



Developmental Disabilities
Council of Oklahoma



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State Plan Committee Meeting Agenda

Friday, December 12, 2025 - 12:30 p.m.
2400 N. Lincoln Blvd, Sequoyah Bldg., 1 North Conf. 120
Oklahoma City, OK 73105


Join ZoomGov Meeting:

https://www.zoomgov.com/j/1603375568?pwd=NuayxwyuHrrdfz3CuZ_RJdmbUIC8nC6.1

Meeting ID: 160 337 5568 Passcode: 8675309

Members attending online:

I.  **Welcome, Call to Order, & Roll Call** – Shelly Greenhaw,
State Plan Vice Chair

II.  **Discussion and Possible Voting** – Shelly Greenhaw, State Plan
Vice Chair

- 1) Funding Request Presentation by Sooner Success
- 2) Committee discussion of presentations.
- 3) Possible voting on funding proposals
- 4) Final Report from Listening Sessions and Surveys
- 5) State Plan Goals

III.  **Other Business and Possible Voting**

IV.  **Announcements**

V.  **Adjournment**

State Plan Committee Members: Shelley Greenhaw, Committee Vice Chair, RoseAnn Duplan, Wanda Felty, Janie Fugitt, Gina Richardson, Bryce Wooten

The mission of the Developmental Disabilities Council of Oklahoma is to advance communities where everyone has the opportunity to live, learn, work, and play where they choose. The Council builds partnerships to change systems to improve services, resources, and supports for Oklahomans with developmental disabilities and their families.

FY27

**Sooner Success Funding Request
Care Connection**

Fiscal Year FY27 Funding Request

Project/Activity: The Care Connection

Organization: Sooner SUCCESS

Proposal Description: The **Care Connection** project, led by *Sooner SUCCESS* at the University of Oklahoma Health Sciences Center, strengthens Oklahoma families raising children with developmental and complex medical disabilities. By embedding a *Family Support Specialist* within Oklahoma Children’s Hospital, the project provides families with direct, hands-on navigation to respite care, community resources, and disability supports at the point of care. Complementary activities include an annual inclusive *Family Retreat* in Oklahoma City, five *Sibling Camps* across the state, and a *student-led respite initiative* that engages and trains medical and nursing students in family-centered, disability-competent care. Together, these strategies reduce caregiver stress, promote connection, and foster resilience among families who often manage hospital-level care at home.

Families of children with complex medical needs represent one of the most underserved and isolated populations in Oklahoma. Over 75% of caregivers report needing respite, yet fewer than 15% are able to access it, resulting in high stress, burnout, and declining health outcomes (ARCH National Respite Network, 2023). Care Connection directly addresses this crisis by linking hospital systems with community-based supports, ensuring families receive coordinated navigation, emotional support, and respite opportunities before and after discharge. During the first year, the project will serve at least 150 families, engage 20–30 student volunteers, and provide respite to over 150 siblings through camp experiences. In Year 2, the model will expand to Tulsa in partnership with an additional children’s hospital, establishing a sustainable, statewide framework for hospital-embedded family support.

Care Connection’s design aligns with national best practices from the *American Academy of Pediatrics*, *ARCH National Respite Network*, and *Sibling Support Project*, ensuring that services are evidence-based, inclusive, and replicable. Its partnerships with OU Children’s Hospital, Oklahoma Department of Human Services, Children’s Health Foundation, and state health agencies provide the infrastructure and reach necessary to create long-term systems change. Funding will enable Sooner SUCCESS to institutionalize the embedded support model, expand respite and education programs, and build a trained workforce pipeline for disability-competent care. With DDCO investment, Care Connection will transform how Oklahoma connects hospitals, communities, and families—creating lasting improvements in caregiver well-being, child health, and statewide capacity to support children with complex medical needs.

Council Goal & Objective: Access to Services, Caregiver Support, Advocacy and Self-Advocacy

Targeted Audience: The Care Connection project serves Oklahoma families raising children and youth with complex medical and developmental disabilities, including those who rely on specialized equipment, multiple specialists, or technology-assisted care. By embedding a Sooner SUCCESS Family Support Specialist within Oklahoma Children’s Hospital—the state’s only tertiary pediatric hospital and Level IV NICU—the project connects families directly to respite, navigation, and community resources at the point of care. This initiative prioritizes families facing the greatest coordination challenges, including those in rural and underserved areas, ensuring that caregivers, siblings, and children receive compassionate, comprehensive support where it is needed most.

Funding requested for Fiscal Year FY27

Council	Match (in kind)	Total
\$103,253	\$34,547	\$137,800

6. General Timelines:

Funding decisions can take time for the Council to discuss. Please allow time for feedback on your proposal and possible revision of your proposal or providing more information. We want to be a partner and are happy to work with you as you complete an application. Please ask questions. If approved for funding, contract dates depend on when the proposal was received, length of review by Council committee, and contract negotiations.

For a proposal requesting funding for a full year, contracts will typically follow the state fiscal year: July 1 through June 30.

Proposals received are evaluated by a Council Committee, and if approved, a recommendation is made to the full Council for a decision. If approved by the full Council, we will make every effort for contracts to be effective as early as possible, typically by July 1. Applicants will be notified by email within 5 business days of the full Council's decision.

IMPORTANT: Do not begin work until a fully executed contract and purchase order (PO) is in hand. Per Oklahoma Statute, no funding can or will be reimbursed for any goods or service prior to the effective date of a contract.

If you have any questions, email our Planning & Grants Director, Jennifer Robinson: Jennifer.Robinson@okdhs.org.

Part 1 - Contact Information**7. Organization Name *****8. Organization Address ***

Mailing address please: Street number, Street name, City, State, 9-digit Zip Code

9. Contact Info *

Name, email address **and** phone number of the person completing this application.

10. Website

Organization's Website

Our State Plan Goals

To qualify for funding, projects must meet the goals in the 5-Year Council State Plan. The state plan is available for review <https://oklahoma.gov/ddco/about/state-plan.html>. The new state plan for 2027-2031 is in the process of being developed.

11. State Plan Goal *

As of August 2025, the Council is in the process of reviewing input from publicly held listening sessions and information about current services and systems in Oklahoma. Goals have not been established for our next 5 Year State Plan (2027-2031), however proposals submitted should fall within one of our themes we have identified.

- Access to Services
- Inclusive Education
- Caregiver Support
- Representation and Public Attitudes
- Advocacy and Self-Advocacy

This proposal falls within three areas: Access to Services, Caregiver Support and Advocacy and Self-Advocacy.

Part 2 - Disclosure of Potential Conflict of Interest

The State of Oklahoma prohibits persons and organizations from participating in the development of a competitive contract where they may receive an actual or perceived benefit. The purpose of this policy is to ensure a fair and impartial procurement process. The questions that follow are designed to help the state determine if such a conflict exists.

12. Any relationships to the organization? *

Do you, or your organization, have any personal, professional or financial relationships to the Developmental Disabilities Council of Oklahoma? This disclosure does not necessarily create a real or perceived conflict of interest, but disclosure of such relationships is required.

☐ Yes

☒ No

13. Identify names and relationships

If you answered yes to "Any relationships to the organization?" please explain in detail. Identify names and relationships, as necessary.

Part 3 - Your activity proposal:

14. Proposal. *

Provide a written overview of your proposal (up to 4000 characters). A good overview should cover the key components of your proposal. This includes:

- **Introduction:** A brief summary of your project's purpose.
- **Problem Statement:** The issue your project aims to address.
- **Proposed Solution:** A clear description of your methodology and how your project will solve the problem.
- **Expected Outcomes:** The anticipated results or impact of your work.
- **Evaluation:** How the work will be measured.
- **Relevance:** How your project aligns with the council's goals and funding priorities.

The Care Connection project strengthens Oklahoma families raising children with disabilities, particularly those with complex medical needs through an embedded hospital-based Family Support Specialist, family retreats, sibling programs, and student-led respite activities.

Primary Activity- Embed a Family Support Specialist

In partnership with OU Children's Hospital, Sooner SUCCESS will embed a Family Support Specialist on-site weekly. This position will provide hands-on assistance to families as they navigate medical and community systems, link them to respite and disability resources, and collaborate directly with the hospital's Complex Care Team.

Activity Two- Increase awareness among medical students and professionals about the challenges families face, such as accessing respite, specifically those that have complex medical needs. Recruit medical students and professionals to serve as volunteers at the Family Retreat and Sibling Camps.

Activity Three- Family Retreat

Families will also benefit from an inclusive Family Retreat in Oklahoma City, prioritizing those caring for a child with complex care needs while welcoming other families raising children with disabilities. Medical and nursing students will assist with respite care during the event, allowing caregivers time to attend educational sessions, participate in wellness activities, and connect with other families.

Activity Four- Sibling Camps

To further support siblings, four one-day sibling camps and one overnight camp will be hosted across Oklahoma, creating fun, inclusive environments for brothers and sisters of children with disabilities to connect, build coping skills, and feel supported.

Project Expansion to serve more families

In Year 2, Sooner SUCCESS will expand the hospital-embedded model to Tulsa, in partnership with another children's hospital serving children with complex care needs.

Together, these activities promote access, reduce isolation, and strengthen family well-being through compassionate, coordinated, and community-based support.

Families of children with complex medical needs manage hospital-level care at home, often with little respite or coordinated help.

Nationally, over 75% of caregivers report needing respite, yet fewer than 15% are able to access it (ARCH National Respite Network, 2023).

According to the American Academy of Pediatrics (2023), families of medically complex children face the highest risk for burnout, depression, and health decline.

The Family Voices National Survey (2024) reports that 86% of these caregivers experience high stress and limited access to community resources.

In Oklahoma, the Department of Human Services (2023) has identified caregiver well-being as critical to child stability and health.

The Care Connection project provides a direct, hospital-embedded response to this need—meeting families where they already are. By integrating clinical and community systems, this project will fill a long-standing gap between healthcare navigation and community-based disability support.

1. Embed a Sooner SUCCESS Family Support Specialist at OU Children's Hospital weekly to assist families in accessing disability, respite, and resource supports.
2. Recruit and train medical and nursing students as respite providers during events and retreats.
3. Host one Family Retreat in Oklahoma City for families (prioritizing complex care), including respite volunteers, caregiver workshops, and family preparedness activities.
4. Implement five Sibling Camps (four day camps and one overnight) to promote social connection, coping, and inclusion for siblings of children with disabilities.
5. Expand to Tulsa in Year 2, embedding a Family Support Specialist within a second hospital system serving children with complex care needs.

15. Have you completed a needs assessment? *

☒ Yes

☐ No

16. Needs assessment:

If you have completed a needs assessment, please provide a summary below. Your response should include:

- A brief description of the methodology used (e.g., surveys, interviews, focus groups).
- The key findings that support the need for your proposed project.
- The population included in your assessment.
- An explanation of how this assessment directly informs your proposal.

Families of children with complex medical needs (CMC) represent one of the most underserved populations in Oklahoma. They experience significantly higher levels of stress, health risk, and isolation than other caregiving groups (Family Voices, 2024, <https://familyvoices.org>).

Nationally, more than 75% of caregivers for children with medical complexity report needing respite, yet fewer than 15% are able to access it (ARCH National Respite Network, 2023, <https://archrespite.org>). The American Academy of Pediatrics (2023, <https://publications.aap.org>) has identified families of medically fragile children as at "greatest risk for caregiver burnout, social isolation, and health decline."

In Oklahoma, respite options that can safely serve this population are extremely limited. Families often rely on hospital admissions or private-duty nursing for temporary relief — approaches that are costly, unsustainable, and emotionally taxing. Many caregivers report they have not had a single full night of uninterrupted rest in years.

The Oklahoma Department of Human Services (2023, <https://oklahoma.gov/okdhs>) recognizes caregiver well-being as essential to child safety and stability, yet no statewide system exists to connect trained medical personnel or students with families in need of respite. Care Connections fills this gap by pairing trained student providers with families, increasing access to safe respite and deepening future providers' understanding of life with complex care needs. Measuring the Value of Respite - A White Paper by the ARCH Committee for Advancement of Respite Research (CARR) found that:

- o There is an urgent need to identify, expand, and develop evidence-based and evidence-informed respite that improves caregiver outcomes.

- o Current research and evaluation methods do not adequately measure the economic value of respite.

- o Caregivers need respite and accrue beneficial effects from respite, even if providing respite does not save money.

The full white paper is available to download and review at: [https://archrespite.org/research/carr-publications/Understanding the Respite Needs of Family Caregivers](https://archrespite.org/research/carr-publications/Understanding-the-Respite-Needs-of-Family-Caregivers)

53 million Family caregivers of children and adults in the US. 490,000 of those caregivers live in Oklahoma

86% of family caregivers of adults in the US receive no respite

75% of family caregivers of children have unmet needs for respite.

Sources: National Alliance for Caregiving and AARP Public Policy Institute, Caregiving in the U.S. 2020.

Assessment results from year 1 through 4 of our project offering Caregiver Respite Retreats revealed that 97.6% of our participating caregivers reported that the retreat reduced the stress level in their family. 82.5% of them reported that they would not have access to respite without the weekend retreat process offered by Sooner SUCCESS.

17. Who will do the work? *

Please list all people and organizations that will be working on the project, and describe their experience and qualifications to provide the proposed goods and services.

This project is led by Sooner SUCCESS within the Department of Developmental and Behavioral Pediatrics at OUHSC.

Key partners include:

- OU Children's Hospital Complex Care Team – clinical collaboration and family referrals
- Colleges of Medicine and Nursing – student recruitment and training for respite participation
- Children's Health Foundation
- DHS Oklahoma Caregivers Lifespan Respite Coalition – coordination of vouchers and resources
- Oklahoma State Department of Health
- Community Partners that provide disability services, support, education and outreach

These partnerships ensure a comprehensive approach that combines medical, academic, and community expertise to best serve Oklahoma families.

Sooner SUCCESS, (State Unified Children's Comprehensive Exemplary Services for Special Needs) is a program established over 23 years ago, under the Child Study Center, a division of the section of Developmental and Behavioral Pediatrics at the University of Oklahoma Health Sciences Center. Sooner SUCCESS remains on the fore-front of systems design, family advocacy, policy change and community engagement specifically for families that have been impacted by disability. Sooner SUCCESS is a community-based service available to anyone and any family in Oklahoma that needs services and connections to programs in their community that will meet their unique needs.

The primary mission of Sooner SUCCESS is to support and empower parents/caregivers of children with disabilities and support the development of inclusive communities. Years of lived experience among our staff as well as extensive, in-depth experience working with parents who feel their family's needs have been dismissed or marginalized due to disability drive Sooner SUCCESS in this mission.

The organizational structure and management model of Sooner SUCCESS creates a continuous loop of communication with families and collaboration with providers that serve in the community. This is accomplished through one-on-one service navigation to families in need and development of community coalitions with a mission to identify and address local service gaps whenever possible. Regional teams serving as technical assistance hubs that share resources and ideas to identify and resolve similar problems occurring in multiple communities statewide. And lastly, our state level interagency council brings together decision makers from multiple disciplines to respond to emerging trends indicating the need for change at the policy and procedure level. At each of these levels, Sooner SUCCESS has assembled partnerships and a continuing history of successful collaboration allowing new projects to coalesce smoothly and move into implementation efficiently.

Sooner SUCCESS in partnership with OKDHS Aging Services, administers the Lifespan Respite Voucher Program as well as the Systems of Care Respite Program in partnership with the Oklahoma State Department of Mental Health and Substance Abuse Services. Sooner SUCCESS has also developed a partnership with the Oklahoma State Department of Health to improve supports for typically developing siblings in families impacted by disability. Sooner SUCCESS works in tandem with Aging Services, Developmental Disabilities Services, Oklahoma State Department of Mental Health and Substance Abuse Services and other state programs to increase access to respite. This care coordination model to serve caregivers across the lifespan through the Oklahoma Caregiver Coalition has improved access to not only respite, but other essential resources for family caregivers that have a loved one with a disability.

18. Targeted population:

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Tell us more about who you are targeting to improve outcomes for? Describe the age, region, familial status, learning or support needs, and type of disability.

The Care Connection project targets Oklahoma families raising children and youth with complex medical and developmental disabilities, including those who require specialized equipment, multiple specialists, or technology-assisted care. Priority will be given to families served by Oklahoma Children's Hospital.

For this initiative, children and youth with complex care needs are defined as those who:

- Require ongoing medical management for one or more chronic conditions significantly impacting daily life;
- Depend on medical technology such as ventilators, tracheostomies, oxygen, or feeding tubes; and/or
- Receive care from three or more specialists or therapeutic providers.

These families often perform medical procedures daily, navigate fragmented systems, and face extreme difficulty finding care providers trained or willing to meet their child's needs.

Oklahoma Children's Hospital is the state's only freestanding tertiary-care pediatric hospital, with 314 inpatient beds and more than 40,000 emergency visits each year (medicine.ouhsc.edu; velocityokc.com). It houses Oklahoma's only Level IV Neonatal Intensive Care Unit (NICU) and Level I Pediatric Trauma Center, caring for the state's most medically complex children (en.wikipedia.org). Many of these children and families require extensive coordination among multiple systems—medical, educational, and social—to maintain stability and safety at home.

Statewide, approximately 23–24 % of Oklahoma children (roughly 217,000 individuals ages 0–17) are identified as having special health care needs (mchb.tvisdata.hrsa.gov; americashealthrankings.org). Families of these children often report high stress, limited respite, and difficulty accessing trained support providers—challenges that are magnified in rural and underserved areas.

The targeted population therefore includes:

- Children and youth ages birth–21 with developmental, intellectual, or complex medical disabilities.
- Parents and caregivers responsible for daily medical and behavioral care coordination.
- Siblings of children with disabilities, who frequently experience isolation or secondary trauma due to intensive caregiving demands.
- Culturally and geographically diverse families, including those in rural counties who face limited transportation and provider availability.

By embedding a Sooner SUCCESS Family Support Specialist within Oklahoma Children's Hospital, the project ensures that families are connected to resources at the point of care—where the need for coordinated navigation, respite, and peer support is greatest.

19. Impact:

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Please describe the anticipated impact of your proposal by addressing the following three components:

- Goals for the targeted population?
 - What are the specific, measurable goals you hope to achieve for the individuals directly served by this project?
- Broader implications for people with developmental disabilities:
 - Beyond the direct participants, how will this project create a broader, positive impact for the population of people with developmental disabilities as a whole?
- Measurable outcomes:
 - What specific, quantifiable metrics will you use to track your success and demonstrate the project's effectiveness?

Goals for the Targeted Population

The primary goal of Care Connection is to improve quality of life, well-being, and access to supports for families raising children with complex medical and developmental disabilities. Families served through Oklahoma Children's Hospital experience significant stress and coordination demands—many caring for children who require ventilators, feeding tubes, mobility devices, or continuous nursing oversight.

Specific goals include:

- Reduce caregiver stress and burnout by embedding a Family Support Specialist within the hospital to provide navigation, respite, and emotional support.
- Increase access to disability resources and respite by connecting at least 150 families annually to community programs, vouchers, and preparedness supports.
- Enhance sibling well-being through five statewide Sibling Camps and one Family Retreat each year.
- Build preparedness and confidence among caregivers through hands-on education and peer networking.

Broader Implications for People with Developmental Disabilities

Oklahoma's Title V assessment reports that nearly one in four Oklahoma children ($\approx 217,000$) has special health-care needs (mchb.tvisdata.hrsa.gov; americashealthrankings.org).

By locating the project within Oklahoma Children's Hospital—the state's only Level I Pediatric Trauma Center and Level IV NICU, serving over 40,000 emergency visits and 314 inpatients annually (velocityokc.com; medicine.ouhsc.edu), this initiative reaches the families most affected by service fragmentation and resource gaps.

Beyond direct participants, Care Connection builds an enduring bridge between health care and community supports. The hospital-embedded model can be replicated in other pediatric centers, fostering system-level collaboration and long-term sustainability. The inclusion of medical and nursing students in respite training also cultivates a new generation of providers skilled in family-centered, disability-competent care.

Measurable Outcomes

To demonstrate both individual and systems impact, the following outcomes will be tracked annually:

Quantitative Measures

- Families served: ≥ 150 families receiving direct navigation assistance.
- Family Retreat participation: families served annually.
- Sibling Camps: ≈ 150 siblings across five events.
- Students trained: 20–30 medical/nursing students.

Qualitative Measures

- Pre/post caregiver surveys.
- Family satisfaction and access-to-resources surveys.
- Hospital staff feedback on improved coordination and reduced crisis encounters.

Long-Term Indicators

- Documented reduction in caregiver stress scores and reported burnout.
- Increased linkage rates between hospital discharge and community supports.
- Establishment of a second embedded hospital site in Tulsa by Year 2, creating a sustainable, statewide model for respite and navigation.

20. Duplication or expansion:

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Does this proposal duplicate or expand upon any existing work in Oklahoma or elsewhere? The Council cannot supplant funding to continue existing work unless the proposal is to expand on the work and enhances what is being done.

If your proposal duplicates or expands upon existing work, please describe the existing work and explain what makes your project unique and innovative. Be specific about how this approach and expected outcomes differ from and add value to what is already being done.

The Care Connection project represents an expansion, not a duplication, of existing family support and respite efforts in Oklahoma. While Sooner SUCCESS and its partners currently operate statewide community-based coordination programs, there is no existing hospital-embedded model that integrates a Sooner SUCCESS medical care coordination with direct access to disability and respite resources at the point of care.

At present, most Oklahoma respite initiatives—such as the Lifespan Respite Voucher Program and regional community coalitions—serve families after discharge or through separate referral processes. Families receiving complex medical care at Oklahoma Children's Hospital often face long gaps between inpatient or specialty services and community navigation supports. Care Connection closes this gap by placing a Sooner SUCCESS Family Support Specialist directly within the hospital setting weekly, ensuring that caregivers receive navigation assistance, respite information, and emotional support before returning home.

This approach is unique and innovative in several ways:

- Integration: It embeds community-based resource navigation into a tertiary pediatric hospital—the first model of its kind in Oklahoma.
- Workforce Development: It incorporates medical and nursing students as trained respite volunteers, preparing future professionals for disability-competent practice.
- Family Inclusion: It expands beyond traditional respite by hosting family retreats and sibling camps, emphasizing connection, education, and emotional well-being for the whole family.
- Data and Evaluation: It introduces measurable research components, including pre/post caregiver stress assessments, to evaluate health impacts of respite participation.

In summary, Care Connection enhances existing statewide respite efforts by linking them directly with hospital systems, creating a replicable model that extends the reach and effectiveness of current programs while filling a critical gap for families of children with complex medical and developmental needs.

21. Best Practices:

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Will your proposed project use current evidence-based best practices in the field of developmental disabilities? Identify the specific practices you will use, explain how you will incorporate them into your project, and cite your sources. Citations should include a mix of professional literature, research studies, and respected organizations or programs.

The Care Connection project is grounded in nationally recognized, evidence-based best practices for supporting families of children with developmental and complex medical disabilities. Its design incorporates principles from family-centered care, coordinated service delivery, respite care, and peer support models that have demonstrated positive outcomes for both caregivers and children.

Key best practices and how they are incorporated into the project include:

1. Family-Centered and Coordinated Care

Care Connection aligns with the American Academy of Pediatrics (AAP) model of family-centered care, which emphasizes shared decision-making, coordinated systems, and integration of community supports to promote child and family well-being (AAP, 2023).

By embedding a Family Support Specialist within Oklahoma Children's Hospital, the project directly supports these principles—ensuring families receive coordinated, compassionate, and context-specific navigation support at the point of care.

2. Evidence-Based Respite Practices

The project draws from national research identifying respite as a proven method to reduce caregiver stress, improve mental health, and prevent crisis or institutionalization (ARCH National Respite Network, 2023).

Respite is implemented through trained medical and nursing student volunteers at family retreats and sibling camps, following ARCH guidelines on safety, training, and family choice.

Families also receive respite to expand access beyond project activities.

3. Peer and Sibling Support Models

Care Connection incorporates best practices in peer support for siblings of children with disabilities.

The Sibling Support Project and Sibshops™ model demonstrate that sibling-focused programming reduces isolation and fosters coping and leadership skills (Sibling Support Project, 2023).

This evidence informs the design of the project's one overnight and four day Sibling Camps, emphasizing inclusion, recreation, and connection.

4. Hospital-to-Community Transitions and Navigation

Studies from the Lucile Packard Foundation for Children's Health and Boston Children's Hospital's SPRINT model show that hospital-to-home transitions supported by dedicated navigators reduce caregiver anxiety, emergency visits, and care fragmentation (Boston Children's Hospital, 2024; Lucile Packard Foundation, 2022).

Care Connection applies these principles by embedding the Family Support Specialist to guide families during and after hospitalization, ensuring continuity of support.

5. Alignment with National Policy Frameworks

The project directly supports the federal Maternal and Child Health Bureau's Title V National Performance Measure 6 on "family partnership in decision-making," as well as National Association of State Directors of Developmental Disabilities Services (NASDDDS) recommendations for integrated, person- and family-centered approaches.

By combining AAP's family-centered care principles, ARCH's respite best practices, Sibling Support Project frameworks, and Boston Children's navigation models, Care Connection establishes an innovative, data-driven, and replicable approach that reflects the most current and credible practices in the field of developmental disabilities.

22. Systems change impact: *

"Systems change" can help improve a problem and change the way we support people with disabilities in Oklahoma. System change may include sharing information to change thinking, implementing best practice models, and/or improving skills for individuals and families to better say what they want and need.

How will your proposed project lead to **lasting systems change** for people with developmental disabilities? Please provide a detailed explanation of how your project's outcomes will shift thinking, improve practices, or empower individuals and families within the state's service system.

Care Connection is designed to create durable, statewide shifts in how Oklahoma identifies, supports, and partners with families of children with developmental and complex medical needs. The project moves beyond one-time services to build structures, skills, and standards that remain in place after funding ends. Concretely, it drives systems change through six, mutually reinforcing levers:

1) Hospital-embedded navigation becomes standard practice.

- By co-locating a Sooner SUCCESS Family Support Specialist inside Oklahoma Children's Hospital (and expanding to Tulsa in Year 2), the project establishes a repeatable referral pathway from hospital teams to community supports (respite, equipment, benefits, education services).

- We will formalize this with written workflows, referral criteria, and shared tools (e.g., discharge checklists that include respite/navigation; quick-reference resource guides; standard consent language).

- Outcome: Hospitals adopt a "warm-handoff" model so families leave care settings with concrete connections, not just lists.

2) A workforce pipeline for disability-competent respite.

- Training medical and nursing students to provide supervised respite at retreats and sibling programs seeds a long-term workforce that understands family-centered, disability-competent care.

- Outcome: A scalable pipeline that reduces the chronic shortage of trained respite providers statewide.

3) Shared data and quality improvement that change decisions.

- Findings will be translated into practice adjustments (e.g., earlier referrals during admission, targeted outreach for rural families, optimized voucher eligibility).

- Outcome: Data drive policy tweaks and resource allocation, not just anecdotes.

4) Family voice embedded in design and accountability.

- Ongoing review of family voice measurements will be adhered to adjust project implementation when feasible.

- Outcome: Families become co-designers and informed decision-makers, improving equity and satisfaction.

5) How thinking and practice will shift

- From "refer and hope" to "warm-handoff and confirm." Hospital discharges include completed linkages.

- From ad-hoc respite to competency-based support. Students and volunteers meet defined training standards.

- From crisis-driven contact to proactive partnership. Families connect earlier and report lower stress.

- From siloed programs to integrated pathways. Clear workflows knit together hospital, public health, education, and community supports.

6) Empowerment for individuals and families

- Families gain timely, navigable access to respite and services, skills to self-advocate, and peer connection through retreats and sibling camps.

- Caregivers see measurable reductions in stress and clearer routes to what they need, when they need it.

Lasting impact

By institutionalizing workflows, curricula, and data routines—and by expanding to a second children's hospital—Care Connection leaves behind replicable infrastructure, a trained pipeline, and family-led feedback loops that persist beyond the grant, aligning directly with DDCO's vision for sustainable systems change.

23. Where implemented:

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Will the proposed project be implemented or offered statewide? If no, please define the specific counties and cities you will serve and provide the rationale for their selection.

Statewide reach, regional focus. Care Connection will operate with a statewide service window because Oklahoma Children's Hospital (OU Health) draws pediatric patients from all 77 Oklahoma counties and serves as the state's comprehensive referral hub for high-acuity and complex care. This is reflected in OU Health communications ("For all 77... for all of Oklahoma") and system statements noting that patients from all 77 counties seek care at OU Health. OU Health+1 In addition, the hospital's Community Health Needs Assessment describes a large catchment area, consistent with its role as the state's tertiary pediatric center. OU Health The children's emergency department alone treats ~40,000 visits per year, underscoring the breadth of families reached through this site. Welcome to Oklahoma's Official Web Site+1

Year 1 – Central Oklahoma (primary operating region, statewide eligibility):

- Primary operating counties: Oklahoma, Canadian, Logan, Cleveland (Oklahoma City metro).
- Rationale: Activities are centered at Oklahoma Children's Hospital in Oklahoma City, the state's only 24/7 pediatric ER and Level I pediatric trauma center/Level IV NICU complex, making it the natural hub for families of children with medical complexity. Families from any county may enroll; proximity simply makes participation easier for the metro and surrounding counties. Wikipedia

How statewide access works in practice:

- Families may be referred from any of the 77 counties by hospital teams, primary care, schools, or self-referral.
- The embedded Family Support Specialist will prioritize on-site navigation for metro/nearby families while providing remote navigation (phone/virtual) to families traveling from farther counties.
- Retreats and sibling camps will be scheduled at accessible community locations in each hub region, with a portion of spots reserved for families traveling from rural counties.

This structure honors OU Children's Hospital's statewide catchment, while making services operationally efficient by anchoring activities where the largest share of complex-care families interface with the health system. OU Health

Performance Measures

The Council is required to submit performance reports to evaluate the effectiveness of all Council activities to our Federal partners. We require all contracted vendors to submit performance measure data prior to final payment. As a required component of your application, please provide **projected data** for the following performance measures. All contractors must collect **baseline data** to evaluate the project's outcomes. If you have questions about these projected and baseline numbers, please reach out to us.

Note: Not all measures may be applicable to your proposal. If a measure does not apply, please enter zero.

- **IA** = Individual and family **A**dvocacy
- **SC** = System **C**hange

24. IA1.1

The number of **people with developmental disabilities who participated in Council supported activities** designed to increase their knowledge of how to take part in decisions that affect their lives, the lives of others, and or systems.

50

The value must be a number

25. **IA 1.2**

The number of **family members who participated in Council supported activities** designed to increase their knowledge of how to take part in decisions that affect the family, the lives of others, and or systems.

The value must be a number

26. **IA 1.3**

The number of **other individuals who participated in Council supported activities** designed to increase their knowledge.

The value must be a number

27. **IA 2.1**

After participation in Council supported activities, the **percent of people with developmental disabilities who report increasing their advocacy** as a result of Council work.

The value must be a number

28. **IA 2.2**

After participation in Council supported activities, the **percent of family members who report increasing their advocacy** as a result of Council work.

The value must be a number

29. **IA 2.2.1**

The **percent of people** who are better able to say what they want or say what services and supports they want or say what is important to them.

The value must be a number

30. **IA 2.2.2**

The **percent of people** who are participating now in advocacy activities.

The value must be a number

31. **IA 2.2.3**

The **percent of people** who are on cross disability coalitions, policy boards, advisory boards, governing bodies and/or serving in leadership positions.

The value must be a number

32. **IA 3.1**

The **percent of people with developmental disabilities satisfied** with a project activity.

The value must be a number

33. **IA 3.2**

The **percent of family members satisfied** with a project activity.

The value must be a number

34. **SC 1.1.1**

The number of policy and or procedures created or changed.

The value must be a number

35. **SC 1.2.1**

The number of statutes and or regulations created or changed.

The value must be a number

36. **SC 1.3.1**

The number of promising practices created.

The value must be a number

37. **SC 1.3.2**

The number of promising practices supported through Council activities.

The value must be a number

38. SC 1.3.3

The number of best practices created.

The value must be a number

39. SC 1.4.1

The number of people trained or educated through Council systemic change initiatives.

The value must be a number

40. SC 1.5.1

The number Council supported systems change activities with organizations actively involved.

The value must be a number

41. SC 2.1

The number of efforts that led to the improvement of best or promising practices, policies, procedures, statute, or regulation changes.

The value must be a number

42. SC 2.1.1

The number of policy, procedure, statute, or regulation changes improved as a result of systems change.

The value must be a number

43. SC 2.1.2

The number of policy, procedure, statute, or regulation changes implemented.

The value must be a number

44. SC 2.1.3

The number of promising and/or best practices improved by systems change activities.

The value must be a number

45. SC 2.1.4

The number of promising and/or best practices that were implemented.

The value must be a number

46. SC 2.2

The number of efforts that were implemented to transform fragmented approaches into a coordinated and effective system that assures individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life.

The value must be a number

Additional Requirements for funding

47. **FINANCIAL INFORMATION** ***Proposal Budget:**

- Include a detailed revenue and expenditure budget, detailing the total costs and revenues of the proposal.
- Identify the amount requested from the Council within the context of the budget.
- **The Council funding cannot exceed 75% of your budget.** For example, if your budget is \$10,000, our funding can be up to \$7,500. Your 25% match would be a minimum of \$2,500. **Start with your budget** and calculate the 75/25 split. *If you believe you are located in/providing services in a Poverty County, please note that, or contact us. For Poverty Counties the split is 90/10.
- Identify the amount of the required 25% funding match for your project's total budget. You also need to explain where this matching funding will come from. **Sources for the match funding** can include non-federal funding, monies from fundraisers or donations/sponsorships, monies from your organization for salary/fringe, donated services or items, discounted services or items, and volunteer time. (*paid employees of a non-profit organization cannot volunteer to provide the same type of services to their non-profit organization that they are employed to provide) If you need help calculating the value of volunteer time, you can contact Jennifer. Match funding helps the Council understand all partners who are helping with the project.
- Identify projected funding sources not currently in place. Provide a narrative explaining each category of expenditure and source or revenue associated with the project. **Revenue sources** include but are not limited to conference registration fees, third party grants, booth rentals, in-kind contributions, etc.
- If space does not permit the details necessary, please **email your budget** to Jennifer.Robinson@okdhs.org and include the Project Name in the subject line.

FY '27 DDCO Sooner SUCCESS Includes 3% cost of living raise

PI: Aietah Stephens

DDCO BUDGET

Personnel Effort Requested Salary Fringe Total

505754 Aieah Stephens 1% \$846.00 \$306.00 \$1,152.00

523970 Deana Wilson 5% \$3,108.00 \$1,125.00 \$4,233.00

529557 Lori Wathen 15% \$9,555.00 \$3,459.00 \$13,014.00

527049 Lisa DeBolt 5% \$3,185.00 \$1,153.00 \$4,338.00

531677 Eva Smith 5% \$3,276.00 \$1,186.00 \$4,462.00

612840 Cooper Turman 5% \$2,056.00 \$744.00 \$2,800.00

TBH Family Support Specialist 50% \$23,750.00 \$8,598.00 \$32,348.00

TOTAL PERSONNEL & FRINGE 86% \$45,776.00 \$16,571.00 \$62,347.00

Supplies & Operating Expenses

Travel TRAVEL \$2,000

Respite Vouchers OTHER Category \$0

Respite Retreats/Camps OTHER Category \$13,900

Postage/Shipping OTHER Category \$100

Printing/Copies SUPPLY Category \$800

Materials/Supplies SUPPLY Category \$2,800

TOTAL SUPPLIES & OPERATING EXPENSES \$19,600

MATCH BUDGET

Supplies & Operating Expenses

Lease \$2,878.91*12 \$34,547

TOTAL SUPPLIES & OPERATING EXPENSES \$34,547

Total Direct Costs \$81,947

Total Indirect Costs 26% \$21,306

TOTAL COSTS \$103,253

TOTAL REQUIRED MATCH 25% \$34,450

TOTAL MATCH \$34,547

Total Indirect Costs 26% \$0

TOTAL MATCH \$34,547

TOTAL PROJECT COSTS \$137,800

48. STATEMENT OF WORK (SoW): *

Provide a proposed statement of work for the contractual requirements. This should include a detailed description of the work to be done, project milestones, deliverables to the Council, and other details important to the work that you will provide in exchange for Council funding. [ProjectManager.com](https://www.projectmanager.com) has some good information for you to develop your statement of work: <https://www.projectmanager.com/blog/statement-work-definition-examples>.

Attachment A

Statement of Work

OUHSC – Sooner SUCCESS

Project Title: Care Connection: Family Respite and Access to Support

DELIVERABLE 1 – Family Support and Navigation Materials

Sooner SUCCESS will develop and maintain an updated packet of information and resource materials focused on respite, self-care, and community support options for family caregivers of children with developmental or complex medical needs.

- Materials will include strategies for managing caregiver stress, information on local respite programs and vouchers, and contact details for statewide supports.
- Packets will be shared with caregivers at the Family Retreat, during hospital-based navigation sessions, and at Sibling Camp drop-offs.
- Information will be made available in English and Spanish, with additional translation upon request.
- Materials will reference tools such as the ARCH National Respite Network's Lifespan Caregiver Resources and LifeCourse Frameworks to help families identify ongoing supports.

DELIVERABLE 2 – Hospital-Embedded Family Support Specialist

Vendor will embed a Sooner SUCCESS Family Support Specialist at Oklahoma Children's Hospital to assist families of children with developmental and complex medical needs.

- The specialist will meet families in clinical and outpatient settings to help them access respite vouchers, community supports, and family navigation services.
- Each family will receive individualized guidance and a brief follow-up to confirm successful linkage to services.
- The specialist will collaborate closely with hospital staff, Title V Maternal & Child Health, and Sooner SUCCESS regional teams to reduce service duplication and strengthen coordination.
- A data dashboard will track the number of families served, resource referrals, and outcomes.

DELIVERABLE 3 – Family Retreat and Sibling Camps

Vendor will host one Family Retreat and five sibling events (four day camps and one overnight camp) designed to strengthen family resilience, connection, and self-care.

- Family Retreat (Oklahoma City): Families will participate, prioritizing those caring for children with complex medical or developmental needs.
 - o Families will enjoy group sessions, recreational activities, and optional educational workshops focused on stress reduction, preparedness, and family communication.
 - o Bilingual staff and accessible materials will be provided.
- Sibling Camps: Approximately 150 siblings will participate in structured day or overnight camp programs incorporating Sibshop principles to promote peer connection and inclusion.
- Medical and nursing students will be recruited and trained to provide supervised respite during retreat and camp sessions.
- Each event will conclude with a post-event DDCO consumer satisfaction survey and respite voucher follow-up survey.

DELIVERABLE 4 – Evaluation and Reporting

Vendor will coordinate evaluation and reporting in collaboration with the OUHSC Core Research Team.

- Conduct pre- and post-event caregiver surveys.
 - Collect participation data, demographic summaries, and qualitative feedback from families and students.
 - Submit quarterly progress reports and one final report summarizing all activities and measurable outcomes.
 - o Reports due: October 15, 2026, January 15, 2027, April 15, 2027, and July 30, 2027 (Final Report).
 - All reports will include data on families served, navigation outcomes, and recommendations for sustainability and replication.
- The Care Connection project will strengthen Oklahoma's system of family support by embedding navigation services directly within a hospital setting, expanding access to respite and education, and training future providers in disability-competent care. This model promotes long-term sustainability and can be replicated statewide.

49. Sustainability Plan: *

It is the Council's hope that funded projects will have a lasting impact on the community and achieve financial sustainability after the Council's funding is complete. The Council's funding is intended as a catalyst to help new work become self-sustaining. To assure the Council of this long-term vision, all applicants must submit a detailed Financial Sustainability Plan. Financial sustainability is defined as maintaining services to the community through a diversified funding model. **Important Note:** *The Council can approve funding for an activity for a maximum of five (5) years. However, our funding is not guaranteed, so applications for Council funding must be submitted annually.* The Council expects all funded work to be self-sustaining by the end of the contract period. Your Financial Sustainability Plan should include, but is not limited to, the following components for each year of your proposed project:

- Annual Funding Goals: Clear, measurable funding targets for each year of the project.
- Projected Budgets: A multi-year budget forecast that demonstrates decreasing reliance on Council funding.
- Identified Partners: A list of specific organizations or entities with whom you will partner, along with a description of their role in your sustainability plan. Please also include any documented commitment of resources they are able to provide.
- Timeline: A clear timeline for all sustainability activities (e.g., "Year 2: Apply for three new grants," "Year 3: Implement a pilot fee-for-service program").

The Care Connection: Family Respite and Access to Support project is intentionally designed to become self-sustaining within five years, using DDCO funding as a catalyst to launch a hospital-embedded family navigation and respite model. Efforts will be ongoing to diversify funding and institutionalize this work within Oklahoma's health and disability systems. After the initial DDCO investment, Sooner SUCCESS and OU Children's Hospital will pursue co-funding and reimbursement pathways to ensure long-term viability.

Key strategies include:

- Partnership-based funding: OU Health, the Department of Human Services (Lifespan Respite), and Title V Maternal & Child Health Bureau programs will be engaged to support navigation and respite coordination as part of ongoing family services.
- Grant diversification: Future funding will be sought from the National Institutes of Health (NIH), Administration for Community Living (ACL), Patient-Centered Outcomes Research Institute (PCORI), and private foundations such as the Children's Hospital Foundation and United Way to sustain evaluation, training, and expansion.
- Potential billing pathways: The team will explore whether portions of the embedded Family Support Specialist role or student respite supervision can become billable care coordination or family-education services under Medicaid or commercial insurance.
- Institutional integration: Explore if OU Health would absorb the Family Support Specialist position within its care-coordination structure, sharing costs with public-health partners.

Through these combined efforts, the program will transition from full DDCO support to blended and eventually independent funding, while maintaining its core mission of reducing caregiver stress and strengthening Oklahoma families raising children with complex care needs.

50. Outreach and Awareness Plan of the Work: *

Too often people with intellectual and developmental disabilities, their families, and others are not aware of resources available in Oklahoma. Please provide a marketing and outreach plan to bring awareness about the work being proposed. Your plan should address the following:

- **Target Audience:** Clearly identify the specific groups within the intellectual and developmental disability community you aim to reach (e.g., specific age ranges, individuals in rural vs. urban areas, diverse cultural communities).
- **Marketing Channels:** Describe the specific marketing channels you will use (e.g., social media, community events, partnerships, print materials) and how you will use them effectively to reach your target audiences.
- **Partnerships:** Explain how you will collaborate with other organizations, advocacy groups, or community leaders to expand the reach of your message.
- **Accessibility and Language:** Detail your strategy for ensuring your outreach is accessible and inclusive. Please discuss your plan for language translations, including which languages you will prioritize and how you will ensure cultural appropriateness.
- **Measurement:** Describe how you will measure the success and impact of your marketing and outreach efforts.

The Care Connection: Family Respite and Access to Support project will use a layered, inclusive outreach strategy to reach Oklahoma families of children and youth with developmental and complex medical disabilities, including those from diverse cultural and geographic backgrounds.

Target Audience

- **Primary:** Families of children and youth (birth – 21 years) with intellectual, developmental, or complex medical disabilities who receive care through Oklahoma Children's Hospital or regional pediatric partners.
- **Secondary:** Siblings, caregivers, educators, and healthcare providers who support these families.
- **Priority populations:** Families in rural and frontier counties, Native American and Hispanic/Latino communities, and households facing financial or transportation barriers.

Marketing Channels

- **Community Engagement:** Presentations at Sooner SUCCESS regional coalition meetings, Family Caregiver Conferences, and partner hospital events.
- **Digital Outreach:** Facebook, Instagram, and X (Twitter) posts featuring family stories, upcoming retreats, and success spotlights. Targeted paid posts will reach rural zip codes and families connected to pediatric hospital systems.
- **Email and Listservs:** Coordination with the Oklahoma State Department of Health, Lifespan Respite Coalition, and OUHSC listservs for direct announcements.
- **Print Materials:** Flyers and resource one-pagers distributed at clinics, county health departments, and schools.
- **Media Relations:** Collaboration with OU Health and DDCO public-relations teams to feature the project in newsletters, podcasts, and statewide caregiver-awareness campaigns.

Partnerships

Outreach will be amplified through strong partnerships with:

- OU Children's Hospital and DDCO.
- Oklahoma State Department of Health, Lifespan Respite Coalition, and Children's Health Foundation (community dissemination).
- Tribal entities and faith-based leaders in rural regions to extend culturally appropriate communication.

Each partner will receive a tailored digital toolkit with flyer templates, social-media captions, and language for newsletters to ensure consistent statewide messaging.

Accessibility and Language

All materials will follow plain-language and universal-design guidelines, featuring clear visuals and inclusive imagery.

- **Translations:** Spanish will be prioritized for flyers, registration forms, and surveys.
- **Formats:** Large-print PDFs, screen-reader-compatible documents, and captioned videos will ensure accessibility for all participants.
- **Cultural review:** Materials will be vetted by bilingual staff and community advisors to ensure cultural relevance and accuracy.

51. Logic Model:

To help the Council and your organization effectively evaluate the program's success, a logic model is a required component for all contracts in excess of \$5,000. A logic model is a simple visual tool that illustrates the connection between your project's resources (inputs), what you plan to do (activities), the immediate results of your work (outputs), and the changes you hope to achieve (outcomes). For a helpful guide to developing a clear and effective logic model, please refer to this resource from The Compass: <https://thecompassforsbc.org/how-to-guide/how-develop-logic-model-0>

INPUTS	ACTIVITIES / SERVICES	OUTPUTS	SHORT-TERM OUTCOMES	INTERMEDIATE OUTCOMES	LONG-TERM OUTCOMES
Collaboration between Sooner SUCCESS, Oklahoma Children's Hospital, OUHSC Core Research Team, and community partners	Embed a Family Support Specialist at Oklahoma Children's Hospital to assist families with navigation, respite access, and referrals	≥150 families receive one-on-one navigation and resource assistance annually	Increased caregiver awareness of supports and available respite options; improved connection to community resources	Hospital-to-community referral workflows established; families report reduced stress and greater confidence in managing care	Sustainable, hospital-embedded model linking health systems with community disability and respite supports statewide
Collaboration with hospital foundations, universities, and volunteer networks	Recruit and train 30–40 medical and nursing students as respite volunteers through structured training and mentorship	Trained student workforce supporting respite activities and family events	Increased provider competence in disability-competent, family-centered care	Creation of a replicable training pipeline for future respite providers	Expanded disability-competent healthcare workforce contributing to statewide respite capacity
Collaboration between Sooner SUCCESS, retreat and camp partners, and local vendors	Host 1 Family Retreat in Oklahoma City (60 families) prioritizing complex care needs; host 4 sibling day camps and 1 overnight camp	60 families and ~150 siblings participate in retreat and camp experiences	Reduced caregiver stress; increased peer connection and emotional support for families and siblings	Stronger family resilience, self-care awareness, and sense of belonging; increased use of respite services	Healthier, better-supported families resulting in improved stability and reduced long-term caregiving burnout
Partnership with OUHSC Core Research Team and evaluation staff	Collect pre/post caregiver surveys	track participation metrics	Comprehensive evaluation report with quantitative and qualitative data	Demonstrated reductions in caregiver stress and measurable improvements in well-being	Data informs hospital and policy partners on effective respite and navigation models
Evidence base supports replication and long-term integration into Oklahoma's family support systems	Partnerships with Title V, Lifespan Respite, DDCO, and philanthropic partners	Apply for grants; identify additional funders and hospital partners	Submitted grants completed; presentations delivered to partners; expansion planning initiated	Increased awareness among policymakers and hospital administrators	Year 2 expansion to Tulsa partner hospital; cost-sharing established

52. Registered Vendor? *

Are you a registered vendor with the State of Oklahoma? All contractors must be registered in the State Supplier Portal. You can do this online: <https://oklahoma.gov/omes/divisions/central-purchasing/suppliers-and-payees/supplier-portal.html>

☒ Yes

☐ No

53. IRS 501(c)3? *

Is the proposed vendor applicant an IRS Registered 501(c)3:

☐ Yes

☒ No

54. Government entity? *

Is the proposed vendor a Government entity:

☒ Yes

☐ No

55. Provide form of government and name of entity *

Agency of the state of Oklahoma: Board of Regents of the University of Oklahoma Health Sciences Center

56. Are you a Tribal Organization? *

Is the proposed vendor a tribal nation:

☐ Yes

☒ No

**Sooner SUCCESS
BUDGET JUSTIFICATION
07.01.26 – 06.30.27**

PERSONNEL

Executive Director: The Executive Director provides administrative leadership to the project. She is responsible for the overall administration of the project, the implementation of the project plan, the supervision of the Regional Coordinators, and the Business Accountant, the Graduate Research Assistant, and fulfilling reporting requirements. The Executive Director is also the Principal Investigator; this position is supported with 1% effort (0.12 CM) with no cost share.

Regional Coordinator: The Regional Coordinators are supported on this project: Regional Coordinators are responsible for project implementation in their respective Regions. This will include the implementation of the Family Respite Retreat. Regional Coordinators will work under the direction of the PI and assist with project requirements in the regions and administering all aspects of the project at the regional level. 4 Regional Coordinators will be on this project, 1 position supported at 15% paid effort (1.80 CM) (Lori Wathen) and 3 positions supported at 5% paid effort (0.60 CM) (Lisa DeBolt, Eva Smith, Deana Wilson).

Special Program Coordinator: 1 Family Support Specialist - TBH is supported on this project. The Family Support Specialist assigned responsible for project implementation at the University of Oklahoma Children's Hospital. The Special Program Coordinator will be responsible for working directly with families that have a loved one with complex care needs. Additionally maintaining an understanding of the needs of those that Sooner SUCCESS serves, communicating regularly with parent groups and participate in activities involving family advocates. Sooner SUCCESS staff serve on committees and agency workgroups addressing these needs. This position is supported at 50% effort (6.0 CM) supported by Council funds with no cost share.

Program Coordinator/Business Accountant/Admin: Program Coordinator/Business Accountant/Admin on this project is responsible to help process project payment expenditures once approved by the Principal Investigator. This position will also assist in providing the budget activity reports as needed. This position is supported at 5% paid effort (.60 CM) (Cooper Turman).

Fringe benefits have been calculated using the SFY26 University of Oklahoma Health Sciences Center fringe benefit rate of 36.2% for full-time employees on sponsored projects, and 31.7% for full-time employees on non-sponsored projects (cost share). Fringe benefits will be applied in strict accordance with the University's approved DHHS rates.

Council Paid Personnel costs total \$62,452 for this project. These amounts include fringe benefits as applicable to the staff on the project.

*3% raise has been included for all full-time staff (not including faculty) that have been employed for over a year. This pay increase is decided upon at the University level, it generally takes place at the start of the state fiscal year.

SUPPLIES/OTHER

Supplies for retreat/camp activities, materials for caregivers, self-advocates and siblings such as bags, family retreat/camp activities and door prizes, snacks/light food items are supported at \$2,800. Printing is supported at \$800.

Other:

Room Rental/Space Rental for Family Retreat and Camp, Meals and Snacks, volunteer stipends/honorariums are supported at \$13,900. Postage is supported at \$100.

SUPPLY/OTHER COMBINED TOTAL: \$17,600

Lease/workspace (cost share): Sooner SUCCESS state team office is located at the University of Oklahoma Health Sciences Center in Oklahoma City. Sooner SUCCESS will report the monthly costs of \$2,878.91 lease amount to count towards cost share obligations. These lease costs are not covered by federal funding therefore are allowed to be reported towards cost share, this amount to be cost shared is projected to be \$34,546.95.

TRAVEL

Travel will be used to support the Respite Retreat, Lodging costs for the hotels and selected lodging sites for program personnel and family caregivers participating in the Retreats. In-State mileage expenses for Program staff, to travel to and from Respite Retreat and Sibling Camp to implement the program. The travel will be reimbursed at actual and reasonable costs based on the established State mileage rate. Travel is supported at \$2,000.

INDIRECT COSTS

Funds contracted to the University of Oklahoma Health Sciences Center will incur the 26% indirect cost rate. Indirect paid costs are \$21,334.

FY '27 DDCO Sooner SUCCESS
 PI: Aietah Stephens

Includes 3% cost of living raise

July 1, 2026 - June 30, 2027

DDCO BUDGET				
Personnel	Effort	Requested Salary	Fringe	Total
Aieah Stephens	1%	\$846.00	\$306.00	\$1,152.00
Deana Wilson	5%	\$3,108.00	\$1,125.00	\$4,233.00
Lori Wathen	15%	\$9,555.00	\$3,459.00	\$13,014.00
Lisa DeBolt	5%	\$3,185.00	\$1,153.00	\$4,338.00
Eva Smith	5%	\$3,276.00	\$1,186.00	\$4,462.00
Cooper Turman	5%	\$2,056.00	\$744.00	\$2,800.00
TBH Family Support Specialist	50%	\$23,750.00	\$8,598.00	\$32,348.00
TOTAL PERSONNEL & FRINGE	86%	\$45,776.00	\$16,571.00	\$62,347.00

Supplies & Operating Expenses

Travel	TRAVEL	\$2,000
Respite Vouchers	OTHER Category	\$0
Respite Retreats/Camps	OTHER Category	\$13,900
Postage/Shipping	OTHER Category	\$100
Printing/Copies	SUPPLY Category	\$800
Materials/Supplies	SUPPLY Category	\$2,800
TOTAL SUPPLIES & OPERATING EXPENSES		\$19,600

MATCH BUDGET

Supplies & Operating Expenses

Lease	\$2,878.91*12	\$34,547
TOTAL SUPPLIES & OPERATING EXPENSES		\$34,547

Total Direct Costs				\$81,947
Total Indirect Costs		26%		\$21,306
TOTAL COSTS				\$103,253

October 27, 2025

To Whom It May Concern,

On behalf of the Complex Care Team at Oklahoma Children's Hospital, I am writing to express our full support for the proposed initiative to embed a member of the Sooner Success team within our hospital to serve children with complex medical needs and their families in both inpatient and outpatient settings.

Children with complex medical conditions require coordinated, multidisciplinary care that spans hospital, home, and community environments. Our Complex Care Team works every day to bridge these systems, but many of our families continue to face significant challenges accessing community-based resources, navigating state and federal service systems, and maintaining continuity of care after discharge. Embedding a Sooner Success representative within Oklahoma Children's Hospital would directly address these needs by providing on-site, family-centered support and expertise in community resource navigation, care coordination, and system integration.

Sooner Success has a long-standing record of connecting families across Oklahoma to vital supports, such as early intervention programs, educational resources, respite care, and behavioral health services. Their collaborative, cross-system approach aligns perfectly with our mission to improve the quality of life and health outcomes for children with medical complexity. By working alongside our physicians, nurses, social workers, and care coordinators, a Sooner Success team member would enhance our ability to provide holistic, equitable, and sustainable care to some of the most medically fragile children in our state.

This partnership would also strengthen the continuum of care from hospital to home, reduce avoidable readmissions, and improve family satisfaction and empowerment. The proposed role represents a model of integrated care that we believe could serve as a template for other pediatric centers across Oklahoma and beyond.

The Complex Care Team at Oklahoma Children's Hospital strongly supports this initiative and is committed to collaborating closely with Sooner Success to ensure its success. We believe that this embedded position will make a meaningful, measurable difference in the lives of the families we serve.

Thank you for your consideration of this important proposal.

Sincerely,



Amanda Page, MD
Director, Pediatric Complex Care Team
Oklahoma Children's Hospital
Amanda.page@ouhealth.com
Phone: (405)271-2774

From: [Stephens, Aietah L. \(HSC\)](#)
To: [Jennifer Robinson](#)
Cc: [Monroe, Carley B \(HSC\)](#); [Wathen, Lori \(HSC\)](#); [Marchand, Samantha \(HSC\)](#); [Jenifer Randle](#)
Subject: Re: [EXTERNAL] RE: FY27- Care Connection RFID 131831
Date: Friday, December 5, 2025 9:32:38 AM

Good morning, just heard back from Dr. Paige regarding question 3.

Here's her response:

I had our nurse coordinator pull the numbers from Epic and it looks like our inpatient complex care consult service had 211 consults placed between January-November 2025, which is an increase from 169 the previous year (which was the first year that we started the complex care team). A few of these may be repeat consults on children who were re-admitted so I don't know that I can say specifically how many unique families but the majority are unique consults.

We're working on an outpatient Complex Care clinic in Sooner Peds to start next year, but it's not up and running quite yet.

Hope this helps with the needed information. If the project is awarded we would collect the data to better report these numbers.

Thanks for your help,
Aietah

On Dec 3, 2025, at 4:49 PM, Stephens, Aietah L. (HSC) <Aietah-Stephens@ou.edu> wrote:

Great thanks, please see my answers to the questions below.

I am happy to update the original proposal if that is the feedback from the Council to include the Retreats across the state. However due to the time constraints I have answered the questions below. As I would need to reroute through ORA to make any changes to the original proposal.

1. Is the Family Support Specialist a part-time position? Yes. The embedded Family Support Specialist is a part-time position assigned to Oklahoma Children's Hospital on a weekly basis to provide in-person navigation, respite linkage, and follow-up support for families of children with developmental and complex medical needs.
2. How many families do you anticipate serving at the Family Retreat? We anticipate serving approximately 15- 20 families at the Family Retreat in Oklahoma City. We would like to plan to serve more however it would be contingent upon actual facility costs, food, activities, and supplies to determine exact number that can participate.
3. How many unique families does the Complex Care Team serve each year? – Inpatient? Outpatient? I am still waiting to hear back from Dr. Paige on this number.

4. For the 150 Families that receive direct navigation assistance – are those the families at Children’s Hospital that the embedded specialist will assist? Or are those the families that are at the Family Retreat and the sibling camps? This number was determined based on number served through the Children’s Hospital, attending Family Retreats and Sibling Camps.
5. Who will be recruiting and training the medical and nursing students? Is that the Family Support Specialist? Recruitment and training will be conducted by Sooner SUCCESS in partnership with the Complex Care Team. The Family Support Specialist will support coordination, but the formal recruitment and training responsibilities remain with Sooner SUCCESS and the academic partners, not the Specialist alone.
6. On the budget, please separate the costs of the Family Retreat from the costs of the Sibling Camps. As submitted the current request is as follows. Supplies for retreat/camp activities, materials for caregivers, self-advocates and siblings such as bags, family retreat/camp activities and door prizes, snacks/light food items are supported at \$2,800. Printing is supported at \$800. Other: Room Rental/Space Rental for Family Retreat and Camp, Meals and Snacks, volunteer stipends/honorariums are supported at \$13,900. Based on the number of participants we would estimate this between prioritizing Retreats costs first then determine funds available to support Sibling Camp. If needed I could try to do a better estimate on these costs breakdown. I just wanted to get this back to you today. This would require more time.
7. Do families on the waitlist for the current Regional Family Caregiver Retreats qualify for this Family Retreat? Yes. Families currently on the waitlist for Sooner SUCCESS Regional Caregiver Retreats may qualify for this Family Retreat; however, priority will still be given to families caring for children with complex medical needs, consistent with the Care Connection model described in the proposal.
8. What happens to the Regional Family Caregiver Retreats that have been successful over the last 5 years? Care Connection does not replace those events; rather, it adds a specialized retreat specifically designed for families of children with complex medical needs. This differentiates the models while maintaining the successful regional retreat structure. We would like to increase the number of Family Retreats or even consider replicating the original Family Caregiver Retreats but would need more time to officially route this request.
9. Are you using curriculum from UCEDD/CLL that is used for LEND? The Care Connection project uses evidence-based principles from ARCH national respite standards, Community of Practice on Respite and Sibshop-aligned sibling support programming, as well as we adhere to all University standards and training for working with Minors and Youth under the guise of OU Risk Management. At this time, we are not using UCEDD/CLL’s LEND curriculum, though the model is consistent with LEND competencies around care coordination, disability-competent practice, and family partnership.
10. For Year 2, will the funding request be larger since another hospital location will be added? Potentially, yes. Year 2 includes expansion to a second embedded hospital site in Tulsa, which may increase personnel and coordination costs. However we will work closely with DDCO to ensure any Year 2 request reflects a realistic, shared-funding approach as the program grows and other sustainability partners are added (OU Health, DHS, Title V, private philanthropy).

2025 Developmental Disabilities Council of Oklahoma Final Report and Findings



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Executive Summary

Background

The Developmental Disabilities Council of Oklahoma (DDCO), in partnership with Oklahoma Human Services (OKDHS) Innovation Services, conducted a mixed methods data collection effort to inform the development of the DDCO 2027-2031 Five Year State Plan. This project was designed to capture qualitative and quantitative insights from key stakeholders, partners, and community members. The process included listening sessions and surveys with stakeholders across the state. This approach was selected to ensure that the resulting State Plan is informed by data-driven evidence as well as the lived experiences of those implementing and impacted by the DDCO. By integrating various modes of data, this effort provides a comprehensive understanding of current strengths, gaps, and emerging needs, supporting strategic, equitable, and sustainable planning decisions.

Methods & Results

This mixed methods project explored the successes, barriers, gaps and emerging needs of individuals with developmental disabilities (IDD), their families, caregivers, service providers, and advocates. The project combined two quantitative surveys ($n = 68$ and $n = 495$) and nineteen in-depth listening sessions with individuals across the state ($n = 147$). The results of this mixed methods assessment reveal a consistent and deeply interconnected set of strengths, gaps, and emerging needs affecting individuals with developmental disabilities and their families across Oklahoma. Across listening sessions and surveys, participants shared experiences that reflected both the positive impact of existing programs and the persistent systemic barriers that limit access, inclusion, and long-term stability.

Overall, the data show that while families benefit from early intervention, school-based supports, public benefits, strong advocacy networks, and inclusive community programs, these services are often difficult to access, inconsistently available, or insufficient to meet demand. Stakeholders repeatedly emphasized challenges navigating complex systems, long waitlists, workforce shortages, financial strain, and the emotional and physical exhaustion experienced by caregivers. Gaps in healthcare—including mental health, trauma-informed care, dental services, and transitions from pediatric to adult care—were among the most significant needs identified.

Participants also highlighted broader structural issues such as inadequate transportation, limited employment opportunities, a shortage of affordable and inclusive housing, and uneven implementation of inclusive education practices. Many reported ongoing experiences of social isolation and stigma, as well as a lack of understanding or support within schools, workplaces, and community settings.

Conclusion

This analysis offers a comprehensive, statewide review of the strengths, gaps, and emerging needs affecting Oklahomans with developmental disabilities. The insights shared by hundreds of individuals underscore both the urgency and the potential for meaningful change. By centering lived experience, applying evidence-based strategies, and coordinating efforts across sectors, DDCO is well positioned to develop a State Plan that advances equity, inclusion, and opportunity for all Oklahomans with developmental disabilities.

Background

The Developmental Disabilities Council of Oklahoma (DDCO), in partnership with Oklahoma Human Services (OKDHS) Innovation Services, conducted a mixed methods data collection effort to inform the development of the DDCO 2027-2031 Five Year State Plan. This project was designed to capture qualitative and quantitative insights from key stakeholders, partners, and community members. The process included listening sessions and surveys with stakeholders across the state. This approach was selected to ensure that the resulting State Plan is informed by data-driven evidence as well as the lived experiences of those implementing and impacted by the DDCO. By integrating various modes of data, this effort provides a comprehensive understanding of current strengths, gaps, and emerging needs, supporting strategic, equitable, and sustainable planning decisions.

Methods

A mixed methods study was chosen as the design for this research to enable an in-depth exploration of the successes, barriers, gaps and emerging needs of individuals with developmental disabilities (IDD), their families, caregivers, service providers, and advocates. A case study was conducted using a concurrent mixed-methods design, with a qualitative component giving context to the quantitative results. The same questions were asked in listening sessions (with an open discussion of the questions) and in surveys. Data were synthesized in this study for analysis.

The two parts of our study were as follows:

- a) listening sessions held with individuals with developmental disabilities (IDD), their families, caregivers, service providers, and advocates;

- b) a survey (provided to those unable to attend a listening session and to a listserv held by the DDCO).

Setting and participants

Extensive stakeholder engagement occurred through a series of in-person and virtual listening sessions. A total of 19 sessions were completed. In addition, participants who could not attend a listening session were invited to complete a survey of the questions asked during the listening sessions. These listening sessions were designed to center the voices of individuals with developmental disabilities (IDD), along with their families, caregivers, service providers, educators, and other key disability advocates and stakeholders in the community. Participants were invited to share their lived experiences related to the strengths, challenges, and gaps within existing systems and services.

To guide these conversations, seven open-ended questions were used to solicit feedback on what is working well, what is lacking, and how supports and services can be improved. The questions are listed within the findings section of this report, and a full list is available in the Appendix. Each session was facilitated by a three-person research team, including one lead facilitator and two notetakers. This team-based approach ensured accurate and comprehensive documentation while allowing the facilitator to focus on guiding the conversation and engaging participants. The use of standardized prompts across sessions supported a coherent analysis of shared themes and divergent experiences. Additionally, the same facilitator led each session, and the note-takers remained consistent in all but two sessions, helping to ensure a uniform approach.

Listening Sessions and Follow-Up Survey Demographics

A total of 147 people (Table 1) participated in listening sessions (N = 79) or completed the survey (N = 68). The majority of listening session participants attended virtual sessions (71%), while 29% attended in-person sessions. A total of 21 listening sessions were scheduled between February 6 and June 5, 2025. Of those, 11 were in-person and 10 were virtual. Three listening sessions, Altus, Clinton, and Okmulgee, were cancelled due to a lack of registration, bringing the total number of listening sessions held to 19.

The four in-person listening sessions occurred in Ada, Oklahoma City, and Owasso. One of the in-person listening sessions was held in Oklahoma City for employees of Oklahoma Human Services who have disabilities, work with individuals who have disabilities, or are related to people with disabilities. Sessions that were scheduled for Duncan, Enid, Poteau, and Woodward were switched to virtual sessions due to low registration.

Ultimately, the participation rate for listening sessions was 36%. Four additional listening sessions contributed to data collection: three pilot sessions with DDCO Staff and council members, partners, and self-advocates, and one listening breakout session at the Oklahoma Association of People Supporting Employment First (OK-APSE) Conference.

The online follow-up survey was open from June 5 to July 18, 2025, in an attempt to reach and include the experiences and perspectives of those unable to participate in any of the scheduled in-person or virtual listening sessions.

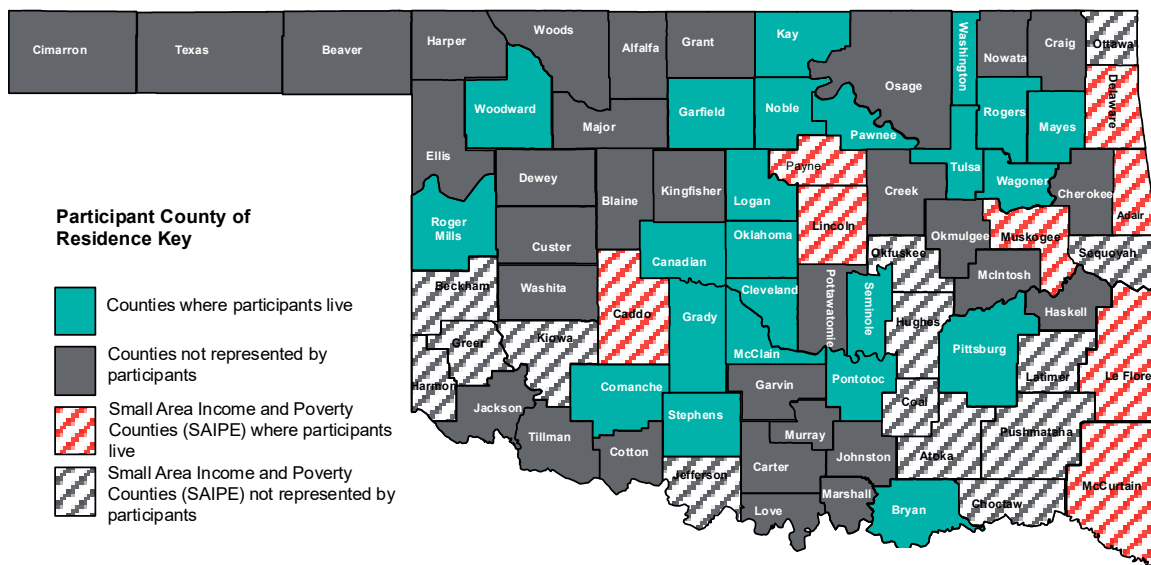
Table 1. Listening session and follow-up survey demographics

Variable	n	%
Participant type (N=147)		
Survey	68	46.3%
Listening sessions	79	53.7%
Listening session type (N=79)		
Virtual	56	70.9%
In-person	23	29.1%
Respondent role (N=205)*		
Caretaker of a person with a disability	59	40%
Work with people with disabilities	57	39%
Advocate for people with disabilities	43	29%
Family member of a person with disabilities	24	16%
Person with disabilities (self)	21	14%
Other	1	1%
Respondent gender (N=144)		
Woman	119	82.6%
Man	19	13.2%
Prefer not to answer	4	2.8%
Gender non-conforming/non-binary	2	1.4%
Respondent racial-ethnic identity (N=161)*		
White	112	77%
Black or African American	16	11%
Native American	16	11%
Hispanic or Latino	9	6%
Prefer not to answer	4	3%
Asian or Asian American	3	2%
Hawaiian or Pacific Islander	1	1%

*Percentages do not sum to 100 due to rounding.

Forty percent of all participants self-identified as caretakers of a person with a disability, 39% reported working with people with disabilities, 29% consider themselves advocates for people who have disabilities, and 16% reported having family members with disabilities. Fourteen percent of participants reported having disabilities of their own. The majority of participants (77%) identified as White, followed by Black or African American (11%), Native American (11%), Hispanic or Latino (6%), Asian or Asian American (2%), and Hawaiian or Pacific Islander (1%). Most participants identified as women (83%). As shown in Figure 1, respondents reported living in 30 of Oklahoma's 77 counties.

Figure 1. Participant County of Residence N = 133



The [U.S. Census](#) reports SAIPE data. Counties shown with stripes on this map have poverty rates of 20% or higher. The data reflects the most recent update from 2023.

Needs Assessment Survey Demographics

The census survey provided a comprehensive snapshot of the experiences, priorities, and persistent challenges faced by individuals with developmental disabilities, their families, and the professionals who support them across Oklahoma. With representation from caregivers, service providers, self-advocates, and community members across 30 counties, the survey captured a wide cross-section of voices that illuminate both strengths in the current system and urgent areas for improvement.

To ensure broad representation, the survey aimed for an ideal sample size of 382 responses based on a statewide population estimate of 66,000, a 5% margin of error, and a 95% confidence level. We exceeded this benchmark, receiving 495 completed surveys.

Survey participants represented a diverse set of roles, with caregivers and professionals forming the largest groups. Many respondents also identified as advocates

or family members of individuals with developmental disabilities, and some reported having disabilities themselves. As shown in tables 2–3, the census survey had strong participation among women—a reflection of national caregiving trends—and notable representation from multiple racial and ethnic communities. Geographic distribution across urban and rural counties provides insight into regional variation in access to transportation, healthcare, and services.

Table 2. Needs assessment survey demographics

Variable	n	%
Participant role (N=569)		
Caregiver	330	58.0%
Service provider	129	23.0%
Person with disabilities (self)	110	19.0%
Respondent age (N=79)		
18-22 years old	3	4.0%
23-35 years old	11	14.0%
36-50 years old	21	26.5%
Older than 50 years old	44	55.5%
Respondent gender (N=484)		
Woman	400	83.0%
Man	70	14.0%
Prefer not to answer	7	1.0%
Gender non-conforming/non-binary	5	1.0%
Other	2	1.0%
Respondent racial-ethnic identity (N=556)		
White	372	67.0%
Native American	79	14.0%
Black or African American	40	7.0%
Hispanic or Latino	39	7.0%
Prefer not to answer	16	3.0%
Other	4	1.0%
Asian or Asian American	3	0.5%
Hawaiian or Pacific Islander	3	0.5%
Caregiver provides assistance (N=79)		
Yes	36	46.0%
No	43	54.0%
Relationship with caregiver (N=35)		
Parent	14	40.0%
Other family member	9	26.0%
Not related	8	23.0%
Friend	3	8.0%
Sibling	1	3.0%

Table 3. Caregiver and care recipient demographics

Variable	n	%
Caregiver age (N=36)		
Younger than 25 years old	1	3.0%
25-50 years old	14	39.0%
51-65 years old	12	33.0%
Older than 65 years old	9	25.0%
Caregiver respondent age (N=323)		
Younger than 25 years old	1	1.0%
25-50 years old	150	38.0%
51-65 years old	124	46.0%
Older than 65 years old	48	15.0%
Age of care recipient (N=321)		
Younger than 18 years old	133	42.0%
18-22 years old	71	22.0%
23-35 years old	68	21.0%
36-50 years old	29	9.0%
Older than 50 years old	20	6.0%
Relationship with care recipient (N=320)		
Child	255	80.0%
Grandchild	27	8.0%
Other family member	14	4.5%
Not related	13	4.5%
Sibling	11	3.0%
Gender identity of care recipient (N=321)		
Woman/girl	132	41.0%
Man/boy	168	52.0%
Prefer not to answer	18	6.0%
Gender non-conforming/non-binary	2	0.5%
Other	1	0.5%

Results

Question 1: What Supports or Services Have Helped You or Your Family?

Listening Session and Follow-Up Survey Results

The first listening session question asked participants to share what supports and services have helped them or their families. Responses highlighted a wide range of resources, including those provided by government agencies, nonprofit organizations, schools, healthcare systems, and informal community networks. These supports address

various aspects of daily life such as education, medical care, financial assistance, and emotional support. Participants reflected on both longstanding services and more recent interventions that had positively impacted their lives. The diversity of responses reflects the complex and multifaceted nature of supporting individuals with developmental disabilities and their families. These insights provide a valuable foundation for identifying patterns in what families view as most helpful.

Through careful analysis, nine umbrella themes emerged to capture the most prominent areas of support described by participants. Each umbrella theme encompasses a set of subthemes, which represent more specific services or experiences mentioned across responses. While subthemes vary in content, they are conceptually tied to the broader categories under which they fall, creating a structure that maintains both detail and cohesion. This layered framework helps preserve the richness of individual experiences while highlighting commonalities that can inform policy and practice. By organizing data this way, the analysis honors the diversity of participant voices while also identifying shared needs and effective supports. This approach provides a comprehensive view of what is working well for families and where efforts might be expanded or strengthened.

Table 4. Umbrella Themes, Descriptions, and Subthemes Identified in Stakeholder Responses

Umbrella Theme	Description	Subthemes
Access to Public Support Services	Publicly funded services that provide foundational supports for individuals with developmental disabilities and their families.	DDS services Medicaid (SoonerCare)/TEFRA SSI/SSDI SNAP Waivers Respite
Medical, Therapeutic & Early Intervention	Health and developmental services that support physical, sensory, and cognitive development, especially in early childhood.	Speech therapy Occupational therapy Early intervention Assistive technology and tools

School-Based & Educational Supports	Services in school settings that help students thrive academically and socially.	IEPs Special education programs Inclusive school environments Advocacy for educational access
Transition Planning & Post-School Options	Services that support planning for life after high school, including adult service navigation, and post-21 options.	Transition services Planning for life after high school Post-21 services
Employment & Vocational Support	Supports focused on building job skills, readiness, and long-term employment opportunities.	Job coaching Youth Leadership Forum (YLF) Oklahoma Department of Rehabilitation Services (DRS) Vocational training services Work-based experiences
Community Participation & Social Inclusion	Programs and services that promote inclusion, connection, and visibility in community life.	Local inclusive events Peer support groups Inclusive arts/music programs Inclusive gyms
Family & Caregiver Supports	Services that assist families and caregivers, recognizing their vital role in supporting individuals with disabilities.	Respite services Housing/living support Financial programs Peer/caregiver networks
Advocacy, Empowerment & System Engagement	Initiatives that build self-advocacy and system navigation skills and promote civic engagement.	Partners in Policymaking (PIP) Advocacy training Self-advocacy supports
Mental & Behavioral Health Services	Services that address behavioral, emotional, and psychological well-being for individuals with developmental disabilities.	Mental health therapy Behavioral supports and interventions

Discrepant Themes

Discrepant themes represent unique or less frequently mentioned perspectives that nonetheless contribute valuable insights to the overall findings (Creswell & Creswell, 2018).

Table 5. Discrepant Themes in Stakeholder Responses

Discrepant Theme	Description
Positive Experiences with Law Enforcement & First Responders	A small number of participants reported positive interactions with first responders who had received disability-specific training, a contrast to the broader trend of concern about safety and misunderstanding.
Satisfaction with Transition Services	While transition was generally viewed as an area of need, a few families described strong partnerships between certain schools/school districts and adult service systems that led to smooth transitions for their children.

Opting Out of Formal Services by Choice	Some self-advocates and families reported intentionally avoiding formal service systems in favor of informal supports due to prior negative experiences or lack of trust.
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Identified Gaps

Gaps refer to areas where services are lacking, inaccessible, or underdeveloped.

These issues were raised consistently across multiple sessions and represent critical areas for improvement.

Table 6. Identified Gaps in Stakeholder Responses

Identified Gap	Description
Lack of Coordinated Transition Planning for Young Adults	Many families described a lack of structured, individualized support as students aged out of the school system, often referring to this transition as a “cliff.”
Inadequate Access to Culturally and Linguistically Appropriate Services	Participants from diverse cultural and linguistic backgrounds described difficulties finding providers who could offer services in their preferred language or with cultural sensitivity.
Insufficient Mental Health Supports for Individuals with Co-occurring Conditions	Families and providers noted the lack of integrated services for individuals who experience both developmental disabilities and behavioral or mental health challenges, particularly in rural areas.

Census Survey Results

Respondents identified several key areas where additional support, information, or resources are most needed. Special Education (SPED) and Individualized education plans (IEPs) emerged as the top priority, with 335 selections, followed closely by public support services (n=325), highlighting persistent challenges navigating school-based services and accessing state and federally funded programs. Early intervention (n=219) and mental health (n=190) were also frequently selected, reflecting concerns about developmental delays, service availability, and timely access to behavioral and emotional supports. Interest in Applied Behavior Analysis (ABA) (n=179) and family or caregiver support (n=173) underscores the need for both specialized therapies and practical assistance for those providing daily care. Community participation and inclusion (n=169)

and employment supports (n=157) point to ongoing efforts to expand opportunities for social engagement and meaningful work for individuals with disabilities. Respondents also expressed a desire for more advocacy training (n=133) and improved transition and post-21 services (n=86), emphasizing gaps in preparation for adulthood and independent living. A smaller number (n=35) identified additional topics such as transportation, housing, and general system navigation challenges.

Table 7. Supports or services that have helped (N=492)*

Variable	n	%
Special education and individualized education plans	335	68%
Public support services	325	66%
Early intervention	219	45%
Mental health	190	39%
ABA Therapy	179	36%
Family/caregiver support	173	35%
Community participation and inclusion	169	34%
Employment	157	32%
Advocacy training	133	27%
Transition and post-21 services	86	17%
Other	35	7%

*Percentages do not sum to 100% due to multi-select responses.

Question 2: What supports or services do you or your family (or the families you serve) still need? What is missing?

Listening Session and Follow-Up Survey Results

Question Two asked participants which services were needed but were unavailable. The intent of this question was to identify ongoing gaps in services and supports for individuals with developmental disabilities. Participants described a wide range of unmet needs, from daily support to long-term planning. Many shared frustrations with navigating siloed service systems, inconsistent access to programs,

and the continued presence of stigma or misunderstanding about developmental disabilities. These accounts highlight how even families who are engaged and resourceful still struggle to find adequate support.

This question resulted in seven distinct umbrella themes that reflect the most frequently mentioned areas of need. These include the lack of reliable transportation, limited services and planning for adults with developmental disabilities, and ongoing barriers to accessing quality and informed health and mental health care. Participants also emphasized the shortage of affordable housing and respite options, the need for clear and timely information, and help navigating complicated systems. Caregivers described high levels of stress and limited formal support, while others noted the lack of inclusive, accessible opportunities in their communities. Together, these themes illustrate persistent gaps in the service landscape that continue to impact individuals and families across multiple life domains.

Table 8. Umbrella Themes, Descriptions, and Subthemes Identified in Stakeholder Responses

Umbrella Theme	Description	Subthemes
Transportation Challenges	Barriers related to a lack of reliable, affordable, and accessible transportation options, particularly in rural areas.	Limited transportation in rural areas Even when transportation is available, the hours of operation remain inaccessible
Adult Support Needs	Gaps in supports and services for individuals with disabilities as they transition to adulthood, especially for those not pursuing college.	Lack of post-secondary programs Insufficient transition planning Limited employment options
Healthcare & Mental Health	Limited access to comprehensive and coordinated physical and mental health services, including provider shortages and long wait times.	Shortage of specialists Long waitlists Transition from pediatric to adult care

		Lack of coordinated care Minimal school-based services
Housing & Respite Care	Insufficient availability of housing and respite options to support independent or semi-independent living and caregiver relief.	Shortage of group homes Lack of respite providers Long-term housing concerns Eligibility barriers
Information & Systems Navigation	Difficulties locating and understanding services, resources, and eligibility criteria due to bureaucratic complexity and a lack of coordination.	Difficulty locating resources Lack of centralized information Bureaucratic confusion Minimal navigation support
Family & Caregiver Supports	Caregivers face challenges in managing care responsibilities, finances, and emotional health, often without adequate external support.	Financial strain Emotional stress and exhaustion Lack of peer support networks Minimal caregiver training or services
Community Inclusion & Accessibility	Limited opportunities and infrastructure for individuals with disabilities to fully participate in community life.	Limited social inclusion opportunities Lack of culturally/linguistically accessible services Inadequate assistive technology access

Discrepant Themes

Discrepant themes represent unique or less frequently mentioned perspectives that nonetheless contribute valuable insights to the overall findings (Creswell & Creswell, 2018).

Table 9. Discrepant Themes in Stakeholder Responses

Discrepant Theme	Description
Access to Paratransit	While most families struggle with transportation, some reported having access to paratransit, though this was inconsistent across regions.
Strong Transition Programs	A few students had access to robust transition services preparing them for adulthood, in contrast to the more common lack of post-secondary or vocational supports.

Positive Mental Health Experiences	Some families described effective or helpful mental health services, even though these were generally characterized as inaccessible or inadequate.
Availability of Respite Services	A minority of families successfully accessed respite care, standing in contrast to widespread reports of shortages and barriers.
Presence of Advocacy Support	Some families noted receiving help from advocacy organizations to navigate systems and services, differing from the more frequent feeling of confusion and being overwhelmed.
Strong Peer or Family Support Networks	A few caregivers reported strong networks of emotional and practical support, unlike the majority who experienced isolation or exhaustion.
Inclusive Community Programs	Some participants highlighted local inclusive programs or accessibility efforts, despite broader trends of limited inclusion and access.

Identified Gaps

Gaps refer to areas where services are lacking, inaccessible, or underdeveloped.

These issues were raised consistently across multiple sessions and represent critical areas for improvement.

Table 10. Identified Gaps in Stakeholder Responses

Gap Identified	Description
Inadequate Transition and Adult Services	There is a widespread lack of meaningful post-secondary options, vocational pathways, and consistent transition planning for youth entering adulthood.
Limited Access to Healthcare and Mental Health Services	Families face barriers such as long waitlists, provider shortages, and poor coordination, especially during the transition from pediatric to adult care and in rural areas.
Severe Shortages in Housing and Respite Care	Few appropriate long-term housing options and an extreme shortage of respite providers leave families without essential supports.
Transportation Barriers, Especially in Rural Areas	Inflexible, costly, or entirely unavailable transportation options limit access to services, employment, and community inclusion.
System Navigation Challenges	Families frequently report confusion, lack of centralized information, and difficulty understanding or accessing services due to bureaucratic complexity.

Caregiver Stress and Lack of Support	Financial strain, emotional exhaustion, and minimal training or formal support services significantly impact family caregivers.
Social Isolation and Community Exclusion	Individuals with developmental disabilities often lack opportunities for meaningful inclusion, recreation, or peer interaction.
Cultural and Technological Accessibility Gaps	Services are not consistently accessible to non-English-speaking families, and there is limited access to assistive technology or device training.

Census Survey Results

Respondents also identified several priority areas where additional resources or supports would improve quality of life and access to services. Financial support was the most frequently selected need (n=235), reflecting widespread concerns about the costs associated with disability-related care and daily living. Employment (n=201) and community inclusion and access (n=201) were equally prominent, highlighting the desire for meaningful work opportunities and fully accessible community spaces and activities.

Peer support (164) and transportation assistance (n=163) were also noted as essential, particularly for reducing isolation and improving access to services, work, and social participation. Mental health needs (n=154) and respite services (n=152) remained significant priorities for families and caregivers, emphasizing the importance of comprehensive behavioral health care and relief for those providing ongoing support.

Post-secondary and transition services (n=150) and public support services (n=147) were frequently cited as well, indicating gaps in preparing youth for adulthood and navigating complex state and federal programs. Housing (n=140) and healthcare (n=121) rounded out the list of major needs, underscoring continued challenges related to stable living environments and timely, appropriate medical care. A smaller number of respondents (57) selected additional topics not captured in the main categories.

Table 11. Supports and services needed or missing (N=477)*

Variable	n	%
Financial support	235	49%
Employment	201	42%
Community inclusion and access	201	42%
Peer support	164	34%
Transportation support	163	34%
Mental health care	154	32%
Respite	152	32%
Post secondary and transition services	150	31%
Public support services	147	31%
Housing	140	29%
Healthcare	121	25%
Other	57	12%

*Percentages do not sum to 100% due to multi-select responses.

Question 3: What obstacles or challenges do you or your family face in accessing opportunities or services?

Listening Session and Follow-Up Survey Results

The third listening session question asked participants to describe the obstacles or challenges they or their families face in accessing opportunities or services. Responses reflected a wide range of systemic, logistical, and emotional barriers that impact individuals with developmental disabilities and their caregivers. Participants spoke about their experiences navigating complex service systems, securing employment, managing healthcare needs, coordinating education, and addressing the daily strains of caregiving. These insights highlighted both persistent structural issues and emerging concerns across geographic and demographic contexts.

Analysis of participant responses led to the identification of nine umbrella themes—broad, recurring categories that organize the various barriers families encounter. Each umbrella theme encompasses more specific subthemes that illustrate the types of challenges families experience. These include, for example, bureaucratic red

tape under “System Navigation & Bureaucracy,” benefit cliffs and limited job options under “Employment & Economic Barriers,” and service fragmentation under “Communication, Coordination, & Information.” While the subthemes are distinct, they are conceptually linked to their respective umbrella themes, allowing the structure of the analysis to reflect both the nuanced diversity and the shared commonalities across participants’ lived experiences.

Table 12. Umbrella Themes, Descriptions, and Subthemes Identified in Stakeholder Responses

Umbrella Theme	Description	Subthemes
System Navigation & Bureaucracy	Families face overwhelming paperwork, unclear roles of case managers, and confusing eligibility processes. Transitions between life stages are especially difficult, and there is a lack of professional navigators to help coordinate services.	Overwhelming paperwork Unclear case manager roles Confusing eligibility Gap during transitions Lack of navigators
Employment & Economic Barriers	Job options are limited, especially for individuals with developmental disabilities. Many face disincentives to work due to benefit cliffs, skill mismatches, and inadequate job coaching.	Limited job options DRS limitations Financial disincentives Mismatch in skills and jobs Job coaching gaps
Transportation & Geographic Limitations	Access to services is restricted by the lack of public or reliable transportation, particularly in rural areas. Travel is often dependent on family or inconsistent transit systems.	Lack of transportation in rural areas Long travel times Even when transportation is available, the operation hours remain inaccessible Dependence on family or unreliable systems
Healthcare & Provider Access	There are significant shortages of trained and trauma-informed healthcare providers. Long waitlists and poor transition planning from pediatric to adult care are persistent issues.	Shortage of trained professionals Lack of trauma-informed care Long wait times Pediatric-to-adult transition issues
Education & Inclusion Barriers	Schools are often unprepared to support students with disabilities. Inclusion in general education settings is inconsistent, and many families report poor Individualized Education Plan (IEP) implementation.	Schools unprepared for disability needs Exclusion from activities/classrooms Inconsistent IEP implementation
Mental & Emotional Burden	Caregivers experience high levels of stress, exhaustion, and isolation due to the fragmented nature of services and the emotional demands of long-term advocacy.	Caregiver exhaustion Stress of managing services Isolation Advocacy fatigue

Communication, Coordination, & Information	Service agencies often provide inconsistent or conflicting information. Families frequently must repeat their stories and navigate misaligned systems.	Inconsistent information Repeating stories Agency misalignment Conflicting requirements
Technology & Digital Divide	Some families lack access to devices, internet, or the skills needed to use online services. Many systems are not user-friendly or accessible.	Lack of devices/skills Inaccessible systems Online forms fail Unequal access to remote services
Housing & Independent Living	There is a severe shortage of affordable, inclusive, and safe housing. Waitlists are long and hard to navigate, and low provider wages deter service availability.	Shortage of inclusive/affordable/safe housing Inaccessible waitlists Low provider incentives

Discrepant Themes

Discrepant themes represent unique or less frequently mentioned perspectives that nonetheless contribute valuable insights to the overall findings (Creswell & Creswell, 2018).

Table 13. Discrepant Themes and Identified Gaps in Stakeholder Responses

Discrepant Theme	Description
Improved Navigation Processes	Some families reported that system navigation became easier over time or that they encountered helpful agency staff.
Employment Success Without Agency Support	A few individuals achieved job success despite minimal help from vocational services or agencies.
Positive Relationships with Providers	Certain medical or service providers were praised for being knowledgeable and responsive, despite overall system shortages.
Resilience Through Advocacy	Some caregivers cited personal growth or resilience gained through support groups or advocacy roles, despite emotional burden.
Supportive Educators	Families described teachers or school staff who were inclusive and supportive, even in systems generally lacking in accommodations.
Remote Services Benefiting Some	A minority found remote services or online platforms convenient or helpful, in contrast to those experiencing digital access issues.
Isolated Housing Support Successes	Rare but notable examples where families successfully navigated housing systems or secured appropriate living arrangements.

Identified Gaps

Gaps refer to areas where services are lacking, inaccessible, or underdeveloped. These issues were raised consistently across multiple sessions and represent critical areas for improvement.

Table 14. Identified Gaps in Stakeholder Responses

Gap Identified	Description
System Complexity and Navigation Barriers	Families face overwhelming paperwork, unclear roles, and confusing eligibility processes, especially during transitions.
Employment and Financial Disincentives	Limited job types, benefit cliffs, and poor job coaching restrict meaningful employment and discourage workforce participation.
Transportation and Location-Based Barriers	A lack of reliable transportation, especially in rural areas, significantly limits access to services, employment, and community engagement.
Shortage of Qualified Healthcare Providers	Long waitlists, lack of trauma-informed or disability-competent care, and difficulty with pediatric-to-adult transitions create major access issues.
Educational Inclusion Challenges	Students face exclusion from classrooms and activities, with widespread inconsistency in IEP implementation and staff training.
Mental and Emotional Strain on Families	Families experience exhaustion and isolation due to the ongoing burden of managing fragmented services with little systemic relief.
Poor Coordination and Communication Across Agencies	Conflicting requirements, misaligned services, and inconsistent information sharing create inefficiency and repeated frustrations.
Technology and Housing Accessibility Gaps	A digital divide limits access to essential online services, and inclusive housing options are extremely limited or inaccessible.

Census Survey Results

Respondents also highlighted a range of challenges that significantly impact their daily lives and their ability to access needed services. The most frequently cited concerns were eligibility and application processes (n=246) and caregiver exhaustion (n=242), reflecting both administrative burdens and the emotional and physical strain placed on families. The stress of managing complex care needs (n=224) and limited job opportunities (n=215) further underscored the pressures experienced by individuals with disabilities and their caregivers. Many respondents also reported feelings of isolation (n=187) and noted that schools are often unprepared to meet student needs (n=172), contributing to inconsistent support across educational settings. System-level barriers were prominent as well, including long waitlists (n=168), inadequate transportation options (n=167), limited availability of health professionals (n=159), and a shortage of housing (n=151). Concerns about low provider incentives (n=124) and exclusion from

classrooms (n=106) pointed to broader issues of access, equity, and workforce sustainability. Additionally, respondents identified challenges related to lack of technology (n=104) and limited access to trauma-informed care (n=84). A smaller group of participants (n=49) noted other issues, reflecting a diverse range of unmet needs not fully represented in the primary categories.

Table 15. Obstacles and challenges in accessing opportunities or services (N=477)*

Variable	n	%
Eligibility and application processes	246	52%
Caregiver exhaustion	242	51%
Stress of managing complex care needs	224	47%
Limited job opportunities	215	45%
Isolation	187	39%
Schools unprepared	172	36%
Waitlists	168	35%
Transportation	167	35%
Availability of health professionals	159	33%
Shortage of housing	151	32%
Low provider incentives	124	26%
Exclusion from classrooms	106	22%
Lack of technology access/education	104	22%
Access to trauma-informed care	84	18%
Other	49	10%

*Percentages do not sum to 100% due to multi-select responses.

Question 4: What health and wellness challenges do people with developmental disabilities face?

Listening Session and Follow-Up Survey Results

Question Four asked participants to describe the health and wellness challenges faced by individuals with developmental disabilities. The purpose of this question was to explore barriers to achieving and maintaining physical, emotional, and social well-being across the lifespan. Participants described difficulties accessing consistent healthcare, navigating disjointed medical systems, and locating providers with adequate disability-

specific training. Families often encountered long waitlists, a shortage of specialists, and a lack of trauma-informed or coordinated care. In rural areas especially, access to necessary medical, dental, and mental health services was described as limited or entirely unavailable. These gaps often forced families to become primary care coordinators, intensifying stress and leaving many unsupported.

In addition to medical and mental health challenges, participants also emphasized broader wellness concerns. These included limited access to inclusive fitness and recreation programs, inadequate or inaccessible sexual health education, and persistent social exclusion. Caregivers highlighted the emotional toll of service navigation and described high rates of exhaustion due to the lack of respite or formal support. Responses also pointed to systemic and financial barriers—such as Medicaid complexity, service interruptions, and coverage gaps—that complicate access to care. Altogether, the experiences shared by families revealed a fragmented health and wellness landscape that places a disproportionate burden on individuals with developmental disabilities and those who support them. These challenges were organized into nine umbrella themes to reflect the recurring patterns of need and the interconnected nature of these barriers.

Table 16. Umbrella Themes, Descriptions, and Subthemes Identified in Stakeholder Responses

Umbrella Theme	Description	Subthemes
Access to Healthcare	Barriers include long waitlists, rural service shortages, limited availability of specialists, and difficulties transitioning from pediatric to adult care.	Long waitlists Rural service gaps Limited specialists Difficulty transitioning from pediatric to adult care Medicaid coverage issues
Mental Health & Emotional Well-being	Challenges include a lack of trained mental health professionals, absence of trauma-informed care, emotional isolation, and co-occurring conditions.	Shortage of trained therapists Lack of trauma-informed care Co-occurring conditions Limited peer support Emotional distress and isolation

Physical Health & Preventive Care	Families reported difficulty accessing inclusive fitness programs, dental care, and managing special diets tailored to developmental needs.	Difficulty accessing inclusive physical activity programs Adaptive fitness and PE Lack of dental care Special diet challenges
Provider Knowledge & Attitudes	Many providers lack adequate training in developmental disabilities, leading to poor communication, dismissive behavior, or inappropriate care.	Inadequate disability-specific training Dismissiveness Communication barriers with disabled individuals
Coordination & Continuity of Care	Care is often fragmented, with poor communication between providers and little proactive planning or follow-through.	Disjointed care models Reactive rather than proactive treatment Poor communication among multiple providers
Systemic & Financial Barriers	Complex Medicaid systems, delays in service authorizations, and high costs present significant challenges, especially after age 21.	Complex Medicaid systems Renewal and authorization delays High cost of services Gaps in coverage after age 21
Caregiver & Family Strain	Families are overwhelmed by the responsibility of managing services and experience emotional and physical exhaustion due to a lack of support.	Emotional exhaustion Lack of respite Overwhelming service coordination duties are placed on families
Sexual Health & Education	There is a lack of accessible, inclusive sex education, often compounded by cultural stigma and family discomfort with the topic.	Lack of accessible sex education Consent challenges Cultural stigma Parent discomfort with the topic
Social Inclusion & Community Access	Individuals often face isolation due to limited inclusive peer opportunities and persistent stigma in broader community settings.	Social isolation Few inclusive recreational/peer programs Stigma and exclusion from broader community spaces

Discrepant Themes

Discrepant themes represent unique or less frequently mentioned perspectives that nonetheless contribute valuable insights to the overall findings (Creswell & Creswell, 2018).

Table 17. Discrepant Themes in Stakeholder Responses

Discrepant Theme	Description
Access to Specialized Providers	Some families successfully located specialized healthcare providers, often due to proximity or personal connections.
Effective Mental Health Support	A few families had positive experiences with counselors or programs addressing mental health needs.
Inclusive Fitness or PE Access	Some communities or schools provided adaptive fitness programs, though access was inconsistent.

Positive Provider Relationships	A few providers were praised for disability-specific knowledge and effective communication.
Coordinated Care Examples	Programs like SoonerSuccess served as rare examples of proactive and connected care.
Successful Medicaid Navigation	Some families managed to navigate Medicaid through personal expertise or informal advocacy.
Support for Caregivers	Isolated instances of support from OT or social workers were noted, though not widespread.
Family Comfort with Sexual Health Topics	Some families were open to discussing and supporting sexual health education despite broader discomfort.
Grassroots Social Inclusion Efforts	Creative, community-led efforts (e.g., meetups) were described but were not scalable or widely available.

Identified Gaps

Gaps refer to areas where services are lacking, inaccessible, or underdeveloped.

These issues were raised consistently across multiple sessions and represent critical areas for improvement.

Table 18. Identified Gaps in Stakeholder Responses

Gap Identified	Description
Limited Access to Comprehensive Healthcare	Families face long waitlists, service shortages, and difficulty transitioning to adult care, worsened by Medicaid limitations.
Inadequate Mental Health Services	There is a lack of trauma-informed professionals and limited access to counseling or emotional support systems.
Barriers to Preventive and Physical Health Services	Families encounter difficulty accessing dental care, nutrition support, and adaptive fitness programs.
Lack of Disability-Specific Provider Training	Many healthcare providers lack knowledge or training to serve individuals with developmental disabilities effectively.
Poor Care Coordination and Continuity	Healthcare is often reactive and fragmented, with minimal communication among providers or proactive planning.
Systemic and Financial Obstacles	Families struggle with Medicaid complexity, coverage gaps, and unaffordable services after age 21.
Unsustainable Caregiver Burden	Caregivers carry the full weight of coordination with little formal support or respite, leading to exhaustion.
Lack of Accessible Sexual Health Education	Few inclusive programs exist for sexual education, and cultural stigma and family discomfort further limit access.
Social Exclusion and Limited Community Access	People with developmental disabilities experience persistent isolation and limited participation in inclusive community activities.

Census Survey Results

Respondents identified a number of significant and persistent barriers affecting their ability to access essential services and maintain stability. The most frequently reported challenges were financial barriers (n=334) and caregiver exhaustion (n=333), underscoring the overwhelming economic and emotional strain on families supporting individuals with disabilities. Waitlists and a lack of specialists (n=265), along with widespread social isolation (n=262), further illustrated the systemic and personal impacts of limited-service availability. Many participants also cited inadequate provider training (n=222) and a shortage of mental health professionals (n=211), pointing to gaps in workforce capacity across multiple sectors.

Additional high-priority concerns included the lack of respite options (n=208), insufficient care coordination and continuity (n=205), and critical Medicaid issues—such as gaps in coverage after age 21 (n=201), limited overall Medicaid coverage (n=197), and challenges with renewals and authorizations (n=160). Respondents also highlighted shortages in inclusive physical education (n=196) and rural service gaps and travel burdens (n=196), both of which restrict access to meaningful participation and needed supports. Other health-related barriers included a lack of dental services (n=193) and difficulties transitioning from pediatric to adult care (n=159). Families also noted challenges related to special dietary needs (n=142) and a lack of sex education (98), both reflecting overlooked areas of support and education. A smaller number of respondents (n=37) raised additional concerns not captured in the major themes.

Table 19. Health and wellness challenges faced by individuals with developmental disabilities (N=489)*

Variable	n	%
Financial barriers	334	68%
Caregiver exhaustion	333	68%
Waitlists or lack of specialists	265	54%
Social isolation	262	54%
Inadequate provider training	222	45%
Shortage of mental health professionals	211	43%
Lack of respite	208	43%
Lack of care coordination and continuity	205	42%
Medicaid gaps post 21 years old	201	41%
Medicaid coverage	197	40%
Shortage of inclusive PE classes	196	40%
Rural gaps or extended travel to urban areas for care	196	40%
Lack of dental	193	39%
Medicaid renewal or authorizations	160	33%
Pediatric to adult transition	159	33%
Specialized dietary needs	142	29%
Lack of sex education	98	20%
Other	37	8%

*Percentages do not sum to 100% due to multi-select responses.

Question 5: What needs to change to provide a more inclusive, supportive environment for people with developmental disabilities?

Listening Session and Follow-Up Survey Results

The fifth listening session question invited participants to reflect on what needs to change to create a more inclusive and supportive environment for individuals with developmental disabilities. Responses to this question were wide-ranging and deeply personal, revealing persistent barriers across multiple systems and sectors. Families and individuals described challenges rooted in public attitudes, policy design, education, service access, and community inclusion. These reflections underscored the idea that inclusion is not a singular issue but one that must be addressed holistically, with intentional change at both the structural and interpersonal levels.

Participants emphasized that meaningful inclusion requires more than just access—it demands respect, visibility, and a commitment to equity. Many responses pointed to the need for greater public understanding of developmental disabilities, stronger legal protections, and expanded opportunities for full participation in community life. While some individuals shared hopeful examples of progress in their schools or towns, the overall message was clear. Much work remains to ensure that people with developmental disabilities are fully supported, valued, and empowered throughout their lives—and truly included as full members of their communities.

Table 20. Umbrella Themes, Descriptions, and Subthemes Identified in Stakeholder Responses

Umbrella Theme	Description	Subthemes
Public Attitudes & Awareness	Addressing stigma, fostering inclusive mindsets, and improving public understanding of developmental disabilities.	Disability education in schools/workplaces Reducing stigma Changing assumptions about capability Inclusive values from an early age
Education Reform & Inclusion	Improving inclusive practices in educational settings and expanding teacher training and peer-based supports.	Inclusive classroom practices Anti-segregation efforts Teacher preparation Peer mentoring/self-advocacy
Community Inclusion & Representation	Expanding access to public spaces, community programs, and disability representation in media and civic life.	Sensory accommodations Inclusive recreation Disability representation Civic participation
Policy & Systems Reform	Reforming policies and systems to improve protections, remove financial disincentives, and increase accountability.	Marriage penalties/asset limits Oversight and monitoring Inclusion in planning Legal protections
Infrastructure & Accessibility	Removing environmental and logistical barriers to access transportation, housing, and health services.	Accessible transportation Inclusive housing Health care access gaps Rural limitations
Employment & Economic Empowerment	Expanding job opportunities, removing systemic obstacles to economic independence and upward mobility, and ensuring accommodations are respectful and effective.	Job training Career diversity Employer education Eliminate subminimum wages
Family & Lifespan Support	Addressing needs beyond childhood and offering support across the life span, including for families.	Post-school supports Life planning and housing

		Family empowerment Adult service gaps
Mental Health, Trauma, and Disability Recognition	Addressing emotional well-being, trauma-informed care, and broader definitions of disability.	Mental health care access Trauma-informed systems Co-occurring conditions SSDI/recognition of invisible disabilities

Discrepant Themes

Discrepant themes represent unique or less frequently mentioned perspectives that nonetheless contribute valuable insights to the overall findings (Creswell & Creswell, 2018).

Table 21. Discrepant Themes in Stakeholder Responses

Discrepant Theme	Description
Access to Specialized Providers	Some families successfully located specialized healthcare providers, often due to proximity or personal connections.
Effective Mental Health Support	A few families had positive experiences with counselors or programs addressing mental health needs.
Inclusive Fitness or PE Access	Some communities or schools provided adaptive fitness programs, though access was inconsistent.
Positive Provider Relationships	A few providers were praised for disability-specific knowledge and effective communication.
Coordinated Care Examples	Programs like SoonerSuccess served as rare examples of proactive and connected care.
Successful Medicaid Navigation	Some families managed to navigate Medicaid through personal expertise or informal advocacy.
Support for Caregivers	Isolated instances of support from OT or social worker were noted, though not widespread.
Family Comfort with Sexual Health Topics	Some families were open to discussing and supporting sexual health education despite broader discomfort.
Grassroots Social Inclusion Efforts	Creative, community-led efforts (e.g., meetups) were described but were not scalable or widely available.

Identified Gaps

Gaps refer to areas where services are lacking, inaccessible, or underdeveloped.

These issues were raised consistently across multiple sessions and represent critical areas for improvement.

Table 22. Identified Gaps in Stakeholder Responses

Gap Identified	Description
Waitlists and shortages	Families face long waitlists, service shortages, and difficulty transitioning to adult care, worsened by Medicaid limitations.
Inadequate Mental Health Services	There is a lack of trauma-informed professionals and limited access to counseling or emotional support systems.
Barriers to Preventive and Physical Health Services	Families encounter difficulty accessing dental care, nutrition support, and adaptive fitness programs.
Lack of Disability-Specific Provider Training	Many healthcare providers lack knowledge or training to serve individuals with developmental disabilities effectively.
Poor Care Coordination and Continuity	Healthcare is often reactive and fragmented, with minimal communication among providers or proactive planning.
Systemic and Financial Obstacles	Families struggle with Medicaid complexity, coverage gaps, and unaffordable services after age 21.
Unsustainable Caregiver Burden	Caregivers carry the full weight of coordination with little formal support or respite, leading to exhaustion.
Lack of Accessible Sexual Health Education	Few inclusive programs exist for sexual education, and cultural stigma and family discomfort further limit access.
Social Exclusion and Limited Community Access	People with developmental disabilities experience persistent isolation and limited participation in inclusive community activities.

Census Survey Results

Respondents also emphasized several broader societal and systemic issues that shape opportunities, access, and overall quality of life for individuals with disabilities. Public attitudes toward disability emerged as the most frequently cited concern (n=312), highlighting the ongoing impact of stigma, misunderstanding, and limited awareness. Post-school supports and life-course planning (n=289), along with the need for stronger disability representation (n=287), reflected a desire for more inclusive pathways into adulthood and greater visibility in media, leadership, and community spaces.

Employment-related issues were prominent as well: respondents pointed to the need for employer education (n=280) and expanded job training opportunities (n=261) to improve workforce participation and reduce barriers to meaningful employment. Transportation challenges (n=259) and limited social inclusion (n=253) further illustrated gaps in community accessibility and belonging. Mental health needs (n=240) and the

necessity for sensory accommodations (n=223) underscored the importance of environments that support emotional well-being and diverse sensory needs.

Participants also called for policy reform (n=213), improved housing options (n=212), and more inclusive classrooms (n=211), noting that structural changes are needed to ensure equitable access across systems. Healthcare barriers (n=195) rounded out the major themes, reflecting persistent difficulties in obtaining timely and appropriate medical support. A smaller number of respondents (n=47) identified additional concerns beyond the primary categories.

Table 23. Changes needed to provide a more inclusive, supportive environment for people with developmental disabilities (N=486)*

Variable	n	%
Public attitudes	312	64%
Post school and life course planning	289	59%
Disability representation	287	59%
Employer education	280	58%
Job training	261	54%
Transportation	259	53%
Social inclusion	253	52%
Mental health services	240	49%
Sensory accommodations	223	46%
Policy reform	213	44%
Housing	212	44%
Inclusive classrooms	211	43%
Health care	195	40%
Other	47	10%

*Percentages do not sum to 100% due to multi-select responses.

Question 6: What programs or approaches work well to promote inclusion and improve the lives of people with developmental disabilities?

Listening Session and Follow-Up Survey Results

The sixth listening session question asked participants to reflect on which programs or approaches work well to promote inclusion and improve the lives of people

with developmental disabilities. In their responses, participants highlighted a diverse range of supports spanning education, employment, healthcare, and social engagement. Many of the most valued programs shared common traits: they were person-centered, community-based, and designed with direct input from individuals with developmental disabilities and their families. These approaches created opportunities not only for access but also for connection, dignity, and long-term growth.

Participants identified specific practices that have been especially impactful, including inclusive classroom models, adaptive recreation, supported employment, peer mentorship, and individualized service planning. While positive examples were shared, responses also revealed disparities in access—especially in rural areas or among underserved communities. Some programs thrived due to strong local leadership or cross-agency collaboration, while others struggled due to workforce shortages or inconsistent implementation. Taken together, the feedback emphasized the importance of sustained investment in inclusive programming and the need to expand proven models across geographic and demographic lines.

Table 24. Umbrella Themes, Descriptions, and Subthemes Identified in Stakeholder Responses

Umbrella Theme	Description	Subthemes
Inclusive Education & Transition Support	Programs that support inclusive schooling, promote understanding among peers, offer after-school activities, and provide post-secondary and transition options.	Inclusive classrooms and school programs (e.g., lunch buddies, inclusive electives) After-school programs (e.g., adaptive dance, cheer groups) Alternative diplomas and inclusive post-secondary options
Employment & Vocational Training	Programs that help individuals prepare for and maintain meaningful employment, including job coaching, training, and community partnerships.	Supported employment (e.g., Walmart, Dale Rogers Center, Braum's) Job skills training (e.g., Project Search, DRS youth transition) Community employment partnerships (e.g., ThinkAbility café, A New Leaf)

Community-Based Inclusion & Recreation	Community events and recreational programs that offer adaptive and inclusive access to arts, activities, and public spaces.	Inclusive events (e.g., Night to Shine, All 4 One show) Arts and recreation (e.g., Penguin Project, Company 21) Accessible public options (e.g., sensory nights, Logan County Trolley)
Advocacy, Education & Peer Support	Efforts to promote inclusion through training, awareness, peer mentoring, and relationship-building.	Parent advocacy training (e.g., Partners in Policymaking) Disability awareness campaigns (e.g., school assemblies) Peer engagement and mentorship (e.g., Youth Leadership Forum)
Organizational Collaboration & Family Support	Collaborative service delivery and support for caregivers and families, including person-centered and flexible program models.	Agency collaboration (e.g., SoonerSuccess, DDSD) Person-centered planning (e.g., Charting the LifeCourse) Caregiver services and supports (e.g., respite, support for parents with disabilities)

Discrepant Themes

Discrepant themes represent unique or less frequently mentioned perspectives that nonetheless contribute valuable insights to the overall findings (Creswell & Creswell, 2018).

Table 25. Discrepant Themes in Stakeholder Responses

Discrepant Theme	Description
School Segregation	Instances of physical separation (e.g., separate lunch rooms) clash with broader inclusion goals.
Rural Program Access	Programs like Best Buddies or inclusive sports are less available in rural areas.
Cost Barriers	Inclusive fitness centers are appreciated but often too expensive (e.g., We Rock the Spectrum).
Perceived Regression	Despite community growth, some feel inclusion efforts have diminished.
Rare Condition Support	Supports for individuals with rare disabilities are less robust despite overall inclusive aims.

Identified Gaps

Gaps refer to areas where services are lacking, inaccessible, or underdeveloped. These issues were raised consistently across multiple sessions and represent critical areas for improvement.

Table 26. Identified Gaps in Stakeholder Responses

Gap Identified	Description
Inconsistent Inclusive Practices within the education system	Schools vary widely in their commitment to and implementation of inclusive education.
Limited Employment Options	Many opportunities are restricted to low-wage jobs without long-term career pathways.
Specialized Provider Access	There are shortages of trained providers, especially for mental health and developmental disabilities services.
Geographic Disparities	Programs and services are less accessible in rural communities.
Weak Advocacy Infrastructure	Some communities lack strong peer or legislative advocacy networks.

Census Survey Results

Respondents highlighted several priority areas that reflect both the needs of families and the aspirations of individuals with disabilities for full inclusion and opportunity. Caregiver support (n=298) emerged as the top need, emphasizing the ongoing strain on families and the importance of resources that strengthen their capacity to provide care. Inclusive community opportunities (n=291) and job skills development (n=279) were also major themes, underscoring the desire for meaningful participation in community life and preparation for future employment. Respondents noted strong interest in more inclusive schools (n=273) and enhanced parent advocacy supports (n=270), both of which are essential for ensuring equitable access to educational services and informed engagement in decision-making. Employment (n=259) and peer engagement (n=255) remained significant priorities as well, reflecting the importance of both work opportunities and social connection.

Many respondents also emphasized disability awareness (n=252) and person-centered planning (n=226) as vital components of building supportive, individualized pathways. Additional needs included increased sensory accommodations (n=208), expanded community employment options (n=207), access to alternative diploma

pathways (n=206), and more robust after-school programs (n=203). A smaller number of respondents (n=28) identified other needs not captured in the primary categories.

Table 27. Programs or approaches that work well to promote inclusion and improve the lives of people with developmental disabilities (N=477)*

Variable	n	%
Caregiver Support	298	62%
Inclusive Community	291	61%
Job Skills	279	58%
Inclusive Schools	273	57%
Parent Advocacy	270	57%
Employment	259	54%
Peer Engagement	255	53%
Disability Awareness	252	53%
PC Planning	226	47%
Sensory Accom	208	44%
Community Employment	207	43%
Alt Diplomas	206	43%
After School Programs	203	43%
Other	28	6%

*Percentages do not sum to 100% due to multi-select responses.

Question 7: If you could make any change or create any program to help people with developmental disabilities, what would it be?

Listening Session and Follow-Up Survey Results

The seventh listening session question invited participants to share what changes or new programs they would create to better support people with developmental disabilities. Responses reflected a bold and visionary spirit, with individuals identifying specific areas for transformation across systems such as housing, employment, healthcare, and transportation. Families and self-advocates called for structural reforms that would improve everyday life—such as better service coordination, accessible housing options, inclusive transit, and disability-informed healthcare. These ideas were

grounded in the lived experience of navigating gaps and barriers, often with limited support.

Participants also expressed a strong desire for cultural change, including reducing stigma and increasing public awareness of disability rights and experiences. Many emphasized that solutions must go beyond compliance or access; they must foster genuine belonging and visibility. Some called for reforms to eligibility criteria and funding structures that currently exclude people with high needs or “invisible” disabilities. Others highlighted the importance of elevating voices from marginalized communities and ensuring programs are inclusive across race, language, and socioeconomic lines. Collectively, these responses underscore the urgency of both policy-level and grassroots action to create a society where people with developmental disabilities can thrive.

Table 28. Umbrella Themes, Descriptions, and Subthemes Identified in Stakeholder Responses

Umbrella Theme	Description	Subthemes
Caregiver & Family Support	Resources aimed at supporting aging caregivers, siblings, and family units through respite, retreats, and navigation tools.	Respite care and retreats Resources for siblings and aging caregivers Wraparound family support services
Housing & Independent Living	Initiatives that promote accessible, inclusive housing with individualized supports to ensure long-term living stability.	Inclusive community-based housing Supported group homes Affordable and accessible living models
Employment & Economic Stability	Efforts to promote meaningful employment, reduce benefit disincentives, and offer career development opportunities.	Mentorship and job opportunities Restructuring benefit thresholds Inclusive hiring incentives for employers
Education & Transition Services	Programs focused on life skills training, post-secondary education, and vocational development for youth with disabilities.	Life skills education Vocational and post-secondary training Standardized transition planning
Transportation Accessibility	Expanding flexible, affordable, and rural-accessible transportation to improve mobility and inclusion.	Rural and regional transport access Flexible scheduling Employer-linked transit options

Healthcare & Mental Health Services	Improving specialized medical access and training providers to offer trauma-informed and coordinated care.	Broad provider training on caring for patients with developmental disabilities and their families Specialized clinics and mental health care Coordinated care across providers
Public Awareness, Policy Change, & Social Inclusion	Efforts to reduce stigma, expand disability culture, improve service navigation, and promote systemic inclusion through policy.	Disability education and awareness Peer mentorship and inclusive community spaces Policy advocacy and systemic reform

Discrepant Themes

Discrepant themes represent unique or less frequently mentioned perspectives that nonetheless contribute valuable insights to the overall findings (Creswell & Creswell, 2018).

Table 29. Discrepant Themes in Stakeholder Responses

Discrepant Theme	Description
Institutional Limitations	Respondents felt institutions and nursing homes were inappropriate, yet alternatives were scarce.
Inclusion Preferences	Some preferred disability-specific spaces like tailored camps, even while promoting universal inclusion.
Service Eligibility Gaps	High IQ individuals were denied services despite clear support needs.
Surface-Level Inclusion	Certification labels and accessibility signals often mask a lack of true inclusion or belonging.

Identified Gaps

Gaps refer to areas where services are lacking, inaccessible, or underdeveloped. These issues were raised consistently across multiple sessions and represent critical areas for improvement.

Table 30. Identified Gaps in Stakeholder Responses

Gap Identified	Description
Fragmented System Navigation	Families struggle with uncoordinated service systems and a lack of centralized access.
Rural and Economic Barriers	Rural areas have fewer programs, and low-income families face affordability challenges.
Provider Workforce Shortages	Direct support professionals and trained providers are underpaid and in short supply.

Limited Social Integration	Despite inclusion rhetoric, true belonging in schools, workplaces, and communities remains elusive.
Policy and Infrastructure Delays	Systemic change efforts are slowed by legislative inaction or a lack of funding incentives.

Census Survey Results

Respondents identified a range of priorities reflecting both personal and systemic needs. Caregiver and family support was the most frequently cited area (n=107), highlighting the importance of resources that alleviate stress and strengthen families' capacity to provide care. Housing and independent living supports (n=69) and education and transition services (n=65) were also prominent, emphasizing the need for stable living arrangements and preparation for adulthood. Employment and economic supports (n=55) and healthcare and mental health services (n=52) further underscored ongoing challenges in accessing meaningful work and timely medical care.

Public awareness and social inclusion (n=54) were noted as key areas for improving societal attitudes and participation opportunities, while transportation (n=31) and policy change (n=25) were identified as additional systemic priorities. A smaller group of respondents (n=37) cited other needs not captured in these categories.

Table 31. Changes to programs or programs to create to help people with developmental disabilities (N=495)*

Variable	n	%
Caregiver and family support programs	107	22%
Housing and independent living programs	69	14%
Education and transition to adulthood programs	65	13%
Employment and economic programs	55	11%
Healthcare and mental health programs	52	11%
Public awareness and social inclusion programs	54	11%
Other	37	7%
Transportation	31	6%
Policy change	25	5%

*Percentages do not sum to 100% due to multi-select responses.

Conclusion

The findings from this mixed methods assessment offer a clear and compelling picture of the experiences, priorities, and persistent challenges faced by individuals with developmental disabilities, their families, caregivers, providers, and advocates across Oklahoma. Through 19 listening sessions, a follow-up survey, and statewide census survey, participants shared honest and often deeply personal accounts of both what is working and what continues to fall short within current systems. Together, these data reveal a consistent message: while meaningful supports exist, they are unevenly distributed, difficult to navigate, and insufficient to meet the growing and diverse needs of the community served by the DDCO.

Across all questions and data sources, several themes emerged with striking regularity. Families and individuals continue to struggle with the complexity of service systems, long waitlists, unavailable or underqualified providers, and a lack of coordinated care across the lifespan. Caregiver exhaustion—emotional, physical, and financial—was one of the most pervasive concerns. Barriers related to transportation, housing, mental health care, and inclusive education were likewise prominent and often interconnected. Participants underscored how these gaps contribute to widespread social isolation, limited opportunities for work and community engagement, and reduced overall quality of life.

At the same time, respondents identified clear examples of what works well: inclusive education practices, supported employment programs, person-centered planning approaches, strong advocacy networks, and community-based activities that create belonging. These strengths, though not universal, demonstrate that with

intentional investments, cross-agency collaboration, and a commitment to inclusion, meaningful progress is both possible and already underway in parts of the state.

The insights gathered in this report provide a solid foundation for the Developmental Disabilities Council of Oklahoma as it develops the 2027–2031 State Plan. The priorities identified by stakeholders point to a need for strategic action in five key areas: reducing systemic barriers, strengthening workforce capacity, expanding inclusive opportunities across the lifespan, improving access to health and mental health care, and investing in family and caregiver supports. Centering the lived experiences of people with developmental disabilities will be critical to ensuring that future efforts are not only data-driven, but also equitable, sustainable, and aligned with what Oklahomans say they need most.

Ultimately, this assessment underscores both the urgency and the possibility of meaningful change. By continuing to listen, collaborate, and innovate, Oklahoma can build a future in which individuals with developmental disabilities are fully supported, valued, and included in every aspect of community life.

References

- Best, S., King, D., Ferri, B., & Test, D. W. (2024). *Youth with developmental disabilities leading change: Exploring advocacy and civic engagement*. *Inclusion*, 12(1), 1–14. <https://doi.org/10.1352/2326-6988-12.1.1>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). SAGE Publications.
- Muñoz-Rivera, K., González, M., Triviño-Juárez, J. M., & Martínez-Santos, A. E. (2024). *Stigma in people with autism spectrum disorder and intellectual disability: A systematic review*. *International Journal of Developmental Disabilities*. Advance online publication. <https://doi.org/10.1080/20473869.2024.2308024>

2027-2031

5 Year State Plan

Draft Goals

2026-2031 State Plan Goal Ideas

Goal 1: Ensure Equitable Access to Services

Goal: Eliminate barriers to people with developmental disabilities and/or families by developing coordinated, technology-driven solutions to reach all communities.

Expected Outcomes:

- People and families will report a decrease in the difficulty of navigating service systems.
- Communities will have equal access to services and supports.
- Communication between agencies that serve people with developmental disabilities will be improved.

Objectives:

- By 2028, a centralized, user-friendly “No Wrong Door” resource will be created.
- By 2029, a statewide community navigator program will be established to provide in-person assistance.
- By 2029, a mobility navigation program will be established to provide transportation assistance in the three community navigator pilot counties.

Goal 2: Foster a Culture of Inclusion and Self-Advocacy

Goal: Elevate the voices and leadership of people with developmental disabilities and their families, changing public perceptions to ensure services and systems are grounded in dignity and respect.

Expected Outcomes:

- Positive attitudes and public awareness towards people with developmental disabilities will measurably increase across Oklahoma.
- Self-advocates and family advocates will be prepared to take on leadership roles.
- Decision-making bodies at the state and local levels will be more inclusive, with greater representation from the disability community.
- All Council Leadership programs will have stronger alumni networks and greater community impact.

Objectives:

- Annually through 2031, launch and evaluate a public education campaign that showcases the contributions of people with developmental disabilities in the workforce, arts, and community.
- Annually through 2031, provide formalized training for 150 emerging self-advocates and family members.
- By 2029, a formal alumni network will be established for graduates of our leadership programs.
- By 2029, Self-Advocate Trainers will create and provide training to 150 self-advocates, local businesses, schools, and organizations.
- By 2031, a cross-disability coalition will be established to help state-level policy discussions, with at least 50% of its members being people with developmental disabilities.
- By 2030, a toolkit will be developed to assist businesses and organizations in creating more inclusive environments for employees and customers.

Goal 3: Strengthen the Support System for Families

Goal: Provide caregivers and families with the resources and training they need to ensure the long-term well-being of their loved ones.

Expected Outcomes:

- Caregivers will report feeling more prepared and supported, leading to a reduction in caregiver fatigue and stress.
- Families will have increased access to respite services and peer-to-peer support networks.

Objectives:

- By 2029, ensure OK Cares maintains and updates a comprehensive plain language Family and Caregiver Resource Guide that includes information on financial planning, legal matters, and long-term care options.
- Annually through 2031, offer at least 20 specialized training workshops for caregivers on topics such as person-centered planning, behavioral support strategies, and navigating service systems.
- Annually through 2031, Oklahomans with developmental disabilities and their families will have increased knowledge and understanding of resources, services and supports across the lifespan that will allow them to live their best lives.
- In the event of natural and/or manmade disasters, emerging statewide needs, the Council may engage in additional activities with and on behalf of Oklahomans with developmental disabilities and their families and serve them.