2025 Developmental Disabilities Council of Oklahoma Final Report and Findings

Developmental Disabilities Council of Oklahoma

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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 18 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 18.

The 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. 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. Ultimately, the participation rate for listening sessions was 36%.

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.

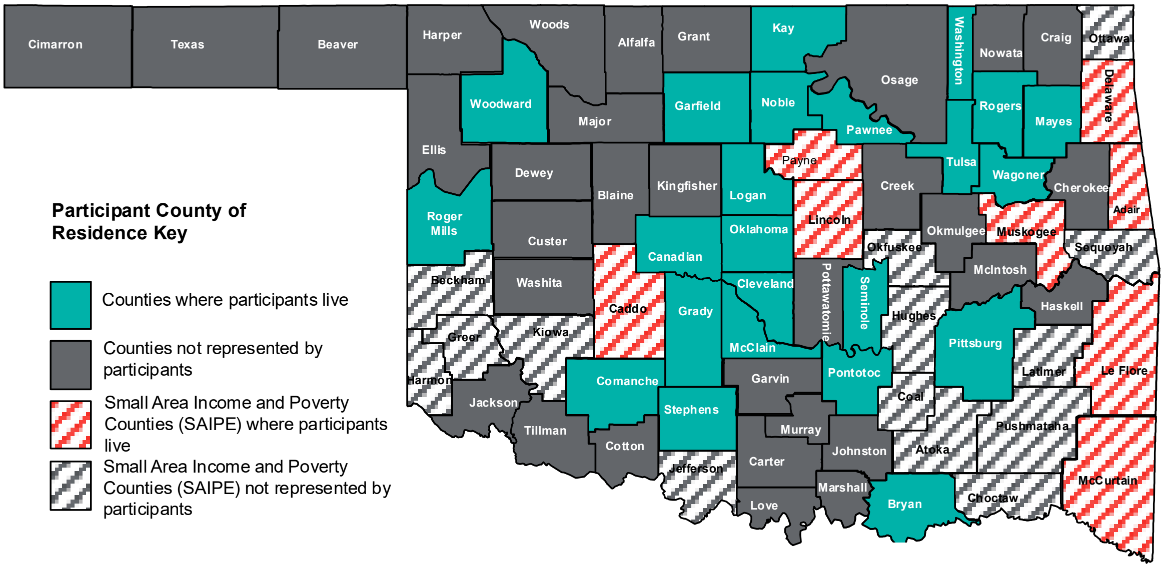
Table 1. Listening session and follow-up survey demographics

Variable	n	%
Participant type (N=147)		
Survey	68	46.3%
Listening sessions	79	53.7%
Listening session participants by 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.

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 18 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.

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