may cause gaps in services for some individuals, especially if transition planning is not occurring or is lacking.

In addition to the lack of coordination with schools, stakeholders also reported perceived limited cross-system coordination between DHHS divisions, specifically between DDD, DBH, CFS, and MLTC. Some individuals and families access programs and services that are overseen by DBH, CFS, or MLTC. Feedback received by stakeholders on the lack of divisional coordination included the following:

- It is the perception of these families that waiver Service Coordinators are not aware of the resources available through other divisions.
- Few stakeholders mentioned being aware of programs provided by CFS. This suggests that divisions are not promoting the use of these programs, especially when individuals and families are waiting to receive 1915(c) waiver services.
- Stakeholders reported that MLTC and the MCOs do not understand how to support individuals with disabilities who also received waiver services.
- When stakeholders utilized case management offered by MCOs, some reported that there was limited consistency in the information received. When asked, most stakeholders suggested that they were unaware the case management is available through the MCOs. Furthermore, stakeholders perceive that the MCOs are not always aware of available services provided through the MCOs and were even less aware of services to support specific DD needs.
- Stakeholders mentioned that individuals with DD would benefit from additional services that are housed under DBH.

Improved cross-system coordination will help to alleviate the confusion reported by stakeholders, as well as duplicative processes and assessments. Cross-system coordination will also improve consistency and transitions for individuals with disabilities.

Overall, Nebraska DHHS could consider improving cross-system coordination by creating or revising their cross-system communication plan and creating more transparency for the public to

understand what each agency is responsible for. Using best practices, such as the tools provided by the National Community of Practice for Supporting Families Across the Lifespan, Nebraska can strengthen cross-system coordination to improve experiences for individuals and families.

Responsible Entities and Rationale

Overall, Nebraska DHHS could consider improving cross-system coordination by creating or revising their cross-system communication plan and creating more transparency for the public to understand what each agency is responsible for. The following entities should be considered as part of a committee system to address gaps across the DD service system.

- Department of Education
    - Identify and implement a plan to educate school staff on services available through DHHS and processes to initiate services to support overall health outcomes.
    - Create an education liaison as a point of contact for school staff when questions arise.
    - Create or revise policies and procedures with the Department of Education to require coordination of services during transition. Identify key stakeholders, work toward a streamlined goal. Integrate employment first and technology first principles into transition planning.
- CFS
    - Identify shared services between CFS and other divisions and provide training and resource materials for Service Coordinators to increase access to services outside of DDD.
    - Consider adding an evidence-based care model, such as high-fidelity wraparound, for individuals with DD who receive services through multiple divisions.
- MLTC
    - MLTC could consider examining MCO contracts to ensure appropriate monitoring protocols are in place for the operationalization of service denials and barriers stakeholders are encountering. MLTC plays an integral part in accessing care for individuals with DD since they provide key state plan services through their MCOs. To do so, MLTC could consider gathering feedback directly from stakeholders at a regular interval. Quality data could be gathered on the different MCOs and shared

as a report card to help inform other individuals when making health care decisions.

- DBH
    - As previously mentioned, DHHS could consider combining DBH and DDD into a unified division and ideas for key initiatives should include planning services for individuals with DD and behavioral health or co-occurring disorders. Currently, DBH has a deputy position that oversees housing, unifying that position under one division for all populations would be beneficial to ensure individuals with DD are in the least restrictive setting appropriate for them. During the reorganization, the team should focus on creating accessible resource lists for services coordinators to share with the public.

Review Managed Care Prior Authorization Processes

The prior authorization process can be difficult to navigate to access needed services for everyone. However, for some individuals with disabilities and their caregivers, it can cause barriers that make access to timely services and supports impossible to navigate.

Stakeholders reported frequent denials for services through the MCOs, notably for specialized services to meet the needs of individuals with DD. Families, individuals, and providers reported struggling with the MCO prior authorization process for similar reasons. All stakeholders cited the length of the prior authorization process as delaying services for individuals. Some providers noted that clinical peer-to-peer reviews occur after a denial for services is issued by an MCO, but these often result in time spent without an approval for services for an individual. These same providers did indicate that they perceive certain MCOs as being more likely to always deny services, regardless of the documentation and evidence of medical need.

Feedback from family members suggested that when denials were made, there was no recourse or appeal process. This feedback is an indication that families and individuals are unaware or do not understand how to request an appeal, rather than there being no true appeal process in place. However, this feedback is still important in understanding how to make improvements to the managed care prior authorization process.

As a result of the feedback from stakeholders, the Team recommends Nebraska consider conducting a review of the for the managed care prior authorization process. The review could include a review for consistency, equity, and adherence to all contracting requirements, included in executed agreements between DHHS and the MCOs. In addition, the review may highlight opportunities for improvement and ways in which the MCOs may want to amend their prior authorization processes.

Responsible Entities and Rationale

As the contract holder with the MCOs MLTC would hold responsibility for overseeing this potential recommendation. MLTC has longstanding relationships with the MCOs and plays both a partnership and oversight role to the MCOs. The Team suggests MLTC, or a contracted vendor, to conduct the prior authorization process review.

Increase Self-Direction Opportunities in all 1915(c) Waivers

Self-direction opportunities are offered currently offered under the CDD and DDAD waivers, only in Nebraska. These waivers allow for both budget and employer authority as noted in *Appendix IV.* The AD and TBI waivers do not offer self-direction opportunities to individuals enrolled. Though the Family Supports Waiver is anticipated to offer budget and employer opportunities, not all services will have self-direction opportunities extended to them.[354] This includes the Family and Peer Mentoring service which is only anticipated to be provided by an independent agency.[355]

The Team's review of peer states and stakeholder feedback suggests that self-direction opportunities can and should be extended to all 1915(c) waivers. Based on this research, it is recommended that Nebraska consider ways to expand self-direction opportunities to include as many services as possible under the 1915(c) waiver programs. Expansion of self-direction may coincide with changes to how Nebraska considers legally responsible individuals as providers, under each of the 1915(c) waiver programs. By considering expansion of self-direction to include a broader scope of legally responsible individuals, the potential provider network will increase in size, leading to support for combating the workforce challenges in the state.

Responsible Entity and Rationale

DDD will be required to work with stakeholders and CMS, should self-direction expansion be considered in the future. Implementation of this recommendation will require DDD to ensure stakeholder feedback is captured to expand self-direction in a way that best serves individuals and their families. DDD would also be required to work with CMS to have all changes included within approved 1915(c) waiver applications.

Review, Revise, and Monitor Grievance and Hearing Processes

Stakeholders, including individuals, family members, and providers, all relayed concerns regarding the grievance and hearing processes. These concerns were specific to denials of:

[354] Nebraska Family Support Waiver 1915(c) Draft Waiver Application. (January 2024). Accessed 17 August, 2023. Page 156.
[355] Nebraska Family Support Waiver 1915(c) Draft Waiver Application. (January 2024). Accessed 17 August, 2023. Page 77.

- Eligibility for the Medicaid program and 1915(c) waivers.
- Service authorizations.

Many stakeholders expressed confusion regarding the grievance and hearing process. Individuals reported confusion about knowing and understanding individual rights, and how to request a hearing. In addition, some stakeholders reported that time spent going through the process was not beneficial to them.

This stakeholder feedback suggests a lack of education on the grievance and hearing process. The Team recommends DHHS consider how to provide clear, concise guidance to families and individuals regarding their rights to request a hearing or submit a grievance.

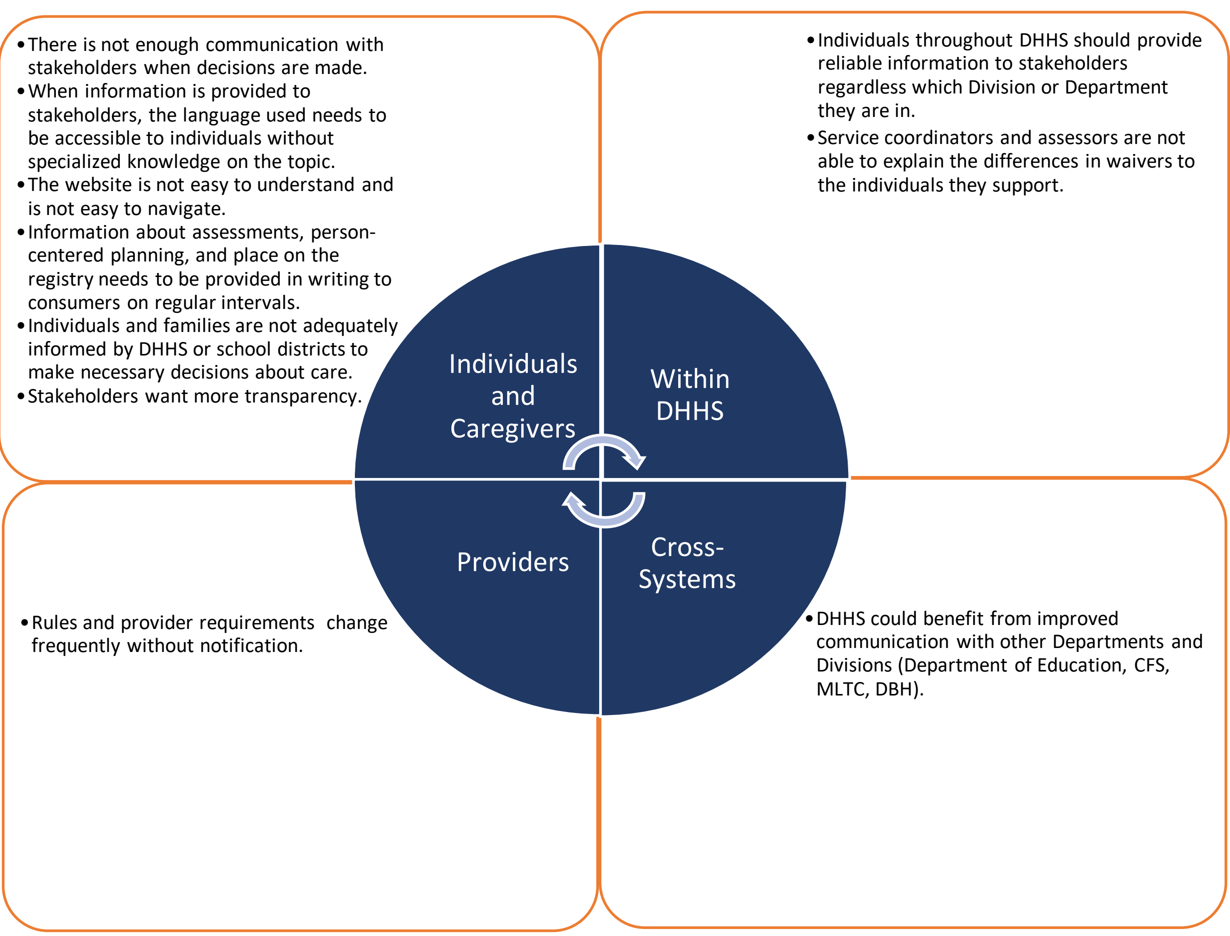
Responsible Entities and Rationale

The Team recommends for all divisions under DHHS to collaborate on developing and providing education to families and individuals for any program in which eligibility is determined, or benefits are administered. Education materials should follow the best practices noted above for accessible communication and should clearly explain how to request a grievance or hearing. It is also suggested that such materials include information about expectations on what the outcomes of a grievance or hearing may be.

Communication Recommendations

Many stakeholders reported that communication was a significant barrier to understanding, engaging with, and accessing needed services in Nebraska. Feedback varied based on specific experiences and was aligned with the roles that each stakeholder plays within the DD service system *Figure 38: Stakeholder Feedback on DHHS Communication* represents feedback received about DHHS' current communication practices by stakeholder type.

FIGURE 38: STAKEHOLDER FEEDBACK ON DHHS COMMUNICATION



Given the feedback gathered on the communication barriers experienced by DHHS and their stakeholders, the following recommendations were identified:

- Provide education and resources to individuals and families in accessible ways.
- Review and revise public-facing notifications and communications strategies.
- Leverage schools to be a "first point of contact" with individuals and families.
- Train all service coordinators and assessors on all waivers, services, and options.
- Continued work with stakeholders.

Provide Standardized Education and Resources to Individuals and Families in Accessible Ways across the Service System

One of the most consistent themes presented by stakeholders was a lack of understanding on service availability and how to access services. When information was provided, often, stakeholders reported struggling to understand the content because of the use of professional jargon or unfamiliar acronyms. Some stakeholders mentioned it was difficult to access materials in English and that resources offered in other languages were limited.

Nebraska may want to create or revise communication policies, aligned with the best practices on accessible communication, to include the following:

- Better communication with families on the registry. This should include providing information about anticipated timelines, updates offered at regular intervals, and lists of other available services and supports.
- Review DHHS' current website design and consider website accessibility standards, using accessible language, logical organization, naming conventions, and limiting the use of jargon and acronyms.[356]
- Training and resources should be available in languages other than English. The option to request accommodations, translation services, or accessible formats should be easily available to all individuals.
- All materials created regardless of being public-facing or internal should be generated with person-first language, using Easy Read formats when appropriate.
- Individuals and their families on waivers should be provided written documentation of assessment results, service planning materials and agreements, and their rights related to grievance procedures within specified amount of time.
- DHHS should create accessible trainings, resource materials, and frequently asked questions to promote informed consent for individuals and their families to navigate the DD service system and understand the different waiver options.
- DHHS, with the Department of Education, should work to create trainings and resources for individuals and families related to their rights to a free and appropriate public education and the requirements for transition age services.

[356] University of Oxford. *Accessible Communication. Guidance for communicating clearly and accessibly*. Accessed 1 August, 2023.

- Assessors and service coordinators should be trained in where to access resources and the procedures to follow to ensure all individuals and families are afforded equitable access to services.

Responsible Entities and Rationale

Accessible education and resources is not the sole responsibility of any one entity in the DD service system. DHHS, other state partners, advocacy organizations, and stakeholders should collaborate to ensure developed materials are appropriate and will meet the needs of individuals served by the system. Using the best practices noted above, DDD and MLTC can share joint responsibility for coordinating these efforts across entities in the DD service system.

Leverage Schools to be a "First Point of Contact" with Individuals and Families

For many individuals with DD and their families, the first interaction they have with the DD service system is either in early childhood or school-age services. Feedback from stakeholders indicated that many school staff are not adequately informed to support individuals with DD to access SSA health care services offered through DHHS. School districts, with the right supports, could address a critical access barrier to initiating services for individuals with DD.

Nebraska could consider the following to leverage school providers to support individuals with DD, as well as their families with accessing services through DHHS:

- Annually, school staff are required to complete staff trainings. An additional training could be created and shared with school districts to inform any individuals who perform case management services about DHHS offered services, how to access them, and any changes that occurred over the last year. Topics to cover would include Medicaid access, waiver availability, services available after graduation, and community resources.

- Create a liaison position as a point of contact for questions. This liaison would act as an intermediary between systems to ensure individuals and families are able to inquire about possible services.

- Refine the transition to adulthood process. Create policies and procedures requiring coordination between school districts and service coordinators and other agencies like VR. The largest barrier to this process right now is the registry, but with the registry's elimination, better coordination could be possible.

- Train schools with documentation requirements to establish waiver services for DD. For individuals who seek eligibility for the CDD and DDAD waivers, a part of the process includes documentation of abilities and needs prior to the age of 22. Frequently, this

comes from school-age documentation as those assessments are also utilized to establish school-age eligibility. If school-age providers were aware of the documentation requirements for waiver eligibility, they could ensure the appropriate documentation was completed prior to the age of 22. This could be useful to waiver assessors to streamline the eligibility process and reduce duplication of assessments.

Responsible Entities and Rationale

DHHS, VR, and the Department of Education will need to partner to implement this recommendation, should Nebraska decide to move forward. There are already dedicated DHHS staff who work with communities, including local school districts, to provide awareness and education to individuals and their families about the DD service system. These staff can build upon their relationships and partner with VR and the Department of Education to ensure schools are leveraged as much as possible to be a first point of contact for families.

Train Service Coordinators and Assessors on All Waivers, Services, and Options

Stakeholders reported that Service Coordinators and Assessors appear to have limited understanding of waivers other than the ones they currently work with. Stakeholders reported that this limited their ability to decide which waiver was appropriate, and at times, resulted in individuals refusing their registry slots after waiting for years for those services. Knowledge and skills gaps in Service Coordinators and Assessors resulted in inconsistent quality of care according to stakeholders.

Nebraska could consider training all staff, regardless of which waiver they support, with an overview of all waivers and the services they provide. Accessible, public-facing materials, such as a table comparison of waivers and services, as well as a frequently asked questions sheet should be maintained to ensure staff, individuals, and families feel confident making informed decisions about their care. Additionally, an accessible, system-wide resource list could be created to support individuals, regardless of if they meet LOC, to access the needed services they may qualify for.

Responsible Entities and Rationale

DDD will need to coordinate training for their staff and contracted staff. DDD should partner with other divisions of DHHS to provide Service Coordinators and Assessors with updated information on a periodic basis. This will allow these staff members to have the best information possible when supporting and working with families and individuals.

Continued Work with Stakeholders

Stakeholders reported that often, decisions are made about services and supports without including public stakeholder feedback. Stakeholders requested more opportunities to engage on topics about the care that affects them and their loved ones.

Using the best practices included in this report, Nebraska could consider the following to encourage inclusion of public stakeholders in all decisions that impact the care Nebraskans need:

- Create intentional opportunities to engage in stakeholder communication with large partners including MMI, The ARC of the United States (ARC), DD Council, DD Advisory Committee, and Nebraska Disability Rights.
- Continue outreach with tribal entities and identify culturally responsive strategies to improve engagement with tribal members.
- Improve public transparency of DHHS responsibilities and decision making.

Responsible Entities and Rationale

All partners within the DD service system should prioritize working with stakeholders as part of the regular course of business. Stakeholders should always be provided with the opportunity and accommodations needed to participate in discussions regarding services and supports. Providing ways in which stakeholders can participate in public forums is the best way to build and design a service system that has meaning to the individuals it serves.

Long-Term Funding Recommendation

None of the above recommendations can be made possible without thought to the long-term funding that will be needed to support a sustainable DD service system. As such, the Team submits the following recommendation for consideration.

Combine American Rescue Plan Act Funding with Long-Term Investments to Support 1915(c) Program Modifications

Research suggests that though helpful, one-time funding allocations may not create systemic change needed to address longstanding systemic issues. For instance, states have had an unprecedented opportunity for funding through the American Rescue Plan Act authorized by Congress as part of COVID-19 response measures. The Center on Budget and Policy Priorities estimated that as of 2021, 11 states dedicated a portion of their American Rescue Plan Act funds

to adding waiver slots or reducing waiting lists for services.[357] However, though American Rescue Plan Act funding is noted as providing critical resources to states to begin making improvements for vulnerable population, the Center on Budget and Policy Priorities notes "…this one-time injection of new funding is insufficient to sustain the kind of long-term improvements that have been needed to improve access to HCBS since before the pandemic began."[358]

It will be important for Nebraska to consider how to use one-time funding in combination with long-term investment options to ensure a sustainable path for making improvements to the DD service system. One-time funding is critically important and should not be overlooked as a way to support individuals and families. However, Nebraska's policymakers will need to determine how to approach making long-term investments into the DD service system to support it into the future.

Long-term funding can occur through a variety of mechanisms, but one of the best solutions to sustainable funding is through maximizing federal financial participation. For services that are coverable under the Medicaid state plan program, the federal government pays a portion of a state's expenditures. Prioritizing the use of Medicaid to shift costs for the provision of services to the federal government is a cost-effective and sustainable way to providing access to services to individuals with disabilities.

Responsible Entities and Rationale

The Team recommends for DHHS, the Governor's Office, and the Nebraska State Legislature to partner to determine how best to leverage one-time funding, while determining a plan for long-term investment into the DD service system. All funds, regardless of if they are one-time or long-term, are important to support Nebraskans with disabilities. This funding is not intended on supporting the administrative activities of DHHS or its divisions, but rather will help to enable Nebraskans with disabilities to receive services in their manner of choosing, while building independence and leading healthy lives.

All three entities will need to work with stakeholders to determine the most immediate priorities to dedicate immediate, one-time funding. Once immediate priorities are funded, a long-term strategy for an investment may be created to support future priorities and needs of the DD service system.

[357] Sullivan, Jennifer. "States are Using One-Time Funds to Improve Medicaid Home- and Community-Based Services, but Longer-Term Investments are Needed." (September 2021). Accessed 24 June, 2023.
[358] Sullivan, Jennifer. "States are Using One-Time Funds to Improve Medicaid Home- and Community-Based Services, but Longer-Term Investments are Needed." (September 2021). Accessed 24 June, 2023.

Conclusion

This comprehensive evaluation of the DD service system aims to identify ways Nebraska may improve access to health care for individuals with I/DD. Nebraska's DD service system assists individuals with I/DD through a number of different programs including:

- HCBS waiver programs, including the AD, CDD, and DDAD 1915(c) programs.
- ICFs/IID, and other Medicaid-funded state plan services.
- Non-Medicaid funded services such as those provided by CFS, DBH, VR and schools.

Many of these programs are operated and overseen by DHHS, specifically DDD and MLTC, but are heavily reliant on a network of community entities and providers to ensure needed services are accessed by individuals and their families. Stakeholder feedback was explicit in describing the importance of all partners within the Nebraska DD service system. Each program, service, and entity, regardless of funding source, is critical to serving individuals and their families in their communities of choice.

Through the Team's review of Nebraska's DD service system, the State was found to have positive features within their service system, including DDD staff. However, barriers exist that limit individuals' and families' ability to obtain services and supports in a manner of their choosing.

Current systemic barriers in Nebraska's service system contribute to:

- Limiting individuals' and families' access to services.
- Confusion and difficulty in navigating the service system.
- Inconsistent care and resources provided to individuals and families.
- Lack of transition planning during specific stages of life.

Strengths and opportunities identified in Nebraska's service system were the foundation for shaping how the Team approached the peer state review process, which included nine peer states. The peer states chosen for this evaluation, in part based on stakeholder feedback included: Colorado, Kansas, Missouri, Ohio, Oklahoma, Pennsylvania, South Dakota, Tennessee, and Wisconsin.

The evaluation focused on the nine peer states' 56 waiver applications (including NF and hospital LOC waivers), Medicaid and non-Medicaid funded services, and policies and practices. Many similarities were found between Nebraska and peer states, including but not limited to: the types of services offered through 1915(c) waivers; use of ICFs/IID; existence of certain Medicaid eligibility flexibilities; and availability of non-Medicaid funded services. However, the Team's

evaluation also identified significant differences between Nebraska and peer states' DD service systems. These distinctions include, but are not limited to the following:

- Allowances for special income level considerations under the Medicaid program.
- Inclusion of ICF/IID and NF LOCs under the Katie Beckett Medicaid-eligibility pathway.
- Payment to guardians for the provision of services under 1915(c) waiver programs.
- Support for competitive and inclusive employment opportunities through Employment and Technology First Initiatives.
- Innovative service options under Medicaid programs including health homes, prepaid inpatient health plans, and managed care for long-term services and supports.

These distinctions impact how individuals and their families access and receive services to support I/DD-related needs. This was confirmed through the stakeholder feedback received as part of this evaluation.

The Team's stakeholder engagement strategy built on the foundation previously established by DDD as part of their development of the Family Support Waiver. The Team met with 116 stakeholders in 14 listening sessions, received 241 responses through an electronic survey, and received 48 stakeholder emails with feedback. Stakeholder feedback collected throughout this evaluation was robust, and included many members of the community, advocates, providers, and State staff. Stakeholders communicated a need for:

- Increased efficiency in eligibility processes, including elimination of DDD's registry.
- A more robust service system supporting individuals with a variety of needs and disabilities.
- Improved cross-system coordination, especially between State entities.
- Transparency and consistency in communication procedures.
- Increased and sustainable funding opportunities.

Stakeholder feedback supported the findings of the Team during the review of Nebraska and peer state DD service systems. Though stakeholders were vocal in their support for the current DDD leadership, their feedback suggests equally strong support for system-wide changes in how services are accessed, delivered, and developed to meet the needs of individuals and families.

Based on the totality of evidence found during reviews of Nebraska's current DD service system, peer state practices, and listening to and learning from stakeholders, the Team has made several recommendations in this report to address systemic barriers and stakeholder concerns. Recommendations informed by the system evaluation process and supported through best practices will serve to enhance the strengths of Nebraska's DD current service system, while mitigating weaknesses that exist.

Importantly, through the implementation of the recommended policy, procedural, organizational, communication, and funding changes, Nebraska will be poised to address many of the stakeholder concerns voiced throughout this evaluation. In addition, implementation of these recommendations in the relative near-term will correspond with Nebraska's new Family Support Waiver. These broad systemic changes will allow Nebraska to improve how individuals and families who are impacted by I/DD-related conditions, live, grow, and thrive in their communities of choice.

Appendices

Appendix I: Mandatory and Optional Medicaid Program Services

Mandatory Services	Optional Services
• Inpatient hospital. • Outpatient hospital. • EPSDT. • NFs. • Home health. • Physician. • Rural health clinics. • Federally-qualified health centers. • Laboratory and X-rays. • Family planning. • Nurse midwives. • Certified pediatrics and family nurse practitioners. • Freestanding birth centers (when licensed or otherwise recognized by the state). • Transportation to medical care. • Tobacco cessation counseling for pregnant women.	• Prescription drugs. • Clinics. • Physical therapy. • Occupational therapy. • Speech, hearing, and language disorder services. • Respiratory care. • Other diagnostic, screening, preventive, and rehabilitative services. • Podiatry. • Optometry. • Dental. • Dentures. • Prosthetics. • Eyeglasses. • Chiropractic services. • Other practitioner services. • Private duty nursing. • Personal care. • Hospice. • Case management. • Services for individuals age 65 or older in an institution for mental disease. • ICFs/IID. • State Plan HCBS (1915(i)). • Self-directed personal assistance services- (1915(j)). • Community First Choice Option (1915(k)). • Inpatient psychiatry services for individuals under age 21. • Other services approved by the Secretary of the United States Department of Health and Human Services. • Health homes for enrollees with chronic conditions.

Appendix II: Available Nebraska Disability Programming and Service Charts

Division of Developmental Disabilities: Services Offered under Current 1915(c) Waivers

Services	AD (1915c)	CDD (1915c)	DDAD (1915c)	TBI (1915c)
Adult Day		X	X	
Adult Day Health Services	X			
Assisted Living Services	X			X
Assistive Technology	X	X	X	
Behavior In-home Habilitation		X		
Child Day Habilitation		X		
Chore	X			
Community Integration		X	X	
Companion	X			
Consultative Assessment		X	X	
Day Supports		X	X	
Environmental Modification Assessment		X	X	
Extra Care for Children with Disabilities	X			
Home Again	X			

Services	AD (1915c)	CDD (1915c)	DDAD (1915c)	TBI (1915c)
Home Modification		X	X	
Home and Vehicle Modifications	X			
Homemaker		X		
Home-Delivered Meals	X			
Independent Living		X	X	
Independence Skills Building	X			
Medicaid Services (includes all services marked with X under the Medicaid Program column)	X	X	X	X
Medical In-Home Habilitation		X		
Non-Medical Transportation	X			
Personal Care	X			
Personal Emergency Response System (PERS)	X	X	X	
Prevocational Services		X	X	
Residential Habilitation		X		
Respite	X	X	X	

Services	AD (1915c)	CDD (1915c)	DDAD (1915c)	TBI (1915c)
Small Group Vocational Support		X	X	
Supported Employment: Follow-Along		X	X	
Supported Employment: Individual		X	X	
Supported Family Living		X	X	
Therapeutic Residential Habilitation		X		
Transitional		X	X	
Transportation		X	X	
Vehicle Modification		X	X	

Division of Medicaid and Long-Term Care: Services Offered under the Medicaid Program

Services	Nebraska Medicaid Program
Adult Psychiatric, SUD, and Medicaid Rehabilitation Option	X
Ambulance Services	X
Chiropractic Services	X
Dental Services	X
Durable Medical Equipment, Orthotics, Prosthetics, and Medical Supplies	X
Family Planning Services	X
EPSDT (Health Check)	X
Hearing Aid Services	X
Home Health Agency Services	X
Hospice Services	X
Hospital Services	X
ICFs/IID	X
Laboratory and Radiology Services	X
Mammograms	X
Medical Transportation Services	X
Mental Health and Substance Abuse Services for Children and Adolescents (ages 0-20)	X
Nurse Midwife Services	X
Nurse Practitioner Services	X
NF Services	X
Physician Services	X
Podiatry Services	X
Prescribed Drugs	X
Private-Duty Nursing Services	X
Services Provided by Clinics	X

Services	Nebraska Medicaid Program
Therapies: Physical, Occupational, Speech Pathology, and Audiology	**X**
Vision Care Services	**X**

Division of Children and Family Services: Services Offered under Children and Family Services Programs, Part 1

Services	Aid to the Aged, Blind, or Disabled	Disabled Children's Program	Disabled Persons and Family Support Program	Genetically Handicapped Persons Program
Accessibility Modifications		X		
Adaptive Equipment			X	
Adult Psychiatric, SUD, and Medicaid Rehabilitation Option			X	
Diagnostic and Consultative Services				X
Disability-Related Counseling or Training			X	
Economic Assistance	X			
Home and Vehicle Modifications			X	
Housekeeping and Essential Shopping			X	
Medical, Surgical, Therapeutic, Diagnostic, and Other Health Services Related to the Disability(ies)			X	
Medicine, Medical Supplies, and Equipment (those not covered by Medicaid)			X	

Services	Aid to the Aged, Blind, or Disabled	Disabled Children's Program	Disabled Persons and Family Support Program	Genetically Handicapped Persons Program
Mental Health and Substance Abuse Services for Children and Adolescents (ages 0-20)			X	
Mileage Reimbursement for Long-distance or Frequent Medical Trips		X	X	
Personal Care			X	
Respite		X		
Specialized Medical Care (Treatment Services)				X

Division of Children and Family Services: Services Offered under Children and Family Services Programs, Part 2

Services	Lifespan Respite	Medically Handicapped Children's Program	Refugee Resettlement	Social Services Aged and Disabled Adults
Adult Day				X
Chore				X
Congregate Meals				X
Diagnostic and Consultative Services		X		
Home and Vehicle Modifications				
Homemaker				X
Home-delivered Meals				X
Private-duty Nursing Services				
Reception and Placement			X	
Respite	X			
Specialized Medical Care (Treatment Services)		X		
Transportation				X

Division of Behavioral Health: Services Offered under Behavioral Health Programs

Services	Mental Health Prescriptions Program (LB95)	Crisis/Emergency Services	Treatment Services (Hospital/Outpatient)	Rehab Services	SUD Services
Prescribed Drugs	X				
24-Hour Crisis Line		X			
Crisis Response		X			
Crisis Stabilization		X			
Emergency Community Support		X			
Emergency Psychiatric Observation		X			
Hospital Diversion		X			
Mental Health Respite (Residential Facility)		X			
Acute Inpatient Hospitalization			X		
Subacute Inpatient Hospitalization			X		
Psychiatric Day Treatment			X		
Intensive Community Services			X		
Behavioral Health Medication Management			X		

Services	Mental Health Prescriptions Program (LB95)	Crisis/Emergency Services	Treatment Services (Hospital/Outpatient)	Rehab Services	SUD Services
Mental Health Assessment			X		
Mental Health Assessment Addendum			X		
Multisystemic Therapy			X		
Outpatient Family Psychotherapy			X		
Outpatient Group Psychotherapy			X		
Outpatient Individual Psychotherapy			X		
Peer Support			X		
Therapeutic Consultation			X		
Assertive Community Treatment				X	
Community Support – Mental Health				X	
Day Rehabilitation: Mental Health				X	
Day Support: Mental Health				X	

Services	Mental Health Prescriptions Program (LB95)	Crisis/Emergency Services	Treatment Services (Hospital/Outpatient)	Rehab Services	SUD Services
Psychiatric Residential Rehabilitation				X	
Recovery Support: Mental Health or Substance Use				X	
Secure Residential Treatment				X	
Supported Employment				X	
SUD Assessment					X
SUD Assessment Addendum					X
ASAM Level 1.1 Community Support					X
ASAM Level 1 Outpatient Family Therapy					X
ASAM Level 1 Outpatient Group Therapy					X
ASAM Level 1 Outpatient Individual Therapy					X

Services	Mental Health Prescriptions Program (LB95)	Crisis/Emergency Services	Treatment Services (Hospital/Outpatient)	Rehab Services	SUD Services
ASAM Level 2.1 Intensive Outpatient					**X**
ASAM Level 3.1 Clinically-managed Low Intensity Residential (Halfway House)					**X**
ASAM Level 3.2WM Clinically-managed Residential Withdrawal Management (Social Detoxification)					**X**
ASAM Level 3.3 Clinically-managed Population Specific High-Intensity Residential (Therapeutic Community Co-Occurring Diagnosis Capable)					**X**
ASAM Level 3.3 Clinically-managed Population Specific					**X**

Services	Mental Health Prescriptions Program (LB95)	Crisis/Emergency Services	Treatment Services (Hospital/Outpatient)	Rehab Services	SUD Services
High-Intensity Residential (Intermediate Residential Co-Occurring Diagnosis Capable)					
ASAM Level 3.5 Clinically-managed High Intensity Residential (Short Term Residential Co-Occurring Diagnosis Capable)					X
ASAM Level 3.5 Clinically-managed High Intensity Residential (Dual Disorder Residential Co-Occurring Diagnosis-Enhanced)					X
ASAM Level 3.7WM Medically-monitored Inpatient					X

Services	Mental Health Prescriptions Program (LB95)	Crisis/Emergency Services	Treatment Services (Hospital/Outpatient)	Rehab Services	SUD Services
Withdrawal Management					
OTP					X

Appendix III: Nebraska Service Definitions

Division of Developmental Disabilities: Definitions of Services Offered under Current 1915(c) Waivers

Service	AD	CDD	DDAD	TBI
Adult Day		Adult day is a non-habilitative service consisting of meaningful day activities which takes place in the community, in a non-residential setting. Adult day provides active supports which foster independence, encompassing both health and social services needed to ensure the optimal functioning of the participant. Adult day includes assistance with ADL, health maintenance, and supervision. Participants receiving adult day services are integrated into the community to the greatest extent possible.	Adult day is a non-habilitative service consisting of meaningful day activities which takes place in the community, in a non-residential setting. Adult day provides active supports which foster independence, encompassing both health and social services needed to ensure the optimal functioning of the participant. Adult day includes assistance with ADL, health maintenance, and supervision. Participants receiving adult day services are integrated into the community to the greatest extent possible.	
Adult Day Health Services	Adult day health services are structured social and health activities provided outside of the participant's home. Providers must offer or make available through arrangements with community agencies or individuals. Each of the services are provided to meet the identified needs in the participant's person-centered plan and plan			

Service	AD	CDD	DDAD	TBI
	specific to adult day health services. The services components include: personal care services, health assessment and nursing services, meal services, recreational therapy, supportive services, and other activities. Transportation is not a component of adult day health and is charged under the transportation service. Physical, occupational, and speech/language therapies are not included as components of adult day health. Meals provided as part of this service do not constitute a full nutritional regimen (i.e., three meals per day). Relatives/guardians who provide adult day health services are either employees of a licensed adult day health agency or are the owner of a licensed adult day health agency.			

Service	AD	CDD	DDAD	TBI
Assisted Living Services	Assisted living services are an array of support services that promote participant self-direction and participation in decisions, which incorporate respect, independence, individuality, privacy, and dignity in a home-like, non-institutional setting. These services include assistance with, or provision of, personal care activities, ADLs, instrumental ADLs, and health maintenance. This includes 24-hour response capability to meet scheduled or unpredictable participant needs and provide supervision, safety, and security.			Assisted living services are provided for participants with a medical diagnosis of a traumatic brain injury in a home-like, non-institutional setting and include personal care and supportive services. This includes 24-hour response capability to meet scheduled or unpredictable participant needs and provide supervision, safety, and security. The following services are available to the participant: medication administration, transportation, escort services, activities, essential shopping, housekeeping services, laundry services, and personal care services.
Assistive Technology	Assistive technology includes the purchase or rent of items, devices, or product systems to increase or maintain a person's functional status. This service includes designing, fitting, adapting, and maintaining equipment, as well as training or technical assistance to use equipment. This service also includes the assessments needed to identify the type of assistive	Assistive technology is equipment or a product system such as devices, controls, or appliances, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of participants and necessary to ensure participants' health, welfare, and safety. The use of assistive technology enables participants who reside in their own	Assistive technology is equipment or a product system such as devices, controls, or appliances, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of participants and necessary to ensure participants' health, welfare, and safety. The use of assistive technology enables participants who reside in their own	

Service	AD	CDD	DDAD	TBI
	technology necessary to aid the waiver participant.	homes to increase their abilities to perform ADLs in their home or to perceive, control, or communicate with the environment they live in, thereby decreasing their need for assistance from others as a result of limitations due to disability.	homes to increase their abilities to perform ADLs in their home or to perceive, control, or communicate with the environment they live in, thereby decreasing their need for assistance from others as a result of limitations due to disability.	
Behavior In-home Habilitation		Behavioral in-home habilitation is a short-term habilitative service provided to waiver participants who have a chronic or severe mental health condition that prevents them from fully participating in community activities or employment opportunities. Behavioral in-home habilitation is provided to participants who may be experiencing episodic or cyclical behaviors, or who may have been prescribed a medication or dosage for which correct dosage and reaction is unknown. Behavioral in-home habilitation is provided to participants who are unable to remain alone during the hours that they would otherwise be away from their residence.		

Service	AD	CDD	DDAD	TBI
Child Day Habilitation		Child day habilitation is a habilitative service that provides teaching and staff supports to meet the age-appropriate needs of a child due to a disability or special health conditions. Child day habilitation takes place in the community, separate from the participant’s private family residence, in a provider setting approved, registered, or licensed by DHHS. Participants receiving child day habilitation must be integrated into the community to the greatest extent possible.		
Chore	Chore activities occur less frequently than services identified under the companion service but assist in ensuring the health and safety of the participant in their own home. Types of assistance furnished may include housekeeping activities, such as in-home cleaning and care of household equipment, appliances, or furnishings; minor repairs of windows, screens, steps or ramps, furnishings, and household equipment; and landscaping.			

Service	AD	CDD	DDAD	TBI
	Landscaping includes snow and ice removal, mowing, raking, removing trash (to garbage pickup point), pest remediation, and clearing water of drains may also be provided.			
Community Integration		Community integration is a habilitative service that provides formalized teaching, person-centered activities, and staff supports for the acquisition, retention, or improvement in self-help, behavioral skills, and adaptive skills that enhance social development. Habilitative activities are designed to foster greater independence, community networking, and personal choice. Community integration provides an opportunity for the participant to practice skills taught in therapies, counseling sessions, or other settings to plan and participate in regularly-scheduled community activities. Community integration includes supports furnished in the community. A participant can choose to receive a portion of this service virtually. Community	Community integration is a habilitative service that provides formalized teaching, person-centered activities, and staff supports for the acquisition, retention, or improvement in self-help, behavioral skills, and adaptive skills that enhance social development. Habilitative activities are designed to foster greater independence, community networking, and personal choice. Community integration provides an opportunity for the participant to practice skills taught in therapies, counseling sessions, or other settings to plan and participate in regularly-scheduled community activities. Community integration includes supports furnished in the community. A participant can choose to receive a portion of this service virtually. Community	

Service	AD	CDD	DDAD	TBI
		integration includes assistance with ADLs, health maintenance, and supervision.	Integration includes assistance with ADLs, health maintenance, and supervision.	
Companion	Companion is a service for adults ages 18 and older in which supervision and/or social supports are provided in a person's home and possibly other community settings. This service may include light housekeeping tasks, as well as bill paying, errand service, essential shopping, food preparation, and laundry service.			
Consultative Assessment		Consultative assessment is provided when a behavior support plan is developed and implemented to assist participants in maintaining their current living environment, while ensuring their safety and the safety of others. Consultative assessment is necessary to improve the participant's independence and inclusion in their community. Consultative assessment activities may include team consultation, behavioral assessment, behavior support plan development, and implementation.	Consultative assessment is provided when a behavior support plan is developed and implemented to assist participants in maintaining their current living environment, while ensuring their safety and the safety of others. Consultative assessment is necessary to improve the participant's independence and inclusion in their community. Consultative assessment activities may include team consultation, behavioral assessment, behavior support plan development, and implementation.	

Service	AD	CDD	DDAD	TBI
Day Supports		Day supports is a service that offers habilitative activities in a provider-owned or controlled non-residential setting, when not delivered virtually. Day supports provide person-centered activities, formalized training, and staff supports for the acquisition, retention, or improvement in self-help, behavioral skills, and adaptive skills that enhance social development. Day supports activities assist in developing skills in performing ADLs and community living. Activities and environments are designed to foster the acquisition of skills, building positive social behavior and interpersonal competence, greater independence, and personal choice. This service is provided to participants that do not have a specific employment goal and are, therefore, not currently seeking to join the general workforce.	Day supports is a service that offers habilitative activities in a provider-owned or controlled non-residential setting, when not delivered virtually. Day supports provide person-centered activities, formalized training, and staff supports for the acquisition, retention, or improvement in self-help, behavioral skills, and adaptive skills that enhance social development. Day supports activities assist in developing skills in performing ADLs, and community living. Activities and environments are designed to foster the acquisition of skills, building positive social behavior and interpersonal competence, greater independence, and personal choice. This service is provided to participants that do not have a specific employment goal and are, therefore, not currently seeking to join the general workforce.	
Environmental Modification Assessment		An environmental modification assessment is a functional evaluation with the participant to ensure the health, welfare, and	An environmental modification assessment is a functional evaluation with the participant to ensure the health, welfare, and	

Service	AD	CDD	DDAD	TBI
		safety of the participant or to enable the participant to integrate more fully into the community and function in the participant's private home (not provider-owned or leased, operated, or controlled), or in the participant's family's home, when living with their family.	safety of the participant or to enable the participant to integrate more fully into the community and function in the participant's private home (not provider-owned or leased, operated, or controlled), or in the participant's family's home, when living with their family.	
Extra Care for Children with Disabilities	Extra care for children with disabilities is the portion of childcare provided to children related to their medical and disability-related needs. Extra care for children with disabilities is provided to children from birth through age 17, on the average of less than 12 hours per day, but more than two hours per week on a regular basis, in lieu of caregiver supervision. Care is provided in a child's home by an approved provider or in a setting approved or licensed by DHHS. The parent or primary caregiver is responsible for the basic cost of routine childcare. Payment of the service above the basic cost of routine childcare is covered in accordance with the person-centered plan.			

Service	AD	CDD	DDAD	TBI
Home Again	Home again is available to support and enable Medicaid-eligible, NF residents to move to a more independent living situation of their choice. To receive this service, a person aged 18 or older must be a current NF resident whose nursing facility services have been paid by Medicaid for at least three months. Persons whose NF stay is rehabilitative are not eligible for this service.			
Home Modification		Home modifications are physical adaptations to the participant's private home or to the family's home when living with their family. Home modifications are necessary to ensure the health, welfare, and safety of the participant or to enable the participant to function with greater independence in their own participant-directed private home or in the family's home, thereby decreasing their need for assistance from paid and natural supports because of limitations due to disability.	Home modifications are physical adaptations to the participant's private home or to the family's home when living with their family. Home modifications are necessary to ensure the health, welfare, and safety of the participant or to enable the participant to function with greater independence in their own participant-directed private home or in the family's home, thereby decreasing their need for assistance from paid and natural supports because of limitations due to disability.	
Home and Vehicle Modifications	Home and vehicle modifications are physical changes to a private			

Service	AD	CDD	DDAD	TBI
	residence, automobile, or van to accommodate the participant or improve his or her function.			
Homemaker		Homemaker service is the performance of the general household activities, such as meal preparation, laundry services, errands, and routine household care, when the participant regularly responsible for these activities is temporarily absent or unable to manage the home and care for him/herself or others in the home. This service does not include direct care or supervision.		
Home-Delivered Meals	Home-delivered meals is a service for adults, ages 18 and older, which provides a meal prepared outside the participant's home and is delivered to their home. Home-delivered meal providers that meet the definition of a food establishment in Nebraska Revised Statutes 81-2,257.01 must follow regulations and procedures outlined in the above statute, also known as the Nebraska Food Code. A "food establishment" is defined as an operation that stores,			

Service	AD	CDD	DDAD	TBI
	prepares, packages, serves, sells, vends, or otherwise provides food for human consumption. It does not include health care facilities (in which assisted living facilities are classified) or nursing facilities. Such facilities are directed by their licensing regulations for food preparation and safety.			
Independent Living		Independent living is provided to the participant in their private home and the community, not a provider-owned or leased, operated, or controlled residence. A participant can choose to receive a portion of this service virtually. The participant lives alone or with housemates and is responsible for rent, utilities, and food.	Independent living is provided to the participant in their private home and the community, not a provider-owned or leased, operated, or controlled residence. A participant can choose to receive a portion of this service virtually. The participant lives alone or with housemates and is responsible for rent, utilities, and food.	
Independence Skills Building	Independence skills building is training in instrumental ADLs and home management to increase independence. It may be provided to the participant and/or to a primary caregiver to promote independence of the participant. Training may occur in the participant’s home or in the community and may be provided			

Service	AD	CDD	DDAD	TBI
	individually or in a group setting. This service differs from chore because it involves training the participant or caregiver, not the actual provision of completing the ADLs or instrumental ADLs			
Medical In-Home Habilitation		Medical in-home habilitation is a short-term habilitative service provided to waiver participants who have a chronic or severe medical condition that prevents them from fully participating in community activities or employment opportunities, or have recently been hospitalized and are continuing to recover in their residence, and their medical needs prevent them from participating in community activities or employment opportunities. medical in-home habilitation is provided to participants who are unable to remain alone during the hours that they would otherwise be away from their residence.		
Non-Medical Transportation	Non-medical transportation is provided to enable a participant to gain access to waiver and other community services and resources			

Service	AD	CDD	DDAD	TBI
	as outlined in the person-centered plan. This service may include accompanying a participant who is unable to travel and wait alone.			
Personal Care	Personal care is a service for adults, ages 18 and older, which includes assistance with ADLs and/or health-related tasks and may include instrumental ADLs provided in a person's home and other community settings.			
PERS	PERS is an electronic device that enables a participant, ages 19 years or older, to secure help in an emergency. The participant may also wear a portable "help" button to allow for mobility. The system is connected to the participant's phone and programmed to signal a response center once a help button is activated. The response center has trained professionals to respond timely when the button is activated. The service includes installation, upkeep, and maintenance of the PERS device.	PERS is an electronic device that enables participants to secure help in an emergency. The participant may also wear a portable PERS button to allow for mobility. The system is connected to the participant's telephone and programmed to signal a response center once a PERS button is activated.	PERS is an electronic device that enables participants to secure help in an emergency. The participant may also wear a portable PERS button to allow for mobility. The system is connected to the participant's telephone and programmed to signal a response center once a PERS button is activated.	
Prevocational		Prevocational is a habilitative service that focuses on teaching the participant to develop general, non-	Prevocational is a habilitative service that focuses on teaching the participant to develop general, non-	

Service	AD	CDD	DDAD	TBI
		job, task-specific skills, which will contribute to future competitive, integrated employment. Services may be furnished in a variety of locations with the majority of the service provided in the community. When delivered in provider-controlled settings where other waiver services are offered, staff providing prevocational cannot provide any other waiver service at the same time. A participant can choose to receive a portion of this service virtually. This service also includes the provision of personal care, activities related to health maintenance, and supervision.	job, task-specific skills, which will contribute to future competitive, integrated employment. Services may be furnished in a variety of locations with the majority of the service provided in the community. When delivered in provider-controlled settings where other waiver services are offered, staff providing prevocational cannot provide any other waiver service at the same time. A participant can choose to receive a portion of this service virtually. This service also includes the provision of personal care, activities related to health maintenance, and supervision.	
Residential Habilitation		Residential habilitation is a habilitative service with three service-delivery options: continuous home, host home, or shared living. Participants may only choose one option. Continuous home is delivered in a provider-owned or leased, operated, or controlled residential setting and provided by agency provider shift-staff not living in the setting. Continuous home consists of individually tailored,		

Service	AD	CDD	DDAD	TBI
		continuous supports to assist with the acquisition, retention, or improvement of skills not yet mastered, which will lead to more independence for the participant to reside in the most integrated setting appropriate to their needs. Host home is delivered in a private home, owned or leased as the sole residence by an individual, couple, or a family chosen by the participant, and who is an employee of the provider agency authorized to provide the service. The host home employee and the participant live together in the host home and the participant shares daily life with the host home family in their home and community. Shared living is delivered in a private home, owned or leased by an individual, couple, or a family chosen by the participant, and who is an independent contractor of the provider agency authorized to deliver direct services and supports. The shared living contractor and the participant live together in the sole residence, and the participant		

Service	AD	CDD	DDAD	TBI
		shares daily life with the shared living family in their home and community.		
Respite	Respite care is temporary care of an aged adult, adult, or child with disabilities to relieve the usual caregiver from continuous support and care responsibilities. Respite care may be provided in or out of the participant's home. Out of home respite care may be provided in the following locations: private residence of a respite service provider, licensed assisted living facility, licensed respite facility, licensed or approved childcare home or center, or other community settings.	Respite is a non-habilitative service provided to participants unable to care for themselves and is furnished on a short-term, temporary basis for relief to the usual, unpaid caregiver(s) living in the same private residence as the participant. Respite includes assistance with ADLs, health maintenance, and supervision. Respite may be provided in the caregiver's home, the provider's home, or in community settings.	Respite is a non-habilitative service provided to participants unable to care for themselves and is furnished on a short-term, temporary basis for relief to the usual, unpaid caregiver(s) living in the same private residence as the participant. Respite includes assistance with ADLs, health maintenance, and supervision. Respite may be provided in the caregiver's home, the provider's home, or in community settings.	
Small Group Vocational Support		Small group vocational support is a habilitative service provided in community, business, or industry settings for single participants or small groups of participants. Generally, participants are a member of a team at a single competitive employment site in a community business or industry, or a mobile crew. Habilitative teaching, supervision, and ongoing	Small group vocational support is a habilitative service provided in community, business, or industry settings for single participants or small groups of participants. Generally, participants are a member of a team at a single competitive employment site in a community business or industry, or a mobile crew. Habilitative teaching, supervision, and ongoing	

Service	AD	CDD	DDAD	TBI
		supports are provided by a specially-trained, on-site supervisor who is an employee of the DD agency provider.	supports are provided by a specially-trained, on-site supervisor who is an employee of the DD agency provider.	
Supported Employment - Follow-Along		Supported employment – follow-along is one-to-one, formalized intermittent teaching and supports to enable a participant who is paid at, or above the federal minimum wage, to maintain employment in an integrated community employment setting. Intermittent support may be provided on-site, remotely, and through phone calls between provider staff and the participant's employer staff, followed up with face-to-face contact with the participant to reinforce and stabilize job placement. Services must be furnished consistent with the participant's service plan.	Supported employment – follow-along is one-to-one, formalized intermittent teaching and supports to enable a participant who is paid at, or above the federal minimum wage, to maintain employment in an integrated community employment setting. Intermittent support may be provided on-site, remotely, and through phone calls between provider staff and the participant's employer staff, followed up with face-to-face contact with the participant to reinforce and stabilize job placement. Services must be furnished consistent with the participant's service plan.	
Supported Employment - Individual		Supported employment – individual is one-to-one, formalized teaching and staff supports available to a participant, who because of their disability, needs intensive, sometimes ongoing, support to maintain an individual job in	Supported employment – individual is one-to-one, formalized teaching and staff supports available to a participant, who because of their disability, needs intensive, sometimes ongoing, support to maintain an individual job in	

Service	AD	CDD	DDAD	TBI
		competitive or customized employment or self-employment in an integrated work setting in the general workforce. A participant is compensated at or above the minimum wage, but not less than the customary wage and level of benefits paid by the employer for the same or similar work performed by a person without a disability. Support may be utilized for referring the participant to an employment network, Ticket to Work services, Work Incentive Planning and Assistance services, or other qualified employment service programs, which provide benefits planning. A participant can choose to receive a portion of this service virtually. The outcome of this service is sustained paid employment, which meets personal and career goals, in an integrated setting in the general workforce, particularly work sites where persons without disabilities are employed.	competitive or customized employment or self-employment in an integrated work setting in the general workforce. A participant is compensated at or above the minimum wage, but not less than the customary wage and level of benefits paid by the employer for the same or similar work performed by a person without a disability. Support may be utilized for referring the participant to an employment network, Ticket to Work services, Work Incentive Planning and Assistance services, or other qualified employment service programs, which provide benefits planning. A participant can choose to receive a portion of this service virtually. The outcome of this service is sustained paid employment, which meets personal and career goals, in an integrated setting in the general workforce, particularly work sites where persons without disabilities are employed.	
Supported Family Living		Supported family living is provided to the participant in the	Supported family living is provided to the participant in the	

Service	AD	CDD	DDAD	TBI
		participant's private family home, not in a provider-owned or leased, operated, or controlled setting. A participant can choose to receive a portion of this service virtually. The participant lives with relatives in their private family home.	participant's private family home, not in a provider-owned or leased, operated, or controlled setting. A participant can choose to receive a portion of this service virtually. The participant lives with relatives in their private family home.	
Therapeutic Residential Habilitation		Therapeutic residential habilitation is a continuous, all-inclusive habilitative service designed specifically for participants living with co-occurring disorders of DD with severe mental illness. The intent of therapeutic residential habilitation is to assist participants in gaining the life skills needed to transition to the least-restrictive settings and services in the community.		
Transitional		Transitional services are services and household set-up expenses, not otherwise provided through this waiver or through the Medicaid State Plan, to enable a participant to have opportunities for full membership in home and community-based services.	Transitional services are services and household set-up expenses, not otherwise provided through this waiver or through the Medicaid State Plan, to enable a participant to have opportunities for full membership in home and community-based services.	
Transportation		Transportation is a service designed to foster greater independence and	Transportation is a service designed to foster greater independence and	

Service	AD	CDD	DDAD	TBI
		personal choice. Transportation enables participants to gain access to waiver services, community activities, and resources as specified by the participant's service plan. Transportation services are not intended to replace formal or informal transportation options, like the use of natural supports.	personal choice. Transportation enables participants to gain access to waiver services, community activities, and resources as specified by the participant's service plan. Transportation services are not intended to replace formal or informal transportation options, like the use of natural supports.	
Vehicle Modification		Vehicle modifications are adaptations or alterations to an automobile or van that is the participant's primary means of transportation, to accommodate the special needs of the participant. Vehicle modifications are specified by the service plan, as necessary, to enable the participant to integrate more fully into the community and ensure the health, welfare, and safety of the participant.	Vehicle modifications are adaptations or alterations to an automobile or van that is the participant's primary means of transportation, to accommodate the special needs of the participant. Vehicle modifications are specified by the service plan, as necessary, to enable the participant to integrate more fully into the community and ensure the health, welfare, and safety of the participant.	

Division of Medicaid and Long-Term Care: Definition of Services Offered under the Medicaid Program

Service	Service Definition
Adult Psychiatric, SUD, and Medicaid Rehabilitation Option	Nebraska Medicaid covers medically-necessary psychiatric and SUD services for medically-necessary, primary psychiatric and/or SUD diagnoses for individuals, ages 21 and older, including outpatient services, day treatment, SUD treatment, and hospital services.
Ambulance Services	Nebraska Medicaid covers ambulance services for certain conditions. The service must be required during an emergency or required to obtain medical care.
Chiropractic Services	Nebraska Medicaid limits coverage of chiropractic services to the following: certain spinal x-rays, manual manipulation of the spine, certain evaluation and management services, traction, electrical stimulation, ultrasound, and certain therapeutic procedures, activities, and techniques designed and implemented to improve, develop, or maintain the function of the area treated.
Dental Services	Nebraska Medicaid covers dental services such as cleaning of teeth, fillings, extractions, x-rays, dental surgery, and dental disease control. Some services require prior authorization.
Durable Medical Equipment, Orthotics, Prosthetics, and Medical Supplies	Nebraska Medicaid covers certain medical equipment and supplies when they are medically necessary and prescribed by a physician.
Family Planning Services	Nebraska Medicaid covers family planning services, including consultation and procedures. This may include initial physical examinations and health history, annual and follow-up visits, laboratory services, prescribing and supplying contraceptive supplies and devices, counseling services, and prescribing medication for specific treatment.
EPSDT, Health Check	Health Check is a service available to all individuals, ages 20 or younger, who are eligible for Medicaid. Health Check provides complete check-ups on a regular basis and diagnosis and treatment services for any health problems found at a check-up. Some treatment services provided as a result of a Health Check examination require the provider to obtain approval from Medicaid before providing the service.
Hearing Aid Services	Nebraska Medicaid covers hearing aids, hearing aid repairs, necessary batteries, and supplies. There are limits on hearing aid services.
Home Health Agency Services	Nebraska Medicaid covers home health agency services when prescribed by a physician or advanced practice nurse practitioner and provided wherever they are necessary. The physician or advanced practice nurse practitioner must certify the services are medically necessary and appropriate to be

Service	Service Definition
	provided in the home. Covered services include nursing services, aide services, necessary medical supplies and equipment, and physical, speech, and occupational therapies if there is no other way to receive these services. There are limits on some services.
Hospice Services	Nebraska Medicaid covers hospice services provided in response to palliative management of a terminal illness. Hospice services include nursing services, physician services, medical social services, counseling services, home health aide/homemaker, medical equipment, medical supplies, drugs and biologicals, physical therapy, occupational therapy, and speech language pathology. Hospice services require prior authorization by Medicaid.
Hospital Services	Medicaid covers medically-necessary inpatient, outpatient, and emergency room services. Medicaid will not cover items such as private rooms, private-duty nursing while in the hospital, and emergency room services for routine treatment.
ICFs/IID	Nebraska Medicaid covers ICFs/IID services for individuals with developmental/intellectual disabilities or a related condition. ICF/IID services are designed to serve individuals who cannot be served in the community through DD Services. ICF/IID services provide diagnosis and active treatment to support individuals to achieve their independence potential. Services include training in all aspects of daily living, social behavior, pre-vocational training, nursing care to the same degree as a NF, physical, occupational, and speech therapies.
Laboratory and Radiology Services	Payment may be made for medically-necessary diagnostic tests, x-rays, and other procedures that are part of a patient's diagnosis or treatment.
Mammograms	Nebraska Medicaid covers mammograms when based on a medically-necessary diagnosis. In the absence of a diagnosis, Nebraska Medicaid covers mammograms according to the American Cancer Society's periodicity schedule.
Medical Transportation Services	Nebraska Medicaid covers transportation for trips, necessary to obtain medical treatment or medical care, when the client has no other transportation. Medicaid may cover transportation services for a parent/caretaker/attendant to escort someone to and from medical treatment or medical care when necessary. Medicaid may also cover travel to a pharmacy.
Mental Health and Substance Abuse Services for Children and Adolescents (ages 0-20)	Nebraska Medicaid covers mental health and substance abuse services for children and adolescents, including outpatient services, middle intensity services, day treatment, and hospital services.
Nurse Midwife Services	Nebraska Medicaid covers nurse midwife services that are medically necessary and provided in accordance with the practice as defined by law. Nebraska Medicaid covers prenatal care, delivery, and post-partum care services.

Service	Service Definition
Nurse Practitioner Services	Nebraska Medicaid covers nurse practitioner services in accordance with the scope of practice applicable to their specific licensure designation. The services must be medically necessary. A nurse practitioner may provide services within the specialty areas in which they hold certification.
NF Services	Nebraska Medicaid covers services provided in nursing facilities, ICFs/IID, and certain other long-term care living arrangements. Services that a NF must provide include: • Regular room. • Dietary services. • Nursing services. • Social services, when required. • Most medical supplies and equipment. • Oxygen. • Other routine services. To receive Medicaid-covered nursing facility care, a patient must meet NF LOC criteria and have a pre-admission screening and resident review.
Physician Services	Medicaid covers medically-necessary physicians' services performed within program guidelines. Medicaid will not cover services such as: acupuncture treatment, reversal of sterilization, sex change procedures, or drugs or items prescribed or recommended for weight control and/or appetite suppression. Services that have special requirements, limitations, and/or require approval from the Medicaid program include: • Medical transplants. • Cosmetic surgery. • Sterilizations and hysterectomies. • Abortions.
Podiatry Services	Nebraska Medicaid covers medical and surgical services provided by a podiatrist, in the podiatrist's office, the client's home, a clinic, hospital, or other location.
Prescribed Drugs	Nebraska Medicaid covers most drugs prescribed by the client's physician. Some over-the-counter drugs may be covered if prescribed by the physician and approved by Medicaid. There are several drugs Medicaid does not cover.
Private-Duty Nursing Services	Nebraska Medicaid covers medically-necessary private-duty nursing services when ordered by the client's physician or advanced practice nurse practitioner. Private-duty nursing services may be provided in the client's home or some other living arrangement outside of a hospital or NF. Prior authorization is required for these services.

Service	Service Definition
Services Provided by Clinics	Nebraska Medicaid covers services provided by clinics, including rural health clinics, federally qualified health centers, community mental health centers, and Indian Health Services clinics if they participate in the Medicaid program.
Therapies: Physical, Occupational, Speech Pathology, and Audiology	Nebraska Medicaid covers speech, physical, and occupational therapies in the office, in the client's home, hospital, NFs, or other facilities. The services must be prescribed by a physician. Therapy is limited to restoration of lost function due to illness or injury for patients, ages 20 and older. Medicaid will cover up to 60 combined visits per year.
Vision Care Services	Nebraska Medicaid covers medically-necessary and appropriate visual care services within program guidelines. Examination, diagnosis, and treatment services are also allowable to diagnose or treat a specific eye illness, symptom, complaint, or injury. Medicaid covers eyeglasses, including lenses and frames, when coverage criteria is met. Eye exams for adults, ages 21 years and older, are limited to once every 24 months. Eye exams for recipients, ages 20 and younger, are limited to once every 12 months. More frequent eye examinations will be covered when medically necessary.

Division of Children and Family Services: Definition of Services Offered under Children and Family Services Programs

Service	Aid to the Aged, Blind, or Disabled
Economic Assistance	Programs promote wellbeing and provide support to achieve self-sufficiency of families, children, individuals, elderly, and persons with disabilities by providing medical, nutritional, and financial services.

Service	Disabled Children's Program
Accessibility Modifications	Special equipment and accessibility modifications are covered services based on the needs of each recipient, available funds, and individual service plans. The maximum dollar amount is $3,600 per recipient's family, per 12-month period. Medical necessity must be documented by a health care professional.
Mileage Reimbursement for Long-Distance or Frequent Medical Trips	Medical mileage reimbursement is a covered service for families who transport recipients to disability-related medical care or treatment. Mileage for routine, general health care is not a covered service. The reimbursement rate for medical mileage follows the annual Internal Revenue Service standard mileage rate per mile driven for medical purposes.
Respite	Respite care is a covered service to provide caregivers a short break from taking care of the recipient with special health care needs. The Department determines the maximum dollar amount of respite care for each recipient based on the needs of the family and available funds, not to exceed $125 per month, which is then included in the individual service plan. Respite care may not be used as childcare when a caregiver is working or going to school.

Service	Genetically Handicapped Persons Program
Diagnostic and Consultative Services	These services may include assistance with locating offices of participating specialists, hospitals, or specialty clinics.
Specialized Medical Care (Treatment Services)	Specialized medical care is covered, according to the diagnosis of each service component, for eligible recipients, ages 21 years and older. The medical care must be outlined in the individual medical treatment plan that is developed and signed by a health care professional. The specialized medical care must be directly related to the medically-eligible diagnosis. Routine, general health care is not a covered service. Funds are used to pay for costs of

Service	Genetically Handicapped Persons Program
	prior authorized, specialized medical treatment related to the eligible diagnosis(es). Treatment must be in accordance with the individual treatment plan.

Service	Lifespan Respite
Respite	Respite is a service designed to give caregivers a break from the demands of providing ongoing care for recipients with special needs, unable to care for themselves, without regard to age, type of special needs, or other status.

Service	Medically Handicapped Children's Program
Diagnostic and Consultative Services	These services may include assistance with locating offices of participating specialists, hospitals, or specialty clinics.
Specialized Medical Care (Treatment Services)	Specialized medical care is covered, according to each diagnoses' service components for eligible recipients. The medical care must be outlined in the individual medical treatment plan that is developed and signed by a health care professional. The specialized medical care must be directly related to the medically-eligible diagnosis. Routine, general health care is not a covered service. Funds are used to pay for costs of prior authorized, specialized medical treatment related to the eligible diagnosis(es). Treatment must be in accordance with the individual treatment plan.

Service	Refugee Resettlement
Reception and Placement	Case managers who help the refugee and/or refugee family locate safe, affordable housing, complete the required medical screenings and vaccinations, enroll in schools, and provide community and cultural orientation, and employment services.

Service	Social Services Aged and Disabled Adults
Chore	Chore services are provided to individuals who are unable to complete household or personal care tasks due to ailments. Chore services can be authorized to assist with light housekeeping, essential shopping, food preparation, laundry services, or personal care.

Service	Social Services Aged and Disabled Adults
Adult Day	Adult day care is authorized to provide a structured, monitored, and social environment that assists in providing manual, physical, and intellectual services for individuals. Adult day is provided for a minimum of three hours per day in a supervised, ambulatory setting, either in a day center or within a home.
Home-Delivered Meals	Delivered meals are provided to individuals who are unable to prepare balanced meals for themselves due to ailments. Meals are delivered to the client's residence typically during the noon hour.
Congregate Meals	Congregate meals are provided to individuals who are unable to prepare balanced meals for themselves due to ailments. Congregate meals are provided at an approved location and offer the individual a warm meal, as well as socialization.
Homemaker Services	Homemaker services are authorized to provide in-home, instructional-based services to eligible clients.
Transportation	Transportation services are authorized to provide non-medical and medical transportation for clients to and from community resources.

Division of Behavioral Health: Definition of Services Offered under Behavioral Health Services Programs

Service	Mental Health Prescriptions Program (LB95)
Prescribed Drugs	A person may be able to receive some medications at low or no cost through a state program to support his or her recovery. LB95 only provides medications prescribed by the participant's treating provider, as necessary, for his or her mental health treatment. A maximum of a 30-day supply will be allowed for any medications. Prescriptions are limited to a maximum of five refills, with exceptions made for Clozapine. Prescriptions are valid for six months for controlled substances and one year for all others.

Service	Crisis/Emergency Services
24-Hour Crisis Line	The 24-hour crisis line must be answered by a live voice 24 hours a day, seven days a week, and have the ability to link to a licensed behavioral health professional, law enforcement, and other emergency services. The 24-hour crisis line is designed to assist callers in pre-crisis or crisis situations related to a behavioral health problem. The desired outcome is ensuring the safety of the consumer in a time of distress that has the potential to lead to a life-threatening situation.
Crisis Response	Crisis response is designed to use natural supports and resources to resolve an immediate mental health or substance use crisis in the least-restrictive environment by creating a plan with the individual to resolve the crisis. The goal of the service is to develop and begin implementation of a crisis-intervention plan, ensure safety, and access the necessary LOC.
Crisis Stabilization	Crisis stabilization provides immediate, short-term, individualized, crisis-oriented treatment to stabilize acute psychiatric symptoms, alcohol, or other drug use, and/or significant emotional distress for voluntary and involuntarily admitted individuals. The psychiatric and/or substance use disorder crisis results in potentially disruptive or dangerous behaviors and impaired functioning that needs a short-term, stabilizing, structured environment. The service treats and supports the individual throughout the crisis by providing crisis assessment and interventions, medication management, linkages to needed behavioral health services, and assistance in transitioning back to the individual's typical living situation.
Emergency Community Support	Emergency community support is designed to assist individuals who can benefit from high levels of support due to an urgent behavioral health need. Often individuals are either at risk of loss of community residence due to behavioral health crisis, homeless, or transitioning from a psychiatric hospital into a community setting. Emergency community support services offer stabilization during a behavioral health crisis by providing case management, behavioral health referrals, assistance with daily living skills, and coordination between the individual, the formal and informal support system, and behavioral health providers.
Emergency Psychiatric Observation	Emergency psychiatric observation provides less than 24 hours of care in a secure, medically-supervised hospital setting for evaluation and stabilization of acute psychiatric and/or SUD symptoms. The service will prevent further exacerbation or deterioration and/or inpatient hospitalization when possible, and facilitates transition to the necessary LOC.

Service	Crisis/Emergency Services
Hospital Diversion	Hospital diversion is a peer-operated service designed to assist individuals in decreasing psychiatric distress which may lead to hospitalization. Hospital diversion offers individuals the opportunity to take control of a crisis, or potential crisis, and develop new skills through a variety of traditional self-help and proactive tools designed to maintain wellness. Certified Peer-Support Specialists provide contact, support, and/or referral for services, as requested, during and after the stay, as well as manning a warm line. Hospital diversion settings are fully furnished for comfort. Participation in the service is voluntary.
Mental Health Respite (Residential Facility)	Mental health respite is a short-term program designed to provide shelter and assistance to address immediate needs for individuals transitioning between residential settings or who benefit from a break from the current home or residential setting. Mental health respite provides a safe, protected, supported residential environment for people with a serious mental illness. The service supports an individual throughout the transition or break, provides linkages to needed behavioral health services, and assists in timely transition back into the community.

Service	Treatment Services (Hospital/Outpatient)
Acute Inpatient Hospitalization	An acute inpatient program is designed to provide medically-necessary intensive assessment, psychiatric treatment, and support to individuals who have a Diagnostic and Statistical Manual of Mental Disorders (current version) diagnosis and/or co-occurring disorder and are experiencing an acute exacerbation of a psychiatric condition. Using comprehensive medical, nursing, and multidisciplinary treatment, the acute inpatient setting provides highly structured care to serve patients requiring a safe and secured setting. The acute inpatient setting provides continuous care using multiple treatment modalities to stabilize the individual's acute psychiatric conditions.
Subacute Inpatient Hospitalization	The purpose of subacute care is to provide stabilization, support, engage the individual in comprehensive treatment, rehabilitation and recovery activities, and transition the individual to the least-restrictive safe setting as rapidly as possible. Subacute inpatient hospitalization is designed to resolve the presence of acute or crisis mental health symptoms, or the imminent risk of onset of acute or crisis mental health symptoms, for individuals experiencing a decreased level of functioning due to a mental health condition. The subacute treatment setting provides 24/7 care in a protective environment that is intended to be short-term, intensive, individualized, and recovery-oriented.
Psychiatric Day Treatment	Psychiatric day treatment provides a community-based, intensive, and coordinated set of individualized treatment services to individuals with psychiatric disorders who have difficulty functioning full-time in a school, work, and/or home environment and need the additional structured activities of this LOC. This service includes diagnostic, medical, psychiatric, psychosocial, and adjunctive treatment modalities in a highly structured setting.
Intensive Community Services	Intensive community services are designed to promote independent and community living skills and prevent the need for a higher LOC. Services are designed for individuals with serious mental illness, including those with co-occurring disorders who experience frequent and debilitating symptoms, resulting in high rates of use of acute and other intensive LOCs.

Service	Treatment Services (Hospital/Outpatient)
Behavioral Health Medication Management	Medication management is the evaluation of the individual's need for psychotropic medications, provision of a prescription, and ongoing medical monitoring of those medications.
Mental Health Assessment	A mental health assessment is a comprehensive biopsychosocial, strengths-based assessment of an individual experiencing mental health and/or co-occurring symptoms. It must be completed prior to the initiation of any non-emergent mental health treatment or rehabilitative service. The mental health assessment is a process of gathering information to assess functioning, determine if the symptoms meet the diagnostic criteria for a mental health or co-occurring disorder, and identify treatment needs. The purpose is to rule in or rule out one or more behavioral health disorders.
Mental Health Assessment Addendum	The purpose of the addendum is to clarify/update the diagnosis, treatment needs, and recommendations and/or gather information that covers the timeframe when an individual was not receiving treatment.
Multisystemic Therapy	Multisystemic Therapy is an evidence-based, intensive treatment process that focuses on diagnosed behavioral health disorders and environmental systems (family, school, peer groups, culture, neighborhood, and community) that contribute to, or influence, an individual's involvement, or potential involvement, in the juvenile justice system. The target age range is youth, 12-17, but youth of other ages can receive the service if medically necessary. The therapeutic modality uses family strengths to promote positive coping activities, works with the caregivers to reinforce positive behaviors, reduce negative behavior, and helps the family increase accountability and problem solving. Families accepting Multisystemic Therapy receive assessment and home-based treatment that strives to change how the individuals, who are at risk of out-of-home placement or who are returning home from an out of home placement, function in their natural settings to promote positive social behavior while decreasing anti-social behavior.
Outpatient Family Psychotherapy	Outpatient family psychotherapy uses therapeutic principles, structures, and techniques to examine family patterns, strengthen communication, and resolve conflicts between an individual and family. The family members are defined by the individual. The objective of treatment is to stabilize or alleviate symptoms of psychiatric disorders that may significantly interfere with interpersonal functioning, particularly in the family-life domain.
Outpatient Group Psychotherapy	Outpatient group psychotherapy is the use of therapeutic principles, structures, and techniques to treat psychiatric disorders through scheduled therapeutic visits between participants with a common treatment goal. Outpatient group psychotherapy treatment uses various active treatment modalities and group interaction to stabilize or alleviate symptoms of psychiatric disorders that may significantly interfere with interpersonal functioning in at least one life domain (e.g., familial, social, occupational, educational).
Outpatient Individual Psychotherapy	Outpatient psychotherapy is the treatment of mental health and/or co-occurring SUDs through therapeutic principles, structures, and techniques between the therapist and the individual. Outpatient psychotherapy uses various active treatment modalities to improve or alleviate symptoms that may be troubling and significantly interfere with functioning in at least one life domain (e.g., familial, social, occupational, educational).

Service	Treatment Services (Hospital/Outpatient)
Peer Support	The provision of peer-support services facilitates recovery as the person served defines it. The service is designed to assist individuals and families in initiating and maintaining the process of recovery and resiliency to improve quality of life, increase resiliency, and promote health and wellness. The core element of the service is the development of a relationship based on shared, lived experience and mutuality between the provider and the individual/family. Services facilitate effective system navigation, empowerment, hope, resiliency, voice and choice, and system of care values. This service can be provided to individuals and families in individual and group settings.
Therapeutic Consultation	Therapeutic consultation, in this context, means: collaborative, organized clinical consultations and recommendations for a child or adolescent who experience symptomology of a serious emotional disturbance and related behavioral health concerns. School staff and/or the family or caregiver initially identify the student's need for behavioral health services. Consultation is designed to focus on the child, with recommendations for behavioral health skills development and potential treatment of critical behavioral health issues that will allow the student to participate and function successfully in academics and career preparation in their natural school environment. An interdisciplinary team, consisting of behavioral health professionals, educators or school staff, the student, family or caregiver, and other key individuals (as identified by the team), will develop and implement recommendations, using a family-driven, multi-disciplinary approach that acknowledges the child and family as equal partners and utilizes the least-restrictive environment and least-intrusive, developmentally appropriate interventions.

Service	Rehabilitation Services
Assertive Community Treatment	Assertive Community Treatment consists of a community-based group of transdisciplinary professionals who use a team approach to meet the needs of individuals with severe mental illness. The team provides comprehensive, high intensity services, with the capacity to provide crisis response and regular, frequent, face-to-face contacts as dictated by client need. Assertive Community Treatment uses an assertive, recovery-focused, and individualized treatment model that values self-determination, strengths, and rehabilitation.
Community Support - Mental Health	Community support is a rehabilitative and support service for individuals in the community with a primary mental health diagnosis, consistent with a serious and persistent mental illness and who have complex and extensive treatment needs. Community support workers provide service coordination and restorative interventions for development of interpersonal, community, coping, and independent living skills to maintain wellbeing, community living, and stabilize mental health symptoms.
Day Rehabilitation - Mental Health	Day rehabilitation services provide individualized treatment and recovery, psychiatric rehabilitation, and support for individuals with a severe and persistent mental illness or co-occurring disorders. Day rehabilitation focuses on skill and resource development related to the individual's ability to manage the illness and the recovery process to function as independently as possible and be successful in a community living setting of choice.

Service	Rehabilitation Services
Day Support: Mental Health	Day support is designed to provide social support to individuals who currently receive, or have received, treatment for serious mental illness and are in the recovery process. The intent of the service is to support the individual's wellbeing so he/she can benefit from socialization, leisure skill development, communication, and coping skill development.
Psychiatric Residential Rehabilitation	Psychiatric residential rehabilitation is designed to provide individualized treatment, psychiatric rehabilitation, and support for individuals with a severe and persistent mental illness and/or co-occurring disorder, needing structured recovery and rehabilitation activities within a residential setting. Psychiatric residential rehabilitation is provided by a treatment/recovery team in a 24-hour staffed residential facility. The intent of the service is to support the individual by improving symptom management and life skills so that he/she can be successful in a community living setting of choice.
Recovery Support: Mental Health or Substance Use	Recovery support services promote successful independent community living by assisting individuals in achieving behavioral health goals, supporting recovery, and connecting the individual to services aiding the goals. Recovery support links individuals to community resources, identifies and problem solves barriers that limit independent living, and builds on strengths and interests that support wellbeing. Crisis relapse prevention, active case management, and referral to other independent living and behavioral health services are provided to assist the individual in maintaining self-sufficiency and wellbeing.
Secure Residential Treatment	Secure residential treatment provides individualized recovery, psychiatric rehabilitation, and support for individuals with a severe and persistent mental illness and/or co-occurring SUD, demonstrating a moderate to high-risk for harm to self/others and in need of a secure, recovery/rehabilitative/therapeutic environment. The safe, structured, residential setting offers extensive supports for implementing a personal, effective recovery plan geared toward independent living skills, strengthening functioning, and wellness management.
Supported Employment	Supported employment provides recovery and rehabilitation services and supports to individuals engaged in community-based, competitive, employment-related activities in integrated settings. A supported employment team provides assistance with all aspects of employment development as requested and needed by the individual. The intent of the service is to support the individual in the recovery process so employment goals, as selected by the individual, can be successfully obtained.

Service	SUD Services
SUD Assessment	The adult SUD assessment is an evaluation, through utilization of validated tools, to guide the process of the assessment in determining if a substance use disorder exists and if so, what appropriate level of intervention is recommended. It should be conducted in accordance with the ASAM guidelines.

Service	SUD Services
SUD Assessment Addendum	The purpose of the addendum is to clarify/update the diagnosis, treatment needs, and recommendations and/or gather information that covers the timeframe when an individual was not receiving treatment. It should be conducted in accordance with the ASAM guidelines.
ASAM Level 1.1 Community Support	Community support: SUD is a rehabilitative and support service for individuals with primary SUD and extensive treatment needs. Community support workers provide direct rehabilitation and support services to the individual in the community, with the intention of supporting the individual in recovery, stable community living, and preventing exacerbation of illness and admission to higher LOCs.
ASAM Level 1 Outpatient Family Therapy	Outpatient family SUD therapy describes the professionally-directed evaluation, treatment, and recovery services for individuals and their families who are experiencing a substance-related disorder that causes moderate and/or acute disruptions in the individual's life. Outpatient family SUD therapy is a therapeutic encounter between the licensed professional, the individual, and the nuclear and/or extended family, as defined by the individual. The goal is to use the family's strengths and resources to help find or develop ways to live without maladaptive use of substances.
ASAM Level 1 Outpatient Group Therapy	Outpatient SUD group therapy is the treatment of substance-related disorders through scheduled therapeutic visits between the therapist and the individual in the context of a group setting. The focus of outpatient group treatment is substance-related disorders which are causing moderate and/or acute disruptions in the individual's life.
ASAM Level 1 Outpatient Individual Therapy	Outpatient individual SUD therapy describes the professionally-directed evaluation, treatment, and recovery services for individuals experiencing a substance-related disorder that causes moderate and/or acute disruptions in the individual's life. Individual therapy consists of interactions geared towards enabling the individual to gain insight, reduce maladaptive behaviors related to the disorder, and restore normalized functioning and appropriate interpersonal and social relationships.
ASAM Level 2.1 Intensive Outpatient	Intensive outpatient services provide group-based, non-residential, intensive, structured interventions, consisting primarily of counseling and psychoeducation about substance-related and co-occurring mental health problems. Services are goal-oriented interactions with the individual or in group/family settings. This community-based service allows the individual to apply skills in natural environments and promotes a rapid and stable integration into the community. Intensive outpatient provides time-limited, comprehensive, and coordinated multi-disciplinary treatment. Services align with ASAM 2.1 guidance.
ASAM Level 3.1 Clinically-Managed Low-Intensity Residential (Halfway House)	Halfway house is a transitional, 24-hour, structured, supportive living/treatment/recovery facility located in the community for individuals seeking reintegration into the community, often after primary treatment at a more intense level. This service provides safe housing, structure, and support, affording individuals an opportunity to develop and practice their interpersonal and group living skills, strengthen recovery skills, and reintegrate into their community, find/return to employment, or enroll in school. Services align with ASAM 3.1 guidance.

Service	SUD Services
ASAM LEVEL 3.2WM Clinically-Managed Residential Withdrawal Management (Social Detoxification)	Social detoxification provides voluntary and involuntary intervention in SUD emergencies on a 24-hour per day basis to individuals experiencing acute intoxication and/or withdrawal. This service has the capacity to provide a safe residential setting with staff present for observation and implementation of physician-approved protocols designed to physiologically restore the individual from an acute state of intoxication when medical treatment for detoxification is not necessary. Services align with ASAM level 3.2WM guidance.
ASAM Level 3.3 Clinically-Managed Population-Specific High-Intensity Residential (Therapeutic Community Co-Occurring Diagnosis Capable)	Therapeutic community is intended for individuals with a primary SUD, for whom shorter-term treatment is inappropriate, either because of the pervasiveness of the impact of SUD on the individual's life or because of a significant history of repeated short-term or less-restrictive treatment. This service provides psychosocial skill building through a set of longer-term, highly structured, peer-oriented treatment activities which define progress toward individual change and rehabilitation and incorporate a series of clear phases. The individual's progress must be marked by advancement through these phases to less restrictiveness and more personal responsibility. Therapeutic community relies on group accountability and support. Services align with ASAM level 3.3 guidance.
ASAM Level 3.3 Clinically-Managed Population-Specific High-Intensity Residential (Intermediate Residential Co-	Intermediate residential treatment encompasses organized services, staffed by designated SUD personnel directing a planned regimen of care in a 24-hour, live-in setting. It is staffed 24 hours a day and serves individuals who need a safe and stable living environment to develop recovery skills. It is intended for individuals with a primary SUD for whom shorter-term treatment is inappropriate, either because of the pervasiveness of the impact of substance use on the individual's life or because of a significant history of repeated short-term or less-restrictive treatment. Typically, this service provides a high level of support and relies less on peer dynamics in its treatment approach. Services align with ASAM level 3.3 guidance.

Service	SUD Services
Occurring Diagnosis Capable)	
ASAM Level 3.5 Clinically-Managed High-Intensity Residential (Short-Term Residential Co-Occurring Diagnosis Capable)	Short-term residential treatment delivers a safe and stable intensive treatment environment to treat complex biopsychosocial issues, facilitate the recovery process and the development of a supportive recovery network, promote successful involvement in regular productive activity, and prevent the use of substances. This service is highly structured and provides primary, comprehensive SUD treatment. Services align with ASAM level 3.5 guidance.
ASAM Level 3.5 Clinically-Managed High-Intensity Residential (Dual-Disorder Residential Co-Occurring Diagnosis-Enhanced)	Dual-disorder residential treatment is intended for individuals with a primary SUD and a co-occurring, severe mental illness, requiring a more intensive treatment environment to treat complex biopsychosocial issues and prevent substance use. This service is highly structured, based on acuity, and provides primary, integrated treatment to further stabilize acute symptoms and engage the individual in a program of maintenance, treatment, rehabilitation, and recovery. Services align with ASAM level 3.5 guidance.
ASAM Level 3.7WM Medically-Monitored Inpatient Withdrawal Management	Medically-monitored inpatient withdrawal management provides voluntary and involuntary medical and therapeutic interventions in an inpatient setting. This setting allows for 24-hour nursing coverage for oversight of hourly monitoring of the patient’s progress and medication monitoring, as needed. These facilities are staffed by physicians or medical Advanced Practice Providers who are available by phone, 24-hours per day, and are responsible for treatment, policies, and clinical protocols.

Service	SUD Services
Opioid Treatment Program	The opioid treatment program provides medical and social services, along with outpatient SUD treatment to individuals with severe opioid use disorder. This service is provided under a defined set of policies and procedures, including admission, discharge, and continued service criteria stipulated by state and federal laws and regulations.

Appendix IV: Nebraska's 1915(c) Waiver Program Comparisons

	AD Waiver	CDD Waiver	DDAD	TBI
Age Minimum or Maximums	• 65+ for aged target group • 0-64 for physically disabled target group	• No	• 21+	• 18-64
LOC	• NF	• ICF/IID	• ICF/IID	• NF
LOC Assessment	• Adults: interRAI HC • Children: interRAI PEDS-HC	• DI	• DI	• interRAI HC
Limit on Individuals Served in Waiver Year	• No	• Yes	• Yes	• No
Waitlist	• No	• Yes	• Yes	• No
Individual Cost Limit[359]	• No	• No	• No	• Yes, institutional cost limit
Payments to Legally Responsible	• In certain circumstances	• In certain circumstances	• In certain circumstances	• No
Payments to Guardians of Adults	• Yes	• No	• No	• No

[359] The CMS waiver technical guide (page 315) defines an individual cost limit as "a limitation on the entrance of individuals to a waiver that is based on the comparison of the expected costs of HCBS waiver and state plan services to the expected costs of institutional and State plan services that the person would receive in lieu of participation in the waiver." The information in this chart reflects the selections in the four waivers operated by Nebraska as of the time of this report, and does not reflect individual's budget amounts.

	AD Waiver	CDD Waiver	DDAD	TBI
Participant-Direction Opportunities	• Budget Authority: No • Employer Authority: No	• Budget Authority: Yes • Employer Authority: Yes	• Budget Authority: Yes • Employer Authority: Yes	• Budget Authority: No • Employer Authority: No

Appendix V: Comparison between State and Federal Developmental Disability Definitions

Nebraska Definition	Federal Definition
Developmental disability shall mean a severe, chronic disability, **including an intellectual disability, other than mental illness**, which: 1. Is attributable to a mental or physical impairment, **unless the impairment is solely attributable to a severe emotional disturbance or persistent mental illness**; 2. Is manifested before the age of 22 years; 3. Is likely to continue indefinitely; 4. Results in substantial functional limitations in **one of each of the following areas of adaptive functioning**: a. **Conceptual skills, including language, literacy, money, time, number concepts, and self-direction;** b. **Social skills, including interpersonal skills, social responsibility, self-esteem, gullibility, wariness, social problem solving, and the ability to follow laws and rules and to avoid being victimized; and** c. **Practical skills, including ADLs, personal care, occupational skills, health care, mobility, and the capacity for independent living; and** 5. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. An individual from birth through the age of nine years, inclusive, who has a substantial developmental delay or specific congenital or	Developmental disability means a severe, chronic disability of an individual that: 1. Is attributable to a mental or physical impairment or combination of mental and physical impairments; 2. Is manifested before the individual attains age 22; 3. Is likely to continue indefinitely; 4. Results in substantial limitations in **three or more of the following areas of major life activity**: a. **Self-care;** b. **Receptive and expressive language;** c. **Learning;** d. **Mobility;** e. **Self-direction;** f. **Capacity for independent living; and** g. **Economic self-sufficiency.** 5. Reflects the individual's need for a combination and sequence of special, interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated. 6. An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a DD without meeting three or more **of the criteria described in paragraphs (1) through (5) of this definition**, if the individual, without services and supports, has a high

Nebraska Definition	Federal Definition
acquired condition may be considered to have a DD without meeting three or more **of the major life activities described in subdivision (4) of this section**, if the individual, without services and support, has a high probability of meeting those criteria later in life.[360]	probability of meeting those criteria later in life.[361]

[360] Nebraska Revised Statute 83-1205. *Developmental disability, defined*. (April 2016). Accessed 1 June, 2023.
[361] Code of Federal Regulations. Title 45 Part 1325 *Requirements Applicable to the Developmental Disabilities Program*. (July 2015). Accessed 1 June, 2023.

Appendix VI: Eligibility for Disabled Children's Program and Medically Handicapped Children's Program

	Disabled Children's Program	Medically Handicapped Children's Program
Age	Birth through 15 years of age.	Birth through 20 years of age.
Financial eligibility	Applicants and recipients must be in current pay status with SSI benefits.	Financial eligibility for MCP is based on: • Probable cost of specialized medical care. • Income and resources available to applicant, parents, or legal guardians. • Recipient's income must be at, or below, 185% FPL (based on household size and allowable income).[362]
Qualifying diagnoses	Applicants and recipients must have an identified disability-related need for services.[363]	One or more of the following diagnoses: • Severe, persistent asthma. • Serious burn injuries. • Cerebral palsy. • Craniofacial anomalies. • Cystic fibrosis. • Diabetes (Type I or Type II). • Eye defects. • Significant hearing loss. • Congenital and acquired heart disease. • Hemophilia and certain bleeding disorders. • Diagnoses determined to be congenital, chronic, or prolonged and in need of active treatment.

[362] Nebraska Administrative Code. Title 467, Chapter 2. "Referral, Application, and Eligibility for the Medically Handicapped Children's Program and the Genetically Handicapped Persons Program." (May 2022). https://www.nebraska.gov/rules-and-regs/regsearch/Rules/Health_and_Human_Services_System/Title-467/Chapter-2.pdf. Accessed 6 June, 2023.
[363] Nebraska Administrative Code. Title 467, Chapter 6. "Referral, Application, Eligibility, and Services for the Disabled Children's Program." (May 2022). https://www.nebraska.gov/rules-and-regs/regsearch/Rules/Health_and_Human_Services_System/Title-467/Chapter-6.pdf. Accessed 6 June, 2023.

	Disabled Children's Program	Medically Handicapped Children's Program
		• Spina bifida, meningomyelocele, or other central nervous system neurological defects; • Cancers or non-malignant tumors when the tumor is potentially disabling. • Other neurological conditions such as Guillain-Barre or seizures. • General orthopedic problems. • Infants with medical complications due to premature birth. • Juvenile rheumatoid arthritis and related conditions. • Scoliosis and other anomalies of the spine. • Kidney, urinary, and genital anomalies determined to be chronic and disabling or potentially disabling and requiring active treatment.[364]

[364] Nebraska Administrative Code. Title 467, Chapter 3. *Diagnoses and Services for the Medically Handicapped Children's Program*. (May 2022). Accessed 6 June, 2023.

Appendix VII: Nebraska School-Age Eligibility Categories and State Definition

School-Age Eligibility Category	State Definition
Autism[365]	This category of eligibility has been defined by both federal and state regulations. A three-part eligibility requirement for a child to be identified as a child with autism is as follows: • Meet educational identification criteria (92 NAC 51.006); • Documentation of adverse effect on educational performance; and • A determination that a need for special education is evident. To qualify for special education services in the category of autism, the child must have a DD that significantly affects verbal and nonverbal communication and social interaction, is generally evident before age three, and that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual response to sensory experiences. • Autism does not apply if a child's educational performance is adversely affected primarily because the child has a behavioral disorder as defined in 92 NAC 51-006.04C • A child who manifests the characteristics of autism after age three could be identified as having autism if the other criteria in 92 NAC 51-006.04B1 are met.
Deaf-Blindness[366]	Deaf-Blindness, or dual-sensory impairments, should mean a combined hearing and visual impairment, the combination of which causes severe communication and other developmental and educational needs. Deaf-Blindness/dual-sensory impairments cannot be accommodated in special education programs solely for children with deafness or blindness, unless supplementary assistance is necessary to address the educational needs resulting from the combined disabilities.

[365] Nebraska Department of Education. *Determining Special Education Eligibility – Autism*. (January 2021). Accessed 23 June, 2023. Page 2.
[366] Nebraska Department of Education. *Determining Special Education Eligibility – Deaf-Blindness*. (March 2021). Accessed 23 June, 2023. Page 2.

School-Age Eligibility Category	State Definition
	Functional deaf-blindness should mean that a child has such severe impairments that the level of sensory (auditory and visual) functioning cannot be adequately determined, or the child requires adaptations in both auditory and visual modes. This category of children has been defined by both federal and state regulations. A three-part eligibility requirement for a child to be verified as a child with deaf-blindness is as follows: • Meet eligibility criteria (92 NAC 51.006); • Documentation of adverse effect on educational performance; • Determination that a need for special education is evident. To qualify for special education services in the category of deaf-blindness, the child must have concomitant hearing and visual impairments, the combination of which causes severe communication needs and other developmental and educational needs. The severity of these needs is such that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.
Deaf or Hard of Hearing[367]	This category of children has been defined by both federal and state regulations. A three-part eligibility requirement for a child to be identified as a child who is deaf/hard of hearing, is as follows: • Meet the eligibility criteria (92 NAC 51.006); • Documentation of adverse effect on educational performance; • Determination that a need for special education is evident. To qualify for special education services in the category of deaf/hard of hearing, a child must have impairment in hearing which is so severe, that the child is impaired in processing linguistic information through hearing, with or without amplification, or is permanent or fluctuating, and adversely affects the child's development or educational performance.

[367] Nebraska Department of Education. *Determining Special Education Eligibility – Deaf or Hard of Hearing*. (February 2021). Accessed 23 June, 2023. Page 2

School-Age Eligibility Category	State Definition
	This term combines the state definition of "deaf," contained in Nebraska Rev. Stat. 79-1118.01(4), the state definition of "hard of hearing" 79-1118.01(7), the federal definition of "deafness" in 34 CFR 300.8(c)(3), and the federal definition of "hearing impairment" in 34 CFR 300.8(c)(5). Nebraska also extends its definition to include permanent and fluctuating losses and recognizes that these losses may have adverse effects on development, as well as educational performance. In those respects, Nebraska has created more flexibility in identifying and serving children with hearing loss. Under the state definition, any child with a hearing loss, regardless of type, degree, configuration, etiology, or permanency of the loss may be eligible for special education services. The initial task of the Multidisciplinary Evaluation Team (MDT) and the continuing task of the individualized family service plan and IEP teams are to determine if the hearing loss has adverse effects on the child's development or educational performance.
Developmental Delay[368]	This category of children has been defined by both federal and state regulations. A three-part eligibility requirement for a child to be identified as a child who is developmentally delayed, is as follows: • Meet the eligibility criteria (92 NAC 51.006); • Documentation of adverse effect on educational performance; • Determination that a need for special education is evident. To be eligible for special education services in the category of developmental delay, the child shall have significant delay as measured by appropriate diagnostic instruments and procedures in one or more of the following areas and, by reason thereof, needs special education and related services: cognitive development, physical development, communication development, social or emotional development, adaptive behavior or skills development, or a diagnosed physical or mental condition that has a high probability of resulting in a substantial delay in function in one or more of such areas. Developmental delay must be considered as one possible eligibility category for children, birth through the school year in which the child reaches age eight (92 NAC 51-006.04D2). Prior to the end of the school year in which the child turns eight years old, with the parent's written consent, the IEP

[368] Nebraska Department of Education. *Determining Special Education Eligibility – Developmental Delay*. (April 2023). Accessed 23 June, 2023. Page 2

School-Age Eligibility Category	State Definition
	Team/MDT should begin the re-evaluation process to determine if the child meets the criteria for eligibility with a different disability or is no longer considered a child with a disability.
Emotional Disturbance[369]	This category of children has been defined by both federal and state regulations. A three-part eligibility requirement for a child to be identified as a child with an emotional disturbance is as follows: • Meet the eligibility criteria (92 NAC 51.006); • Documentation of adverse effect on educational performance; • Determination that a need for special education is evident. In order to qualify for special education in the category of emotional disturbance, the child must have a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance, or in the case of children below age five, development: • An inability to learn that cannot be explained by intellectual, sensory, or health factors. • An inability to build or maintain satisfactory interpersonal relationships with peers and teachers. • Inappropriate types of behavior or feelings under normal circumstances. • A general pervasive mood, unhappiness, or depression. • A tendency to develop physical symptoms or fears associated with personal or school problems. The term includes schizophrenia. The term does not apply to children with social maladjustments, unless it is determined that they have an emotional disturbance.
Intellectual Disability[370]	This disability category has been defined by both federal and state regulations. A three- part eligibility requirement for a child to be identified as a child with an intellectual disability is as follows: • Meet eligibility criteria (92 NAC 51.006); • Documentation of adverse effect on educational performance; and • Determination that a need for special education is evident.

[369] Nebraska Department of Education. *Determining Special Education Eligibility – Emotional Disturbance*. (March 2021). Accessed 23 June, 2023. Page 2
[370] Nebraska Department of Education. *Determining Special Education Eligibility – Intellectual Disability*. (January 2021). Accessed 23 June, 2023. Page 2

School-Age Eligibility Category	State Definition
	There are three important components of the definition for children to be identified as having an intellectual disability: 1. Intellectual functioning. 2. Adaptive behavior. 3. Educational/developmental performance. To be eligible for special education services in the category of intellectual disability, the child must demonstrate significantly subaverage, general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period that adversely affects a child's educational, or in the case of a child below age five, developmental performance.
Multiple Disabilities[371]	This disability category has been defined by both federal and state regulations. A three-part eligibility requirement for a child to be identified as a child with multiple disabilities is as follows: • Meet eligibility criteria (92 NAC 51.006); • Documentation of adverse effect on educational performance; and • Determination that a need for special education is evident. To qualify for special education services in the category of multiple disabilities, the child must have concomitant impairments (e.g., intellectual disability-visual impairment, intellectual disability-orthopedic impairment), the combination of which causes such severe developmental or educational, or in the case of a child below age five, developmental needs, that they cannot be accommodated in special education programs solely for one of the disabilities. This classification does not include children with deaf-blindness.
Orthopedic Impairment[372]	This disability category has been defined by both federal and state regulations. A three-part eligibility requirement for a child to be identified as a child with an orthopedic impairment is as follows: • Meet eligibility criteria (92 NAC 51.006);

[371] Nebraska Department of Education. *Determining Special Education Eligibility – Multiple Disabilities*. (January 2021). Accessed 23 June, 2023. Page 2.
[372] Nebraska Department of Education. *Determining Special Education Eligibility – Orthopedic Impairment*. (January 2021). Accessed 23 June, 2023. Page 2.

School-Age Eligibility Category	State Definition
	• Documentation of adverse effect on educational performance; and • Determination that a need for special education is evident. To qualify for services in the category of orthopedic impairment, the child must have a severe orthopedic impairment that adversely affects a child's educational, or in the case of a child below age five, developmental performance. The category includes impairments caused by a congenital anomaly, impairments caused by disease (e.g., poliomyelitis, bone tuberculosis), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures).
Other Health Impairment[373]	This disability category has been defined by both federal and state regulations. A three-part eligibility requirement for a child to be identified as a child with other health impairment is as follows: • Meet eligibility criteria (92 NAC 51.006); • Documentation of adverse effect on educational performance; and • Determination that a need for special education is evident. To qualify for special education services in the category of other health impairment, the child must have limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that is due to chronic or acute health problems which adversely affects the child's educational, or in the case of a child below age five, developmental performance, such as: asthma, attention-deficit disorder or attention-deficit hyperactivity disorder, diabetes, epilepsy, heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, or Tourette syndrome.
Specific Learning Disabilities[374]	This category of children has been defined by both federal and state regulations. A three-part eligibility requirement for a child to be verified as a child with a specific learning disability (SLD) is as follows: • Meet eligibility guidelines (92 NAC 51); • Documentation of adverse effect on educational performance; and

[373] Nebraska Department of Education. *Determining Special Education Eligibility – Other Health Impairment*. (June 2021). Accessed 23 June, 2023. Page 2
[374] Nebraska Department of Education. *Determining Special Education Eligibility – Specific Learning Disabilities. (January 2021).* Accessed 23 June, 2023. Page 2-35

School-Age Eligibility Category	State Definition
	• Determination that there is a need for special education. **CRITERION 1:** Failure to meet age- or grade-level state standards in one of eight areas, when provided appropriate instruction: • Oral expression; • Listening comprehension; • Written expression; • Basic reading skills; • Reading fluency skills; • Reading comprehension; • Mathematics calculation; or • Mathematics problem-solving. The first criterion for identification of SLD requires a determination that the student is failing to meet age- or grade-level state standards in one of eight areas (see definitions). A student needs to meet this criterion in only one of the eight areas but may potentially meet criteria in multiple areas. The school team should identify the area(s) of concern during its review of existing data. The area(s) of low achievement that have not been responsive to instruction/interventions of varying intensities should be what prompted referral for evaluation for the possible presence of SLD. **CRITERION 2:** Lack of progress in response to scientific, research-based intervention. The child does not make sufficient progress to meet age- or state-approved grade-level standards in one or more of the areas identified in 34 C.F.R. 300.309(a)(1) and 92 NAC 51 when using a process based on the child's response to scientific, research-based intervention; or the child exhibits a pattern of strengths and weaknesses in performance, achievement, or both, relative to age, state-approved grade-level standards, or intellectual development, that is determined by the group to be relevant to the identification of an SLD, using appropriate assessments, consistent with 92 NAC 51 and 34 C.F.R. 300.304 and 300.305.

School-Age Eligibility Category	State Definition
	While federal regulations provide two options for determining that the student is not making sufficient progress, this guide focuses exclusively on the use of response to scientific, research-based intervention when making a determination regarding Criterion 2. **CRITERION 3:** The MDT determines that its findings under 92 NAC 51 are not primarily the result of (i) A visual, hearing, or motor disability; (ii) Intellectual Disability*; (iii) Emotional disturbance; (iv) Cultural factors; (v) Environmental or economic disadvantage; or (vi) Limited English proficiency. §300.309(a)(3) This step in the SLD identification process is designed to ensure that students are not identified as having SLD when their lack of academic achievement (Criterion 1) and lack of response to scientific, research-based intervention (Criterion 2) are primarily the result of other factors. The fundamental question is whether the poor performance is primarily the result of any of these factors. It is possible for one or more of these factors to contribute to a student's lack of achievement and response to intervention and for the student to have an SLD. Therefore, the school team must determine the degree to which each factor affects the student's performance. The existence of the factors is not the issue; the issue is the degree to which each factor adversely affects performance. **CRITERION 4:** Ensure that underachievement is not due to lack of appropriate instruction in reading, writing, or math. To ensure that underachievement in a child suspected of having an SLD is not due to lack of appropriate instruction in reading or math, the group must consider, as part of the evaluation described in §300.304 through 300.306: 1. Data that demonstrate that prior to, or as a part of, the referral process, the child was provided appropriate instruction in regular education settings, delivered by qualified personnel; and

School-Age Eligibility Category	State Definition
	2. Data-based documentation of repeated assessments of achievement at reasonable intervals, reflecting formal assessment of student progress during instruction, which was provided to the child's parents. §300.309 (b). This step in the SLD identification process is designed to ensure that students are not identified as having an SLD and needing special education when lack of appropriate instruction is the cause of the student's underachievement. This is required for all eligibility methods. **CRITERION 5:** Observation. Observing student behavior in the classroom offers opportunities for teams to better understand the educational ecology within which student learning is occurring. This ecology might include the student's rate of active engagement, rate of correct responses to instruction, and the student's opportunity to respond and practice skills within the suspected area(s) of difficulty. Observations also provide opportunity to determine the quality of instruction and implementation of curriculum and instructional strategies. The district must ensure that the child is observed in the child's learning environment (including the regular classroom setting) to document the child's academic performance and behavior in the areas of difficulty. **CRITERION 6:** Documentation. (a) For a child suspected of having an SLD, the documentation of the determination of eligibility must contain a statement of: 1. Whether the child has an SLD; 2. The basis for making the determination, including an assurance that the determination has been made in accordance with 92 NAC 51; and Nebraska eligibility-determination guidelines; 3. The relevant behavior, if any, noted during the observation of the child and the relationship of that behavior to the child's academic functioning; 4. The educationally relevant medical findings, if any; 5. Whether: i. The child does not achieve progress commensurate with the child's age.

School-Age Eligibility Category	State Definition
	ii. The child does not achieve progress to meet age- or state-approved grade-level standards consistent with 92 NAC 51; 6. The determination of the MDT concerning the effects of visual, hearing, or motor disability; intellectual disability; behavior disorder; cultural factors, environmental or economic disadvantage; or limited English proficiency on the child's achievement level; and 7. If the child has participated in a process that assesses the child's response to scientific, research-based intervention: i. The instructional strategies used and the child-centered data collected; and ii. The documentation that the child's parents were notified about: A. The school district's policies regarding the amount and nature of student performance data that would be collected and the general education services that would be provided; B. Strategies for increasing the child's rate of learning; and C. The parent's right to request an evaluation. (b) Each MDT member must certify, in writing, whether the report reflects the member's conclusion. If it does not reflect the member's conclusion, the team member must submit a separate statement presenting his/her conclusions. Addressing the requirements of the specific documentation for eligibility determination involves a compilation of the information gathered to address Criteria 1–5.
Speech-Language Impairment[375]	This category of children has been defined by both federal and state regulations. A three-part eligibility requirement for a child to be eligible as a child with a speech-language impairment is as follows: • Meet eligibility criteria (92 NAC 51.006); • Documentation of adverse effect on development or educational performance; • Determination that a need for special education is evident.

[375] Nebraska Department of Education. *Determining Special Education Eligibility – Speech Language Impairment*. (January 2021). Accessed 23 June, 2023. Page 2

School-Age Eligibility Category	State Definition
	To qualify for special education services in the category of speech-language impairment, the child must have a communication disorder, such as stuttering, impaired articulation, language impairment, or voice impairment. This disorder must adversely affect the child's educational, or in the case of a child below age five, developmental performance.
TBI[376]	This category of children has been defined by both federal and state regulations. A three-part eligibility requirement for a child to be identified as a child with a TBI is as follows: • Meet eligibility criteria (92 NAC 51.006); • Documentation of adverse effect on educational performance; • Determination that a need for special education is evident. To qualify for special education services in the category of TBI, the child must have an acquired injury to the brain, caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational, or in the case of a child below age five, developmental performance. The category includes open or closed head injuries resulting in impairments in one or more areas, such as: cognition, language, memory, attention, reasoning, abstract thinking, judgment, problem solving, sensory, perceptual, and motor abilities, psychosocial behavior; physical functions, information processing, and speech. The category does not include brain injuries that are congenital or degenerative or brain injuries induced by birth trauma.
Visual Impairment[377]	This category of children has been defined by both federal and state regulations. A three-part eligibility requirement for a child to be identified as a child with a visual impairment is as follows: • Meet eligibility criteria (92 NAC 51.006); • Documentation of adverse effect on educational performance; • Determination that a need for special education is evident.

[376] Nebraska Department of Education. *Determining Special Education Eligibility – Traumatic Brain Injury*. (March 2021). Accessed 23 June, 2023. Page 2
[377] Nebraska Department of Education. *Determining Special Education Eligibility- Visual Impairment*. (January 2021). Accessed 23 June, 2023. Page 2.

School-Age Eligibility Category	State Definition
	To qualify for special education services in the category of visual impairment, including blindness, the child must have an impairment in vision that, even with correction, adversely affects a child’s educational performance. This category includes children who have partial sight or blindness. Both federal and state special education laws use the term “visual impairment, including blindness,” to describe children who are blind, legally blind, or partially sighted. Under the state definition, any child with a visual impairment, including blindness, will experience deficiencies in one or more of the following areas: ADLs, social interaction and academic achievement, performance in the educational setting, or orientation and mobility. The task of the MDT is to determine if the visual impairment has an adverse effect on the child’s development or educational performance.

Appendix VIII: Populations Served by Vocational Rehabilitation

Detailed Primary Disability Type[378]	PY 17 Number of Participants	PY 17 Percent	PY 18 Number of Participants	PY 18 Percent	PY 19 Number of Participants	PY 19 Percent
Blindness	-	0%	-	0%	-	0%
Other Visual Impairments	-	0%	-	0%	-	0%
Deafness: Primary Communication Visual	107	1.9%	61	2%	49	2.4%
Deafness: Primary Communication Auditory	-	0%	-	0%	-	0%
Hearing Loss: Primary Communication Visual	302	5.3%	166	5.5%	100	4.9%
Hearing Loss: Primary Communication Auditory	-	0%	-	0%	-	0%
Other Hearing Impairments	4	0.1%	1	0%	2	0.1%
Deaf-Blindness	1	0%	-	0%	-	0%
Communicative Impairments	56	1%	31	1%	23	1.1%
Mobility Orthopedic/ Neurological Impairments	80	1.4%	52	1.7%	41	2.0%
Manipulation/ Dexterity Orthopedic/ Neurological Impairments	19	0.3%	8	0.3%	5	0.2%

[378] United States Department of Education. *Federal Fiscal Year 2021 Report On The Review Of Nebraska Vocational Rehabilitation*. Accessed 6 June, 2023. Pages 48-49.

Detailed Primary Disability Type[378]	PY 17 Number of Participants	PY 17 Percent	PY 18 Number of Participants	PY 18 Percent	PY 19 Number of Participants	PY 19 Percent
Both Mobility and Manipulation/ Dexterity Orthopedic/ Neurological Impairments	315	5.6%	206	6.9%	151	7.4%
Other Orthopedic Impairments	277	4.9%	133	4.4%	65	3.2%
Respiratory Impairments	20	0.4%	9	0.3%	8	0.4%
General Physical Debilitation	179	3.2%	100	3.3%	74	3.6%
Other Physical Impairments	248	4.4%	127	4.2%	78	3.8%
Cognitive Impairments	1,975	34.9%	1,192	39.6%	932	45.6%
Psychosocial Impairments	1,415	25%	658	21.9%	393	19.2%
Other Mental Impairments	657	11.6%	263	8.7%	122	6.0%

Appendix IX: Peer State Summary Information

	Colorado	Kansas	Missouri	Nebraska	Ohio	Oklahoma	Pennsylvania	South Dakota	Tennessee	Wisconsin
Population[379]	5,812,069	2,934,582	6,168,187	1,963,692	11,780,017	3,986,639	12,964,056	895,376	6,975,218	5,895,908
Estimate of Population with a Disability[380]	12.3%	13.1%	14.6%	12.5%	14.0%	16.8%	13.6%	12.1%	14.7%	11.8%
Number of 1915(c) Waivers	10	6	10	4	8	6	6	4	3[381]	3
Medicaid Managed Care[382]	Yes	Yes	Yes	Yes	Yes	Yes[383]	Yes	Yes[384]	Yes	Yes
Federally Recognized Tribes[385]	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes
Requested for Inclusion by DD Advisory Committee	No	No	No	No	No	No	Yes	No	Yes	Yes

[379] United States Census Bureau. *American Community Survey: Demographic and Housing Estimates*. (2021). Accessed 30 July, 2023.
[380] United States Census Bureau. *American Community Survey: Disability Characteristics.* (2021). Accessed 30 July, 2023.
[381] Tennessee still operates three 1915(c) waivers, though all three programs are closed for enrollment.
[382] Kaiser Family Foundation. *Share of Medicaid Population Covered Under Different Delivery Systems*. (July 2022). Accessed 30 July, 2023.
[383] Oklahoma operates a primary care case management, versus a risk-based managed care model.
[384] South Dakota operates a primary care case management, versus a risk-based managed care model.
[385] U.S. Department of the Interior, Indian Affairs. *Search Federally Recognized Tribes*. Accessed 30 July, 2023.

Appendix X: Peer State 1915(c) Waivers

State	1915(c) Peer State Waivers
Colorado	• Children's Extensive Support waiver • Children's Home and Community-Based Services • Complementary and Integrative Health • Developmental Disabilities • Elderly, Blind, and Disabled • HCBS – Children's Habilitation Residential Program • HCBS Waiver for Children with Life-Limiting Illness • Persons with Brain Injury • Supported Living Services • Colorado HCBS waiver for Community Mental Health Supports
Kansas	• Autism waiver • Brain Injury waiver • Intellectual Disabilities and Developmental Disabilities waiver • HCBS for the Frail Elderly waiver • Physical Disability waiver • Serious Emotional Disturbance waiver • Technology Assisted waiver
Missouri	• Adult Day Care waiver • Aged and Disabled waiver • AIDS waiver • Brain Injury waiver • Children with Disabilities waiver • Developmental Disabilities Comprehensive waiver • DD Community Support waiver • Independent Living waiver • Medically Fragile waiver • Partnership for Hope • Structured Family Caregiving
Ohio	• Assisted Living • Individual Options • Level One • MyCare OH • Ohio Home Care • OhioRISE • PASSPORT • SELF

State	1915(c) Peer State Waivers
Oklahoma	• ADvantage waiver • Community waiver • Homeward Bound waiver • In-Home Support waiver – For Adults • In-Home Support waiver – For Children • Medically Fragile waiver
Pennsylvania	• Adult Autism waiver • Community Living waiver • Consolidated waiver • Infants, Toddlers, and Families waiver • OBRA waiver • PFDS waiver
South Dakota	• Assistive Daily Living Services waiver • CHOICES • South Dakota Family Support 360 waiver • HOPE waiver
Tennessee	• Comprehensive Aggregate Cap Home and Community Based Services (CAC) waiver • Self-Determination waiver Program • Statewide Home and Community Based Services waiver
Wisconsin	• Children's Long-Term Support waiver Program • Family Care waiver • IRIS waiver

Appendix XI: Peer State Waiver Application References

State and Waiver Application Name	Waiver and Amendment/Renewal Number	Effective Date	Source
Colorado – Brain Injury waiver	CO.0288.R06.04	July 1, 2023	Brain Injury waiver source.
Colorado – HCBS Waiver for Children with Life-Limiting Illness	CO.0450.R03.15	July 1, 2023	HCBS Waiver for Children with Life-Limiting Illness source.
Colorado – Children's Habilitation Residential Program	CO.0305.R05.22	July 1, 2023	Children's Habilitation Residential Program source.
Colorado – HCBS Waiver for Community Mental Health Supports	CO.0268.R06.04	July 1, 2023	HCBS Waiver for Community Mental Health Supports source.
Colorado – Complementary and Integrative Health	CO.0961.R02.17	July 1, 2023	Complementary and Integrative Health source.
Colorado – Developmental Disabilities	CO.0007.R08.22	July 1, 2023	Developmental Disabilities source.
Colorado – Elderly, Blind, and Disabled	CO.0006.R09.04	July 1, 2023	Elderly, Blind and Disabled source.
Colorado – Supported Living Services	CO.0293.R05.23	July 1, 2023	Supported Living Services source.

State and Waiver Application Name	Waiver and Amendment/Renewal Number	Effective Date	Source
Kansas – Autism waiver	KS.0476.R03.00	April 1, 2022	Autism waiver source.
Kansas – HCBS Brain Injury waiver	KS.4164.R06.07	July 1, 2021	HCBS Brain Injury waiver source.
Kansas – HCBS for the Frail Elderly	KS.0303.R05.02	July 1, 2021	HCBS for the Frail Elderly source.
Kansas – HCBS I/DD waiver	KS.0224.R06.06	July 1, 2021	HCBS I/DD waiver source.
Kansas – Physical Disability waiver	KS.0304.R05.02	July 1, 2021	Physical disability waiver source.
Kansas – Serious Emotional Disturbance waiver	KS.0320.R05.00	April 1, 2022	Serious Emotional Disturbance waiver source.
Kansas – Technology Assisted waiver	KS.4165.R06.06	July 1, 2021	Technology Assisted waiver source.
Missouri – Adult Day Care waiver	MO.1021.R02.08	July 1, 2023	Adult Day Care waiver source.
Missouri – Aged and Disabled waiver	MO.0026.R09.00	July 1, 2023	Aged and Disabled waiver source.
Missouri – AIDS waiver	MO.0197.R07.03	July 1, 2023	AIDS waiver source.
Missouri – Brain Injury waiver	MO.1406.R00.09	July 1, 2023	Brain Injury waiver source.

State and Waiver Application Name	Waiver and Amendment/Renewal Number	Effective Date	Source
Missouri – Children with Developmental Disabilities waiver	MO.4185.R06.00	July 1, 2023	MOCDD waiver source.
Missouri – Developmental Disabilities Comprehensive waiver	MO.0178.R07.06	July 1, 2023	DD Comprehensive waiver source.
Missouri – Division of Developmental Disabilities Community Support waiver	MO.0404.R04.06	July 1, 2023	DD Community Support waiver source.
Missouri – Independent Living waiver	MO.0346.R04.11	July 1, 2023	Independent Living waiver source.
Missouri – Medically Fragile Adult waiver	MO.40190.R05.06	July 1, 2023	Medically Fragile Adult waiver source.
Missouri – Partnership for Hope waiver	MO.0841.R03.00	July 1, 2023	Partnership for Hope waiver source.
Missouri – Structured Family Caregiving waiver	MO.1706.R00.04	July 1, 2023	Structured Family Caregiving waiver source.
Ohio – Assisted Living waiver	OH.0446.R03.05	January 1, 2022	Assisted Living waiver source.
Ohio – Home Care waiver	OH.0337.R05.01	January 1, 2022	Home Care waiver source.
Ohio – Individual Options waiver	OH.0231.R05.10	July 1, 2022	Individual Options waiver source.
Ohio – Integrated Care Delivery System ICDS waiver (MyCare Ohio)	OH.1035. R01.05	July 1, 2021	MyCare Ohio waiver source.
Ohio – Level One waiver	OH.0380.R04.03	July 1, 2022	Level One waiver source.

State and Waiver Application Name	Waiver and Amendment/Renewal Number	Effective Date	Source
OhioRISE waiver	OH.2226.R00.00	July 1, 2022	OhioRISE waiver source.
Ohio – PASSPORT	OH.0198.R07.00	July 1, 2023	PASSPORT waiver source.
Ohio SELF waiver	OH.0877.R02.08	July 1, 2022	SELF waiver source.
Oklahoma – ADvantage waiver	OK.0256.R06.04	October 1, 2022	ADvantage waiver source.
Oklahoma – Community waiver	OK.0179.R07.07	June 19, 2023	Community waiver source.
Oklahoma – Homeward Bound waiver	OK.0399.R04.07	June 19, 2023	Homeward Bound waiver source.
Oklahoma – In-Home Supports Waiver for Adults	OK.0343.R05.03	June 19, 2023	In-Home Supports Waiver for Adults source.
Oklahoma – In-Home Supports Waiver for Children	OK.0351.R05.03	June 19, 2023	In-Home Supports Waiver for Children source.
Oklahoma – Medically Fragile waiver	OK.0811.R03.00	July 1, 2023	Medically Fragile waiver source.
Pennsylvania – Adult Autism waiver	PA.0593.R03.03	January 1, 2023	Adult Autism waiver source.
Pennsylvania – Community HealthChoices waiver	PA.0386.R04.12	April 1, 2023	Community HealthChoices waiver source.
Pennsylvania – Community Living waiver	PA. 1486.R01.00	January 1, 2023	Community Living waiver source.
Pennsylvania – Consolidated waiver	PA.0147.R07.00	January 1, 2023	Consolidated waiver source.

State and Waiver Application Name	Waiver and Amendment/Renewal Number	Effective Date	Source
Pennsylvania – Medicaid Waiver for Infants, Toddlers, and Families	PA.0324.R05.00	July 1, 2021	Medicaid Waiver for Infants, Toddlers, and Families source.
Pennsylvania – OBRA waiver	PA.0235.R06.04	April 1, 2023	OBRA waiver source.
Pennsylvania – Person/Family Directed Support waiver	PA.0354.R05.00	January 1, 2023	Person/Family Directed Support waiver source.
South Dakota – Assistive Daily Living Services waiver	SD.0264.R06.00	June 1, 2022	Assistive Daily Living Services waiver source.
South Dakota – CHOICES waiver	SD.0044.R09.00	June 1, 2023	CHOICES waiver source.
South Dakota – Family Support 360 Waiver	SD.0338.R05.00	June 1, 2022	Family Support 360 waiver source.
South Dakota –HOPE waiver	SD.0189.R07.00	October 1, 2021	Home and Community-Based Options and Person Centered Excellence (HOPE) waiver source.
Tennessee – Comprehensive Aggregate Cap Home and Community-Based Services Waiver	TN.0357.R04.00	January 1, 2020	Comprehensive Aggregate Cap Home and Community Based Services waiver source.
Tennessee – Self-Determination Waiver Program	TN.0427.R03.02	January 1, 2020	Self-Determination Waiver Program source.
Tennessee – Statewide Home and Community Based Services Waiver	TN.0128.R06.06	April 1, 2023	Statewide Home and Community Based Services waiver source.
Wisconsin – Children's Long-Term Support Waiver Program	WI.0414.R04.01	June 1, 2022	Children's Long-Term Support Waiver Program source.

State and Waiver Application Name	Waiver and Amendment/Renewal Number	Effective Date	Source
Wisconsin – Family Care waiver	WI.0367.R04.00	January 1, 2020	Family Care waiver source.
Wisconsin – IRIS waiver	WI.0484.R03.00	January 1, 2021	IRIS waiver source.

Appendix XII: Assessment Tools Used by Peer States

States	LOC Assessment Tool	1915(c) Waiver
Colorado	• LOC Screen[386]	• Children's Extensive Support waiver • Children's Home and Community Based Services • Complementary and Integrative Health • Developmental Disabilities • Elderly, Blind, and Disabled • HCBS – Children's Habilitation Residential Program • HCBS Waiver for Children with Life-Limiting Illness • Persons with Brain Injury • Supported Living Services • CO HCBS waiver for Community Mental Health Supports
Kansas	• Adult Behavior Checklist	• Serious Emotional Disturbance waiver (HCBS)
Kansas	• Child Behavior Checklist	• Serious Emotional Disturbance (HCBS)
Kansas	• Child and Adolescent Functional Assessment Scale	• Serious Emotional Disturbance waiver (HCBS)
Kansas	• Community Mental Health Center Screening Form	• Serious Emotional Disturbance waiver (institutional care)
Kansas	• DD Profile	• HCBS for I/DD waiver (HCBS and institutional care)
Kansas	• Medical Assistive Technology LOC Instrument	• Technology Assisted waiver
Kansas	• Medicaid Functional Eligibility Instrument	• Autism waiver (HCBS) • HCBS Brain Injury waiver (HCBS and institutional care) • HCBS for the Frail Elderly (HCBS and institutional care) • Physical Disability waiver (HCBS and institutional care)

[386] Colorado Department of Health Care Policy & Financing. *Level of Care Screen Training Manual*. (June 2018). Accessed 13 July, 2023.

States	LOC Assessment Tool	1915(c) Waiver
Kansas	• Vineland 3	• Autism waiver (institutional care)
Missouri	• Brain Injury Waiver LOC Determination Form	• Brain Injury waiver (HCBS and institutional care)
Missouri	• Evaluation of Need for and ICF/DD LOC and Eligibility for the DD Waiver	• Partnership of Hope waiver (HCBS and institutional care) • Missouri Children with DD (MOCDD) waiver (HCBS and institutional care) • Community Support waiver (HCBS and institutional care) • DD Comprehensive wavier (HCBS and institutional care)
Missouri	• HIV Specialty LOC instrument	• AIDS waiver (HCBS and institutional care)
Missouri	• interRAI Home Care	• Adult Day Care waiver (HCBS and institutional care) • Aged and Disabled waiver (HCBS and institutional care) • Independent Living waiver (HCBS and institutional care) • Structured Family Caregiving
Missouri	• Medically Fragile Adult Waiver Level of Care Determination	• Medically Fragile Adult waiver (HCBS and institutional care)
Ohio	• Adult Comprehensive Assessment Tool	• Assisted Living waiver (HCBS and institutional care)
Ohio	• Adult Level of Care Questionnaire	• PASSPORT waiver (HCBS and institutional care) • MyCare Ohio waiver (HCBS and institutional care) • Ohio Home Care waiver (HCBS and institutional care)
Ohio	• Child and Adolescent Needs Assessment	• OhioRISE waiver (HCBS and institutional care)
Ohio	• Child Level of Care Assessment	• Ohio Home Care (HCBS and institutional care)
Ohio	• Developmental Disabilities Level of Care Instrument	• Individual Options waiver (HCBS and institutional care) • Level One waiver (HCBS and institutional care)

States	LOC Assessment Tool	1915(c) Waiver
		• SELF waiver (HCBS and institutional care)
Oklahoma	• Level of Care Evaluation Unit	• Community waiver (HCBS and institutional care) • Homeward Bound waiver (HCBS and institutional care) • In-Home Supports Waiver for Adults (HCBS and institutional care) • In-Home Supports Waiver for Children (HCBS and institutional care)
Oklahoma	• Uniform Comprehensive Assessment Tool	• Advantage waiver (HCBS and institutional care) • Medically Fragile waiver (HCBS and institutional care)
Pennsylvania	• Form MA-51	• Medicaid Waiver for Infants, Toddlers, and Families (institutional care)
Pennsylvania	• Form PW-123	• Medicaid Waiver for Infants, Toddlers, and Families (HCBS)
Pennsylvania	• Functional Eligibility Determination tool	• Community HealthChoices waiver (HCBS and institutional care) • OBRA waiver (HCBS and institutional care)
Pennsylvania	• A specific assessment was not clearly defined within the waiver	• Adult Autism Waiver (HCBS and institutional care) • Community Living waiver (HCBS and institutional care) • Consolidated waiver (HCBS and institutional care) • Person/Family Directed Supports waiver (HCBS and institutional care)
South Dakota	• Assistive Daily Living Services Assessment	• Assistive Daily Living Services waiver (HCBS)
South Dakota	• Birth to Three Assessment	• Family Support 360 waiver (birth to 3 years old, HCBS and institutional care)
South Dakota	• interRAI – Home Care Assessment	• HOPE (HCBS)
South Dakota	• Institutional Level of Care	• Assistive Daily Living Services waiver (institutional care)
South Dakota	• Inventory for Client and Agency Planning Assessment	• CHOICES waiver (HCBS and institutional care) • Family Support 360 waiver (ages 3+, HCBS and institutional care)
South Dakota	• Minimum Data Set – Resident Assessment Instrument	• HOPE (institutional care)

States	LOC Assessment Tool	1915(c) Waiver
Tennessee	• PreAdmission Evaluation	• Comprehensive Aggregate Cap Home and Community-Based Services waiver (HCBS and institutional care) • Tennessee Self-Determination Waiver Program (HCBS and institutional care)
Tennessee	• A specific assessment tool was not clearly defined in the waiver	• Statewide Home and Community Based Services (or "Statewide") waiver (HCBS & institutional care)
Wisconsin	• Functional Screen	• Children's Long-Term Support Waiver Program (HCBS and institutional care)
Wisconsin	• Long-Term Care Functional Screen	• Family Care waiver (HCBS and institutional care) • IRIS Waiver (HCBS and institutional care

Appendix XIII: Peer State Developmental Disability Definitions

Peer State	State Developmental Disability Definition
Colorado	Intellectual and developmental disability means a disability that manifests before the person reaches twenty-two years of age, that constitutes a substantial disability to the affected person, and that is attributable to an intellectual and developmental disability or related conditions, including Prader-Willi syndrome, cerebral palsy, epilepsy, autism, or other neurological conditions when the condition or conditions result in impairment of general intellectual functioning or adaptive behavior similar to that of a person with an intellectual and developmental disability. Unless otherwise specifically stated, the federal definition of "DD" found in 42 U.S.C. sec. 15002(8) does not apply.[387]
Kansas	Developmental disability means: (1) Intellectual disability; or (2) a severe, chronic disability, which: (A) Is attributable to a mental or physical impairment, a combination of mental and physical impairments or a condition which has received a dual diagnosis of intellectual disability and mental illness; (B) is manifest before 22 years of age; (C) is likely to continue indefinitely; (D) results, in the case of a person five years of age or older, in a substantial limitation in three or more of the following areas of major life functioning: Self-care, receptive and expressive language development and use, learning and adapting, mobility, self-direction, capacity for independent living and economic self-sufficiency; (E) reflects a need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are lifelong, or extended in duration and are individually planned and coordinated; and (F) does not include individuals who are solely and severely emotionally disturbed or seriously or persistently mentally ill or have disabilities solely as a result of the infirmities of aging.

[387] Colorado Legal Resources. *Colorado Revised Statute 25.5-10-202 Definitions*. (May 2023). Accessed 13 July, 2023.

Peer State	State Developmental Disability Definition
	(g) "Institution" means state institution for people with intellectual disability as defined by subsection (c) of K.S.A. 76-12b01, and amendments thereto, or intermediate care facility for people with intellectual disabilities of nine beds or more as defined by subsection (a)(4) of K.S.A. 39-923, and amendments thereto. (h) "Intellectual disability" means substantial limitations in present functioning that is manifested during the period from birth to age 18 years and is characterized by significantly sub average intellectual functioning existing concurrently with deficits in adaptive behavior including related limitations in two or more of the following applicable adaptive skill areas: Communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work.[388]
Missouri	"Developmental or physical disability", a severe chronic disability that: (a) Is attributable to cerebral palsy, epilepsy, or any other condition other than mental illness or autism spectrum disorder which results in impairment of general intellectual functioning or adaptive behavior and requires treatment or services; (b) Manifests before the individual reaches age nineteen; (c) Is likely to continue indefinitely; and (d) Results in substantial functional limitations in three or more of the following areas of major life activities: a. Self-care; b. Understanding and use of language; c. Learning; d. Mobility; e. Self-direction; or f. Capacity for independent living; [389]

[388] Kansas Legislative Sessions. *2021 Statute-Chapter39-Article18.* Accessed 28 July, 2023.
[389] Missouri Revisor of Statues. *Chapter 376.1224.* Accessed 28 July, 2023.

Peer State	State Developmental Disability Definition
Ohio	"DD" means a severe, chronic disability that is characterized by all of the following: (1) It is attributable to a mental or physical impairment or a combination of mental and physical impairments, other than a mental or physical impairment solely caused by mental illness, as defined in division (A) of section 5122.01 of the Revised Code. (2) It is manifested before age twenty-two. (3) It is likely to continue indefinitely. (4) It results in one of the following: (a) In the case of a person under three years of age, at least one developmental delay, as defined in rules adopted under section 5123.011 of the Revised Code, or a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay, as defined in those rules; (b) In the case of a person at least three years of age but under six years of age, at least two developmental delays, as defined in rules adopted under section 5123.011 of the Revised Code; (c) In the case of a person six years of age or older, a substantial functional limitation in at least three of the following areas of major life activity, as appropriate for the person's age: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and, if the person is at least sixteen years of age, capacity for economic self-sufficiency. (5) It causes the person to need a combination and sequence of special, interdisciplinary, or other type of care, treatment, or provision of services for an extended period of time that is individually planned and coordinated for the person. Developmental disability includes intellectual disability.[390]

[390] Ohio Laws & Administrative Rules. *Chapter 5132 Department of developmental disabilities definitions*. Accessed 28 July, 2023.

Peer State	State Developmental Disability Definition
Oklahoma	“Developmental disability” means a severe, chronic disability that is characterized by all of the following: (1) Is attributable to a mental or physical impairment or combination of mental and physical impairments, such as intellectual developmental disorder, cerebral palsy, or autism; (2) Is manifested before the person attains twenty-two (22) years of age; (3) Is likely to continue indefinitely; (4) Results in substantial functional limitations in three or more of the following areas of major life activity: a. self-care, b. receptive and expressive language, c. learning, d. mobility, e. self-direction, f. capacity for independent living, and g. economic self-sufficiency; and (5) Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated. The term DD shall not include mentally ill persons, as those persons are defined by Section 1-103 of Title 43A of the Oklahoma Statutes, whose sole disability is mental illness. [391]

[391] Oklahoma Statutes. *Title 10 Children-10.1408 Definitions*. Accessed 28 July, 2023.

Peer State	State Developmental Disability Definition
Pennsylvania	''Developmental disability'' means a severe, chronic disability of an individual 5 years of age or older that: (1) Is attributable to a mental or physical impairment or a combination of mental and physical impairments. (2) Is manifested before the individual attains age 22. (3) Is likely to continue indefinitely. (4) Results in substantial functional limitations in three or more of the following areas of major life activity: (i) Self-care. (ii) Receptive and expressive language. (iii) Learning. (iv) Mobility. (v) Self-direction. (vi) Capacity for independent living. (vii) Economic self-sufficiency. (5) Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports or other assistance that is of lifelong or extended duration and is individually planned and coordinated. (6) When the term is applied to infants and young children, it means individuals from birth to 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.[392]

[392] Pennsylvania Code. *Title 4-Chapter 5:5.147.* Accessed 28 July, 2023.

Peer State	State Developmental Disability Definition
South Dakota	A developmental disability is any severe, chronic disability of a person that: (1) Is attributable to a mental or physical impairment or combination of mental and physical impairments; (2) Is manifested before the person attains age twenty-two; (3) Is likely to continue indefinitely; (4) Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and (5) Reflects the person's need for an array of generic services, met through a system of individualized planning and supports over an extended time, including those of a life-long duration.[393]
Tennessee	Developmental disability in a person over five (5) years of age means a condition that: Is attributable to a mental or physical impairment or combination of mental and physical impairments; Manifested before twenty-two (22) years of age; Likely to continue indefinitely; Results in substantial functional limitations in three (3) or more of the following major life activities: Self-care; Receptive and expressive language; Learning; Mobility; Self-direction; Capacity for independent living; or Economic self-sufficiency; and

[393] South Dakota Codified Laws. *Section 27B-1-18 - DD defined.* Accessed 28 July, 2023.

Peer State	State Developmental Disability Definition
	Reflects the person's need for a combination and sequence of special interdisciplinary or generic services, supports, or other assistance that is likely to continue indefinitely and need to be individually planned and coordinated. Developmental disability in a person up to five (5) years of age means a condition of substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in a developmental disability as defined for persons over five (5) years of age if services and supports are not provided.[394]
Wisconsin	Developmental disability means a disability attributable to brain injury, cerebral palsy, epilepsy, autism, Prader-Willi syndrome, intellectual disability, or another neurological condition closely related to an intellectual disability or requiring treatment similar to that required for individuals with an intellectual disability, which has continued or can be expected to continue indefinitely and constitutes a substantial handicap to the afflicted individual. Developmental disability does not include dementia that is primarily caused by degenerative brain disorder. (b) Developmental disability for purposes of involuntary commitment, does not include cerebral palsy or epilepsy.[395]

[394] 2021 Tennessee Code Title 33 - Mental Health and Substance Abuse and Intellectual and Developmental Disabilities. *Chapter 1 - General Provisions: Part 1 – Definitions § 33-1-101.* Accessed 28 July, 2023.
[395] Wisconsin State Legislature Statues. *Chapter 51 State Alcohol, Drug Abuse, Developmental Disabilities And Mental Health Act.* Accessed 28 July, 2023.

Appendix XIV: Peer State Waitlist Comparison

State	Program for Which Registry/Waitlist Exists	Estimated Number of Individuals on Waitlist	Registry/Waitlist Management[396]	State Screens People on 1 or More Waiting Lists for Eligibility[397]
Colorado	Home and Community Based Services – DD waiver	3,000[398]	First come, first served	Yes
Kansas	(I/DD) waiver and Physical Disability waiver	4,500[399]	First come, first served	Yes
Missouri	Developmental Disabilities Services (DDS) waivers – MOCDD, DD Comprehensive, DD Community Support, Medically Fragile Adult, Partnership for Hope	256	Priority and wait time	Yes
Nebraska	Comprehensive Developmental Disabilities Services and DD Adult Day Services waiver for Adults	2,400[400]	Priority[401]	Yes

[396] Medicaid and Chip Payment and Access Commission. *Compendium of Medicaid Home-and Community-Based Services waiver Waiting List Administration*. (2020). Accessed 20 April, 2022.
[397] Kaiser Family Foundation. *Medicaid HCBS waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility*. (2021). Accessed 20 April, 2023.
[398] Kaiser Family Foundation. *Medicaid HCBS waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility*. (2021). Accessed 20 April, 2023.
[399] Kaiser Family Foundation. *Medicaid HCBS waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility*. (2021). Accessed 20 April, 2023.
[400] Developmental Disabilities *Advisory Committee Meeting Minutes*. (March 2023). Accessed 20 April, 2023.
[401] Nebraska Revised Statute 83-1216. *Department; duties; services; legislative intent; priorities*. Accessed 20 April, 2023.

State	Program for Which Registry/Waitlist Exists	Estimated Number of Individuals on Waitlist	Registry/Waitlist Management[396]	State Screens People on 1 or More Waiting Lists for Eligibility[397]
Ohio	Individual Options (IO), Level 1, and SELF 1915(c) waivers	2,000[402]	Priority	No
Oklahoma	Developmental Disabilities Services (DDS)	4,000[403]	First come, first served	No
Pennsylvania	Intellectual disabilities services and supports (including the Adult Autism, Community Living, Consolidated, and PFDS waiver).	12,400[404]	Priority and first come, first served	Unable to determine[405]

[402] Burns, Alice, Molly O'Malley Watts, and Meghana Ammula. *A Look at Waiting lists for Home and Community-Based Services from 2016 to 2021*. (November 2022). Accessed 20 April, 2023.
[403] Oklahoma Department of Human Services. *Developmental Disabilities Services Waitlist*. Accessed 20 April, 2023.
[404] Finalized PUNS as of February 28, 2023 By Region, County joinder, and Urgency of Needs. (March 2023). Accessed 27 April, 2023.
[405] Information obtained from KFF (2021) suggests that Pennsylvania was not determining eligibility for individuals on the states waiting list. However, the information the Pennsylvania Department of Human Services (2022) indicates that individuals on the waitlist are "eligible" for services under one of the 1915(c) waiver programs operated by the Office of Developmental Programs. Due to the conflicting information, the Team is noting "unable to determine" for Pennsylvania under this column.

Appendix XV: Ohio's Assessment for Immediate and Current Needs

ACTION: Final	EXISTING Appendix 5123-9-04	DATE: 11/09/2018 11:16 AM

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Ohio Assessment for Immediate Need and Current Need

Name of person assessed:	
Date of birth:	
Address:	
County of residence:	
Date of interview:	
Name of person completing assessment:	
Title of person completing assessment:	
Names of participants and relationship to person assessed:	
In what areas does the person report needing help?	

Condition [If "No" to any item, stop. This person does not meet the criteria to be added to the Waiting List for Home and Community-Based Services.]

Does this person have a condition that is attributable to a mental or physical impairment or combination of mental and physical impairments, other than an impairment caused solely by mental illness?	**Yes or No**
Was the condition present before age 22?	**Yes or No**
Is the condition likely to continue indefinitely?	**Yes or No**

Current Living Arrangements [Check one.]

- ☐ Lives alone
- ☐ Lives with family or other caregivers
- ☐ Lives with others who are not caregivers
- ☐ Lives in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICFIID)
- ☐ Lives in a Nursing Facility
- ☐ Other (describe):

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Currently Used or Available Resources/Services

County Board services/funding	**Yes or No**	Medicaid State Plan Private Duty Nursing	**Yes or No**
Help Me Grow/Ohio Early Intervention	**Yes or No**	Ohio Home Care Waiver	**Yes or No**
Bureau for Children with Medical Handicaps	**Yes or No**	PASSPORT Waiver	**Yes or No**
Family and Children First Council	**Yes or No**	Assisted Living Waiver	**Yes or No**
Ohio Department of Education	**Yes or No**	MyCare Waiver	**Yes or No**
Vocational Rehabilitation/ Opportunities for Ohioans with Disabilities	**Yes or No**	Self-Empowered Life Funding Waiver	**Yes or No**
Children Services	**Yes or No**	Level One Waiver	**Yes or No**
Medicaid State Plan Home Health Aide	**Yes or No**	Other (describe):	**Yes or No**
Medicaid State Plan Home Health Nursing	**Yes or No**		

Questionnaire

1 a. Is the individual an adult facing substantial risk of harm due to potential loss of existing caregiver(s) due to caregiver's declining or chronic condition or due to other unforeseen circumstances?

(i) Is there evidence that the primary caregiver has a declining or chronic condition or is facing other unforeseen circumstances that will limit his or her ability to care for the individual?
[Mark "Yes" if evidence is provided for 1a(i)(a).]

Yes or No

(a) List documentation used to verify presence of declining or chronic condition or unforeseen circumstances.

(b) Is action required within the next 30 days due to the caregiver's inability to care for the individual?

Yes or No

Describe required action:

[If "Yes" to 1a(i) and 1a(i)(b), the individual has an immediate need. Proceed to Question 2.]
[If "Yes" to 1a(i) and "No" to 1a(i)(b), this is a current need area. Proceed to next question.]

(ii) Is there evidence of declining skills the individual has experienced as a result of either the caregiver's condition or insufficient caregivers to meet the individual's current needs?

Yes or No

(a) List documentation used to verify presence of caregiver's condition, if not already described above.

(b) Describe decline. **[Required field.]**

[If "Yes" to 1a(ii), this is a current need area. Proceed to next question.]

1 b. Does the individual have behavioral, physical care, and/or medical needs that create substantial risk of harm to self/others?

(i) Is the individual a child/adult currently engaging in a pattern of behavior that creates a substantial risk to self/others? **[Mark "Yes" if 1b(i)(a) and 1b(i)(b) are completed.]**

Yes or No

(a) Check all that apply:

- ☐ Not applicable; there is currently no pattern of behavior that creates a substantial risk.
- ☐ Elopement
- ☐ Fire Setting
- ☐ Physical Aggression
- ☐ Self Injury
- ☐ Sexual Offending
- ☐ Other

* Describe type, frequency, and intensity of behavioral needs:
[Required if item in 1b(i)(a) is selected.]

(b) Documentation available: **[Only one option is required.]**

☐ Not applicable; there is currently no pattern of behavior that creates a substantial risk.

☐ Behavior Tracking Sheets

☐ Incident Reports

☐ Police Reports

☐ Psychological Assessment

☐ Other (describe):

[Proceed to next question.]

(ii) Is the individual a child/adult with significant physical care needs?
[Mark "Yes" if any one item in 1b(ii)(a) is selected.]

Yes or No

(a) Check all that apply:

☐ Not applicable; there are no significant physical care needs.

☐ Frequent hands-on support required with activities of daily living (personal care, mobility/positioning, toileting, etc.) throughout the day and night

☐ Size/condition of the individual creates a risk of injury during physical care

☐ Other

* Describe type, frequency, and intensity of physical care needs:
[Required if item in 1b(ii)(a) is selected.]

[Proceed to next question.]

(iii) Is the individual a child/adult with significant or life-threatening medical needs?
[Mark "Yes" if any one item in 1b(iii)(a) is selected.]

Yes or No

(a) Check all that apply:

☐ Not applicable; there are no significant or life-threatening medical needs.

☐ Frequent hospitalizations or emergency room visits for life-sustaining treatment

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- ☐ Ongoing medical care provided by caregivers to prevent hospitalization or emergency room intervention
- ☐ Need for specialized training of caregiver to prevent emergency medical intervention
- ☐ Other

* Describe type, frequency, and intensity of medical needs:
[Required if item in 1b(iii)(a) is selected.]

[Proceed to next question.]

(iv) Is action required within the next 30 days to reduce the risk presented by the behavioral, physical care, and/or medical needs identified in 1b(i), 1b(ii), and/or 1b(iii)?

Yes or No

[If "Yes," the individual has an immediate need. Proceed to question 2.]

(v) If "No," do the significant behavioral, physical care, and/or medical needs identified above require continuous support to reduce risk?

Yes or No

[If "Yes," this is a current need area. Proceed to next question.]

1 c. Is the individual an adult who has been subjected to abuse, neglect, or exploitation and requires supports to reduce risk? [Mark "Yes" if response to 1c(i) and 1c(ii) is "Yes."]

Yes or No

(i) There is currently an open investigation with: **[Check all that apply.]**

- ☐ Not applicable; there is currently no open investigation.
- ☐ Adult Protective Services
- ☐ County Board
- ☐ Law Enforcement
- ☐ Other (describe):

* Describe incident under investigation and supports needed to reduce the risk. **[Required if item in 1c(i) is selected.]**
(ii) Is action required within the next 30 days to reduce the risk? **Yes or No** **[If "Yes" to 1c, the individual has an immediate need. Proceed to question 2.]** **[If "No" to 1c, proceed to next question.]**

1 d. Is the individual a resident of an ICFIID or Nursing Facility who has either been issued a 30-day notice of intent to discharge or received an adverse Resident Review determination? [Mark "Yes" if response to 1d(i), 1d(ii), and 1d(iii) is "Yes."]

Yes or No

(i) Is the individual currently a resident of an ICFIID or Nursing Facility? **Yes or No** (ii) Has the individual been issued a 30-day notice of intent to discharge or received an adverse Resident Review determination? **Yes or No** (iii) Is action required within the next 30 days to reduce the risk? **Yes or No** **[If "Yes" to 1d, the individual has an immediate need. Proceed to question 2.]** **[If "No" to 1d, proceed to next question.]**

1 e. Does the individual have an ongoing need for limited/intermittent supports to address behavioral, physical, or medical needs in order to sustain existing caregivers and remain in the current living environment with existing supports? [Mark "Yes" if response to all three questions below is "Yes."]

Yes or No

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(i) Does the individual have a need for limited or intermittent supports within the next 12 months?

Yes or No

(ii) Does the individual desire to remain in the current living environment?

Yes or No

(iii) Are existing caregivers willing AND able to continue to provide supports, if some relief were provided?

Yes or No

[If "Yes" to 1e, this is a current need area. Proceed to next question.]

1 f. Is the individual reaching the age of majority and being released from the custody of a child protection agency within the next 12 months and has needs that cannot be addressed through alternative services? [Mark "Yes" if response to 1f(i) and 1f(ii) is "Yes."]

Yes or No

(i) Is the individual being released from the custody of a child protection agency within the next 12 months?

Yes or No

If "Yes," indicate anticipated date:

(ii) Does the individual have needs that cannot be addressed through alternative services?

Yes or No

[If "Yes" to 1f, this is a current need area. Proceed to next question.]

1 g. Does the individual require waiver funding for adult day or employment-related supports? [Mark "Yes" if response to all three questions below is "Yes."]

Yes or No

(i) Are the needed services required at a level or frequency that exceeds what is able to be sustained through local County Board resources?

Yes or No

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(ii) Are the needed services beyond what is available to the individual through the local school district/Individuals with Disabilities Education Act?

Yes or No

(iii) Are the needed services beyond what is available to the individual through Vocational Rehabilitation/Opportunities for Ohioans with Disabilities or other resources?

Yes or No

[If "Yes" to 1g, this is a current need area. Proceed to next question.]

1 h. Does the individual have a viable discharge plan from the current facility in which he/she resides? [Mark "Yes" if response to all three questions below is "Yes."]

Yes or No

(i) Is the individual currently a resident of an ICFIID or a Nursing Facility?

Yes or No

(ii) Has the individual/guardian expressed an interest in moving to a community-based setting within the next 12 months?

Yes or No

(iii) Is the individual's team developing a discharge plan that addresses barriers to community living, such as housing and availability of providers?

Yes or No

[If "Yes" to 1h, this is a current need area. Proceed to next question.]

2. Is there an immediate need identified that requires an action plan within 30 days to reduce the risk? If "Yes" to any of the following, an immediate need has been identified:

- **1a(i) + 1a(i)(b)**
- **1b(i), 1b(ii), and/or 1b(iii) + 1b(iv)**
- **1c**

or

- **1d**

Yes or No

If "Yes," describe the area of immediate need: **[Required if "Yes."]**   **[If "Yes" to 2, proceed to question 4.]** **[If "No" to 2, proceed to next question.]**

3 a. If "No" to 2, does the individual have a need identified in:

- **1a(i)**
- **1a(ii)**
- **1b(i), 1b(ii), and/or 1b(iii) + 1b(v)**
- **1e**
- **1f**
- **1g**

or

- **1h?**

["Yes" is required if any of the criteria listed is "Yes."]

Yes or No

3 b. If "Yes" to 3a, will any of those needs be unmet by existing supports/resources within the next 12 months? ["Yes" or "No" is required if 3a is "Yes."]

Yes or No

If "Yes," describe the unmet need: **[Required if "Yes."]**

4. Will the unmet immediate need or unmet current need require enrollment in a waiver due to the lack of community-based alternative services to address the need? ["Yes" or "No" is required.]

Yes or No

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If "No," describe the community-based alternative services that can address the unmet need: **[Required if "No."]**

Conclusion [Check one.]

☐ The individual has unmet needs that require enrollment in a waiver at this time to address circumstances presenting an immediate risk of harm.
- **Requires ALL of the following:**
  - **"Yes" to all three condition questions**
  - **"Yes" to question 2**
  - **"Yes" to question 4**

☐ The individual has needs that are likely to require waiver-funded supports within the next 12 months and will be placed on the Waiting List for Home and Community-Based Services at this time.
- **Requires ALL of the following:**
  - **"Yes" to all three condition questions**
  - **"Yes" to question 3a**
  - **"Yes" to question 3b**
  - **"Yes" to question 4**

☐ The individual does not require waiver enrollment or placement on the Waiting List for Home and Community-Based Services as alternative services are available to meet assessed needs.
- **This is the outcome if one of the other two outcomes above are not met. Requires the following:**
  - **"No" to question 4**

☐ The individual is not eligible for waiver enrollment or placement on the Waiting List for Home and Community-Based Services, as he/she has no qualifying condition.
- **This is the outcome if one or more of the three condition questions is "No."**

Name of person determining conclusion:
Title of person determining conclusion:
Date conclusion determined:

Appendix XVI: Peer State Service Examples - Descriptions

State[406]	Service	Description
Colorado	Case Management	• Assistance provided by a case management agency to include referrals to needed Medicaid services and supports. • Case management also includes LOC determinations and person-centered planning supports. • Scope of services does not include provision of direct services to an individual.
Colorado	In-Home Support Services	• Limited under the Children's Home and Community-Based waiver to health maintenance activities. • Health maintenance activities are the routine skilled tasks needed for health and normal bodily functioning. • A child's need for In Home Support Services must be determined to be above normal care for a child that a parent or legal guardian is not responsible for providing.
Kansas	Assistive Services	• Services that modify or improve an individual's home through home modifications or enhance the ability to live independently. • Assistive services include adaptive equipment (includes durable medical equipment), van lifts, communication devices, and home modifications. • Up to $300 may be approved on an annual basis to pay for the maintenance and/or repair of a previously approved Assistive Service.
Kansas	Enhanced Care Service	• Provides supervision and/or non-nursing physical assistance during a participant's normal sleeping hours in his/her place of residence. • Available to participants who demonstrate an assessed need for a minimum of six hours of additional care for overnight support, during the participant's normal

[406] All service descriptions were in the same waiver application for each state. Please reference Appendix XI for waiver application references.

State[406]	Service	Description
		hours of sleep, and the assessed need cannot be met by the use of Personal Emergency Response Services, informal supports, or other less restrictive services.
Kansas	Overnight Respite	• Overnight Respite Care is designed to provide relief for the participant's family member who serves as an unpaid primary caregiver. • Since it is the intention of Overnight Respite to provide relief for the participant's family member who serves as an unpaid primary caregiver, the unpaid primary caregiver cannot be paid to provide respite. • A self-direct option may be chosen for Overnight Respite by the participant if the participant is not a child in custody living in a licensed foster care setting.
Kansas	Residential Supports	• Adult Residential Supports are provided to waiver individuals who live in a residential setting and do not live with their birth or adoptive parents, or a person meeting the definition of family. Family is defined as any person immediately related to the participant, such as parents/legal guardian, spouse, siblings, adult children, aunts, uncles, first cousins and any stepfamily relationships. • Provides assistance with and acquisition, retention, and/or improvement of skills related to activities of daily living such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, and the social and adaptive skills necessary to enable the individual to reside in a non-institutional setting.
Kansas	Specialized Medical Care	• This service provides long-term nursing support for medically fragile and technology-dependent participants. The required LOC must provide medical support for participants needing ongoing, daily care that would otherwise require the participant to be in a hospital. The intensive medical needs of the participant must be met to ensure the participant can live outside of a hospital or ICF/IID.
Kansas	Wellness Monitoring	• Wellness Monitoring is a process whereby a registered nurse evaluates the level of wellness of a participant to determine if the participant is properly using medical health services as recommended by a physician and if the health of the

State[406]	Service	Description
		participant is sufficient to maintain him/her in the participant's place of residence without more frequent skilled nursing intervention. • Wellness Monitoring includes checking and/or monitoring orientation to surroundings, skin characteristics, edema, personal hygiene, blood pressure, respiration, and pulse adjustments to medication.
Missouri	Structured Family Caregiving	• Structured Family Caregiving means a homemaker and attendant care service in which a waiver participant with a diagnosis of Alzheimer's or dementia lives in his/her private home or the private home of a principal caregiver who may be a non-family member, a family member, or a legal guardian. • Allowable activities include but are not limited to homemaker care, attendant care services, medication oversight, and escorting and attendance at medical appointments.
Ohio	Community Respite	• Community Respite means services provided to individuals unable to care for themselves that are furnished on a short-term basis because of the absence or need for relief of those persons who normally provide care for the individuals. • Community Respite shall only be provided outside of an individual's home in a camp, recreation center, or other place where an organized community program or activity occurs.
Ohio	Career Planning	• Career Planning means individualized, person-centered, comprehensive employment planning and support that provides assistance for individuals to attain or advance in competitive integrated employment. • Activities that constitute career planning include but are not limited to: Situation observation and assessment, Career exploration, Benefits education and analysis, Career discovery, worksite accessibility, and Purchasing or modifying equipment that will be retained by the individual at the current employment site and/or in other settings when documented that funding from the opportunities for Ohioans with disabilities agency or any other source is not available.

State[406]	Service	Description
Ohio	Functional Behavioral Assessment	• Functional Behavioral Assessment is an assessment not otherwise available under the state Medicaid program to determine why an individual engages in intensive behaviors and how the individual's behaviors relate to the environment. • Describes the relationship between a skill or performance problem and the variables that contribute to its occurrence. • Can provide information to develop a hypothesis as to why the individual engages in the behavior, when the individual is most likely to demonstrate the behavior, and situations in which the behavior is least likely to occur.
Ohio	Home Delivered Meals	• Home delivered meals means the preparation, packaging, and delivery of one or more meals to individuals who are unable to prepare or obtain nourishing meals. • A maximum of two meals per day shall be provided.
Ohio	Residential Respite	• Residential Respite is a service provided to individuals unable to care for themselves that are furnished on a short-term basis because of the absence or need for relief of those persons who normally provide care for the individuals. • Residential Respite shall only be provided in the following locations: ○ An intermediate care facility for individuals with intellectual disabilities (ICF/IID) ○ A residential facility, other than an ICF/IID, licensed by the Department of Developmental Disabilities under section 5123.19 of the Revised Code ○ A residence, other than an ICF/IID or a facility licensed by the Department of Developmental Disabilities under section 5123.19 of the Revised Code, where Residential Respite is provided by an agency provider
Ohio	Waiver Nursing Delegation	• Waiver nursing delegation services means the initial and ongoing supports provided by a licensed nurse who is delegating a nursing task or assuming responsibility for individuals who are receiving delegated nursing care. • The service includes two distinct components: assessment of the individual receiving delegated nursing care that includes a face-to-face interview and

State[406]	Service	Description
		observation of the individual receiving care and supervision of the performance of the nursing task performed by the unlicensed person.
Oklahoma	Agency Companion	• A living arrangement meant to support the specific needs of the waiver participant in a shared living arrangement. • Agency companion services provide supervision, supportive assistance, and training in daily living skills, and integrates the member in the shared experiences of a family.
Oklahoma	Dental	• Dental services include maintenance or improvement of dental health, as well as relief of pain and infection.
Oklahoma	Family Counseling	• Family Counseling, offered specifically to members and their natural, adoptive, or foster family members, helps to develop and maintain healthy, stable relationships among all family members to support meeting the needs of the member. • Emphasis is placed on the acquisition of coping skills by building upon family strengths. • Knowledge and skills gained through family counseling services increase the likelihood that the member remains in or returns to his or her own home.
Oklahoma	Psychological Services	• Includes evaluation, psychotherapy, consultation, and behavioral treatment provided in any community setting. • Are intended to maximize a member's psychological and behavioral well-being. • Services are provided in both individual and group (six person maximum) formats.
Oklahoma	Specialized Foster Care	• Specialized Foster Care is an individualized living arrangement offering up to 24 hour per day supervision, supportive assistance, and training in daily living skills. • Services are intended to allow a member to reside with a surrogate family. • Four levels of specialized foster care, based on the member's age and level of need as determined by the Team are: (1) maximum supervision, 18 years and under, for those members with extensive needs; (2) close supervision, 18 years

State[406]	Service	Description
		and under, for those members with moderate needs; (3) maximum supervision, 19 years and older, for members with extensive needs; and (4) close supervision, 19 years and older, for members with moderate needs.
Pennsylvania	Community Transition Services	• Community Transition Services are non-recurring set-up expenses for individuals who have transitioned from a Medicaid-funded institution to a private residence where the person is directly responsible for his or her living expenses. Community Transition Services are limited to the following: ○ Essential furnishings and initial supplies (e.g., household products, dishes, chairs, and tables) ○ Moving expenses ○ Security deposits or other such one-time payments that are required to obtain or retain a lease on an apartment home ○ Set-up fees or deposits for utility or service access (e.g., telephone, electricity, heating, etc.) ○ Personal and environmental health and welfare assurances (e.g., pest eradication, allergen control, one-time cleaning prior to occupancy)
Pennsylvania	Family Support	• Provides counseling and training for the participant's unpaid family and informal network to help develop and maintain healthy, stable relationships among all members of the participant's unpaid informal network, including family members, and the participant to support the participant in meeting the goals in the participant's individual service plan. • Family Support assists the participant's unpaid family and informal care network with developing expertise so that they can help the participant acquire, retain, or improve skills that directly improve the participant's ability to live independently. • Emphasis placed on the acquisition of coping skills, stress reduction, improved communication, and environmental adaptation by building upon family and informal care network strengths.

State[406]	Service	Description
Pennsylvania	Specialized Skill Development	• Specialized Skill Development is used to address challenges participants may have because of limited social skills, perseverative behaviors, rigid thinking, and difficulty interpreting cues in the natural environment, limited communication skills, impaired sensory systems, or other reasons.
Pennsylvania	Therapies	• Therapies are services provided by health care professionals that enable individuals to increase or maintain their ability to perform activities of daily living. • Therapies in this waiver are limited to: ○ Speech/language therapy provided by a licensed speech therapist or certified audiologist upon examination and recommendation by a certified or certification-eligible audiologist or a licensed speech therapist. ○ Counseling provided by a licensed psychologist, licensed psychiatrist, licensed social worker, and licensed professional counselor, or licensed marriage and family therapist.
Pennsylvania	Temporary Supplemental Services	• Provides additional staff in the short term when it has been determined that the participant's health and welfare is in jeopardy and needed supports and services cannot be provided without additional staff assistance. • Temporary Supplemental Services is intended for unforeseen circumstances which trigger a need for a time limited increase in support and is intended for circumstances such as unplanned stressful life events which increase a participant's risk of a crisis event (such as the recent loss of a family member), or to support a participant to return to baseline following a recent crisis event, which triggered a need for a time-limited increase in support.
South Dakota	Adult Day Services	• Adult day services provide regular care, supervision, and structured activities in a non-institutional community-based setting. • Includes both health and social services needed to ensure the optimal functioning of the consumer for a period of less than 24 hours per day. • Provided to a consumer who lives at home.

State[406]	Service	Description
South Dakota	Assisted Living	• Assisted living centers offer homemaker, personal care, chore, and meal preparation to consumers who reside in a home-like, non-institutional setting that includes 24-hour on-site response capability to meet scheduled or unpredictable consumer needs and to provide supervision, safety, and security. • The assisted living location promotes the health, treatment, comfort, safety, and well-being of residents, with easy accessibility for visitors and others. • Services also include social and recreational programming, and medication assistance (to the extent permitted under state law).
South Dakota	Chore Services	• Includes chore services needed to maintain the consumer's home in a healthy and safe environment. • Chore services are lawn mowing, snow and ice removal from sidewalks and driveways, or other services which the homeowner is required to complete by city or county ordinance.
South Dakota	Community Living Home	• Community living home residential services offer waiver participants an opportunity to receive services and supports in a small licensed home. • The purpose of this service is to provide necessary care and supervision for the participant and to provide an opportunity for the participant to remain in the community in the most integrated setting. • Participant's needs shall be addressed in a manner that supports and enables the individual to maximize abilities to function at the highest level of independence possible.
South Dakota	Residential Respite Care	• Care will be provided short-term (less than 30 consecutive days) for an individual who is unable to care for him or herself in the absence of or for the relief of the caregiver.
South Dakota	Structured Family Caregiving	• The structured family caregiving service offers waiver participants an opportunity to reside with a principal caregiver in the participant's own private home or in the private home of the principal caregiver.

State[406]	Service	Description
		• The goal of this service is to provide necessary care and supervision for the participant, and to provide an opportunity for the participant to remain in the community in the most integrated setting.
Tennessee	Behavioral Respite Services	• Short-term, behavior-oriented services for a supported person who is experiencing a behavioral crisis that requires removal from the current residential setting to assist in resolving the behavioral crisis. • Behavioral Respite Services providers shall also help to plan, coordinate, and prepare for the individual's transition back to his/her residential setting.
Tennessee	Family Model Residential Supports	• Family Model Residential Support shall mean a type of residential service selected by the person supported, where he or she lives in the home of a trained caregiver who is a not family member in an "adult foster care" arrangement. • A family member(s) of the persons supported shall not be reimbursed to provide Family Model Residential Support services. • Family Model Residential Supports may include medication administration as permitted under Tennessee's Nurse Practice Act and performance of other non-complex health maintenance tasks, as permitted by state law.
Tennessee	Intermittent Employment and Community Integration Wrap-Around Supports	• These supports are expressly designed to support waiver participants in engaging in integrated community participation and integrated community employment when sustained, all-day participation in these opportunities outside the home is not possible for the individual due to intermittent needs related to personal care (where this care requires certain environments and/or equipment to perform, which is not otherwise available to the individual in any integrated community setting), personal assistance with preparing and eating a meal, and/or regaining stamina (physical and mental readiness and/or motivation for integrated community participation and/or employment occurring later on the same day). • Designed to avoid the need for people to attend a facility-based day service setting to have intermittent needs met, and to enable people with these needs to

State[406]	Service	Description
		use their home as the base from which they routinely access their neighborhood and broader community.
Tennessee	Residential Habilitation	• Residential Habilitation shall mean a type of residential service selected by the person supported, offering individualized services and supports that enable the person supported to acquire, retain, or improve skills necessary to reside in a community-based setting and which supports each resident’s independence and full integration into the community, and ensures each resident’s choice and rights.
Tennessee	Transitional Case Management	• Case management services provided for the purpose of community transition of a Medicaid-eligible person residing in an ICF/IID or other institutional setting who has been determined to qualify for HCBS waiver services upon discharge during the last 180 consecutive days of the person’s institutional stay prior to being discharged and enrolled in the waiver. • Shall assist the person supported in identifying, selecting, and obtaining both paid services and natural supports to enhance the independence, integration in the community, and productivity of the person supported, as specified in the transitional plan of care.
Wisconsin	Community Transportation	• Community Transportation is the transport of a participant to and from a waiver service, place of employment, or community service, activity, or resource. • Is offered in addition to medical transportation.
Wisconsin	Consultative Clinical and Therapeutic Services for Caregivers	• Clinical and therapeutic services assist unpaid caregivers and/or paid support staff in carrying out the participant’s treatment/support plans and are necessary to improve the participant’s independence and inclusion in their community. • The service includes assessments, development of home treatment plans, support plans, intervention plans, training and technical assistance to carry out the plans, consultation with providers and potential providers, and monitoring of the participant and the provider in the implementation of the plans. This may be

State[406]	Service	Description
		provided in the individual's home or in the community, as described in the participant's service plan.
Wisconsin	Consumer Education and Training	• Consumer education and training services are designed to help participants develop self-advocacy skills, support self-determination, exercise civil rights, and acquire skills needed to exercise control and responsibility over services and supports. • Self-advocacy skills enable participants to communicate wants and needs, make informed decisions, and develop trusted supports with whomever they can share concerns. • The consumer education and training service includes education and training for participants, their caregivers, and legal representatives that is directly related to developing such skills.
Wisconsin	Residential Services (1-2 Bed)	• Residential services are a combination of individually tailored supports, services, treatment, and care provided within a community-integrated residential setting above the level of room and board. • Residential services also include collaboration with health care, vocational, or day service providers. • The scope of residential services may include performing personal care or supportive home care; however, such activities may not comprise the entirety of the service.
Wisconsin	Training Services for Unpaid Caregivers	• This service is the provision of training services for individuals who provide uncompensated care, training, companionship, supervision, or other supports to participants. • Training includes instruction about treatment regimens and other services that are included in the participant's person-centered service plan. • Training must be aimed at assisting the unpaid caregiver in meeting the needs of the participant.

State[406]	Service	Description
		• This service includes, but is not limited to, online or in-person training, conferences, or resource materials on the specific disabilities, illnesses, or conditions that affect the member.

Appendix XVII: Peer State Self-Direction Opportunities

State	Peer State 1915(c) Waivers – Employer Authority Only[407]	Peer State 1915(c) Waivers – Budget Authority Only	Peer State 1915(c) Waivers – Both Authorities	Peer State 1915(c) Waivers – No Self-Direction
Colorado	• Children's Home and Community-Based Services	Not applicable	• Brain Injury • HCBS for Community Mental Health Supports • Complementary and Integrative Health • Elderly, Blind, and Disabled • Supported Living Services	• Children's Extensive Support • Children's Habilitation Residential Program • Developmental Disabilities • HCBS waiver for Children with Life-Limiting Illness
Kansas	• Autism • HCBS Brain Injury • HCBS Frail Elderly • HCBS-I/DD • Physical Disability waiver • Technology Assisted	Not applicable	Not applicable	• Serious Emotional Disturbance waiver

[407] Please reference Appendix XI for waiver application references.

State	Peer State 1915(c) Waivers – Employer Authority Only[407]	Peer State 1915(c) Waivers – Budget Authority Only	Peer State 1915(c) Waivers – Both Authorities	Peer State 1915(c) Waivers – No Self-Direction
Missouri	• Independent Living	Not applicable	• Children with Developmental Disabilities • Community Support • DD Comprehensive waiver • Partnership for HOPE	• Adult Day Care • Aged and Disabled • AIDS • Brain Injury • Medically Fragile Adult • Structured Family Caregiving
Ohio	• Assisted Living	• OhioRISE	• Individual Options • Level One • MyCare Ohio • PASSPORT • SELF	• Assisted Living • Ohio Home Care
Oklahoma	Not applicable	Not applicable	• ADvantage • Community • In-Home Supports waiver for Adults • In-Home Supports for waiver for Children • Medically Fragile	• Homeward Bound
Pennsylvania	• OBRA	Not applicable	• Community Living • Consolidated	• Adult Autism • Medicaid waiver for Infants,

State	Peer State 1915(c) Waivers – Employer Authority Only[407]	Peer State 1915(c) Waivers – Budget Authority Only	Peer State 1915(c) Waivers – Both Authorities	Peer State 1915(c) Waivers – No Self-Direction
				Toddlers and Families • Person/Family Directed Support
South Dakota	• Assistive Daily Living Services	Not applicable	• Family Support waiver	• Choices • HOPE
Tennessee	Not applicable	Not applicable	• Self-Determination waiver Program	• Comprehensive Aggregate Cap Home and Community-Based Services • Statewide Home and Community-Based Services
Wisconsin	Not applicable	Not applicable	• Children's Long-Term Support • Family Care waiver • IRIS	Not applicable

Appendix XVIII: State Definitions of Legally Responsible Individuals and Guardians

State	Legally Responsible Individuals Definition	Guardian Definition
Colorado[408]	The parent of a minor child or an individual's spouse.	An individual at least 21 years of age, resident or non-resident, who has qualified as a guardian of a minor or incapacitated person pursuant to appointment by a parent or by the court. The term includes a limited, emergency, and temporary substitute guardian but not a guardian ad litem S, as set forth in state regulation.
Kansas	Any one of the following: Parent (biological or adoptive) of a minor child. Spouse of a waiver participant. Legal guardian or activated durable power of attorney of a waiver participant. Foster parent.[409]	An individual or a corporation certified in accordance with Kansas statute who or which is appointed by a court to act on behalf of a ward, and who or which is possessed of some or all of the powers and duties set out in statute. Guardian does not mean a "natural guardian" unless specified. Natural guardian means both the biological or adoptive mother and father of a minor if neither parent has been found to be an adult with an impairment in need of a guardian or has had parental rights terminated by a court.[410]

[408] Code of Colorado Regulations. 10 CCR 25505-10 8.500.1 Definitions. Accessed 8 September, 2023. Page 3.
[409] Kansas HCBS-I/DD waiver Application. (July 2021). Accessed 13 July, 2023. Page 105.
[410] Kansas State Statute. Article 30. Guardians or Conservators. 59-3051. Definitions. Accessed 8 September, 2023.

State	Legally Responsible Individuals Definition	Guardian Definition
Missouri	Unable to determine	A person appointed by a court to have the care and custody of the person of a minor or of an incapacitated individual.[411]
Nebraska	A spouse or the natural or adoptive parents of minor children.	A person appointed by a court to serve as a guardian for someone ages 19 years or older.[412]
Ohio	Definition applies only to 1915(c) waivers administered by the Ohio Department of Medicaid. "An individual's spouse, or in the case of a minor, the individual's birth or adoptive parent." [413]	Any person, association, or corporation appointed by the probate court to have the care and management of the person, the estate, or both of an incompetent or minor. When applicable, "guardian" includes, but is not limited to, a limited guardian, an interim guardian, a standby guardian, and an emergency guardian appointed pursuant to division (B) of section 2111.02 of the Revised Code. "Guardian" also includes an agency under contract with the department of developmental disabilities for the provision of protective service under sections 5123.55 to 5123.59 of the Revised Code when appointed by the probate court to have the care and management of the person of an incompetent.[414]
Oklahoma	Any one of the following: A minor child's biological or adoptive parent(s). A legal guardian of a minor.	A person appointed by the court to take care of the person or property of another.[416]

[411] Revisor of Missouri. Chapter 475.010 Definitions. Accessed 8 September, 2023.
[412] DHHS, DDD. *LRI Reference Guide*. (March 2023). Accessed 8 September, 2023. Page 1.
[413] Ohio Administrative Code. *5160-45-01 Ohio department of Medicaid (ODM)-administered waiver programs: definitions*. (October 2020). Accessed 15 July, 2023.
[414] Ohio Revised Code. Section 2111.01 Guardian and conservatorship definitions. (October 2016). Accessed 8 September, 2023.
[416] Oklahoma Statutes. Title 30. Guardian and Ward. (December 1988). Accessed 8 September, 2023. Page7.

State	Legally Responsible Individuals Definition	Guardian Definition
	A spouse of an individual. Anyone deemed by a court as legally responsible.[415]	
Pennsylvania	Spouse or legal guardian.[417]	A person lawfully invested with the power, and charged with the duty, of taking care of and managing the property and rights of another person.[418]
South Dakota	Includes the parent of a minor child (under the age of 18) or the spouse of an individual.[419]	A legal relationship that gives one or more individuals or agencies the responsibility of the personal affairs of the protected person.[420]
Tennessee	A person or persons appointed by the court to provide partial or full supervision, protection and assistance of the person or property, or both, of a minor.[421]	Unable to determine.
Wisconsin	"Legally responsible" means a spouse's liability for the support of a spouse or a parent's liability for the support of a child.[422]	A person appointed by a court order to manage the income and assets and provide for the essential requirements for health and safety and the personal needs of an individual found incompetent or a spendthrift or to manage the income and assets of a minor.[423]

[415] Oklahoma Human Services. *Library: Policy*. (May 2007). Accessed 15 July, 2023.
[417] Legislative Budget and Finance Committee. *Family Caregivers in Pennsylvania's Home and Community-Based Waiver Programs*. (June 2015). Accessed 8 September, 2023. Page 48.
[418] Jenkins Law Library. *Guardianship in Pennsylvania*. (May 2023). Accessed 8 September, 2023.
[419] South Dakota Family Support 360 Waiver. (June 2022). Accessed 19 July, 2023. Page 91.
[420] Department of Human Services. *Guardianship and Conservatorship FAQ's*. Accessed 8 September, 2023.
[421] Tennessee Code Annotated. Title 34 Guardianship. 34-1-101. Chapter 1-3 definitions. (2023). Accessed 8 September, 2023.
[422] Wisconsin Administrative Code. DHS 101.03 Definitions. Accessed 8 September, 2023.
[423] Wisconsin State Legislature. Chapter 54.01 Definitions. Accessed 8 September, 2023.

Appendix XIX: Peer State Payments to Legally Responsible Individuals

State[424]	Payment to Legally Responsible Individuals- Personal Care	Payment to Relatives/Legal Guardians in Specific Circumstances	Other Policies
Colorado	**Yes** • Brain Injury • Children with Life-Limiting Illness • Children's Home and Community-Based Services • Community Mental Health Services • Complementary and Integrative Health • Elderly, Blind, and Disabled • Supported Living Services **No** • Children's Extensive Support • Children's Habilitation Residential Program • Developmental Disabilities	**Yes** • Brain Injury • Children with Life-Limiting Illness • Children's Extensive Support • Children's Habilitation Residential Program • Children's Home and Community-Based Services • Community Mental Health Services • Complementary and Integrative Health • Developmental Disabilities • Elderly, Blind, and Disabled • Supported Living Services	Not applicable
Kansas	**Yes** • Brain Injury • HCBS-I/DD • HCBS Frail and Elderly • Physical Disability • Technology Assisted **No**	**Yes** • Brain Injury • HCBS-I/DD • HCBS Frail and Elderly • Physical Disability • Technology Assisted **No**	Not applicable

[424] Please reference Appendix XI for waiver application references.

State[424]	Payment to Legally Responsible Individuals- Personal Care	Payment to Relatives/Legal Guardians in Specific Circumstances	Other Policies
	• Autism • Serious Emotional Disturbance	• Autism • Serious Emotional Disturbance	
Missouri	**Yes** • Structured Family Caregiving **No** • Adult Day Care • Aged and Disabled • AIDS • Brain Injury • Children with Developmental Disabilities • Community Support • DD Comprehensive waiver • Independent Living • Medically Fragile Adult • Partnership for Hope	**Yes** • Adult Day Care • Aged and Disabled • Children with Developmental Disabilities • Community Support • DD Comprehensive waiver • Medically Fragile Adult • Partnership for Hope • Structured Family Caregiving **No** • AIDS • Brain Injury • Independent Living	Not applicable
Ohio	**No** • Assisted Living • MyCare Ohio • Ohio Home Care • OhioRISE • Individual Options • Level One • PASSPORT • SELF	**Yes** • Individual Options • Ohio Home Care • OhioRISE • Level One • SELF **No** • Assisted Living	• MyCare Ohio • PASSPORT
Oklahoma	**Yes**	**Yes**	Not applicable

State[424]	Payment to Legally Responsible Individuals- Personal Care	Payment to Relatives/Legal Guardians in Specific Circumstances	Other Policies
	• ADvantage • Medically Fragile **No** • Community waiver • Homeward Bound • In Home Supports for Adults • In Home Supports for Children	• ADvantage • Community waiver • Homeward Bound • In Home Supports for Adults • In Home Supports for Children • Medically Fragile	
Pennsylvania	**Yes** • Community Living • Consolidated waiver • Person/Family Directed Support **No** • Adult Autism • Medicaid waiver for Infants, Toddlers, and Families • OBRA	**Yes** • Adult Autism • Community Living • Consolidated waiver • OBRA • Person/Family Directed Support **No** • Medicaid waiver for Infants, Toddlers, and Families	Not applicable
South Dakota	**Yes** • Assisted Daily Living Services • HOPE **No** • CHOICES • Family Support 360	**Yes** • Assisted Daily Living Services • HOPE **No** • CHOICES	• Family Support 360
Tennessee	**Yes** • Comprehensive Aggregate Cap HCBS waiver • Statewide HCBS waiver **No**	**Yes** • Comprehensive Aggregate Cap HCBS waiver • Self-Determination waiver Program	Not applicable

State[424]	Payment to Legally Responsible Individuals- Personal Care	Payment to Relatives/Legal Guardians in Specific Circumstances	Other Policies
	• Self-Determination waiver Program	• Statewide HCBS waiver	
Wisconsin	**Yes** • Family Care waiver • IRIS **No** • Children's Long-Term Support	**Yes** • Family Care waiver • IRIS	• Children's Long-Term Support

Appendix XX: Peer State ICFs/IID References

State	ICFs/IID In Use	Resources
Colorado	Yes	Colorado ICF/IID Services
Kansas	Yes	Kansas ICF/IID Services
Missouri	Yes	Missouri ICF/IID Services
Ohio	Yes	Ohio ICF/IID Services
Oklahoma	Yes	Oklahoma ICF/IID Services
Pennsylvania	Yes	Pennsylvania ICF/IID Services
South Dakota	Yes	South Dakota ICF/IID Services
Tennessee	Yes	Tennessee ICF/IID Services
Wisconsin	Yes	Wisconsin ICF/IID Services

Appendix XXI: Peer State Non-Medicaid Funded Program Examples

State	Program Name	Description
Colorado	School-Based Health Center (SBHC) Program	SBHCs are medical clinics that offer health care to children in a school or school grounds. Services provided by SBHCs include but are not limited to: • Well-child exams • Sick visits • Health screenings • Substance use screening • Mental health and other counseling • Oral health screenings The SBHC funding comes from a combination of state and federal appropriations. Most funds are distributed through grants to local SBHCs. Priority is given to centers that serve a disproportionate number of uninsured children, low-income populations, or both. The SBHC program partners with other state agencies and grant programs to expand services available in SBHCs.[425]
Kansas	Kansas Special Health Care Needs Program	The Kansas Special Health Care Needs Program provides specialized medical services to individuals up to age 21 who have multiple medical conditions in addition, the program supports specialized formula services to individuals of any age who are diagnosed with phenylketonuria and maple syrup urine disease. Services

[425] Colorado Department of Public Health & Environment. *What is a school-based health center?* Accessed 25 July, 2023.

State	Program Name	Description
		may include diagnostic evaluations, treatment, or care coordination.[426]
Missouri	Child Care Subsidies	Individuals are eligible for childcare subsidies if they are the parent or guardian of a child under age 13, a child 18 or under with a disability, or a child with a disability 19 or under if they are still in school, who are: • Earning a low-income • Employed or searching for work • Attending school • Disabled • Homeless • Participating in job training or a placement program • Receiving services from the Missouri Children's Division[427] Parents and guardians of children with disabilities will have their sliding fee waived, and the child's provider is paid an additional amount for services provided.[428]
Ohio	Pediatric Respite Care Program	The Pediatric Respite Care Program is targeted to providing respite and related services to pediatric patients and their families who are experiencing a terminal pediatric illness. Pediatric respite care patients must be less than 27 years of age who were diagnosed with a life-threatening disease expected to shorten life, prior to the age of 18.[429]

[426] Kansas Department of Health and Environment, Kansas Division of Public Health. *Special Health Care Needs*. Accessed 24 July, 2023.
[427] Missouri Department of Social Services. *Apply for Child Care*. Accessed 24 July, 2023.
[428] Missouri Department of Social Services. *Children with Special Needs*. Accessed 24 July, 2023.
[429] Ohio Department of Health. *Pediatric Respite Care*. Accessed 24 July, 2023.

State	Program Name	Description
Oklahoma	Respite Voucher Program	The Respite Voucher Program provides funding to caregivers to pay for respite services. To be eligible, the person a caregiver supports: • Cannot receive HCBS 1915(c) waiver services. • Receives less than 20 hours per week of state funded services (with some exceptions). • Has a DD as defined by Oklahoma rules. • Must live in a kinship home if in the custody of the state. The caregiver: • Cannot receive a payment from the Family Support Assistance Program. • Must live in Oklahoma. • Must not receive respite services funded through another state or federal program. • Reside with and provide at least eight hours of care per day for the individual. • Have an adjusted gross income of less than $75,000 per year.[430]
Pennsylvania	Special Kids Network	The Special Kids Network is a hotline dedicated to assisting providers and parents of children with special health care needs access to local services and supports. The Network serves individuals with physical, developmental, behavioral, or emotional needs from birth through age 21.[431]

[430] Oklahoma Human Services. *Respite Voucher Program*. Accessed 24 July, 2023.
[431] Pennsylvania Department of Health. *Special Kids Network*. Accessed 24 July, 2023.

State	Program Name	Description
South Dakota	South Dakota Statewide Engagement Center	The South Dakota Statewide Engagement Center is separate from the State's Early Intervention program. The Statewide Engagement Center serves individuals from birth to age five by providing training and resources to families and early childhood professionals to help prepare kids for success in school.[432]
Tennessee	Tennessee Technology Access Program	This statewide program provides increased access to and acquisition of assistive technology and devices. The program is specific to individuals with disabilities and their families access needed to services to help support living independent lives. The program partners with assistive technology centers in different regions of the state. The centers provide training, evaluation, minority outreach, and advocacy services.[433]
Wisconsin	Children and Youth with Special Health Care Needs Program	The Children and Youth with Special Health Care Needs Program services individuals from birth to 21 by: • Identifying special health care needs early. • Ensuring high quality care is delivered by multiple systems serving the individual. • Providing support to families and individuals. To be eligible, individuals must have a chronic physical, developmental, behavioral, or emotional condition such as: • Attention-deficit hyperactivity disorder • Asthma

[432] South Dakota Statewide Family Engagement Center. Birth to 5. Accessed 24 July, 2023.
[433] Department of Human Services. *Tennessee Technology Access Program (TTAP)*. Accessed 24 July, 2023.

State	Program Name	Description
		• Autism • Cerebral palsy • Childhood cancers • Deafness or blindness • Diabetes • Down syndrome • Heart disease • Mental health conditions[434]

[434] Wisconsin Department of Health Services. *Children and Youth with Special Health Care Needs*. Accessed 24 July, 2023.

Appendix XXII: Peer State Aging and Disability Resource Center Services

State	ADRC Services Available	Reference
Colorado	Assistive technology. Care coordination. Caregiver counseling. Caregiver education. Caregiver support. Congregate meals. Emergency Response systems. Equipment and supplies. Friendly visitors and telephone reassurance. Home-delivered meals. Home health care. Home modifications. Information and assistance. In-home services. Legal assistance. Long-term care Ombudsman. Nutrition services. Outreach. Person-centered options counseling. Physical activity. Planning for future long-term service and support needs. Respite. Senior community services employment. Support services. Transportation.	Colorado ADRC

State	ADRC Services Available	Reference
Kansas	Care coordination. Caregiver support services. Chore services. Community services. Home delivered meals. Home health care. Homemaker services. Home repair and modifications. Household tasks. Housing and long-term care. Medical services. Nursing homes. Personal care assistance. Personal care services. Respite. Transportation.	Kansas ADRC
Missouri	Caregiver services. Case management. Exercise & health programs. Home modifications. Information & assistance. In-home services. Legal assistance. Nutrition. Respite. Social opportunities.	Missouri Area Agencies on Aging

State	ADRC Services Available	Reference
	Telephone reassurance. Transportation. Volunteer opportunities.	
Ohio	Caregiver support services. Chronic conditions education. Community connections. Falls prevention education. Heating and cooling assistance programs. Home delivered meals. Home maintenance and modification services. Long-term care consultations. Medicaid home and community-based long-term care services. Nutrition education and counseling. Transportation.	Ohio Area Agencies on Aging
Oklahoma	Caregiver assistance. Congregate and home-delivered meals. Health promotion. In-home assistance. Information and assistance. Legal assistance. Long-term care Ombudsman program. Nutrition education. One-on-one assistance for life decisions. Resources for grandparents raising grandchildren. Respite. Transportation.	Oklahoma Aging Services Division

State	ADRC Services Available	Reference
Pennsylvania	Caregiver support Employment. Health & wellness. Help at home. Housing. Legal assistance. Meals. Medicare counseling. Ombudsman. PACE – prescription assistance. Financial exploitation. Protective Services. Transportation.	Pennsylvania Department of Aging
South Dakota	Adult companion services. Adult day services. Adult Protective Services. Assistive devices. Family and self-advocate training and resources. Financial assistance to become a guardian for a vulnerable adult. Homemaker and chore services. Housing and vehicle modifications. Incontinence supplies. Light housekeeping. Medication management. Medications. Meal preparation.	South Dakota ADRC

State	ADRC Services Available	Reference
	Nutritional supplements. Personal hygiene services. Paid family caregiver. Recreational opportunities. Resources for people who are blind or visually impaired. Respite and caregiver services. Respite services for caregivers of people with DD. Services for people who are Deaf or hard of hearing. South Dakota Developmental Center information for families. Strengthening families program. Supporting family's community of practice. Transportation. Travel expenses for medical care.	
Tennessee	Caregiver support. Dementia related resources. Health promotion and prevention. Home delivered meals. Homemaker services. Information and assistance. Long-term care Ombudsman program. Personal care. Public Guardianship. Older adult transportation resources. State health insurance assistance program. Transportation assistance.	Tennessee Area Agencies on Aging and Disability

State	ADRC Services Available	Reference
Wisconsin	Adaptive equipment. Caregiver support. Dementia care services. Health, nutrition, and home-delivery meal programs. Housekeeping and chore services. Housing options. In-home personal care and nursing. Long-term care programs. Medicaid, Medicare, and Social Security. Safety updates to the home. Transportation. Wellness programs.	Wisconsin ADRC

Appendix XXIII: Peer State UCEDD Programs and Services

UCEDD Services	Service Description
Colorado: JFK Partners, University of Colorado-Denver	
Assessment and Treatment Services	Interdisciplinary team evaluations may include the following disciplines: psychology, occupational therapy, speech/language pathology, developmental-behavioral pediatrics, and child psychiatry. These evaluations provide diagnostic clarification and recommendations for treatment. Families seeking evaluations generally request an initial diagnosis, second opinion, recommendations for an Individualized Educational Plan (IEP), or follow-up treatment recommendations. A variety of therapy services are available through JFK Partners' faculty and trainees. They include speech/language therapy, occupational therapy, individual psychotherapy, family therapy, group therapy, supportive counseling, parent guidance, and behavioral therapies.
ENRICH – Early Intervention Services	ENRICH is an early intervention team that provides supports and services to families who have children up to three years of age with developmental delays.
Facing Your Fears (FYF) Program	FYF is an intervention program for youth with autism spectrum disorders who need assistance managing anxiety symptoms that interfere with daily life.
Kansas: University Center on Developmental Disabilities (KUCDD), University of Kansas	
Assistive Technology for Kansans	Assistive Technology for Kansans connects people with Assistive Technology to support learning, working, playing, and participation in a community setting, safe and with independence.
Telehealth	Telehealth is a collaborative program between the KUCDD in Parsons, Kansas, and the KU Center for Telemedicine and Telehealth. It provides for local health care needs and problems that are amenable to a telemedicine approach.
COVID-19 Resources	This resource provides people with disabilities, their families, and those that support them with supports and resources that might be useful to support

UCEDD Services	Service Description
	learning and engagement at home and in navigating health and safety during the COVID-19 pandemic.
Kansas Disability and Health Program (DHP)	The Centers for Disease Control and Prevention funded the DHP from 2016 to 2021. The DHP helps improve the health and quality of life of Kansans with disabilities by increasing access to programs and services that promote healthy living.
Kansas In-Service Training System	The Kansas In-Service Training System has extensive experience and is designed to provide training, technical assistance, and resources for early intervention and early childhood special education program staff on a comprehensive statewide basis.
Self-Determination Inventory System (SDIS)	SDIS is a free, online system of tools that can be used to understand self-determination in young people. It includes three assessments.
Missouri: Institute for Human Development, University of Missouri-Kansas City	
Health and Wellness Promotion	Health and Wellness Promotion projects focus on enhancing the quality of life for at-risk populations and a general promotion of healthy lifestyles by coordinating efforts in research, service demonstration, training, and evaluation of health and wellness activities.
Early Childhood and Youth	Early Childhood and Youth focuses on issues related to young children (from birth to eight years) with special needs and their families including: Community training and technical assistance to promote family-centered and interagency systems of care. Inclusive early intervention and preschool programs. Secondarily, this area focuses on issues of school-aged children with and without developmental disabilities.
Individual Advocacy and Family Supports	Individual Advocacy and Family Supports encompasses two interrelated areas: enhancing the capacity of natural supports to meet the needs of people with DD and addressing whole-family support needs.

UCEDD Services	Service Description
Adult Community Living	Innovative alternatives are clearly needed in the areas of employment, housing, and community living. The demand for these alternatives require not only demonstrations but also training, technical assistance, and dissemination of available information.
Aging and Developmental Disabilities	The population of aging individuals with DD is increasing nationally. This puts new strains on care-giving families, who are also aging, thus requiring new types of services as they become unable to provide informal supports. The range of issues encompasses living arrangements, person-centered retirement planning, relationship development, health care planning, and decision making.
Interdisciplinary Personnel Preparation	Interdisciplinary Personnel Preparation synthesizes research findings and best practices identified in the other six areas for development and implementation of interdisciplinary pre-service education.
Program, Organization, and Community Capacity Building	Program, Organization, and Community Capacity Building focuses on developing the capacity of programs and organizations to better meet the needs of the persons they serve and to adapt to changing values and policy environments. Projects also address capacity building of communities.
Ohio: University of Cincinnati Center for Excellence in Developmental Disabilities (UCCEDD)	
Community Living Programs Initiatives	As a part of the Community Living initiatives, the UCCEDD offers support in the following areas: • Be Safe Training • Emergency Preparedness Training • Law Enforcement Partnership • Law Enforcement Disability Awareness Training • Project Starting Our Adventure Right with Cincinnati Children's Hospital Medical Center • Regional Autism Advisory Council of Southwest Ohio • Supported Decision Making

UCEDD Services	Service Description
	• Transition Planning Training
Early Intervention	Early intervention provides home-based services for children birth to three years of age, who have, or are at risk of developmental delays or disabilities. Delays can be found in any of the five developmental domains (cognitive, communicative, physical, adaptive, or social/emotional). All children at Cincinnati Children's who may be at risk of, or who are suspected of having a developmental delay or disability in one of these categories, should be referred to be evaluated for eligibility
Family Support	The UCCEDD facilitates and leads many family support activities, workshops, and trainings on topics of importance to families of children and adults with disabilities. Support is provided to families to help them navigate health care, education, and other service systems.
Health and Wellness Initiatives	The UCCEDD offers the following health and wellness initiatives: • Center for Dignity in Healthcare for People with Disabilities • COVID-19 Support • Health Promotion • Living Independent from Tobacco • Next Step Collaborative • Project Supporting Children of the Opioid Epidemic
Ohio: Nisonger Center, The Ohio State University	
Child Clinics and Services	Nisonger Center offers a wide range of clinics and services designed to meet the unique needs of children with I/DD. Our programs are tailored to each individual child, and we partner with families to help them achieve their own goals with their children in a fun and safe learning environment.
Adolescent Clinics and Services	The clinics and services at Nisonger Center are designed to meet the unique needs of adolescents with I/DD. Our faculty and staff tailor our programs to

UCEDD Services	Service Description
	each adolescent, and we work closely with families to ensure all individuals achieve their goals in an engaging and safe learning environment.
Adult Clinics and Services	Many of the programs and services offered by Nisonger Center are designed to meet the unique needs of adults with I/DD. In all our programs, faculty and staff tailor the services for each individual, enabling everyone to achieve their goals in a positive and safe environment.
Oklahoma: Center for Learning and Leadership, University of Oklahoma	
COVID-19 Prevention Project	Expanding Disabilities Network's Access to COVID-19 Vaccines is a COVID-19 prevention project funded through the Administration for Community Living and the CDC. Center for Learning and Leadership helps with vaccine access, coordinates vaccine and booster scheduling, when needed, offers training to clinic staff on providing care to people with disabilities, and provides technical assistance to local health departments and other agencies to improve vaccine accessibility.
Oklahoma Family Support 360° (FS360°) Center	The FS360° Center serves families who are caring for children or young adults with developmental disabilities and are Medicaid eligible. The FS360° Center staff provide family-centered services to enrolled Hispanic families who speak Spanish as their primary language.
Oklahoma Self-Advocacy Network	The Oklahoma Self-Advocacy Network is a collaborative effort to strengthen the self-advocacy movement in Oklahoma and to increase the inclusion and independence of people with disabilities.
Self-Advocates/Family Advocates as Medical Educators	Self-Advocates/Family Advocates as Medical Educators will teach health care students basic information about patients with I/DD, family caregivers, and the systems that shape their lives and experiences across the lifespan.
Legacy for Children™	Legacy for Children™ is an evidence-based parenting program focused on strengthening the parent-child relationship and social support, as well as promoting children's health and socio-emotional development.

UCEDD Services	Service Description
Nutrition is for Everyone	Nutrition is for Everyone was a project providing nutrition education for and by people with disabilities, their families, and friends.
Pennsylvania: Institute on Disabilities, Temple University	
Advocacy Programs	Programs and resources promoting, supporting, and training self-advocacy/advocacy for people with disabilities and families.
Assistive Technology	TechOWL PA is Pennsylvania's Assistive Technology Act program.
Employment Here and Now	The Employment Here and Now program matched eligible people with I/DD, age 18 to 26, to unpaid internships at Temple University Hospital and Temple's University Main Campus in Philadelphia with a goal of achieving long-term, part-time employment.
Media Arts and Culture	Guided by the belief that the power and beauty of the arts benefits and lifts us all, the Institute's Media Arts and Culture unit develops new arts initiatives and works collaboratively with university and community-based arts organizations and practitioners to create innovative, fully accessible cultural programming. The work includes oral history, archival preservation, documentary, exhibition, and public performance.
Public Policy	Programs and resources which offer training, support, and technical assistance for and about people with disabilities and families to help understand and shape policy at the local, state, and national levels.
South Dakota: Center for Disabilities, University of South Dakota	
Autism Spectrum Disorder Services (ASD)	The Center for Disabilities offers a diagnostic clinic for individuals who may have an ASD. Clients who receive an evaluation may leave the clinic with a wide variety of diagnoses and recommendations.
Birth to 3 Services	The Center for Disabilities provides free early intervention services, including developmental screenings and evaluations for families with children from birth to age three who have difficulty learning, growing, or behaving like other

UCEDD Services	Service Description
	children in their age group, or have a medical condition which doctors feel may need special attention.
Deaf-Blind Program	This program provides technical assistance, training, and resources to families and service providers of children (birth to 21) with varying levels of both hearing and vision loss.
Fetal Alcohol Spectrum Disorder Services	The clinic provides appropriate diagnoses of Fetal Alcohol Spectrum Disorder Services with technical assistance to assist with the implementation of clinic recommendations. The diagnosis will allow professionals and families to develop strategies to improve the educational and health outcomes for the person with Fetal Alcohol Spectrum Disorder Services.
Lend Developmental	The Lend Developmental clinic works to improve the health of infants and children with neurodevelopmental and related disabilities. They help families who are interested in learning how to support their child's strengths and address their weaknesses and health care needs.
Oyàte Circle	The Oyàte Circle is a resource, education, outreach, and training effort that serves Native Americans with disabilities in South Dakota.
Transition-in-Action	The Transition-in-Action clinic generates recommended "next steps" to successful transitions for young adults with a disability and/or significant chronic health care needs.
Tennessee: Center on Developmental Disabilities, University of Tennessee Health Science Center	
Attention Deficit Hyperactivity Disorder Clinic	The University of Tennessee Health Science Center, Center on Developmental Disabilities offers an Attention Deficit Hyperactivity Disorder clinic. Disciplines of developmental pediatrics and social work are involved in delivery of specialized care.
Applied Behavioral Analysis (ABA)	Behavioral therapy programs such as ABA are provided by faculty and staff within our department of psychology. Through ABA, children and families receive intensive behavioral therapy and suggestions for positive behavioral

UCEDD Services	Service Description
	supports. Most of our treatment programs include in-depth parent counseling and parent training regarding the services provided during therapy sessions.
Audiology	Audiological evaluations for children for whom there is concern of hearing loss.
Inborn Errors of Metabolism	The state of Tennessee and surrounding states screen all newborns for several genetic disorders. When the test is positive, the Regional Genetic, Endocrine, or Hematology treatment centers in Memphis, Knoxville, or Nashville are notified. The primary care provider is also notified.
Developmental Pediatrics	The University of Tennessee Health Science Center, Center on Developmental Disabilities' Developmental Pediatrics Clinic offers consultations for a variety of known or suspected developmental problems.
Occupational Therapy, Physical Therapy, and Speech	Therapy programs are provided by physical therapy, occupational therapy, and speech language pathology. All treatment programs involve parent counseling and training regarding the child's condition, as needed.
Parent-Child Interaction Therapy	Parent-Child Interaction Therapy at the Center for Developmental Disabilities in Memphis, Tennessee is a behavioral family-oriented therapy and an evidence-based practice for children with disruptive behavior problems between the ages of two and six. Parent-Child Interaction Therapy integrates concepts from social learning theory, traditional play therapy, and attachment theory to enhance the parent-child relationship, increase children's' prosocial behaviors, and increase parents' behavior management skills.
Psychology	The psychology clinic primarily provides comprehensive developmental and psychological evaluations for children suspected of having a neurological DD to inform a differential diagnosis and provide individualized recommendations for treatment to our families.
Tennessee: Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (VKC), Vanderbilt University	
Arts and Disabilities	Quarterly exhibits of art by children and adults with disabilities or mental health disorders.

UCEDD Services	Service Description
Autism Services	People with autism spectrum disorders and their families, as well as professionals who work with autism spectrum disorders, are offered services through the Vanderbilt Kennedy Center Treatment and Research Institute for Autism Spectrum Disorders.
Basics of Advocating Special education In your Child's School	This online course is designed to give parents and caregivers some of the Basics of Advocating Special education In your Child's School of advocacy.
Disabilities, Religion, and Spirituality	This program provides training and supports for individuals with disabilities and families, faith communities, and disability services providers.
Kindred Stories of Disability in Tennessee	A collection of stories from individuals with disabilities, families, friends, and disability service providers in Tennessee.
Learning Assessment Clinic	A clinic for students experiencing learning challenges.
Reading Clinic	The Reading Clinic provides intensive, individualized, one-on-one tutoring using assessments and evidence-based instructional methods shown to promote reading. Serves children in grades K through 8.
Rett Syndrome Program	This VKC multi-disciplinary program includes the Rett Syndrome Clinical Research Center of Excellence, as well as opportunities to take part in research.
Self-Advocacy	Self-advocacy involves people with I/DD speaking up for themselves to express their individual needs, goals, and desires. VKC has pulled together a list of links to VKC self-advocacy activities and resources and to the activities of some of our partners.
Sibling Programs	Support and networking programs designed specifically for the siblings of people with disabilities.
Social Work Services	Provides assessments, crisis intervention, brief counseling, and referral services to individuals and families with DD.
StudyFinder	By participating in research, sometimes free services are provided that will directly benefit an individual or a family member.

UCEDD Services	Service Description
Summer Programs and Community Activities	Curriculums designed by multi-disciplinary teams of disabilities professionals make for an experience that is fun and beneficial for participants. Programs include ACM Lifting Lives Music Camp, Next Steps Summer Institute, and SENSE Theatre.
Tennessee Cares Network at VUMC	Its mission is to connect families and medical providers to resources in their communities and to each other. It focuses on children under age 5 years at risk of developmental delay or autism spectrum disorder.
Tennessee Disability Pathfinder	A free statewide, multi-lingual clearinghouse of disability resources. Phone helpline, website with searchable Services Database and Community Calendar, and Multi-cultural Outreach Program.
Tennessee Works	Tennessee's web hub for information related to employment of people with disabilities.
Volunteer Advocacy Project	Training (40 hours over 12 sessions) for persons interested in becoming special education advocates to support families, held at multiple Tennessee sites.
Wisconsin: Waisman Center, University of Wisconsin-Madison	
Act Early Wisconsin COVID-19 Recovery and Resilience Initiative	The purpose of the Act Early Wisconsin COVID-19 Recovery and Resilience Initiative is to identify and respond to current barriers and opportunities related to improving early identification of developmental delay and disability in each of four steps across early childhood systems: developmental and autism monitoring, screening, referral and evaluation, and access to early intervention.
Augmentative and Alternative Communication (AAC) Partnership Programs (PP)	The Augmentative and Alternative Communication Partnership Programs is a statewide program designed to expedite clients' access to evidence-based, high-quality Augmentative and Alternative Communication evaluations and treatment by building the capacity of speech-language pathologists across Wisconsin.
Autism Care Network	The purpose of this project is to design, develop, and test refinements to an improvement and research network focused on autism, to use the Autism Care

UCEDD Services	Service Description
	Network to simultaneously improve clinical care, redesign care delivery systems and conduct quality improvement, health services, outcomes, and comparative effectiveness research. The over-arching aim of the Network is to improve quality of life and health of children with autism.
Autism Treatment Programs	The Waisman Center Autism Treatment Programs, in partnership with University of Wisconsin Health, offer focused behavioral treatment to individuals with autism and their families.
Communication Aids and Systems Clinic	The Communication Aids and Systems Clinic provides augmentative alternative communication and computer access services. Interdisciplinary services include direct outcome-focused evaluation and intervention, consultation, technical support, student training, and outreach.
Communication Development Program	The Communication Development Program provides augmentative and alternative communication and computer access services for individuals living in Dane County, Wisconsin.
Community Outreach Wisconsin	The Community Training and Consultation Program provides service to family members, volunteers, direct care providers, special education teachers, transportation providers, para-professional and professional service providers from all settings providing services in Dane County for people with DD.
Community of Practice on Cultural and Linguistic Competence in Developmental Disabilities	The goal of the Community of Practice is to increase the number, diversity, and capacity of formal and informal leaders to transform their state/territorial DD systems by advancing and sustaining cultural and linguistic competence systemically through changes in values, policy, structures, and practices, and responding effectively to the growing cultural and linguistic diversity among people with DD and their families.
Community Solutions for Health Equity	Community Solutions for Health Equity is a program of the Robert Wood Johnson Foundation focused on elevating the voices of communities of color and other communities left out of discussions when local health care systems in the United States are creating policy.

UCEDD Services	Service Description
Community Training, Intervention, and Evaluation Services (TIES)	The TIES program offers support to children, adolescents, and adults with DD who reside in Dane County and present challenging behaviors.
Community TIES Psychiatric Clinic	TIES Clinic provides psychiatric care and consultation to individuals with DD who are unable to obtain psychiatric care from other providers due to financial situation, behavioral issues, or medical complexity. Patients seen in the TIES Clinic are also supported by the Community TIES Program.
Crisis Response Program	Crisis response services for adult Dane County residents with DD are designed to prevent or shorten stays in more restrictive settings.
DD Community Training and Consultation	Provides service to family members, volunteers, direct care providers, special education teachers, transportation providers, para-professional and professional service providers from all settings providing services in Dane County for people with DD. Provision of a variety of training, consultation, and educational opportunities individual, small group, and larger audiences related to DD.
Genetics Systems Integration Hub-Wisconsin	This project provides a central source for the exchange of information and resources related to maternal child health genetics services and programs in Wisconsin, maintains the Genetics in Wisconsin website, and facilitates the delivery and evaluation of genetics education for health care providers in Wisconsin.
Health Transition Wisconsin	The Youth Health Transition Initiative provides Wisconsin's youth, family members, providers, and other community collaborators with information on the movement from the pediatric world to adult health care. Tools, materials, and resources are available to help teens, families, and health care systems in the health care transition process.
Nourishing Special Needs Nutrition Network (Women, Infants, and Children)	This contract with the state Birth Defects Surveillance Program provides training and technical assistance to Women, Infants, and Children nutritionists in the state of Wisconsin, including a monthly series of educational teleconferences, an annual workshop on nutrition topics for children with special needs, and an

UCEDD Services	Service Description
	updated nutrition toolkit available publicly and for all Women, Infants, and Children nutritionists in the state.
Southern Regional Center Children and Youth With Special Health Care Needs	The Southern Regional Center for Children and Youth With Special Health Care Needs, funded by the State Maternal Child Health block grant, benefits families with Children and Youth With Special Health Care Needs and the providers who support them through providing information, referral, and follow-up services; promoting a parent-to-parent support network and family leadership development; and increasing local capacity of community-based systems of support.
Waisman Early Childhood Program	A model university child development program at the University of Wisconsin - Madison for children ages one to eight years old that offers early education and year-round care to meet the needs of a developmentally diverse group of children. The model focuses on inclusivity and universal design for all children, specializing in supporting children with disabilities. The program pairs with university researchers, educators, and clinicians to promote inclusion.

Appendix XXIV: Peer State Respite Services

State	Respite Service Description
Kansas	**Overnight Respite:** • Is provided in planned increments. • Allows for overnight payment. • Is provided in a family home or place of residence, licensed foster home, approved facility which is not a private residence, or a licensed respite care facility/home.
Missouri	**In-Home Respite:** • Can be provided for up to three individuals at a time. • Can be provided in an individual's home or private place of residence. • Personal assistant services may be a component, if necessary, for the individual. **Out of Home Respite:** • Consists of planned relief, limited to no more than 60 days annually, unless an exception is approved. • Is provided outside the home in a licensed, accredited, or certified waiver residential facility, ICF/IID, standalone facility, or shared living host home.
Ohio	**Community Respite:** • Is only provided outside of an individual's home in a camp, recreation center, or other place where an organized program or activity occurs. • Is provided only by agency providers. **Informal Respite:** • May be provided in the individual's home or place of residence, home of a friend or family member, or sites of community activities. • Is provided only by independent providers. **Residential Respite:** • Is provided only in ICFs/IID, a residential facility, other than an ICF/IID, or a residence other than an ICF/IID or a facility licensed by the Department of Developmental Disabilities.
South Dakota	**Respite Care:** • Is provided in multiple locations, including an individual's home or place of residence, a foster home, hospital, ICF/IID, group home, a home approved in the plan of care, which may be a private residence, or other community care residential facility approved by the State, such as a licensed day care.
Tennessee	**Behavioral Respite**

State	Respite Service Description
	• Consists of short-term behavior-oriented services for a supported person who is experiencing a behavioral crisis requiring removal from the current residential setting. • Providers help to plan, coordinate, and prepare for the individual's transition back to their place of residence. • May be provided in an ICF/IID, in a licensed respite care facility, or a home operated by a licensed residential provider. **Respite:** • May be provided in the person's place of residence, in a Family Model Residential Support home, in an ICF/IID, a home operated by a licensed residential provider, or in the home of an approved respite provider. • Providers may also accompany the person on short outings for exercise, recreation, shopping, or other purposes.

Appendix XXV: Listening Session Communications

Finalized Flyer

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

STAKEHOLDER LISTENING SESSIONS

EVALUATION OF DEVELOPMENTAL DISABILITIES SYSTEM FOR LB376

The Nebraska Department of Health and Human Services has contracted with Optumas and Myers and Stauffer, who are performing an evaluation of Nebraska's developmental disability (DD) service system for Legislative Bill 376. The evaluation is focused on understanding how Nebraska can better serve individuals with a variety of disabilities and complex medical conditions and their families, and includes a comprehensive evaluation of Nebraska's current service system.

Optumas and Myers and Stauffer want to hear from you!

We are interested in learning more about the experiences of individuals with disabilities, family members, advocates, providers, and other members of the public who support these individuals. We invite you to participate in a virtual listening session, and encourage people who are new to the system, those on the Medicaid Aged and Disabled Waiver and waiting for or on the DD Waiver, people who have never provided feedback on services, or those with ideas on how to improve disability services in Nebraska, to join us.

Your experiences, feedback, and opinions are valued!

To Register

Please use the QR code below or this link to fill out a short sign-up form and select your meeting preference(s). You will then receive an email from NE_DDSystemEval@mslc.com confirming registration details. Sessions will be limited to 30 participants each to allow for meaningful, focused feedback. If sessions are full, you will be notified and receive a link from the Optumas and Myers and Stauffer team to complete a voluntary electronic feedback survey.

Please use the QR code or access https://mslc.qualtrics.com/jfe/form/SV_9oZCuB9H8UC4ddl to fill out a short sign-up form.

DHHS Webpage Posting

LB376 Stakeholder Listening Sessions - Evaluation of DD System

In response to LB376, DHHS has contracted with Optumas and Myers and Stauffer to complete an evaluation of Nebraska's developmental disabilities (DD) service system. As part of their evaluation, Optumas and Myers and Stauffer want to hear from you! Virtual listening sessions are going to be held soon.

- Complete a short survey to register for a listening session
- Open Listening Session flyer

Tribal Postcard – Side 1

STAKEHOLDER LISTENING SESSIONS

EVALUATION OF DEVELOPMENTAL DISABILITIES SYSTEM

The Nebraska Department of Health and Human Services has contracted with Optumas and Myers and Stauffer, who are performing an evaluation of Nebraska's developmental disability (DD) service system for Legislative Bill 376. We want to learn more about the experiences of individuals with disabilities, their family members, advocates, providers, and other members of the public who support them. We invite you to participate in a virtual listening session. We encourage people who are new to the system, those on the Medicaid Aged and Disabled Waiver and waiting for or on the DD Waiver, people who have never provided feedback on services, or those with ideas on how to improve disability services in Nebraska, to join us.

Tribal Postcard – Side 2

To Register
Please use the QR code below or this link to fill out a short sign-up form and select your meeting preference(s). You will then receive an email from NE_DDSystemEval@mslc.com confirming registration details. Sessions will be limited to 30 participants each to allow for meaningful, focused feedback. If sessions are full, we will notify you and send a link from the Optumas and Myers and Stauffer team to complete a voluntary electronic feedback survey.

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Appendix XXVI: Feedback Online Survey Questions

Group/Question	Sub-Question	Answer Options
Introduction – All		
1) Welcome to the Nebraska DD Evaluation for LB376 Feedback Questionnaire! **The Nebraska Department of Health and Human Services has contracted with Optumas and Myers & Stauffer, who are performing an evaluation of Nebraska's developmental disability (DD) service system for Legislative Bill 376. The evaluation is focused on understanding how Nebraska can better serve individuals with a variety of disabilities & complex medical conditions and their families. This feedback questionnaire will help the team gather valuable feedback from individuals impacted by Nebraska's disability programs and services.** **If you need assistance or have questions, please email the Optumas and Myers & Stauffer team at NE_DDSystemEval@mslc.com.**	Please validate you are a real person.	I'm not a robot reCAPTCHA Privacy - Terms
2) Please select the option that best describes you:		• Person with an intellectual or developmental disability

Group/Question	Sub-Question	Answer Options
		• Parent/family member of a person with an intellectual or developmental disability • Legal guardian of a person with an intellectual or developmental disability • Provider • Tribal Member • Member or volunteer of an advocacy organization for people with intellectual or developmental disabilities (please add the name of the organization): (text box) • State agency employee or member of a state committee/council (please add state agency/committee/council name): (text box) • Other, Please Specify: (text box)
2a.) If Tribal Member selected:	Please select the Tribe/Nation located in Nebraska that you are representing:	• Omaha Tribe of Nebraska • Ponca Tribe of Nebraska • Santee Sioux Nation • Winnebago Tribe of Nebraska • Iowa Tribe of Kansas and Nebraska • Sac & Fox Nation of Missouri in Kansas and Nebraska

Group/Question	Sub-Question	Answer Options
2b.) If Tribal Member selected:	Which type of Tribal member best describes you?	• Tribal member with a disability • Family of a Tribal member with a disability • Tribal Leader • Advocate for disabled Tribal individual and their family • Provider of disability services to Tribal individual and/or their family
Feedback Questions Intro – All		
The questions that follow are based on the same questions utilized in the stakeholder listening sessions being conducted as part of this project. Please answer with as much detail as you can to help us fully understand your experience with Nebraska's disability services system.		
Individuals, Families, Caregivers, Guardians, Advocates		
3) Do you or someone you care for currently receive any services to support needs related to a disability?	If yes, check all that apply:	• Services covered by private or employer-based health insurance a) Services provided by Heritage Health (Medicaid) i) If Yes, Have you or someone you care for ever received services from Nebraska's managed care organizations (Healthy Blue, Nebraska Total Care, or

Group/Question	Sub-Question	Answer Options
		UnitedHealthcare Community Care of Nebraska)? Yes/No (1) If yes, (a) What services were received? (text box or give examples to select- Primary Care, Emergency Room Services, Specialist Care, Mental Health Care, Other) (b) Do you or someone you care for have an assigned care or case manager through a managed care organization? (i) If yes, describe your experiences with the care or case managers provided by the managed care organizations?

Group/Question	Sub-Question	Answer Options
		b) Medicaid waiver program services (AD Waiver, CDD (Comprehensive) Waiver, DDAD (Day) Waiver, TBI Waiver) c) Services from the Nebraska Vocational Rehabilitation. • Other services offered to support a genetic or medical condition. Please describe. (Comment box to enter response)
	If no, check all that apply:	• In need of services but have not been found eligible • Not sure where to apply for services • Waiting on the DD Registry for Medicaid waiver services • Not applicable • Other. Please describe (Comment box to enter response)
4) Have you ever worked with state agencies to find needed services for you or someone you care for? Yes/No	If yes, see sub-questions. If no, go to question #3.	• Please describe the experience working with the state agency(s) in the text box below; include what went well and any challenges you faced: (Text box) • Did you or someone you care for receive needed services? Yes/No
5) Were you or someone you care for ever placed on the DD Registry to receive	If yes, see sub-questions. If no, go to question #4.	• Please describe your experience while waiting for

Group/Question	Sub-Question	Answer Options
Medicaid waiver services? Yes/No		Medicaid waiver services? (Text box) • Did you or someone you care for qualify for Heritage Health (Medicaid) services while on the DD Registry? Yes/No a) If yes, please describe what types of services were received? (Text box)
6) Have you or someone you care for ever been denied Medicaid waiver services because they were told they did not meet "level of care" requirements? Yes/No	If yes, see sub-question. If no, go to question 5.	If you or the person you cared for was denied Medicaid waiver service, what happened next? (Retained Medicaid without Waiver Services, Transitioned to another Waiver, Other)
7) Please describe how you believe Medicaid waiver services can be used to supplement services covered by Heritage Health (services provided by Healthy Blue, Nebraska Total Care, or UnitedHealthcare Community Care of Nebraska), private, or employer insurance).		• Text box • What extra support could Medicaid waiver services provide for you or someone you care for that you cannot get from Heritage Health? • What other supports would be helpful to you or those that help take care of you? • Other comments: (text box)
8) Has access to state-offered services by you or someone you care for been	If yes, see sub-question. If no, go to question 7.	If yes, please describe your experience below. (text box)

Group/Question	Sub-Question	Answer Options
impacted by transportation or travel distance?		
9) What do you believe are the biggest challenges in accessing needed services for individuals with disabilities?	Check all that apply:	• Not having the right services to meet individual's needs • Not understanding how to access needed services • Limited support in accessing services • Not qualifying for needed services • Language or cultural barriers. • Lack of providers close enough to provide services • Denials for services by insurance carriers (private insurance, Heritage Health, etc.) • Other, please describe: (text box)
10) If you could write the future of services for Nebraskans with disabilities, what does that future look like in 3 to 5 years?	Please describe.	Text box
11) What are the 3 to 5 most important issues which you would like to see DHHS address to improve services for individuals with disabilities?	Please describe.	Text box
State Agencies/Committees		
1) Please describe the type of social or support		Text box

Group/Question	Sub-Question	Answer Options
services your agency offers for individuals with disabilities or their caregivers.		
2) Describe how services offered by different state agencies are coordinated for an individual who:	• Describe how services offered by different state agencies are coordinated for an individual who is Medicaid program eligible: • Describe how services offered by different state agencies are coordinated for an individual who is on the AD or DD waiver: • Describe how services offered by different state agencies are coordinated for an individual who neither qualifies for the Medicaid program (State Plan) or a Medicaid waiver:	Text boxes
3) Describe how you identify those in need of the services offered by your agency?		Text box

Group/Question	Sub-Question	Answer Options
4) Do you serve someone enrolled on the Katie Beckett Program?	If yes, see sub-question. If no, go to question 5.	If yes, a) It has been described that the Katie Beckett eligibility program is relatively “small.” Please explain why you think so. (text box) b) Are children not meeting hospital LOC as prescribed in 477 NAC Chapter 27 §010.01? Answer Yes/No and please describe your answer. (text box)
5) Are there gaps or needed changes in state policy to improve service delivery for individuals with disabilities?	If yes, please describe your ideas on needed changes to policy. If no, go to question 6.	Text box
6) Are you aware of any future policy strategies to eliminate the DD registry?	If yes, are you aware of future policy strategies to eliminate the DD registry, please describe below: If no, go to question 7.	Text box
7) What are you hearing from members of the public about Medicaid waiver service access?		Text box
8) From your perspective, please describe how the Medicaid managed care organizations are helping caregivers and individuals with disabilities navigate and access needed services?		Text box
Tribal Members		

Group/Question	Sub-Question	Answer Options
1) Does your tribe offer services for caregivers and individuals with disabilities that are available only to members of your tribe?	If yes, • What are those services and who provides them? • Please describe any service gaps? If no, go to question 2.	Text box
2) Have you or your tribal members ever worked with state agencies to find needed services for themselves or someone they care for?	If yes, please describe that experience: • Were needed services received? yes/no o Please describe what challenges you or someone from your community faced when working with state agencies, if any? • Do you believe these experiences are unique to your Tribal members or do you think they are statewide? Please select one of the following: (pick one) o Unique to Tribal members o Statewide issues	Text box

Group/Question	Sub-Question	Answer Options
3) Does transportation or travel distance impact you or your tribal community's access to state-offered disability services?	If yes, please describe how. If no, go to question 4.	Text box
4) What are the biggest challenges for tribal members with disabilities and their caregivers in accessing needed services?	Select all that apply:	• Not having the right services to meet their needs • Not understanding how to access needed services offered by the State • Not qualifying for needed services • Language or cultural barriers • Location of services • Other (text box) • Not applicable
5) As a member of your tribal community, what are the 3 to 5 most important issues you would like to see DHHS address for members of your community with disabilities and their caregivers?	List the 3 to 5 most important issues here:	• Text box • Not applicable
6) As a tribal member, do you feel that you have a pathway to contribute to the discussions about strategic policy initiatives for your members who have disabilities and their caregivers?	If yes, please describe: If no, go to question 7.	Text box

Group/Question	Sub-Question	Answer Options
7) If you could write the future of services for tribal members with disabilities in Nebraska, what does that future look like in 3 to 5 years?	Please describe:	Text box
Providers		
1) What are the most common services that you provide individuals with disabilities?		Text box
2) Please describe how you coordinate with state agencies other than the Department of Health and Human Services to provide comprehensive care for individuals you serve?		Text box
3) What are the biggest challenges in providing services to individuals with disabilities?	Select all that apply:	• Lack of qualified staff • Insufficient provider training. • Limited care coordination between individuals and caregivers, government entities, and providers • Specific licensing or certification barriers. • Service delivery gaps in state policy or processes • Language or cultural barriers • Individual and family follow through • Prior authorization process • Other, please describe: (text box)

Group/Question	Sub-Question	Answer Options
4) Please describe what strategies you have implemented to address the challenges faced by individuals with disabilities and their caregivers in accessing services.		Text box
5) Please describe your experience with Medicaid managed care organizations, and how they impact the services you provide to the individuals you serve.		Text box
6) Please describe what challenges you face in working with managed care organizations.		Text box
7) Please describe how you approach transportation or travel distance for individuals accessing state-offered services?	Please describe your thoughts on incorporating technology to provide services remotely?	Text boxes
8) What are your suggestions for improving services for Nebraskans with disabilities?		Text box
9) Please describe what partnerships or collaborations you think could be created or modified to improve		Text box

Group/Question	Sub-Question	Answer Options
access to services for Nebraskans with disabilities?		
10) What changes or improvements would you like to see in the Medicaid program or Medicaid 1915(c) waiver programs (AD, DD, TBI)?		Text box
End of Feedback Survey – All		
1) Are there any other comments you would like to provide to us?		Text box
2) Thank you for completing this online questionnaire. Your feedback is critical to the evaluation of Nebraska's DD system and services. If you have any questions, please contact the Optumas and Myers & Stauffer team at NE_DDSystemEval@mslc.com.	Would you like to receive additional information about this project and its findings? • Yes, I would like to receive additional information. • No, I do not want to be contacted again about this project.	Contact Information: • First name: (text box) • Last name: (text box) • Email address: (text box)
3) End of Survey	We thank you for your time spent taking this survey. Your response has been recorded.	

Appendix XXVII: Stakeholder Feedback Summary

Cumbersome Process for Individuals and Families
Unclear application process which make it difficult for families to navigate.
Automatic denials. A common perception is that you individuals/families will be denied automatically the first time upon applying for a waiver.
People lose waiver services because they can't find providers to let them use their services and then they get taken away because they aren't able to use them.
Individuals, families, etc. are passed between multiple staff in multiple divisions who all provide differing and conflicting information.
Inconsistent information provided by people from same state agencies.
No resolution when complaints are made.
Insensitive process requirements.
Asking repetitive and insensitive questions when we know that conditions do not change.
Barrier to continued access, individuals are unenrolled due to cumbersome administrative processes.
Coordination was easier when they had a single consistent person.
The process is insensitive to grieving parents, adds additional paperwork to busy parents.
Grievance process isn't easy to understand.
The assessment process is too invasive, asks inappropriate questions for some populations.
The system is setup for families to fail, even if the individuals qualifies for services.
All the programs are disconnected making it tough for families to navigate.
Qualified for a while up to age 12, then was denied services and was eligible at 18. The family incurred great costs at that time. Service disruption makes it hard for families to survive.
Impact of Access Limitations on Individuals and Families
Lost employment and homes due to lack of childcare.
Multiple iterations of applications, questions, processes leads to sense of grief and loss of hope for a child with a lifelong condition.
Difficulty retaining consistent employment.
Supports offered aren't enough to meet needs, relies heavily on parents to provide unpaid support, which adversely impacts their mental and physical wellbeing.
The period of school/child transitions to adulthood was reported as putting strain on families because of lack of clarity around future available services and supports.
Families are exhausted by a burdensome process full of barriers, can cause them to abandon services they likely would qualify for.
Paying for services out of pocket puts individuals and families at risk for bankruptcy and economic hardship while waiting for services.
Technology Barriers
Providers need training in how to use assistive technology, communication devices, smart TVs, and smartphones.

It would be nice – is not something currently used.
I think that there are some good reasons in the right circumstances to provide remote services for certain individuals. There are some people who may not need or want that hands-on service, but need reminders or need to be walked through certain things or situations and remote services are a great option.
That can work on a limited basis. Not everyone can learn or receive help remotely, some services cannot be provided through technology, and we must have sufficient resources on both ends.
It is best to have human interaction in person. Just because you can do something remotely, does not mean you should. Zoom meetings are great for staff and participants. Delivery of services by technology sounds like segregation and impersonal.
Nothing replaces the human resource, especially for people who are already experiencing a lack of natural resources.
If they can be provided remotely that would often be very helpful, however, clients and their families will still need assistance navigating all of that.
Improved payment processing to providers is needed.
Transportation Barriers
Very limited accessible transportation for individuals with complex medical needs.
VR and supported employment do not include transportation.
Age limitations under 19, needs an adult.
Long travel times.
Telehealth isn't always an accessible option.
Bus routes aren't an option, even in the city.
Delays in medical care due to limited transportation.
The vehicle modification process is unnecessarily burdensome.
Independent providers need to be educated on transportation pay.
Not all services are offered in all areas.
Have to travel out of county or state for some services.
Funding isn't enough to cover transportation costs.
Transportation provided by Medicaid is unreliable, late, or leaves individuals stranded.
Would like to be able to have Uber covered by Medicaid.
Need transportation for day services.
Nearest programs or events are one to four hours away.
Rural after-hours transportation is unavailable and needed.
Depending on income/resources, I pay for gas out of pocket or ask family to cover gas.
Service System Barriers
Limited access to waiver services because of the registry.
Differences in what waiver services are accessible for children and adults.
Length of time needed to get approval for services (Medicaid State Plan and waiver) varies.

Katie Beckett is small and limited. People don't know it is available and the requirements to qualify are too high for most people to qualify.
Perception that leadership of DDD is open to building relationships with stakeholders and attempt to address problems for families and individuals.
Perception that DHHS is under-resourced, particularly with service coordinators and front-line staff.
Services have improved since the AD moved to DDD, but interactions with Medicaid continue to be difficult to access.
Requirements change frequently.
Medicaid doesn't fund social determinants of health.
Money earmarked for individuals with disabilities isn't getting to the individuals who need it.
Lack of a streamlined referral system.
Housing.
Dental care is limited, most providers don't accept Medicaid.
Supports provided are inadequate for the individual's needs.
The provider network is lacking.
Reimbursement rates are too low to keep quality staff.
State definition of DD differs from the federal and creates many service gaps and barriers.
No childcare support for parents so they can work to support their families.
No transportation to work for older individuals with disabilities.
Limited ability to transport children with high medical complexity.
Mixed responses on the availability of vehicle modifications.
Limited location of services.
Limited service availability in the areas of recreational activities, educational activities, and respite.
Services are unavailable for medically complex children, and Katie Beckett is very difficult to access.
There are gaps in services for individuals who struggle with executive functioning.
Katie Beckett: Only a few kids meet hospital LOC to be eligible for the program. Then if kids are eligible, they still run into barriers with nursing shortages.
Provider options are limited, and of those available, many are not accepting Medicaid or new Medicaid members.
The enrollment and management processes for independent providers is difficult.
Reimbursement discrepancies between waiver providers.
Service coordinators are unprepared and unhelpful in accessing the right services.
Person-centered planning isn't happening, once completed nothing comes of it.
Slow service coordination response times.
No follow-up from service coordinators.
Lack of service coordination consistency.

Limited empathy from service coordinators.
Lack of providers of all types, including dentistry and mental health services, especially in western Nebraska.
Limited supports for individuals with highly complex needs.
Price of Medicaid covered devices is more than just purchasing outright.
Challenge of accessing independent providers.
Limited location of services.
Reimbursement rates from Medicaid are significantly lower than other payers.
Services are not provided in a timely manner.
Mixed feelings on the quality of services received by community and facility-based providers (community versus facility-based care elicited strong feelings from many participants).
Concerns with the quality of services provided by staff who are not perceived to be trained.
Mixed responses regarding quality and helpfulness of VR services.
Stricter standards for all types of providers and public transparency regarding providers with criminal histories.
Having the department labeled DDD is confusing and frustrating to individuals with other disabilities.
Don't combine programs into one division, it makes it more difficult for outsiders.
Many families stated frustration with the complexities of applying for, qualifying for, and receiving services.
Many families expressed concern over the lack of available services and service coordinator turnover and quality.
Many individuals and families expressed frustration over the amount of time before services were received.
VR system is inaccessible.
The requirements of guardianship are too high, parents who act as speech language pathologists have to surrender their rights to do it. Need another avenue to employ parents who want to continue caring for their children.
Having the department labeled DDD is confusing and frustrating to individuals with other disabilities.
The services offered often don't match what is needed.
Parental income barriers limit access to needed services.
Individualized family service plan services are not adequate.
No childcare options for children who are too old for daycare.
There needs to be a day program available. What is offered has no providers because the rate is too low. There are not any person-centered residential placements other than nursing homes.
The AD waiver program has declined over the last few years, participants were better served under managed long-term care (MLTC), and staff cannot answer the most basic questions.

Lack of respite providers in the state.
Service coordinators don’t understand the different waivers to help individuals and families understand when they may better be served by a different waiver.
Communication Barriers
Difficulty accessing services without language barriers, but worse for individuals who don’t speak the language.
The DHHS website is difficult to navigate for families.
Cultural barriers exist in immigrant and minority communities whose primary language may not be English (Karen and Spanish noted as top examples).
There is a lack of trust in government institutions between some community members and in some minority communities.
Information isn’t accessible.
Terminology and acronyms used are not well known by all families such as LOC and ADL.
Providers use the wrong terminology or are uninformed on the process.
Limited communications from DD.
Nothing is provided in writing.
Service coordination in other languages isn’t adequate.
Maximus was challenging to access.
Families aren’t informed on all VR options available.
Perception is that staff are not highly trained, leading to misinformation to the public.
Programs are available but hard to find out about them.
Schools are not informed about what services are offered through DD and what they provide for information is inconsistent.
MCOs do not always inform individuals about services they provide.
Communication is limited, hard to understand and navigate the process.
Ask for feedback in accessible language.
Families need more training about the options available.
Lack of education to parents of school-aged children about services.
Decisions made without stakeholder input.
Funding taken away from a population who cannot advocate for themselves.
Waiver Eligibility Barriers
Somewhat disconnected Eligibility & Enrollment and SC coordination.
Lack of a streamlined referral system.
Unclear application process which make it difficult for families to navigate.
Individuals, families, etc. are passed between multiple staff in multiple divisions who all provide differing and conflicting information.
Insensitive process requirements.
Asking repetitive questions when we know that conditions do not change.
Individuals are unenrolled due to cumbersome administrative processes.

The process is insensitive to grieving parents; adds additional paperwork to busy parents.
The assessment process is too invasive; asks inappropriate questions for some populations.
All the waiver programs are disconnected, making it tough for families to navigate.
Service coordinators don't understand the different waivers to help individuals and families understand when they may better be served by a different waiver.
Many individuals and families expressed frustration over the amount of time before services were received.
Many families stated frustration with the complexities of applying for, qualifying for, and receiving services.
Lack of automatic access to waivers for progressive diagnoses in which proactive care can improve quality of life for the duration of their life.
Lack of staff who understand the whole process, no synergy between waivers to help people access the appropriate services.
Lack of equitable access in the process based on how well you understand the system.
Developmental Disabilities Waiver Registry
Long wait times for waiver services due to length of time spent on registry.
Unless you know to get on the registry early, likely won't have services until adulthood, after school transition services end.
Removed from waitlist due to inability to pay for service coordination. Occurred multiple times.
Limited service access even for those who qualify.
Lack of staff who understand the whole process, no synergy between waivers to help people access the appropriate services.
Lack of equitable access in the process based on how well you understand the system.
Other states have better waiver services.
Limited follow-up and support in accessing other non-DHHS services and programs for individuals placed on the registry.
Lack of education about what the waitlist is and what waiver services offer once a slot is open.
Difference between state and federal DD definition causes gaps and barriers.
No updates, communication, or services while on the registry.
The registry should not exist, it violates people with disabilities rights and puts vulnerable people at unnecessary risk.
Most people wait more than five years for registry services.
Had to pay for services out of pocket while waiting for registry.
Should provide additional education on what the waivers provide and who qualifies.
Cross-System Limitations
Many individuals reported being unaware of the availability of case/care management through an MCO.

School-based services are limited, and this is a particularly prevalent issue for transition age students.
Children with disabilities (especially behaviors) are not afforded a full educational day like neurotypical peers, or the amount of services in accordance with an IEP.
Sometimes, children with disabilities are encouraged to sign away their rights to school services up to the age of 21.
Lack of coordination between DHHS and other state-level departments.
Many siloed processes in place.
Limited coordination of programs between the DDD, CFS, and Medicaid.
MCO Denials
Mixed feedback based on specific MCO case manager.
Case managers have been able to provide guidance to my families as they try to navigate a complicated, confusing medical system. The system seems to always be changing which complicates our family's abilities to navigate the system. Each manage Medicaid system seems to have different requirements that are always evolving. Case managers are essential to accessing health care.
When I have tried to assist families to get special equipment (such as a wheelchair) who are solely on Medicaid, it is incredibly difficult to get anything through. They look at how much things cost, not how a family is impacted.
We've had situations where the MCO wouldn't approve the needed adaptive equipment. This would be necessary to live and function equipment that they wouldn't approve. Then there is no recourse for them not approving.
I don't think they think about the individual. They think about the bottom line. Money.
Some authorizations do not come easily, so we try to work to overcome barriers to help with funding and necessary services for our supported people. We work with Inventory and Client Agency Planning, functional behavioral assessments, and other assessments to try to get our supported people the help they need.
Depending on which MCO they have depends on what benefits they will end up receiving from different doctors and other entities.
Some do not cover what is needed for the people we support. They are kind to work with but often have their own hands tied and cannot get access to the necessary care or items they need.
It's been my experience with Medicaid MCOs that services get cut or they get limited because the State does not give them enough money to operate on or to make a profit.
Billing is a nightmare, care coordinators are not feet on the ground, and telephone assistance can lead to frustration and distress.
Lack of dental.
Managed care is devastating. Attractive to the State so it can stay in budget, but at what cost? It complicates accessibility for health care and passes cost on to the person. Having to

ensure you pick just the right managed care health insurance to cover what you need doesn't benefit anyone but the State. There is zero benefit for the person despite the bells and whistles that are sometimes offered if you choose their plan like gym memberships or benefit cards. Keep it simple and spend the money on accessible care that is easy for all involved.
A lot of dental offices no longer want to use MCOs and the people who work at the MCO offices change so often that you cannot build a rapport with anyone.
Nebraska Total Care is intentionally denying needed medical equipment to pad their bottom line.
Equity
Difficulty accessing services without language barriers, but worse for individuals who don't speak the language.
Cultural barriers exist in immigrant and minority communities whose primary language may not be English (Karen and Spanish noted as top examples).
There is a lack of trust in government institutions between some community members and in some minority communities.
Service coordination in other languages isn't adequate.
Paying for services out of pocket puts individuals and families at risk for bankruptcy and economic hardship while waiting for services.
Miscellaneous Feedback
Personal Assistant Services work better; hard to find the services they need because they are sprinkled between departments.
Non-profit "region-based" providers struggle to cover costs while new providers cut corners to line their pockets and treat participants like commodities. The SLPs are often just fronts for sub-standard care and illegal activities. Statutes and regulations and lengthy appeal processes for agency providers do not protect participants or assure quality services.
Right now, DHHS DDD is moving to change Shared Living services. There are a few complaints from stakeholders and poorly run agencies about agency hopping. This rarely is the decision of the participant (I would say it never is but there may be an exception). If the Shared Living Provider goes with the participant, it is completely transparent to the participant. They see nothing different. Protecting the participant is not an issue here. We have surveyors and service coordinators coming down on us for various documentation requirements. One of the greatest complaints we have is that we require our staff to comply. When we require them to comply, they leave us for another agency that is not the target of so much intense oversight as we are. All agencies should be required to comply with the same requirements.
Children with autism need special consideration as stakeholders look at policies and implementation for programs.

Continued availability of ICF/IID services through BSDC. BSDC provides a safe environment for individuals served there, and the existence of BSDC is valued by families with loved ones living there.
There needs to be a good way for parents and guardians to be able to find the right supports. So often, we find ourselves doing extensive searches and coming up with so little. There also needs to be a way to connect to more community “fun” activities for these people, as those of us who do not have this challenge really take for granted the freedoms that we have to meet others and interact. Many times, those with DD are relegated to the few opportunities that are provided to them.

Appendix XXVIII: Stakeholder Vision for Future Services

Stakeholder Vision of Future of Services
Emphasis on targeted case management, supported decision-making, and more real and genuine inclusion with the community.
Eliminate the waiting list.
More systematic approach to determine level of need and access financial and emotional support.
Better reminder services.
More coordination with the courts.
Increase expectation of employment and acceptance for people with DD. Less reliance on adult day care for people who are employment ready.
More providers who can complete a Functional Behavior Assessment, not just for people with autism, but developing the mental health workforce to focus on people with ID and DD.
I am very worried about where we will be in three to five years. Anyone trying to be independent might as well just give up. I don't want to live with a stranger, and I don't want to live in an SLP. I am able to live alone except I need help with transportation and helping me save my money. The only way I get this is to be dependent on an agency and they don't listen most of the time. I can hardly afford an apartment and I live in one of the worst areas because that is all I can afford, but I am able to live independently and have to give up my independence to live in a safe neighborhood that I can afford.
Better pay for providers and better working conditions to attract and retain caregivers.
More funded residential programs for adults, particularly in rural areas.
Coordinators that can help a parent or guardian navigate the state waiver programs and find the best care for their loved one. My perfect world: modeled on Minneapolis. Specifically Hammer Residences and Living Well. They struggle with retaining caregivers, but I like the idea of having managed centers over sticking my non-verbal daughter in a stranger's home.
Person-directed budgets that are used to select and purchase services. Beatrice State Developmental Center and intermediate care facilities closed; Sheltering Tree and Ambassador closed and services in the community for residents made available.
Specialized settings for those with severe psychiatric/behavioral or medical needs available in the community.
Settings Rule strictly adhered to, particularly ensuring heightened scrutiny is utilized whenever questions arise about a setting and inclusion concerns.
A specific, detailed Olmstead Plan that is used as part of a continuous improvement process for state and private services.
Ongoing planning with stakeholders to maintain the registry at the lowest possible levels.
State-funded navigation and advocacy training for persons with disabilities and family members who want or need it. Outreach to parents of young children newly identified with a focus on peer support in place.

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Expansion of waivers to include new initiatives in service delivery and community inclusion. Major shift in service focus away from workshops towards competitive employment. All of these are achievable if we start planning and working toward them now.
Continued availability of ICF/IID services through BSDC. BSDC provides a safe environment for individuals served there, and the existence of BSDC is valued by families with loved ones living there.
Fully funded and equipped to lead community integrated, self-directed lives with competitively, professionally paid support staff.
We can access whatever medical and mental health services we need without the barriers of red tape.
We work alongside typical others, for the same pay or better, with the same relative opportunity for advancement. Not residentially segregated unless we choose. No forced poverty ($2,000 asset limit) to qualify for supports and services. We should qualify based on our support needs, not my asset limit.
Prioritize what the disabled person truly needs instead of goals imposed by professionals, Medicaid, etc. For example, disabled person has a complicated medical life. Provider and SC stressing community access, this is way down on the priority list. Family hopes that someday this will be a priority. It still is not person centered, person choice when professionals are prioritizing.
All individuals with disabilities would be provided every therapy and/or service they require to live their best life, whether that is independently, with some assistance, or in their own home or a facility where exceptional care is provided to them. These services would be provided without a major cost to the individual or their family, within a convenient distance to their home and loved ones, without any discrimination, by sufficiently qualified professionals, and for as long as services are needed to meet the goals agreed upon by the individual and/or their family members and Nebraska DD.
Currently, budgets for DD services are determined by the ICAP. In the future, more relevant and current evaluations should be used. There should be an opportunity to evaluate the reliability of the assessment, particularly for those who cannot respond on their own. In those cases, the system relies on provider data collection and interviews of staff. Especially with staff turnover these days, the data is often collected by inexperienced and overworked staff who may not really know the person that well. Additionally, use of budget money should not be limited by the "tiers" the assessment tests someone at. In other words, the participant should be able to choose to use their budget for one-on-one services at fewer hours even if they do not "test" at that tier. I would advocate for statistics being transparent and available for all to view, for example, how many appeals, what were the results, how many budgets increased, how many decreased, etc.
No waitlist, transitional programming meeting the needs of young adults aged 19 and beyond, private/partner collaboration to meet the needs within the broader community

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context (i.e., intergenerational programming, etc.), transportation, respite for families, more residential services, and jobs/experiences that are available to those with special needs in the broader community.
If following the pattern of the last five years, we have watched a backwards slide of acceptance and integration into society. When attending the Unicameral to support an increase in funding we received messages from our state senator that our child was eating lunch on the taxpayer's dollar and there should be less funding to return to property tax owners. We cannot imagine the quality of life our son would lead if we were not contributing to his support to provide him with a happy life. So many of our special needs population have been abandoned by their families. His caregivers are amazing and doing all they can on such limited budgets, and as their funding continues to decrease and with rising inflation, their quality of life will also suffer.
Flexible funding, outcome-based payments for providers, family involved in plans, more collaboration with education, behavioral health, VR etc.
Go back and look at the legislative intent of the Developmental Disabilities Services Act. Remove the registry/waiting list. Keep DDSC under DHHS; train them well, pay them well, and treat them well (e.g., union contracts). Maximize federal funding and rewrite waivers, if needed. Pay direct support staff appropriate wages. Look at the agencies with skewed overhead and admin salaries in comparison with direct service providers (DSPs). Get a survey/licensure team that has some teeth to actually do something about failed service reviews, abuse, neglect, and exploitation (not just relying on adult protective services to make a determination). Finally, I will re-state what I said in response to an earlier question. The registry should not exist. All eligible persons should be receiving waiver services from the day they are deemed eligible. Waiting seven years or longer for residential and losing the entitlement clause after graduation from high school is a sham. The legislative intent of the Developmental Disabilities Services Act was clear, that ALL persons with DD receive services. All means ALL.
There needs to be a proactive movement to establish safe communities to assist people with DD to have meaningful lives once their parents have passed. This means an orderly transition to supported community living arrangements, helping them to leave their parents' home before the parents die. Helping these young adults obtain the VR services they need so that it is not all services "given" to them, but so they can contribute by working themselves in the community would be best. Adults with DD have varying ability to be productive, but it should be a priority to help them live the most rewarding lives that they can.
Having occupational therapists involved in the level of care determination as they are the professionals strictly trained in ADLs. Nurses alone should not be able to determine that. Family support waiver to assist with medications and equipment that are not covered.

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Parents should be able to maintain their guardianship but also be certified as shared living providers. Many parents of adults with special needs—and the individuals themselves—do not feel comfortable with the residential care offered elsewhere, so they choose to keep them living at home. But that care is a full-time job. They require financial and legal support to do so.
Training and paying caregivers. Including Nebraskans with disabilities in all decision-making processes. Ending the seclusion and restraint that's being used in our schools, it's called all kinds of different stuff, so they avoid legal issues because people don't understand what is happening. Starting services as soon as possible, like as soon as they ask. That would save lives, make quality of life better for the people being served and the community in general, less institutionalization, and more services in the community.
Don't combine programs into one division.
User friendly software for Maximus Tellus.
Better cooperation between individuals, guardians, and case managers to serve individuals. Much more oversight of agencies and contractors.
Open up the funding for both parents to be paid as caregivers on the DD Waiver. Allow parents to access respite services when working. Have more facilities for kiddos and young adults to be at night and on weekends when parents need a break, but don't have family members who can watch their child for them. My child is extremely social and desires to be around her peers, not always with her parents.
Automatic enrollment into DD waiver when diagnosed with a severe mental disability. No cancellation of waiver when services are not used for a quarter.
I would start designating funds to go toward younger children with needs, and not just ones who don't qualify for Medicaid based on income. I literally had someone from Medicaid tell me to call back and reapply if I had another child or lost my job. A parent should not have to choose between working for a living and getting help for their child. And, we absolutely shouldn't be encouraging people to quit their jobs or have more children to get help. That kind of system makes people need more services than they originally would have if they had just gotten the help they needed originally. Putting money toward the younger children would make it very likely that the person would not need as much support as an adult as well.
Not everyone plans to be employed or can be employed. Not all services should focus on employment. General population needs education about working with people. Better advocating for individual with DD, finding opportunities for them that is dignified.
Families need to be supported. It is a huge burden to care for someone with multiple disabilities while working. Appointments, meetings, required home visits, transportation needs, and 24/7 supervision needs all make having a full-time job extremely difficult. The backlog needs to be cleared. Make services available sooner so families don't struggle. Funding for quality providers needs to be increased. Trusting someone to care for a disabled

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loved one is tough enough, but if it is a low-paying position, you will be left with less than quality care.
There would be flexible care so that parents don't have to choose between work and keeping their children safe. There would be client-centered care that is more focused on problem solving that barrier creation.
Allow telehealth as a mode of service delivery when proven to provide increased accessibility and the same or better quality of care for individuals.
Shorter wait lists for Comprehensive Developmental Disabilities waiver and more options for families with children aged 11 to 17.
I don't believe it will ever get better, and in fact, I believe it will get worse. It would make sense to move to another state, especially as my daughter ages and we lose more and more support. It already feels like we are doomed to a life of rarely leaving our home because of the difficulty. The less therapies my daughter gets, the more she loses what very few abilities she has.
Improved person-centered care.
That managed care would cover nursing hours for those who are deemed nursing facility LOC by AD waiver. We have not had respite or time away or a break for years.
Children with progressive diseases could be allowed on the waiver without waiting until they are so bad it costs more money. If we could have had help with medication earlier, or physical therapy sooner, our son might still be able to walk. We paid for things out of pocket for a long time, but we couldn't afford the only medication at the time ($90,000 per year). Recently, our primary insurance has denied an infusion of medications that would stop the progression. It costs $300,000 per year. The costs of these medications is unreal and I don't want our government to just pay it. I want our government to regulate drug companies, so our medications don't break our government.
Knowledgeable staff. DD seems to want the control of AD but lacks anyone that really wants to support the program. They are two separate programs for a reason. I would suggest MLTC resume oversight of AD and to be the well-run program it was. The DD oversight was simply a ploy by DD to have the funds and lack of waitlist AD had and shuffle clients between the programs to say they were addressing the wait list problem.
Help with autism reimbursements other than ABA.
It needs to take single-parent households into consideration. I am basically being forced to quit my job and stay home to care for my daughter, whom I feel needs to be in day services. She needs socialization and a purpose from day to day. I feel the only option for us is the AD waiver at this time because my daughter does not get enough funding though DD waiver to cover day services, transportation, and someone to care for her till I can return home. Jobs that fit her schedule do not pay enough for us to live off of. If I was a two-income household, I would have more options, but that is not the reality of the situation and for other families.

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The DD waiver need to make it possible for single families, as well be able to live and not be forced to give up guardianship to do so.
A future where it is not so difficult to obtain needed services. A future when the people you talk to at DHHS are all educated on DHHS programs and the policies and procedures where you call Access Nebraska and get different answers from different people each time you call.
I would look much closer at family members being independent providers. In my opinion, I haven’t seen good things for individuals when their mother becomes their independent provider. There are two in my town and the general consensus around town is they aren’t meeting the needs of the individuals they are just collecting a paycheck.
I have wondered what it would be like to have the federal monies follow the person no matter what state they live in, so individuals have more choices and opportunities to live abundant lives, like most Americans.
In three to five years, there would be a list of providers and their availability—perhaps people who want to be independent providers are on a list would check a box for hours available, type of disabilities they will work with, etc.
Improvements to how interested individuals enroll as independent providers.
Also, housing options for people with disabilities who are able to live more independently with support versus living in a shared living provider’s home.
Easy to understand definitions of the different types of services and what the individual actually has and what is offered.
Providers in areas like Gretna or transportation to services.
Job training and opportunities for individual that have physical and intellectual disabilities and individuals that need training beyond 21.
We are part of a group of families of children with a progressive neuromuscular disease that is life limiting. It is very difficult to understand why some families receive waiver and others don’t. Most families have no idea what ADLs or LOC means, so they don’t have a clue how to answer the application for services questions. Also, it seems to be open to interpretation by those making the decisions.
Families are often denied necessary equipment and items needed for future use in their wheelchairs.
Parents need to be given information about services available and what steps they need to take before their child enters high school. There needs to be more collaboration between DHHS and the elementary schools. Parents are often overwhelmed by the process and put off applying for services. This causes a crisis when a parent or caregiver passes away, or a young adult needs housing due to other circumstances.
Having more creative employment opportunities in our rural communities would also be helpful.

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Having quality caregivers and supervisors in both the group homes and day service centers is very important. This requires a competitive wage. Adequate funding from the state is crucial.
All families receive ongoing education and awareness that starts when their children are young about the services that are available to them as their child gets older.
People with disabilities would have more say in their planning process, education on self-advocacy, and more education and awareness of their rights and the grievance processes.
A single resource network for internal and external (client and family) that is easy to navigate, understand, and moves from area to area to streamline the process. Invest in the employees in the network at the highest and lowest level of the disabilities chain.
Invest in technology that stimulates and improves cognitive and physical coordination for individuals with disabilities.
Pay one daily rate for people getting comprehensive day/res services. Take away the requirement to be out of their house a certain amount of time. Pay the provider for providing the service that the person wants. Other states don't have a requirement for this. If people just want residential services 24/7, they can. They still leave their home to do things like shopping, recreation, etc.
Free training and reimbursement for gas mileage.
Getting more dental offices to take Medicaid. Getting the medical and nursing schools to train on this so that they are not afraid of it.
Bring back mental hospitals. Too many people need help.
Make waiver settings feel less institutionalized. Stop parking lots of cars in front of waiver homes. Increase dual diagnosis health. Partner with neighboring states to take the lead on reciprocity and honoring granting waiver to clients who are moving to/from neighboring states.
It would be helpful if the various agencies could and did talk to each other. It would also be helpful if it was easier to navigate through the agencies by knowing what each one does and how to help families access the services.
I'm confused over what quality Liberty Health is providing for the people receiving services. Perhaps this could be shared during an upcoming provider meeting. The state of Nebraska needs to ask itself "What does this do to add value to the services people receive." If the answer is 'it doesn't,' then the state of Nebraska should not do that thing.
Utilize the entire budget appropriated by the legislature so agencies can be paid what it costs to provide services and so they can hire and maintain competent staff.
More activity-based partnerships and learning based partnerships.
Continue to modify the Liberty contract.
Monthly open access to professional assistance and navigation of applications for assistance and education on what is available and the needed procedures to access services.

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More connection with provider agencies with DHHS SC. Meet and greet, ways to express what agencies support for services, and availability of their services.
Creating agreements with neighboring states to provide people with disabilities the same flexibility to move out of state, but without a loss in needed services.
It would be nice if there was one place to contact so you could describe your issue/need and then they would direct you where to go, rather than being told "we don't do that." Super, so where do we go from here? There are so many agencies and it's so difficult to keep it all straight. If I am struggling as a professional, you can imagine how a family feels. They don't know what is out there and they ask us at the school, and we don't know either. Plus, those agencies don't always want our input.
Add music, art, and recreational therapy as service options. Partner with a college to create day programing and waiver-approved housing on campuses for people with DD.
I am pretty resourceful and connected and still don't feel confident that after the seven-year wait for services that what our son needs will be available. I often wonder if we are on the right list, talking to the most appropriate resources, etc. I do not have confidence that we will find an appropriate solution for our son. He is too capable in many ways, as well as severely challenged in others. For example, he has worked two fast food jobs at the same time but also called the police because I asked him to take a shower.
Train case managers better so they are all consistent with waiver coverage. Please stop draining the families caring for medically complex children and simplify the process for coverage; don't make them fight for best care practices. Develop a reasonable way for families to care for their loved ones based on the realities of a limited workforce.
It's sad to see that other people that are low income but do not have a disability get Medicaid and kids with disabilities still wait on a waiver to hopefully get approved one day.
1. The authorization process is very challenging. Often times, we are told our testing is not "medically necessary" even when we can cite components of the Diagnostic and Statistical Manual of Mental Disorders that support the minimum level of testing that we are doing (ASD evaluations). We actually do need to do direct testing. Caregiver report is often not accurate and there are times when people are seeking an ASD diagnosis because they think this will get them access to certain things, rather than because it is the best diagnosis for their child. Four hours of testing is nothing. I spend at least 15 minutes prepping for my evaluations, 90 minutes report writing (assuming a clear presentation), and 30 minutes going over results. An Autism Diagnostic Observation Schedule (ADOS) is going to take anywhere from 40 to 60 minutes to complete, and anywhere from 10 to 20 minutes to score. That means I am at the four-hour mark having done one test, which is not enough for a diagnosis. I get pushback on doing cognitive testing in the context of ADOS testing. If you read the ADOS manual, then you should know that you need to know the patient's developmental level to score the ADOS, and you get that through cognitive or developmental testing. I can't tell you how many misdiagnosed kids I have seen because the provider did not do a cognitive test or

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developmental test. In general, humans are not great at estimating developmental levels, which is why we have tests that help us figure it out. I have seen a bunch of kids diagnosed with ASD when they really have IDD or borderline intellectual functioning. This is confusing to parents and really messes up service flow. If other providers, pressured by trying to avoid peer to peers, decide to do lousy evaluations, then that is going to result in the need for more evaluation in the future. About 10 to 15 percent of my evaluations could have been avoided if the first psychologist my patients saw bothered to do comprehensive testing. With waiting lists for ASD evaluations and services so long, this is a huge problem. 2. Peer to Peers also take a ton of time. 3. We also have a backlog of patients because they are limited to seeing only certain providers. We are a training clinic and have a ton of advanced doctoral interns who are provisionally licensed mental health practitioners (PLMHPS) but who are limited in who they can see. It's also frustrating that if a provisionally licensed psychologist (PLP) sees a patient for an initial diagnostic interview, then a licensed psychologist (LP) has to see them for follow-up care. This creates a crazy backlog. If the PLP is good enough to do the intake and provide initial diagnoses, then why are they not good enough to provide treatment? It's not like PLPs can even practice on their own, they are all being supervised by LPs. I also think the same could be said for our PLMHPs as well. Seriously, some of our PLMHPS hold multiple master's degrees and have even had these degrees for several years. Supervisors are required to provide supervision. Shouldn't supervisors be able to consider whether the trainee is skilled enough to engage in certain activities and the level of support that is needed? 4. Nebraska has many rural pockets. These folks rely heavily on telehealth options. It's also helpful for families who do not have paid time off, because then they can schedule appointments more easily around breaks, instead of risking losing their jobs. Moreover, we still have patients who have medical conditions that make it dangerous for them to travel to clinic (e.g., uncontrolled epilepsy/diabetes, cancers, severe behaviors, etc.). Telehealth really helps increase access. Again, if I do not think that a patient can benefit or they do not show a benefit from telehealth services, then as a provider, I would work to find an alternative, but I think the appropriateness of telehealth for a patient should be up to the provider and the patient, not insurance.
Eliminate the registry, or at the very least, shorten the length of time individuals spend waiting on the registry.
Considerations for evaluating why waiver services are not being used.
Expand person-centered planning to be more like an IEP.
More accessible communication to families, including families whose primary language is not English.

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Increase flexibility for families to choose how to spend waiver funding.
More training for service coordinators and providers.
Model training conducted in facilities for community-based providers.
Coordinate with schools to align services, and ensure schools have support to communicate throughout a student's educational years to families the availability and benefits of applying for DD services through DHHS-DDD prior to transition.
Have DHHS provide training to school districts to provide more awareness, education, and supports to teachers and paraprofessionals who work closely with students/families.
More consistency in assessments for LOC.
Expand services to families with high acuity needs.
Pay parents for providing services.
Increase provider rates.
Provide more accessible childcare, inclusive of after school hours, especially for older children (Note: need to look at licensure policy for older children).
Have a dedicated hotline for individuals with disabilities and their families instead of using AccessNebraska.
Align DD definition with the federal definition.
Create an online blueprint for services.
Increase flexibility for families to choose how to spend waiver funding.
Needed services and supports for: • Safety equipment. • Over the counter medications and thickeners. • Employment building skills. • Offer medically trained staff/nursing services. • More providers for respite and mental health, and are experienced with DD and ID. • Independent living skills. • Genetic testing. • Physical therapy, occupational therapy, and speech therapy. • Pull-ups and gloves. • Coverage for gyms for exercising in the winter. • ABA. • Transition support. • Transportation. • Assistance for all ages. • Nursing care. • Dentists. • Durable medical equipment. • Flexibility for funds.

Stakeholder Vision of Future of Services
• More comprehensive developmental programs as alternatives to medication. • Paid parent caregivers. • Nutritional supports and home-delivered meals. • List of providers willing to work with families. • In-home care. • Recreational activities. • Socialization. • Companionship. • Family counseling services. • Supported decision-making. • Rent and additional assistance encouraging community access. • Financial support. • Better vision coverage. • Qualified, knowledgeable, enthusiastic, creative providers. • In-home care for individuals with behavioral needs. • More communication about the waivers for the public. • Better community integrated employment services, and better transition supports from school to adult services. • Transportation for medically complex individuals. • Programs designed to support individuals on the autism spectrum beyond what is provided in schools. • After school programs or care. • Additional support in the summer for children/families. • Peer programs. • More transitional training. • Summer camps. • Consistency for program requirements; stop changing requirements so frequently. • Support for aging caregivers to support community transition. • Allow parental shared living providers to maintain their guardianship. • To have enough providers to actually receive the approved services. • Allow both parents to be paid providers. • Higher pay for providers. • Supports so youth can stay in home instead of moving to a group home. • Discontinue the registry. • Children are ending up in foster care due to lack of support from DD. • Weekend assistance. • More residential care other than nursing homes, like roommate or supported housing.

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• Access to nursing care for respite. • More dental providers. • Help with SSI. • Better customer service and processes. • Homeless services. • Support for families on the registry. • After-hours services to allow individuals to attend community functions.

Appendix XXIX: Stakeholder Reported Critical Issues for Improvement

Stakeholder Reported Critical Issues for Improvement
Help people find solutions to their problems. When my payee calls to find out why my food stamps are less and less each month, they tell her that my income is too high or that it isn't changing, but it does change and now I can't even save $60.00 a month. I pay $640.00 in rent, and between utilities, spend down, food, clothing, and cleaning supplies, I am broke.
Better vision and dental.
Better pay and benefits to attract and retain qualified caregivers.
More comprehensive service coordination. Consider using Zoom for rural areas.
More services (day services and residential services) offered in regions that are NOT on the interstate.
Address the waiting list.
Better information provided to parents of school-age youth on what services are, when they need to apply, and the different waiver options available after school. This should be done at IEP meetings routinely, so parents are not left scrambling or feeling lost.
Strict adherence to Settings Rule requirements; oversight of the same by stakeholders. The State should make a firm and lasting commitment to HCBS as to where we need to direct state resources and quit wasting state dollars on congregate settings.
Support training for service provider staff on best practices in service delivery and ensure they receive a living wage.
Support families directly who care for a family member with disabilities with resources, whether adults or children.
Implement policy and procedures in relation to supported decision-making so DHHS and affiliate providers can support people without requiring more legally restrictive interventions by way of a substitute decision maker.
Make employment supports more accessible. VR is not always willing to support individuals with disabilities based on complex needs, and DD will not approve employment supports until VR services have been exhausted. This ends up resulting in barriers to supports and can cause stagnation or even regression for individuals who are trying to work toward independence by seeking gainful community employment.
Provide more person-centered case management. Generally speaking, DD service coordinators only work with DD systems. So, a person may have multiple separate case workers for separate services (VR, DD, MCO, special education, if applicable, etc.), but none that cooperate within different systems.
More funding for more services.
Quality oversight of provider service delivery. DHHS adherence to federally approved waivers and state regulations and state approved policies. Internal director and administration collaboration and support of/for policy, quality, and waiver teams.

Stakeholder Reported Critical Issues for Improvement
Have options for youth under the age of 19. Parents and guardians need more assistance in the family home to maintain the youth in the family home. Need more providers who will do FBAs on persons who are not diagnosed with autism. Need to know the function of the behaviors. Services need to be based not just on ADLs, need to also look at behavioral needs.
More community involvement.
To not deny an individual with disabilities services because they are “not disabled enough.” Provide affordable assisted living housing for the vast number of individuals living with autism spectrum disorder and other disabilities who can work and live semi-independent lives but not live completely independently.
Work with cities to provide expanded transportation services to individuals with disabilities who are unable to drive but can live independently.
Coordinate with the federal government so individuals who are disabled and receiving social security income can work and make a higher income without losing their social security benefits. The current system incentivizes individuals to not try to get a better paying job or to work more hours each week, because if they exceed the income limit, then they lose their social security benefits.
Flexibility—being able to accommodate the disabled person or caretaker to a process that works best for them for their needs and equipment.
Care providers, for Kearney for example, being able to find after school, no school, or summer care is a stressful challenge. Either there is no room available, or provider does not want to take care of a person with disabilities.
Increase providers in rural areas.
Increase transition programming for all, regardless of waitlist status.
DHHS becomes an independent/non-political agency to advocate for appropriate budgets.
Quality of service.
Transparency
Self-advocacy.
Increased quality providers.
Keep service coordination in DHHS.
Expand service definitions for older adults with IDD to self-direct their lives.
Transition services for people who have the ability to work, even those with challenging behaviors, as many of those behaviors can be worked through to get the person to be successful.
Access to care.
Ease of finding providers.
Increased coverage of medications.
Educating and empowering families to provide financially supported long-term care.

Stakeholder Reported Critical Issues for Improvement
Earlier waiver support. I had to quit my job when my daughter was eight to provide better care for her when school was not in session and was not able to earn a full-time salary until she was eligible for the DD waiver, and I was trained as an SLP.
Better Medicaid reimbursement for medical offices, primarily dental. It is very hard to find good, special needs-qualified offices that take Medicaid.
Training and paying caregivers including caregivers of children.
Retention of good providers and staff, more transparent process for individuals and guardians to choose agency providers, as well as audit processes.
Take allegations of abuse or neglect more seriously.
More facilities.
Better explanation of services available. Better introduction to the program when enrolled. Easier to access required services.
Services tailored to younger individuals who are enrolled in school.
Less denials for needed items.
Alternative opportunities outside of school through 21.
Business leader support and resources to employ individuals with disabilities.
Red tape/paperwork/required meetings are redundant/time consuming.
Funding schemes to include transportation considerations and home modifications for those that are wheelchair bound.
Assign a service coordinator to individuals who are 14 years old.
Host a workshop for young family how to sign up for services. Maybe a mobile computer lab with internet access.
Service coordinators who take the time to communicate by phone or text.
Help accessing services and therapy.
Help during the summer; childcare programs.
Expand service availability.
Nursing coverage paid for under AD waiver.
Automatic coverage for progressive disorders.
Providing services in the community that represent an inclusive setting in a general population setting.
Respite care options.
Day services for younger children.
No one should have to give up guardianship to receive the help needed to the whole family.
Customer service.
Parents being independent providers.
Need services to help support families when parents are aging and still have an adult child with disabilities. Service transitions for family members.
Allow legal guardians or powers of attorney to be service providers.

Stakeholder Reported Critical Issues for Improvement
Housing options for individuals with IDD – supported living options.
Classes for persons with DD for the Section 8 voucher system, Rent Wise classes geared to people with disabilities, assistance with finding apartments that are affordable, etc.
Job training beyond 21.
Providers for folks with multiple disabilities.
Access: sooner and clear routes to services. Variety: understanding the spectrum of needs are varied. Effectiveness: are serviced offered actually fulfilling needs and helpful. Choice: ability to determine what services are most beneficial for each person and their caregiver.
More clarity on who is eligible and the criteria.
More vocational opportunities in rural communities.
Medicaid approval.
Services for homeless individuals.
Services all across the state.
Support.
Provide an easier way for families to access and understand the application process for DD waiver services.
Start educating families and individuals as early as elementary school age, collaborate with the Department of Education, to ensure their planning for transition begins earlier than the high school years.
Provide other opportunities for assistance to help families on the waiting list, such as some respite funding, some funding to help those on the waiting list stay active and involved in the community and recreational activities.
Increase the person-centered practices and support individuals receiving services to become self-advocates.
Become involved in helping individuals receiving services learn about person-centered practices and self-advocacy and learn from other states that have done this.
Please consider counseling for extended family.
After-hours transportation services that permits individuals to be part of their community.
There are no services for families who can't/don't work other than respite. This is not adequate to meet many of their daily care needs. AD waiver for children needs more services to fill a large gap in family's needs. Something such as personal care or companion services are needed in situations in which there is a single parent household, a disabled parent, etc.
Until children with disabilities are adults there is a huge gap for middle income families that have children that don't meet AD waiver criteria, but also do not have a low enough income to be eligible for income-based Medicaid. Specifically, kids with autism, their parents/insurance cannot cover the cost of the services the child needs.

Stakeholder Reported Critical Issues for Improvement
Parents are still getting lost in the application process for HCBS—specifically AD waiver applicants. They are still being denied Medicaid and then that's it, it doesn't get passed on or assigned to the Medicaid workers who do the specific AD waiver cases.
The families that are eligible for AD waiver appreciate the service so much, but there is always a fear that if their child improves in health (no longer meets nursing facility LOC) then they will miss out on Medicaid and other needed services, such as specialized childcare and respite care. Even with private insurance, most middle-income families really struggle to pay for needed services when their child is no longer Medicaid-eligible.
The waiting lists are long, families need more support to access respite care, and the paperwork is difficult to navigate. It's also disheartening that children who do not have citizenship status are not able to qualify for Medicaid waiver and other related services. This is a huge disservice to my patients in particular.
I do not like the Independent Provider program as too many independent providers take advantage of the money and do minimal to no work, and it is difficult to manage while they are performing Medicaid fraud. In addition, independent providers do not do the required training and expect the DDD service coordinators to do all the work, program writing, etc.
In our agency, we are able to help families who are eligible for AD waiver access childcare and respite care and gain access to Medicaid. The problem is that AD waiver only services around 10 percent of our total children served, so there are kids with very significant disabilities that do not meet nursing LOC and don't have access to what they would if they were Medicaid-eligible.
It does not sound like they get adequate support or explanation about services. The families we see tend to rely heavily on our care coordinators to be able to navigate the process.
The State isn't funding services at the level it costs to provide the service. The State doesn't allow utilization of all service codes when needed. Over regulation and over oversight leads to time wasted that could be better spent serving the person in services rather than the funding entity. Time and time again, the State has pushed off things that used to be the State's responsibility on to providers with no compensation (e.g., share of cost, billing, etc.).
Extreme oversight redundancy. There is a tremendous burden on administration which apparently is being ignored by everyone.
Therap/EVV Tellus system process, holes, lack of service coordinator knowledge on how to troubleshoot is the biggest barrier.
There are so many different organizations, and I don't know what each does.
DHHS and stakeholders currently are focused on pay for DSPs. That is not the problem. They continue to increase the administrative burden which sucks money away from participants and providers' ability to pay DSPs. SLPs are not DHHS employees and should remain subcontractors or the agencies. Olmstead should be followed. It appears to me that it is not. Stakeholders should be better educated as to the purpose of it rather than letting DHHS give in to a few complainers who want day centers and group homes. That is another problem.

Stakeholder Reported Critical Issues for Improvement
DHHS changes the rules for everyone every time a few complainers complain. That is a very poor way to run an organization. Doing what is best for participants should be the focus rather than placating a few complainers.
Requiring services to be provided by employees rather than subcontractors was a mistake based on an incorrect interpretation of the laws and regulations. This led to the unfortunate situation of needing to carve out the exception for Shared Living. All of this is unnecessary meddling in the business models of agencies. DHHS should only be concerned with the quality and continuation of services provided by the agencies rather than how they pay their staff.
Clarification on what each entity is, who they serve, and how to contact them would be a good place to start. I learned the hard way that the AD program doesn't care about the individual, they just care that the individual stays in the home. I had a terrible experience with a person in the AD program. She ignored neglect and she ratted the school out to the family. It wasn't until my student got a caseworker that cared and believed us and my student that things finally started happening. My student is now in a safe environment. I feel that if you luck out and are given caring people to work with it makes all the difference. It shouldn't take luck though. Each person deserves the level of care and attention that my student finally got.
Parents don't know what resources are available. Schools are not appropriate advocates for individuals. Who really is able to read and navigate the parent handbook for IEPs. I employee disabled individuals. Some need constant support to do the job. VR doesn't provide appropriate amount of support.
Stop making everything so difficult. Raising a child with special needs is difficult enough. Help families so that the parents don't get burned out. Help supplement income since finding quality providers is almost impossible. Reduce the paperwork and red tape for getting services.
It would be nice that if DD is going to implement a new policy that it would be applied across the board.
Make sure that there is communication with Medicaid as they do NOT understand the Medicaid reviews for those with disabilities.
More training for person-centered planning, more community integration, more focus on independent living and less restrictive options, more access to community transportation and more transportation options.
We implore you to help make this system better and make it so that those with progressive, life-ending diseases automatically qualify for waiver services.

Appendix XXX: Peer State Websites Review

State	Observations	Website Links

Colorado	• Can easily navigate to:
	  ○ Medicaid services
	  ○ Waiver services
	  ○ State subsidized childcare
	  ○ Programs for genetic or medical complexities
	  ○ School-based programs
	• Graphics were included to demonstrate process flows on the Medicaid and childcare sites.
	• Eligibility criteria was not explicitly stated for the school-based program and the waivers.
	• Limited information was available about what supports are available through 1915(c) waivers and school health services.
	• Using clickable links instead of hyperlinked key works makes it harder for individuals to access.
		• Colorado Medicaid
		• Colorado Medicaid Waivers
		• Colorado Child Care Assistance
		• Colorado Programs for Individuals with Physical and Developmental Disabilities
		• Colorado School-Based Program

Ohio	• Can easily navigate to:
	  ○ Medicaid services
	  ○ Waiver services
	  ○ State subsidized childcare
	  ○ Programs for genetic or medical complexities
	  ○ School-based programs
	• The genetic services page was difficult to understand eligibility criteria.
	• Understanding of the services available was found for Medicaid, waiver, childcare, genetic, and school-based programs.
	• Ohio Medicaid was easy to navigate because it offered images along with key words to help individuals navigate the application process.
		• Ohio Medicaid
		• Ohio Medicaid Waivers
		• Ohio Child Care Assistance
		• Ohio Genetics Programs
		• Ohio Medicaid Schools Program

State	Observations	Website Links
Oklahoma	• Can easily navigate to: ○ Medicaid services ○ Waiver services ○ State subsidized childcare ○ Programs for genetic or medical complexities ○ School-based programs • Eligibility information was easily available for: ○ Medicaid services ○ Waiver services ○ School-based programs • Information was easily available regarding the services provided by Medicaid, Medicaid waivers, childcare, genetic programs, and school-based programs. • Consistent terminology and cleaner formatting would improve the ease of navigating some pages. • The childcare website had a very helpful frequently asked questions section.	• Oklahoma Medicaid • Oklahoma Medicaid Waivers • Oklahoma Child Care Assistance • Oklahoma Genetics Programs • Oklahoma Medicaid Schools Program
Wisconsin	• Can easily navigate to: ○ Medicaid services ○ Waiver services ○ State subsidized childcare ○ Programs for genetic or medical complexities ○ School-based programs • The waiver services page are not clearly broken out by waiver, but more as supports for the population they support. • The Medicaid website was easy to navigate and paired graphics and grouped applications by populations who may be applying.	• Wisconsin Medicaid • Wisconsin Medicaid Waivers • Wisconsin Child Care Assistance • Wisconsin Genetics Programs • Wisconsin Medicaid Schools Program

State	Observations	Website Links
	• The formatting on the pages with bolded print helped make the pages overall easy to navigate.	

Appendix XXXI: Considerations for Service Array Expansion

Service or Service Need	Rationale
More supports for individuals with autism	• Autism spectrum disorder can manifest along a range of symptoms. • Services should be available to support all individuals with autism spectrum disorder, regardless of where they are on the spectrum.
Improved access to dental care	• Stakeholders suggested that dental care under the Medicaid State Plan is not widely available or is non-existent in certain areas of the state. • Not only should access to dental care be prioritized, but training to dentists on the needs of individuals with DD should be expanded. • A review of provider reimbursement may be needed to ensure dentists are receiving proper and appropriate reimbursement for services provided. This will help to ensure a robust network of service providers.
Expanded state plan services in 1915(c) waivers	• For adults with disabilities, access to State Plan services may be limited in scope. • Providing for expanded state plan services through 1915(c) waivers will help provide more needed services to adults with disabilities.
Services for individuals who do not meet 1915(c) waiver LOC or Medicaid eligibility	• For individuals who do not qualify for services under the Medicaid program or 1915(c) waiver, services and supports should be available to meet needs. • A focus on DBH and CFS programs and services, VR services, and other community-based services should be prioritized for individuals not meeting Medicaid or waiver eligibility.
Care for individuals between 19-22	• Childcare services are not available to individuals starting at the age of 19, for those enrolled on the TBI waiver.

Service or Service Need	Rationale
	• Even when available, childcare may be difficult to find for individuals with complex or multiple disabilities. • Childcare services were noted as not being available when school is not in session. • Expanding childcare through the age of 22 and supporting reimbursement to providers supporting individuals with complex conditions should be considered.
Improved transportation options	• Transportation, even in urban settings, was noted as being difficult to obtain in Nebraska. • With input from stakeholders, improved transportation options should be considered, along with modifications to reimbursement rates. • Self-directed transportation options could be explored to increase the use of ride sharing, public transportation, and informal (paid) supports.