Developmental Disabilities
Council of Oklahoma

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# State Plan Committee Meeting Agenda

Friday, Sept. 27, 2024, 11:00 a.m.
2400 N. Lincoln Blvd, Sequoyah Bldg., Room 513
Oklahoma City, OK 73107

I.__ **Call to Order & Roll Call** – Michelle Kelley, State Plan Chair

II.__ **Welcome:** Welcome Jennifer Robinson.

II.__ **Discussion and Possible Voting*:** Review Meeting minutes of March 15, 2024, State Plan meeting.

III.__ **Discussion and Possible Voting***:
Funding Proposals for FY26 are due Oct. 30. Set dates for November State Plan Committee to review proposals.

IV.__ **Committee discussion*– Michelle Kelley**
Discuss information gathering ideas for next 5-year state plan.

- ☐ Listening Sessions
- ☐ Survey

V.__ Other Business *

VI.__ Announcements

VII.__ Adjournment *

***State Plan Committee Members:*** *Michelle Kelley, Committee Chair, Shelley Greenhaw, Committee Vice Chair, RoseAnn Duplan, Wanda Felty, Janie Fugitt, Sharon Garrity, Lori Hauge*

*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.*


Black Mesa
4973
Boise City
Guymon
Buffalo
Alva
Blackwell
Ponca City
Pawhuska
Bartlesville
Miami
Grove
Vinita
Oologah Lake
Lake O' The Cherokees
Woodward
Cimarron
Enid
35
Arkansas
Claremore
44
Pryor
Shattuck
North
Perry
Seiling
Stillwater
Tulsa
Broken Arrow
River
Cushing
Sapulpa
Tahlequah
Watonga
Canadian
Guthrie
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Muskogee
Canadian
River
Edmond
Okmulgee
Clinton
El Reno
Oklahoma City
Robert S Kerr Res
40
Henryetta
Elk City
Washita
River
Moore
Shawnee
Eufaula
Sayre
Norman
Seminole
Eufaula Lake
Poteau
Hobart
Anadarko
Chickasha
Holdenville
McAlester
Wichita Mts
River
Ada
OUACHITA MTS
Altus
Pauls Valley
Lawton
Coalgate
Broken Bow Lake
Duncan
Sulphur
Frederick
Arbuckle Mts
Atoka
Antlers
Red
Ardmore
Lake Texoma
Hugo Lake
Little River
Waurika
Madill
Hugo
River
Durant
Idabel

## 7/21/2020 – Supporting the Tribal Nations of Oklahoma

**15 Attendees**

**Question 1: What tribal supports and services are available to people with developmental disabilities and their families?**

- Hero project
  - Cherokee Nation
  - Pediatric behavioral health program – Provides early intervention trainings.
- C.A.R.E.S. program – No longer available.
  - Choctaw Nation
  - Autism and early intervention
- Redbird Smith Health Center
  - Cherokee Nation
  - Offers physical therapy.
- Early Access
  - EA has worked with a number of tribal nations to increase awareness and do early intervention/screening trainings.
  - EA has worked with tribal Head Start programs and childcare centers.
  - The Oklahoma Autism Center has also partnered with the Shawnee Tribe and Citizen-Potawatomi Nation on their Early Foundation program to provide early intervention screening and services.
- Tribal nations collaborate so that tribal members can get medical support at any tribal hospital.

**Question 2: What state or federal supports or services are available to people with developmental disabilities and their families in your tribe?**

- State and federal services and supports are often unknown to tribal communities because tribal nations have their own human services and government systems. There is an overall lack of education about what services are available outside of the tribe.
- The Department of Rehabilitation Services has grants available for tribal nations. DRS resources are not always being taken advantage of.

**Question 3: What supports or services have been successful in helping you and your family to live your best lives?**

- When someone has a disability, tribal communities come together to support the individual and family. The family and community work together to create a person-centered life plan.
- People First Industries in Durant provides resources for Bryan County that are helpful to the local tribal communities. Their resources look at an individual’s goals and what they want to do with their lives to help people find meaningful employment options. Their efforts are person-centered.
- The Cherokee and Choctaw tribes have collaborated with other tribes in the state to support early intervention screenings for developmental disabilities or delays. Disability awareness has continued to increase.

  - The tribes have also worked together to create peer mentoring programs.

**Question 4: What supports or services for people with developmental disabilities are missing?**

- Culturally, some tribes do not "acknowledge" developmental disabilities.
  - Tribal families say that: "You were born them way you are. You were created this way." Families take care of each other.
- Specific services for people with intellectual or developmental disabilities (especially adults) are not available. Part of this is due to cultural norms – Disabilities are not talked about.
  - In order to effectively work with tribal communities, you need to have a good cultural understanding of the tribal resources and traditions.
- There is an age gap of supports for people aged 21-65.
  - Transition services are limited.
- Transportation is limited, and people struggle with getting to their jobs or appointments.

**Question 5: What barriers to equal opportunities have you or your family encountered due to a developmental disability?**

- People with disabilities, especially those with intellectual disabilities, and their families do not seek help outside of their families. Part of this is because they don't know what resources are actually available.
- There is a higher than average level of grandparents raising grandchildren in tribal communities.
  - Older adults may not know how to access services and supports for developmental disabilities.
  - The older generations also tend not to acknowledge a disability as a disability, making it hard to connect with those families that have a family member with an intellectual or developmental disability.
  - The authoritative member of a family or tribe is not always the parent.
- Language barriers – Including that a number of tribal languages do not have a word for disability.
- Cultural barriers – There are unique nuances to dealing with each tribal community. There needs to be a cultural broker whenever you are working with tribal communities.
  - Each tribe has different resources and regulations.
- Low graduation rates for high school and college, coupled with teenage parents, means that parents may not be in charge of decision making. The head of the family may be the one to make decisions.
- Tribal human services programs are underfunded. This is particularly evident with the smaller tribal nations.
  - There is a resource divide between the small and large tribal nations.
- Lack of knowledge – Native American (along with rural populations) don't know the resources that are available.

**Question 6: What is your greatest concern about health or wellness supports and services for people with intellectual or developmental disabilities in your community?**

- Concerns about health and wellness have risen since the beginning of COVID-19:
    - How are tribal members getting medical services? Members may not be able to get the same level of services or supports that they were receiving in the past.
    - Some tribal communities and jurisdictions have limited technology and internet capabilities. This affects those whose doctors have gone to virtual medicine.
        - Telehealth screenings are being met with hesitation and may be seen as less valid.
    - For school-aged children – What do families do if school is virtual, but the family only has one computer for more than one kid? How do they share technology resources within a family?
    - COVID has caused layoffs in places where people with developmental disabilities have been traditionally hired (for example: sporting venues). And, the jobs that are coming available do not have advancement opportunities or benefits.
    - A higher than average rate of tribal leaders has passed away from COVID-19 than the general U.S. population. This is due to a number of reasons but may be partially attributed to higher poverty rates and more rural living conditions. There was also a lag in COVID-19 testing within some tribal communities at the beginning of the pandemic.
- High poverty rates

**<u>Question 7</u>: How can the Council help improve supports and advocacy for people with developmental disabilities in tribal communities?**

- Capacity building – Virtual trainings have the possibility of remote professional development and can target specific audiences.
    - However, tribal communities in rural and frontier areas still have limited connectivity and internet.
    - Would it be possible for the Council to sponsor “technology grants” to the more rural communities?
- The Council should “beef up” its partnerships and collaboration efforts with tribal organizations.
    - To be successful, the Council should sit down with tribal leaders to build connections and meaningful relationships. The Council should start these efforts by partnering with the larger tribes, who will then be able to connect the Council with the other, smaller tribes.
    - The Council should connect with the Indian Child Welfare Association.
        - The Chair is from the Seminole Nation.
    - Connect with tribal health professionals and tribal communications teams.
- Awareness, resources and access to those resources.

**<u>Question 8</u>: How can the Council better support tribal communities to create a more inclusive community for people with developmental disabilities?**

- In the past, Tribal Nations and their members were often isolated from the rest of the U.S. society. Tribal communities were misunderstood by the wider population.
    - Integrating children into the public school system has helped to lead to more inclusion overall.
- The Council should partner with American Indian Resource Centers to reach tribal members because these area-wide resource centers are well-known to tribal members.

<u>Question 9</u>: **What community organization or entities need additional training to support people with developmental disabilities?**

- Law enforcement
  - Cherokee tribal law enforcement has worked with other law enforcement units for additional training about how to better interact with people with developmental disabilities.
- State entities need additional training about tribal cultural norms and how to better partner with tribal leadership.

<u>Question 10</u>: **If you had the opportunity to create any program to better the lives of people with developmental disabilities and their families, what kind of program would you create?**

- The dream would be equal income qualifications.
- Develop supports that do not rely on income levels. Resources should be made available for everyone and should be accessible in one place.

<u>Question 11</u>: **Please share any successes or program models that have positively supported inclusivity and best lives for people with developmental disabilities.**

- Oklahoma Head Start requires that 10% of their enrollment is for children with disabilities. Many of the tribes in Oklahoma work with Head Start programs.
  - The question that remains – How can we work with Head Start (and other programs for young children) to educate parents or guardians about the resources available for families with children who have developmental disabilities?

**7/13/2020 – Open Topic Forum**

**25 Attendees**

**Question 1: What things are going well for people with disabilities and their families in Oklahoma?**

- The city of Stillwater is in the process of building an inclusive and accessible park and play area.

**Question 2: What concerns keep you up at night?**

- Employment:
  - There is little or no awareness of the DD Act or ADA standards among employers.
    - Employers either do not know or do not want to hold themselves to federal standards.
    - Too often city and municipality workers (even government employees/employers) don't know the regulations or don't want to grant simple accommodations.
    - Once told that someone has a DD, some employers won't hire, or don't want to deal with, that individual.
    - Employers are not being held accountable for not meeting ADA regulations.
    - Limited federal protection and advocacy activities to support people with developmental disabilities.
  - Limited employment opportunities.
    - There is too high a rate of unemployment for the DD population. - This is an awareness issue. We need a strong campaign to gain awareness about the things that the DD population can do.
    - No one under 25 can enter a workshop.
  - Would like to see more DRS training with young adults and their families. DRS does limited life-planning or transition planning.
- Transition services are needed.
- Question: How do I reach out to other Traumatic Brain Injury Survivors?
  - What support groups are available? How can we be better self-advocates?
- Law enforcement concerns
  - Question: How do we better train officers to interact with people with intellectual or developmental disabilities?
  - Heavy concerns that some groups want to have ID cards for people with intellectual or developmental disabilities.
- Healthcare
  - People with intellectual disabilities aren't getting proper healthcare. They are getting pushed away.
  - Question: How do we train family members to advocate for better healthcare?
- Emergency preparedness and crisis management
  - There is a lack of self-advocates who are prepared for emergencies.
  - Idea: The DDCO should look into the creation of crisis management plans for people with developmental disabilities.
- Lack of long-term planning and supports
  - Long-term planning is currently heavily focused on the family being the support systems for people with developmental disabilities.

  - Concern: What happens when the family member that takes care of a person with a developmental disability dies? Who takes over that person's care? Does the person with a DD have the ability to make decisions at this point? The options available are very limited.
  - Residential supports are only available for people who have absolutely no family. Currently, residential supports are a last resort.
    - Residential support needs should be respected and available.

- Childcare
  - It is very difficult to find childcare that will accept children with intellectual or developmental disabilities, especially now – with COVID.
  - Concern: How do I know that childcare workers are prepared and trained to work well with children with developmental disabilities? Is my child being adequately (and inclusively) taken care of?

**Question 3: What is the number one reason that you joined this call today?**

- This question was not a matter of specific conversation.

**Question 4: If you had the opportunity (and money wasn't a factor), what is one big idea that you would implement to better the lives of people with developmental disabilities and their families in Oklahoma?**

- Increase caregiver supports – There is a lack of caregiver support and respite care, especially for families of people with developmental disabilities under the age of 60.

**Question 5: Over the next five years, how can the Council help Oklahomans with developmental disabilities get closer to achieving their dreams?**

- Employment education – The DDCO could better share the types of employment opportunities that are actually available in the community.
  - The DDCO could better support volunteers to be job coaches to prepare people with intellectual and developmental disabilities to be successful in employment.
  - Are there training or work study options for people with developmental disabilities during the transition from school?

**Question 6: Over the next five years, how can the Council help improve supports, advocacy, training and inclusion for people with developmental disabilities in Oklahoma?**

- Oklahomans need to be better educated about Medicaid issues and supports.
- Would like to see the DDCO expand supports for skills development from school to adult life?
  - It was suggested that Among Friends could be used as a possible model for success.
  - How can families and community partners help train/teach life skills?
  - Idea: How can we make transition a part of a student's IEP?
- Increase supports for people with developmental disabilities between the ages of 21-65.
- There needs to be more awareness of supports and services available for individuals with intellectual and developmental disabilities.

  - (This comment initially noted the need of awareness for people with traumatic brain injuries but was followed up with agreement that this was a need across all disabilities.)
- Question: What (if anything) can the DDCO do to support better communication between State agencies?

**<u>Question 7</u>: What community organizations or entities need additional training to better support people with developmental disabilities and their families? What trainings are currently missing?**

- Rural areas
  - Need increased supports and awareness of resources available.
  - Idea: Is there a way to identify, learn from, and then, duplicate successes in smaller communities throughout the state?
    - Could the DDCO support small seed grants for rural programs?
    - Example mentioned – United Way Innovation Grants
- Employers – Need more education about ADA regulations. There is currently a lack of enforcement of ADA regulations.
- Note (residential supports): New Mexico has a training program for "mini-partners" for self-advocates. New Mexico's Office of Guardianship: https://www.nmddpc.com/guardianship_program.

## 7/14/2020 – Oklahoma City and Central Oklahoma

**28 Attendees**

**Question 1: What central-Oklahoman supports and services have been successful in helping you and your family to live your best lives?**

- Most supports are for those younger than 21 and older than 65. There is a gap between childhood and aging services.
- Oklahoma Family Network
- Project Outreach – Respite care in Norman
- Down Syndrome Association of Oklahoma provides early support and training for families.
  - Kylee's Kitchen – a program to teach independent living skills.
- Dream Night at the Zoo
- IEP and school resources
  - Limited, but still helpful.
- TARC – Provides family and guardian supports.
- Ability Connection OK
- Waiting List Facebook page

**Question 2: What concerns or stresses keep you up at night?**

- COVID
  - There has been a backward movement in services.
  - Some families are seeing a regression in learning and development due to restrictions to supports and services.
  - COVID has caused restricted access to supports and the community.
  - The question now is: how do we support developmental needs when services are unavailable in person?
  - Education – How do kids get their credits if they are not in school?
  - Technology limitations – More access to technology is needed.
  - People with intellectual and developmental disabilities may not have the ability to use technology or the understanding.
  - Even with live schools, many parents are debating the decision whether to send their children back to school with COVID.
- Lack of strong and inclusive communities for people with developmental disabilities.
  - There are limited extracurriculars and social connections available.
    - This has been amplified with COVID.
- Daycare/Childcare
  - Limited even more due to COVID.
  - There are not many options of summer camps or day services that are inclusive. Some camps and organizations have noted that they want to be more inclusive, but they do not have the training and supports to adequately do so. Same with community centers.

  - There are limited childcare/daycare options for middle school or high school aged kids with developmental disabilities.

- Transportation
  - Outside of the Central Oklahoman area, it is hard to get transportation, even to medical care.

- “Inclusive groups” aren’t actually inclusive.
  - There is no integration of “special needs” children with students without developmental disabilities. There is separation within groups.

- What happens when I’m not here?
  - There is limited/no information or resources available about how to prepare for when you are not around to take care of your family member with a developmental disability.
  - No guardianship trainings/information is available.
  - Guardianship costs high legal fees to work with attorneys and the court system.

- Supports and services are even more limited for people with multiple disabilities.

- Social Security – The decision makers don’t understand disabilities.
  - It would be great to have a liaison between disability agencies and SSI.

- Employment
  - For people with intellectual or developmental disabilities who want to work – there is a fine line for how much someone can work without losing their medical coverage.
  - Medicaid and social security limitations.
  - Often, employers don’t want to, or know how to, support people with developmental disabilities. There is a continued struggle with inclusivity issues.

**Question 3: If you had the opportunity (and money wasn’t a factor), what is one big idea that you would implement to better the lives of Oklahomans with developmental disabilities and their families?**

- Increased accessibility to the internet and technology.

**Question 4: Over the next five years, how can the Council help Oklahomans with developmental disabilities get closer to achieving their dreams?**

- It would be nice to have more support for transitional periods. Increased circles of support and person-centered planning training efforts would greatly help.
  - More support and information for supported decision making.

- More STEM programs.
  - It would be great if we could adapt STEM programs and events to be continued virtually/safely.

- More family engagement events, like Sib Shops.

- Increased accessibility to the internet and technology.
  - There is a lot of social anxiety with zoom and other online social platforms.
  - Digital trainings and engagement.
  - It would be great to have training for students with disabilities to better use online education platforms.

- Are there any examples of successful programs to train people with developmental disabilities to use virtual platforms more successfully and more effectively?
- Are there options for people with developmental disabilities to work from home? How do we help those who want to work from home make a successful transition?

**<u>Question 5</u>: How can the Council help improve supports, advocacy, training and inclusion for people with developmental disabilities in Central Oklahoma and Oklahoma City?**

- This question was covered within the other questions, and therefore, was not a matter of specific conversation.

**<u>Question 6</u>: Please share any successes or program models that have positively supported inclusivity and best lives for people with developmental disabilities.**

- DRS has hosted summer STEM camps for the past few years. The program was hosted twice, virtually, this year.
- Girl Scouts online – GS of Western Oklahoma
- ILRU (Independent Living Research Utilization) – ilru.net offers free trainings.

**<u>Question 7</u>: What Central Oklahoman community organizations or entities need additional training to better support people with developmental disabilities and their families? What trainings are currently missing?**

- Daycares
- More advertising about available trainings would be a great way to move Oklahoma forward to being a more inclusive community/state.

## 7/15/2020 – Social Justice

**25 Attendees**

**Question 1: When you hear the words "social justice" and "developmental disabilities" together, what do you think about?**

- The Convention on the Rights of Persons with Disabilities was signed in 2008 by 163 countries in the United Nations. The United States has not signed.
- There is a lack of education of the wider community about developmental disabilities.
- There is also a lack of education and advocacy for people with developmental disabilities.

**Question 2: What community supports and services have been successful in promoting social justice for you and your family?**

- This question was not a matter of specific conversation.

**Question 3: What barriers to equal opportunities have you or your family encountered?**

- If you don't "look" like you have a disability, you get cut off and received limited support. Too often, if someone cannot "see" a disability, they won't acknowledge a disability.
- For a person with a speech impairment, there is often a misunderstanding of the person's abilities. These people are not always treated as capable.
- There are stigmas on certain disabilities.
- Social Security Administration rules
  - Marriage disincentive – SS benefits decrease if two people with a disability get married.
- There was a comment made about Buck v. Bell and forced sterilization being an issue. The case that allowed for forced sterilization for people in institutions has not yet been overturned.
- Interactions with law enforcement – law enforcement officers need additional training to better interact with people with intellectual or developmental disabilities.

**Question 4: What supports are needed to ensure that civil and voting rights are protected for people with developmental disabilities?**

- Are ADA accommodations being met at voting stations? How do we ensure this?
- Transportation! A big issue for voting – How do you get people with developmental disabilities to the polling stations?
  - Note: State employees can taking administrative leave to help at polling stations or drive people with disabilities to polling stations.
- Would additional support for early voting allow for more people to vote?
- Concerns have been raised this year about absentee ballots.
- Voting Education

  - Are there information videos or instructions to help people with intellectual and developmental disabilities prepare to go to the polls to vote?
  - We need to support informed voters - Education about the actual election (like who is running or what issues are being voted on) would also be a good resource for people prior to getting to the polling stations.

**<u>Question 5</u>: What supports are needed in Oklahoma to help caregivers and people with developmental disabilities determine if guardianship is the right decision for them?**

- Reframing the guardianship conversation in Oklahoma would help families better understand the alternatives to full guardianship.
  - 99% of the time, full guardianship is not the right option.
  - Full guardianship is too often recommended by the legal system.
- Full guardianship means that the person is unable to vote or make certain legal/personal decisions.
- Limited guardianship is an alternative option to full guardianship.
  - How can we better work with the legal system (lawyers, judges) to educate them on the option of limited guardianship?

**<u>Question 6</u>: How can the Council better support people with developmental disabilities who are members of unserved or underserved populations?**

- Increased awareness
- There is an overall lack of knowledge of the existence of the Council and what it does, especially in the more rural areas of Oklahoma.
- There are not many (if any at all) advocates or self-advocates for people in underserved communities.
  - Specific communities underrepresented are the LGBTQ, rural and racial communities.
- Rural areas – There are a large number of people with disabilities who are not being reached.
- Communities where English is a second language are not connected or adequately supported.
  - Spanish-speaking communities
  - Other communities – Vietnamese, Congolese, Burmese
- Suggestion: Community building – Instead of expecting people to come to the Council, we need to go to them, meet people where they are.
  - To work with underserved or unserved populations, the Council needs to learn about the different cultural norms that surround developmental disabilities.
  - How can the Council connect with “cultural brokers”?

**<u>Question 7</u>: How would you define meaningful inclusion? How can the Council support a more inclusive community in Oklahoma?**

- Why doesn’t Oklahoma celebrate disability awareness month?
  - Small clusters of people and organizations will celebrate, but there are no coordinated cross-disability efforts.

  - Is this something that the Council can spearhead?

- School “segregation” vs. inclusivity
  - Many times, when schools try to be inclusive, they really just segregate children with disabilities from those without disabilities.

- There is a lack of diversity on school boards.

- Currently community groups/non-profits are disconnected. Cross-disability coalitions are missing. By increasing partnerships, the overall Oklahoma community would benefit. It would be great if the Council could lead these partnership efforts.

**Question 8: What successful programs have you encountered that positively supported inclusivity and best lives for people with developmental disabilities?**

- Down Syndrome Association of Oklahoma – Has a program to help self-advocates develop community skills. (Kylee’s Kitchen)

**Question 9: How can the Council better support and promote social justice and equality for people with developmental disabilities?**

- There needs to be more education about how to better advocate for people with developmental disabilities, especially people in underrepresented populations.

- Partnerships between the different government organizations and non-profits would help increase coordination between the groups and allow them to better serve the community.

**Question 10: What community organizations or entities need additional training to better support people with developmental disabilities and their families? What trainings are currently missing?**

- Law enforcement officers
- Criminal justice officers – Both within the legal system and at prisons/jails
- Educators
- Increased state-wide self-advocacy trainings

## 7/17/2020 – Tulsa and Northeastern Oklahoma

**9 Attendees**

**Question 1: What supports and services have been successful in helping you and your family to live your best lives?**

- TEFRA - Allows Sooner Care benefit to support families who would not otherwise be qualified for SSI benefits.
- Family and Children Services is helpful for people with intellectual disabilities.
- Sooner Ride – Transportation available for those on Sooner Care to get rides to medical appointments.
  - Coverage for the Northeastern part of the state is out of Sallisaw.
- Express Bus Line – Available through Tulsa transit and provides paratransit options.

**Question 2: What concerns or stresses keep you up at night?**

- Some families are struggling to get government services and noted that they feel like they keep hitting a wall.
  - One family noted that they have been struggling with their public school district to keep their child in school until the age of 21. The district is asking for specific ID requirements. The family also noted that they have been on the Waiting List for 13 years.
- The Waiting List
  - Families have found that even once they start getting benefits from the Waiting List, there are some gaps in coverage.
  - It was also noted that there are a lot of gaps in coordination between state agencies.
- Vocational programs tend to be limited and are difficult to get into.
- Lack of transition and young adult supports.
- One person with a developmental disability mentioned that he is concerned about what happens as his natural support system continues to get older. What happens when your family is no longer able to support and help you?

**Question 3: What barriers to equal opportunities have you or your family encountered?**

- Employment
  - It is hard to get government benefits if you are also working, but if you can't do both – you will have trouble paying bills.
  - Changing careers or jobs is exceedingly difficult for people with intellectual or developmental disabilities.
- It takes too much time to get tested and results for early intervention.
  - One family noted that it took upwards of 6 months to get a referral and test for speech services.
- Gaps in services
  - Particularly in the more rural areas.
  - The number of speech therapists is really limited is really limited.

  - Gaps in services for people with autism.
  - Gaps for behavioral services – There are only two ADA certified behavioral specialists in the state.
  - Dentists and optometrists – It is hard to find specialty doctors who are trained and understand how to work with people with autism, sensory issues or other developmental disabilities.
- Some doctors will not work with people who have more than one disability or people who have both an intellectual and developmental disability.

**Question 4: How can the Council help improve supports and advocacy for people with developmental disabilities in Tulsa and Northeastern Oklahoma?**

- Virtual advocacy training would be helpful for families to better support their family members with developmental disabilities.
  - Virtual advocacy trainings would be helpful for families who live outside of the Oklahoma City and Tulsa areas.
- A public awareness campaign for equality.
- Training for employers throughout the state about ADA requirements and how to support employees with developmental disabilities.
  - Individual placement support would help both employees and employers work together more successfully.
- Life skills training, like cooking, cleaning, financial management, etc.
  - Some personal care services are offered by Aging Services.
- Transition supports and information – There is limited support for high school kids (ages 14-21).
  - Most people going through the transition period (and their families) do not have the resources to make educated decisions about what to do post-high school.
  - Some can't even get help to connect with a sheltered workshop.
  - Peer support for teens would be extremely helpful as they work through the transition period.

**Question 5: How would you define meaningful inclusion? How can the Council better support a more inclusive community in Tulsa and Northeastern Oklahoma?**

- Inclusion will take a continued effort.
- Inclusion should start in schools.
  - However, schools tend to "segregate" students with developmental disabilities.

**Question 6: What community organizations or entities need additional training to better support people with developmental disabilities and their families? What trainings are currently missing in your community?**

- Community wide – There needs to be a massive effort to increase awareness and understanding of developmental disabilities.
- Schools – Anyone who works with students, including administrators and teachers.

  - The Tulsa public education system has special education training, but there are concerns that it may not be up to date.

- Law enforcement – Need additional training to recognize when someone has an intellectual or developmental disability and training for how to better interact with those people.
- Specialty doctors – Need training about how to work with people with intellectual or developmental disabilities.
  - Dentists
  - Optometrists
  - Behavioral specialists
- Legal system – An attendee suggested that the Disability Law Center may be a good organization to sponsor awareness trainings within the State's legal system.
- For people with certification that requires continuing education units – Would establishing courses related to working with people with developmental disabilities be feasible?
  - This may be an option for medical professionals, lawyers, teachers, law enforcement, etc.

## 7/17/2020 – Lawton and Southwestern Oklahoma

**9 Attendees**

**Question 1: What supports and services have been successful in helping you and your family to live your best lives?**

- Sooner Care and the Health Care Authority are able to support limited health care while families wait for services and are on the Waiting List.
- Disability-specific non-profits and foundations are helpful, especially for creating a good family support system.
- Oklahoma Family Network
- Regional family support groups

**Question 2: What concerns or stresses keep you up at night?**

- What happens when I die?
- Transition from high school
  - There are limited resources within Oklahoma about preparing for a child's transition out of school. Many families do not have adequate information to determine the best option for their child after high school.
  - Transition of doctors – Moving from a pediatrician to an adult doctor. They must also work with Medicare and insurance to transition medical coverage and supports.
- Intermediate Care Facilities – Is putting my family member into an ICF the best option?
  - Some families have found that an ICF will not house someone with behavioral issues.
- How do you support a family member with both intellectual and developmental disabilities?
- The Waiting List
  - There is a lack of support services.
  - One mother noted that her child was on the Waiting List for 12 ½ years before they were able to get an In-Home Support Waiver.
- COVID – I have lost the ability to receive some of my services.
  - Some rural school districts are not doing virtual schooling. What does this mean for children with developmental disabilities or who have health issues that make them at risk?
  - Virtual school options have the potentiality of setting a child behind in school.
  - Technology limitations may leave children without connectivity behind.
  - Virtual learning also limits social interactions that usually help children develop.

**Question 3: What barriers to equal opportunities have you or your family encountered?**

- Rural Oklahoma has issues with access to supports and services.
  - Service providers are limited. Rural areas do not have the resources to support additional medical professionals.
  - It is hard to get appointments for ABA therapy. There are not any outpatient or afterschool appointments available. – This means that kids have to be taken out of school for therapy appointments.

    - There are not any social programs like Among Friends
    - Being from a rural area influences and limits the high school transition process.
    - It's difficult to get early intervention or autism screening.
    - Families find that they must go to Oklahoma City for services. (Lawton does not have all of the supports and services needed.)
    - Limited respite providers.
    - The services available may not fit someone's needs.

- There are different opportunities and barriers related to a person's level of disability. As the amount of support needed increases, the availability of support decreases.

- There is a major shortage of providers of direct support staffing.
    - This means that too often family members and natural support systems are heavily, if not fully, relied upon for care. The reliance on natural supports (coupled with limited respite) can cause major burnout for families.
    - We need to make efforts to expand interest in the field of direct support staffing. We need to do better at recognizing people who have been successful in the field.
    - How can we better educate people about the opportunities available to join the field of direct support staffing? Would a partnership with the Dept. of Education or the colleges throughout the state be an option?
    - The shortage has a number of causes, including funding.

- Transportation
    - This barrier is amplified in rural areas where public transportation is rare.
    - If there are transportation option, you must schedule early.
    - Mileage reimbursement can be a barrier. People may not have the ability to pay for gas upfront.

- There are some limitations related to grandparents raising grandchildren. This situation can make it harder for families to prepare for the future.

- Government red tape and limitations. The lack of coordination between agencies causes issues.

- Limited information in languages other than English. There is a high level of need for Spanish language resources.

**<u>Question 4</u>: How can the Council help improve supports and advocacy for people with developmental disabilities in Lawton and Southwestern Oklahoma?**

- We need to change the perspective of disabilities. Instead of looking at what someone can't do, we should focus on what they CAN do.
    - This is particularly important when workings with employers and employment options.
    - FEAT trainings may be a good way to help families determine what opportunities are available. But, even with FEAT, options for employment may still be limited in the more rural areas.

- How can we advocate for the state to create better benefits (maybe financial) for rural doctors?

**<u>Question 5</u>: How would you define meaningful inclusion? How can the Council better support a more inclusive community in Lawton and Southwestern Oklahoma?**

- A reoccurring struggle that families encounter is the lack of coordination and collaboration among state agencies and doctors. It would be nice to see more interagency collaboration.
- The Council should work more with the Department of Education to support schools.
  - Schools need better inclusion and integration for students with developmental disabilities. Would more training for teachers (who teach at all levels) help encourage inclusion? Could we work with the Dept. of Education to develop courses that will count towards a teacher's continuing education requirements?
  - How do we start changing perceptions early to encourage real inclusion?

**<u>Question 6</u>: What community organizations or entities need additional training to better support people with developmental disabilities and their families? What trainings are currently missing in your community?**

- We need to go back to the basics and have more concerted effort to spread awareness and understanding.
- Schools and teachers need more training to work with families and prepare for the transition process. Increased understanding about early intervention can help teachers start working with families earlier, rather than later. It can also help develop more successful IEPs.
- Information about the resources available for families would be helpful. Information and resources needed for families include the following topics:
  - Introductory information and resources for a family with a newly diagnosed disability.
    - Next steps and informational resources should be made available for doctors to use with families. This could include medical information, as well as long-term planning.
    - It would be helpful for the Council to connect with rural doctors and medical centers.
  - Transition planning
  - Guardianship options
  - STABLE
  - Social Security
  - The Waiting List & DDSD
  - Availability of resources with DRS – Employment options

**<u>Question 7</u>: If you had the opportunity to create any program to better the lives of Oklahomans with developmental disabilities and their families, what would you do?**

- Create tribal liaisons that are able to work directly with tribal nations and navigate cultural norms.
- Establish partnerships with the military installations in the state to better coordinate with them to support military families.

**<u>Question 8</u>: Please share any successes or program models that have positively supported inclusivity and best lives for people with developmental disabilities.**

- In terms of supports available, other states are way ahead of Oklahoma. This is related to funding and legislative support for services and supports.

## 7/20/2020 – Health and Wellness

**17 Attendees**

**Question 1: What health or wellness supports and services have been successful for you, your family, or others with developmental disabilities in Oklahoma?**

- Personal Care Attendant Program – A statewide program through DHS that helps people with their daily activities at home. (However, DHS care workers don't always know about the program.)
- Oklahoma People First
- Among Friends' activity center in Norman
- Tulsa Center for Disabilities (Activity day center)
- Full Circle Activity Center (Norman)
- Welcome Home (South Oklahoma City)

**Question 2: What barriers to health or wellness resources have you or your family encountered?**

- Doctors don't always trust your experiences. Families and people with developmental disabilities can find it difficult to advocate for themselves.
- Dealing with Medicare and Medicaid can be a nightmare.
    - This can be exasperated when you are dealing with mental health issues.
- Mental health – It can be hard to get help for a disability that can't be "seen."
- Therapists are not always trained to work with people with different disabilities. Additionally, sometimes a longer appointment is needed for people with multiple disabilities, and therapists are not always open to having longer appointments.
- It is hard to find a doctor that will do a sexual health examination for someone with an intellectual or developmental disability.
- Doctors and nurses aren't always trained to work with people with intellectual or developmental disabilities.
- For people who have speech impairments – Doctors may need additional help to communicate.
- Transportation limitations
- Health insurance can have a "marriage penalty."
- Health literacy – Doctors will prescribe medications, but don't always explain what they are for. This issue is made worse when doctors don't communicate with one another and do not know what other prescriptions that their patients are taking.
- There is a lack of knowledge among the greater population about how to meaningfully interact with people with intellectual or developmental disabilities. There needs to be a societal shift of awareness.

**Question 3: What is your greatest concern about health supports or services for people with intellectual or developmental disabilities in Oklahoma?**

- The Waiting List
- There are a number of public health measures being discussed in the Legislature. There is a movement for expanded access to healthcare for the more vulnerable populations.
- COVID-19 has amplified the lack of empathy that people with developmental disabilities are shown.
  - For example – At the beginning of the pandemic, the news would note that "only old, disabled or vulnerable" populations were being at risk of death from COVID-19. This implied that these populations were not as important as other people. It demonstrates a bigger issue of neglect and discrimination towards people with developmental disabilities.
- Efforts to make community supports and events more accessible can be unsuccessful if people with developmental disabilities are not asked for input.
  - For example: Norman built a network of sidewalks to increase accessibility. However, once completed, the sidewalks were not actually fully accessible. The issues of accessibility could have been avoided if people with disabilities had been asked for their input.
  - One person noted – "You don't know what you don't know."

**<u>Question 4</u>: What supports or services for good health across the lifespan are missing in Oklahoma?**

- Healthcare during the transition period:
  - It is not easy to transition from your pediatrician to a new doctor. New doctors often struggle working with people with developmental disabilities.
  - Doctors will sometimes only communicate with a parent or guardian, assuming that the person with a developmental disability can't speak for himself.
    - Basic communication and respect can be forgotten.
- Transportation

**<u>Question 5</u>: What is your greatest wellness concern for people with intellectual or developmental disabilities in Oklahoma?**

- COVID-19 has caused new social limitations.
  - Zoom is not an easy way for everyone to communicate. Trying to teach older people how to use Zoom for virtual meetings and communication is not simple.
  - It has become increasingly difficult to have meaningful connections with other people when all of your communication is virtual.

**<u>Question 6</u>: What supports or programs would you like to see in Oklahoma that support the personal and social wellness of people with developmental disabilities?**

- Adult day centers in the more rural areas of the state would be a great addition to the social wellness of Oklahomans.

**<u>Question 7</u>: What supports are needed in Oklahoma to ensure health and wellness for caregivers and family members?**

- Support groups for caregivers of adults are really helpful but are often difficult to find. Most support groups tend to focus on young families.

**Question 8: What supports or services have been the most beneficial for you and your family during the COVID-19 pandemic?**

- Zoom trainings have been helpful. The opportunity to continue to connect with people has been extremely important and has opened the possibility for future connections throughout the state.

**7/20/2020 – Open Topic Forum**

**15 Attendees**

**Question 1: What supports and services have been successful in helping you and your family to live your best lives?**

- Oklahoma Family Network
- STABLE/ABLE

**Question 2: What concerns or stresses keep you up at night?**

- Transition concerns
  - Guardianship
- Marriage inequality/penalty
- The system is too reliant on natural supports. What are the other direct support options?
- Guardianship
  - Many families don't know the different options that are available other than total guardianship. Total guardianship tends to be the suggestion as families are investigating the options for their family members. Courts tend to default to total guardianship.
  - Partial guardianship should be the default.
  - Total guardianship takes away voting and some personal rights.

**Question 3: What barriers to equal opportunities have you or your family encountered?**

- Limited accessibility in public spaces and at community events.
- Transportation is limited by financial accessibility.
- People with developmental disabilities are getting boxed into jobs. How do we better support people's goals and dreams?

**Question 4: What is your greatest concern about health or wellness supports/services for people with intellectual or developmental disabilities in Oklahoma?**

- COVID-19 has caused a lot of concerns for people with weak immune systems.
  - One good outcome from COVID-19 has been increased access to telemedicine and healthcare services from home.
  - However, what happens when you actually need in-person services?

**Question 5: How can the Council help improve supports and advocacy for people with developmental disabilities?**

- Provide more information and resources to help families better develop long term plans. Families can feel overwhelmed and don't even know what questions to ask or know where to start planning.

**Question 6: How can the Council better support a more inclusive community across Oklahoma?**

- A more inclusive community begins in daycare and childcare.
- There needs to be a statewide change in perception about how we see people with developmental disabilities.
- Rural areas would benefit from an increase in awareness and educational trainings about developmental disabilities.
- We need to get the word out across the state about supports and services available for people with developmental disabilities.
  - Families and guardians of people with developmental disabilities would benefit from more information about resources available.
- To create a more inclusive community across the lifespan, Oklahoma needs to focus on continuing support for people with developmental disabilities post-high school. There is an age gap (21-65) for supports and services.
  - We need more social and employment opportunities for these age groups.
- Many employers will automatically turn down people with developmental disabilities, especially those who need additional physical accommodations.
  - People with speech impairments also face employment limitations.

**Question 7: What community organizations or entities need additional training to better support people with developmental disabilities and their families?**

- Childcare specialists – Both directors and teachers need more training to better support children with developmental disabilities.
  - There seems to be a misperception about how much work it takes to work with children with special needs or developmental disabilities. Some childcare facilities will not accept children with developmental delays or disabilities.
  - Childcare specialists would benefit from training about how to identify children who may have developmental delays and how to work with those children.
  - Currently, there are no specific certifications or trainings required for childcare centers to support children with special needs.
- Community leaders and churches
- Law enforcement and first responders
- Policymakers
- Medical specialists
- Those in the legal system – judges, lawyers
- Educators and school administrators

**Question 8: If you had the opportunity to create any program to better the lives of Oklahomans with developmental disabilities and their families, what would you do?**

- No more Waiting List.

- More direct support professionals and recognition for the job that they do. Right now many direct support specialists are burning out at high rates.

__Question 9__**: How can the Council help Oklahomans with developmental disabilities get closer to their dreams?**

- Meet people where they are. It would be great if people with developmental disabilities were able to express their personal dreams and have the opportunity to work towards those dreams.

## 7/21/2020 – Supporting the Tribal Nations of Oklahoma (Session #2)

**9 Attendees**

**Question 1: What tribal supports and services are available to people with developmental disabilities and their families?**

- Hope Program – Helps low-income tribal members who are displaced from their jobs during crisis.

**Question 2: What state or federal supports or services are available to people with developmental disabilities and their families in your tribe?**

- TEFRA – Helps families with children get Medicaid funding, even if they are not eligible for Social Security benefits. The child must have a significant disability.
  - The question was raised – Does TEFRA work with tribal healthcare programs? What services are/not covered by TEFRA?
- The Department of Mental Health has IPS (Individual Placement and Support) team trainings to talk about how to work with tribal vocational rehabilitation programs.

**Question 3: What supports or services for people with developmental disabilities are missing?**

- Waiting List information
  - Many tribal members do not even know about the Waiting List.
  - Currently, there is no way to cross-reference the Waiting List with tribal community lists.
- Tribal communities may be concerned about DHS imposing on tribal resources and my not want to work with DHS or the State.
- Transition resources
- Employment planning and training programs don't start until someone is 16. For people with a developmental disability, it would be beneficial to start preparing for post-high school at an earlier age. There needs to be an increase in support across the lifespan. Jobs and community interaction allow people with developmental disabilities to live full lives.
- For military families, it is challenging to get adequate medical coverage and continuity of care.

**Question 4: What barriers to equal opportunities have you or your family encountered due to a developmental disability?**

- The Native American community is underserved and growing.
- The Native American community has seen an increase in the number of grandparents who are raising grandchildren. These incidents overlap with tribal members with developmental disabilities and their families.
- Matching families with the correct amount of support and technology is vital to overcoming barriers.
- Transportation can be difficult to find, which also limits employment opportunities.
  - It was noted that the Oklahoma Department of Transportation is also currently doing public input sessions that specifically target people with disabilities and people over 65 throughout more rural regions across the state. (oktransitplan.org)

- Technology gap – Especially for families who only have one unit/computer to support the virtual needs of the entire family.

**Question 5: How can the Council help improve supports and advocacy for people with developmental disabilities in tribal communities?**

- In order to successfully support tribal communities, the Council needs to work with cultural brokers. Collaboration with tribal leadership will be a key aspect of any successful efforts to best support tribal communities and members with developmental disabilities.
    - Instead of imposing ideas, we need to ask what we can do for them.
    - There is a long history of negative interactions with the state, including a history of sterilization of Native American women without consent.

**Question 6: What community organization or entities need additional training to support people with developmental disabilities?**

- There needs to be more collaboration across agencies and tribal entities.

**Question 7: Please share any successes or program models that have positively supported inclusivity and best lives for people with developmental disabilities.**

- In Arizona – The Navajo tribe has created a pilot program in which teachers continue to work with the same students through their entire educational career. This allows teachers to support their students as they grow and develop. This also allows students and parents to have a solid support group throughout their education. The teachers also feel more responsible for the education of those kids. This program design helps to create a strong support system that includes family members, teachers, case workers and the community at large.

**7/28/2020 – Open Topic Forum**
**15 Attendees**

**Question 1: What supports and services have been successful in helping you and your family to live your best lives?**

- Among Friends – Norman adult activities center
- Family and Children Services – Tulsa mental health support center
- Zoom has helped during COVID-19 to stay connected.
- Wings – Edmond day center

**Question 2: What supports or services for people with developmental disabilities are missing?**

- Direct support specialists – Major shortage
  - It was suggested that by solving the staffing problem, we would also be able to solve other issues that affect people with developmental disabilities, like transportation.
  - There need to be creative solutions to solve this shortage.
    - For example: How can we use events like Tim Tebow's Foundation supports the Night to Shine to bring a light to the staffing shortage? There is a lot of support for the event, but what happens the next day to continue to support the community?
  - In addition to the shortage of direct support staff, there is also an issue with finding good staff.
    - Subpar staff members were described as lazy and unempathetic by one person with a developmental disability. He explained that a big part of being a good support specialist includes seeing you as a person and treating you with basic respect.
    - People with developmental disabilities should be respected by their support specialists and should be able to tell the staff what they need and want.
    - There is a lack of adequate training. It was noted that trainings have been put online, and staff are not able to get hands on training.
    - Also, different people need different levels of support. What is considered to be "good help" is different for each person.
    - Even once you get good staff, it is hard to keep them because the pay isn't great.
  - With a shortage of good direct support specialists, family members often end up being the staff and support. Then, what happens if these natural supports are not enough?
- Since the beginning of COVID-19, service providers have struggled with how to share support or medical services.

**Question 3: What barriers to equal opportunities have you or your family encountered?**

- Exacerbated by COVID-19, there is a disparity in technology.
  - For people who are physically isolated at home, internet access and connectivity have become vital to the emotional and mental health of a person.
  - Populations that have been hardest hit by the disparity include lower-income and rural groups.
  - One way that the Council has already helped is by doing Zoom and technology trainings. Additional trainings or assistive technology would be helpful to narrow the disparity.

- Virtual learning has proven to be a barrier for children with developmental disabilities.
  - Virtual schooling means that children are missing out on important social connections, and children with developmental disabilities are missing out on their developmental services and supports.
  - The question that a number of parents are concerned about is: How is my child going to get the services that they get at school if they are only going virtually?

**Question 4: What is your greatest concern about health or wellness supports/services for people with intellectual or developmental disabilities in Oklahoma?**

- The government's COVID-19 response did not take people with intellectual or developmental disabilities into account, and there have been gaps in support since the beginning of the pandemic.
- There is a health literacy issue throughout the state, particularly in the more rural areas. The lack of health education has been made even more evident with COVID-19 and the mix of confusing messages.
  - For example – Do I need to wear a mask?
  - With COVID-19, vulnerable populations are afraid to leave their homes because other people are not making good decisions.
  - It's hard to teach "social distancing" to huggers.
- There is a lack of healthcare providers in rural areas.
- For people living alone – What if something happens to me? Isolation is a scary reality that COVID-19 has brought to the forefront.

**Question 5: How can the Council help improve supports and advocacy for people with developmental disabilities?**

- As the COVID-19 pandemic and social distancing continues, it is important that people with developmental disabilities continue to keep connected and involved. Specifically, the Campfire Chat that was started by Jen Randle was noted as a good way for people to stay connected.
  - The discussion noted that these connections, even via Zoom, are particularly important for people who live alone.
- The Council should continue its Zoom trainings for children and others with developmental disabilities. It would be particularly beneficial if the Council could extend these trainings to the more rural locations throughout the state.
  - Technology trainings are important for both schooling purposes and for continued social interactions.

## 7/29/2020 – Great Lives Across the Lifespan

**16 Attendees**

**Question 1: Fill in the blank: To me, a great life means ___.**

- That I can love and be loved. That I am able to have friends.
- All of my basic needs are being met, and I am able to reach as far as possible to meet my dreams.
- That everyone sees people with intellectual and developmental disabilities like everyone else and there are no barriers to living my best life.

**Question 2: What is preventing you from living your best life?**

- The playing field is not level. People do not know hot to accommodate people with developmental disabilities and don't know how to meet us on the same level.
- A lack of resources.
- A lack of inclusion.
    - It is hard to get an equal level of independence.
    - It is hard to find "pockets of inclusion."
- COVID-19
    - Some support programs and services have been cancelled.
    - Virtual is not the same.
    - All the work that you have done to get closer to meeting your goals and growing is going backwards.
- Access to services is limited by the Waiting List. Waiting on services is like putting your future on hold.
- You age out of school services at 21 and lose a lot of your supports.
- Community-wide awareness about developmental disabilities.
    - Bullying begins in schools.

**Question 3: What supports or services would help you get closer to living your greatest life?**

- Special Olympics and sport groups are good for social interactions.
- More personal care and aid.
- More community and local services, especially for those who are on the Waiting List.
    - Without DDSD support or collaboration between organizations, it gets put on the family to find resources. Often families don't know where to find information and resources.
- It would be nice to know what resources are available as early as possible so that families can better prioritize and plan for their specific needs.
- Mental health supports and social connections – Particularly now, with COVID-19.

**Question 4: What barriers to creating a person-centered plan have you or your family encountered?**

- The Waiting List
    - Being on the Waiting List is like putting your life on hold. It is hard to plan when you don’t have access to resources or services.
    - Even once you get off the Waiting List and can start arranging services, it takes months to get the right services set up. A lack of coordination between state entities makes getting services more disjointed.
- School services
    - Special education resources in services and schools are good.
    - There is a lack of coordination and collaboration among schools and other agencies.
        - A Sooner SUCCESS resource manager specifically noted that it is hard for her to partner with schools just to provide resources and information for families.
    - It would be nice if DDSD would partner more closely with schools to better prepare students and families for the transition process. Starting to plan earlier would also be helpful.
        - Professionals don’t tend to take the time to really understand an individual.
        - It would benefit the planning process if DDSD workers were involved in developing and IEP and person-centered planning.
        - Why doesn’t DDSD work with parents through the whole IEP process or partner with schools? Especially since DDSD policy prohibits overlapping services between DDSD and a person’s IEP? How do we bridge the gap? Collaboration would help.
        - DDSD is underfunded and understaffed.
- There are few supports or resources for adults (over 21) with developmental disabilities.
- Society does not see a person with an intellectual or developmental disability equally as a person.
- People with developmental disabilities are being told “no” too many times. They lose hope for equal and good lives.
- Service gaps
    - If you have an IQ below 70, you can find services, but there are others who do have an IQ above 70 who cannot find services. They run into roadblocks and can turn to substance abuse or getting in trouble with the law.
- Natural supports are took heavily relied upon.
- State services don’t account for flexibility of needs.

**<u>Question 5</u>: How can the Council help Oklahomans with developmental disabilities get closer to achieving their dreams?**

- Partner more with other organizations to train them on person-centered thinking and person-centered planning. A partnership with the Department of Education would be great so that person-centered planning can start at an early age, during IEP meetings.

**<u>Question 6</u>: What supports and services would help Oklahoman families to live their best lives?**

- More person-centered planning.
    - IEPs – Professionals come to the meeting with recommendations but fail to see the parents as the experts on their own child. Parents are met with “no.”

- Training for families about how to better advocate for their children and other family members would help them to become a bigger part of the person-centered planning team.

**Question 7: What supports are missing for families of Oklahomans with developmental disabilities?**

- Resources drop off with adulthood (ages 21-65).
- There is a lack of supports for people who have more than one disability, especially if a person has both a developmental and intellectual disability. The combination makes it hard to get supports.
  - Doctors and medical specialists don't know how to, or don't want to, deal with someone with both a developmental and intellectual disability.
  - There needs to be more providers.
- Access to transportation.
- Respite services – It is hard to find services even if you have a Waiting List waiver.
- In-home care is limited. Resources for caregivers are limited.
  - Is it possible to build a better support system for background checks and more training?
  - DHS regulations for childcare facilities don't take special needs into account. It is hard to find childcare options that really support children with developmental disabilities.
  - Childcare options for older children are missing.

**Question 8: What organizations need additional training in person-centered planning to better support people with developmental disabilities?**

- Church groups and leaders
- Teachers and school administrators

**Question 9: Please share and successes or program models that have positively supported best lives for people with developmental disabilities.**

- Deer Creek Public Schools have "service learners" – Students without disabilities are able to use an elective period to work with other students who do have an intellectual or developmental disability. This is a model of inclusion that begins in high schools. It bridges social gaps and leads to better emotional intelligence for all students involved.

**7/30/2020 – Education**

**14 Attendees**

**Question 1: What educational supports and services have been successful for students with developmental disabilities in Oklahoma?**

- Among Friends is a great option for young adults right after high school to stay connected.
- Oklahoma Parents Center helps with special education and IEP questions.
- Sooner SUCCESS
- Oklahoma Family Network is good for cross-disability resources.
- Oklahoma Autism Center – MESA Project provides consultation and professional development to educators and professionals who work with students on the spectrum. This program partners with Oklahoma's Department of Education.

**Question 2: Pre-COVID: What educational supports or services for students with developmental disabilities were missing?**

- Supports for people with severe or more than one disability. Community supports and inclusion are not available.
- Young people lose services after high school. This too often means that families go from a two-income household to a one-income because someone has to stay home with their family member.
- Specialists can "intimidate" parents who aren't trained in advocacy, and therefore, a child's IEP and special education plan depends on teachers and professionals who may not know the individual child well.
  - There can be big communication gaps between the school and families. There isn't always much explanation of resources to family members.
- Resources vary by district.
  - There is a big discrepancy of resources. Plus, families may get different information about resources from district to district.

**Question 3: Post-COVID: What are your greatest concerns about educational supports or services for students with developmental disabilities in Oklahoma?**

- Parents are having to weigh the pros and cons of sending their children back to in-person school.
- What is the best option for my child and my family?
  - If we have to continue to do virtual schooling, does that mean that one of a child's parents then has to figure out how to work from home, or even leave their job?
- Distance or virtual learning
  - Learning plans are vague and ever-evolving.
  - Virtual learning helps keep children with immune deficiencies healthy.
  - Virtual learning isn't the best form of learning for many children.
  - How do students get the services that they previous got through the school?
  - Will a lack of socialization set your child back further?

- Virtual learning also poses a technology issue. Some families, like those in the more rural areas of the state or from a lower income bracket, may not have internet or the technology necessary to do virtual learning.
  - Even if a family has access, do they have enough access to support all of their children to do virtual schooling?
- For children who go back to in-person school:
  - Parents wonder how to talk with their children about masks and social distancing.
- Not all school districts are offering virtual or hybrid school options.

**Question 4: What educational supports or services are needed for students with developmental disabilities due to COVID-19?**

- Resources about how to explain the social distancing and masks to kids would be helpful.

**Question 5: How can the Council better support more inclusive social and educational opportunities for students?**

- Particularly for students who are attending virtual or hybrid schooling options, technology training would be beneficial. In addition to providing training for the children, it would be helpful to also have training and resources available for their family members who will be helping those kids with their schoolwork.
- Collaboration is key to a more inclusive educational experience. Everyone needs to work together with the common goal of inclusion. This will take an individualized approach.

**Question 6: How can the Council help improve educational supports and advocacy for students with developmental disabilities?**

- Parents are having to advocate at all levels to make sure that their children are being protected and can have the best education possible in these circumstances.
- Increased collaboration and coordination of advocacy throughout all levels of the community would be helpful for families. Families feel like they have no control or say in education decisions for their children.
- It was noted that there continues to be a gap between inclusion and integration. Inclusion is a longer process and is something that should begin at an early age.

**Question 7: What specific trainings do school administrators or teachers need to better support students with developmental disabilities?**

- For teachers who need continuing education trainings, would it be possible to add training about working with children with developmental disabilities and their families. This training would be helpful for all teachers and administrators, not just special education teachers. Expanding the training to other teachers will allow schools to better support a more inclusive community.

**<u>Question 8:</u> What person-centered planning guidance did you receive? What guidance would have been helpful?**

- There is very limited guidance for person-centered planning.
- People would like to see the concept of person-centered planning shared more.
- Increased communications of available resources - It would be nice if transition teams started person-centered planning early. That would also help families to get on the Waiting List earlier.
- Right now, person-centered planning is not the main process used by doctors or schools.
  - Professionals are not always taking the time necessary to get to know the personal needs of a person with a developmental disability.
  - Instead, professionals get a short, one-page profile that is just a snapshot into a person.
  - These short snapshots are being used as the impetus for a student's IEP.
- Person-centered planning would take a collaborative effort from parents, teachers, administrators, and local professionals. It will also take a cultural change – children with developmental disabilities need to be seen as an actual person, not just someone with a disability. People should not be defined only by their disabilities.
- Personal connections are key to success.

**<u>Question 9</u>: What transition guidance did you receive? What transition guidance would have been helpful?**

- There is very little preparation about life after high school for students and families. Any guidance that they do get comes late in a student's education and leaves limited time for planning.

## 7/31/2020 – Technology and Assistive Technology

**18 Attendees**

**Question 1: When you hear the term "assistive technology," what comes to mind?**

- Assistive technology is anything that makes life easier for people.
- Assistive technology helps people with developmental disabilities to work. It allows them to have supported and meaningful employment.
- The disparity in access to technology and assistive technology has come to the forefront during the COVID-19 pandemic.
    - The disparity is present in both rural areas and metro areas, due to limited connectivity, economic disparity and level of ability to use the available technology.

**Question 2: If you currently use assistive technology, how did you hear about it/access it?**

- Home design is really important for people with developmental disabilities, particularly for those with physical restrictions and those who use a wheelchair.

**Question 3: What technology or assistive technology has been successful in helping you and your family to live your best lives?**

- Headsets are helpful to allow people to work, volunteer or spend recreational time reading.
    - During the COVID-19 pandemic, headsets are being used for remote working.
- ABLE Tech
- There are phone apps that people with a speech impairment to communicate better with people around them.
- Liftware – Eating utensils for people with mobility issues.

**Question 4: What technology or assistive technology supports or services are not accessible in Oklahoma?**

- There is limited access to assistive technology for independent living.
- Sidewalks and public transportation
    - There is a lack of accessible vehicles available.
    - Uber and Lift do not offer many accessible vehicles in Oklahoma.
    - Vehicles for people with hearing or seeing impairments.

**Question 5: What technology or assistive technology supports or services would help you and your family to live your best lives?**

- With an increase in remote work (due to COVID-19), virtual trainings would help people with developmental disabilities better continue to do their jobs while at home.
- Technology allows people to continue skill-building while at home.

- More affordable mobility options, including more mobile chairs.
  - Power chairs need more accessible options and creative solutions that are designed specifically for the person using the chair.
- More accessible housing and buildings

**Question 6: What barriers to obtaining adequate technology or assistive technology have you or your family encountered?**

- Cost
  - Is there a way that we can work with companies to decrease the costs of assistive technology?
  - Are there possibilities for cross-market features that would make technology and devices beneficial for the wider population?
- Awareness – Just being aware of the assistive technology that exists would allow professionals and employers to find technological solutions so that people with developmental disabilities are able to work.
  - Sometimes, employers don't want to hire a person with a developmental disability because they think that the technology required to support that person will cost too much money. But, not all assistive technology is expensive, and employers should be made more aware of possible solutions.
- For families who choose to have their children do virtual schooling during COVID-19, they may lose some of their assistive technology and services that are only available to students who go to school in-person.
- Getting assistive technology through public entities or nonprofits is usually a long process and takes a lot of paperwork.
- There needs to be more plain language technology trainings that include visuals/pictures.

**Question 7: What technology or assistive technology do you need now because of COVID-19?**

- Zoom is not fully accessible, especially for people with speech impairments. The virtual format also does not work well for people with hearing impairments. Many apps do not have captions.
- It would be helpful if the Council would do more trainings about Zoom and other technologies.
- Technology trainings for caregivers would also be useful because they don't always know how to use technology or apps either.
- Some schools are providing Chromebooks or technology for students to do virtual schooling. Are students with developmental disabilities able to use these? What trainings or assistance is required to make these items effective assistive technology devices?
- Virtual doctor visits – Are people with developmental disabilities able to use technology to do virtual medical appointments? There are limits to how much can be accomplished on a virtual appointment.
- Masks – Many people with developmental disabilities are having trouble making the adjustment to wearing masks in public. There are a few reasons for this:
  - Masks can make it harder for people to breathe or get oxygen.

- There is debate whether face shields are as effective as masks.
- People with hearing or speech impairments struggle with masks because they are not able to read lips.
- Masks fog up with glasses.
- Some people just don't understand the need for it, and therefore, it is hard to get them to keep a mask on.

**Question 8: Please share any successful programs that have positively supported increased technology or assistive technology for people with developmental disabilities.**

- ➢ The Department of Rehabilitation Services offers access to some forms of assistive technology, but it is not always easy to get the technology. Any assistive technology (ex: laptops) that someone got through DRS can only be used for work purposes.

## 8/3/2020 – Advocacy and Self-Advocacy

**12 Attendees**

**Question 1: Have you been involved with any advocacy or self-advocacy organizations? If so, which ones? If not, why not?**

- The Council for Exceptional Children – Professional organization dedicated to improving the educational experience for children with developmental disabilities.
- Oklahoma Transition Council
- Oklahoma Special Education Legislative Summit
- Self-Advocates Becoming Empowered (SABE) – The national organization for self-advocates.
- Disability-specific advocacy and self-advocacy organizations
- Oklahoma People First has stepped up since the beginning of COVID-19. OPF embraced Zoom and started fireside chats to keep self-advocates engaged. They have also continued to use Zoom for local chapter meetings. OK-APSE will also be virtual this year.
- TARC (Tulsa)
- Oklahoma Institute for Child Advocacy
- Oklahoma Self-Advocacy Network (OKSAN) – SALT trainings and health trainings
  - Peer to peer trainings
- Oklahoma Rehabilitation Council

**Question 2: What trainings or resources have helped you and your family to become better advocates or self-advocates?**

- Partners in Policymaking does a great job of pulling together all of the tools, skills and information you need to be a successful advocate.
  - PIP is a comprehensive, beneficial training.
  - Allows for helpful networking.
  - Provides education for people about topics that they may not have known much about prior to the PIP courses.
- Since the beginning of COVID-19, technology has helped to connect people and train specialists.
- Social media groups, support groups, and disability-specific groups allow for an exchange of information outside of local groups.

**Question 3: What additional trainings would help you and your family to become better advocates or self-advocates?**

- Trainings led by self-advocates to advocates, family members and professionals are particularly important aspects of becoming a better advocate. It allows advocates to continue to learn and develop their advocacy skills.
- Training about how to advocate for yourself or your family members to support your interests (For example: how to advocate to doctors and other professionals).

- Training about how to advocate without becoming defensive. And, about how to advocate to different types of groups.

**<u>Question 4</u>: What supports or resources would help you become a better advocate or self-advocate?**

- Attendees noted that they would benefit from additional training about how to connect with state legislators and other local city/county officials.

**<u>Question 5</u>: What can the Council do to increase the number of people with developmental disabilities involved in self-advocacy?**

- The Council can increase the number of people involved by connecting and collaborating with other disability organizations and groups.

**<u>Question 6</u>: What should Oklahoman advocates or self-advocates focus on over the next 5 years?**

- Self-advocates would like to focus on trainings about how to improve self-esteem and self-worth.
- Advocates would like to re-introduce bills to the Legislature that were not passed this past year, due to COVID-19.
- Awareness – How do we work together to better advocate for the needs of people with developmental disabilities in the wider community?
- Guardianship reform – The default setting for guardianship should be partial, not full guardianship.
- Eliminate the Social Security disincentives for marriage or work.
- Raise or eliminate the resource limits.
- More access to caregiver services, regardless of income.
- Better special education supports throughout the state.

**<u>Question 7:</u> How can the Council help improve supports and advocacy for people with developmental disabilities?**

- Reach out more to rural, unserved and underserved communities throughout the state.
- Continue to work with DDSD to get more money for the Waiting List.
- Start advocacy and self-advocacy training in schools. Self-advocacy training in schools could include self-esteem and anti-bullying self-advocacy.

**8/3/2020 – Safety and Prevention of Abuse, Neglect & Exploitation**

**10 Attendees**

**Question 1: What are your greatest concerns about safety for yourself or other people with developmental disabilities?**

- Being alone at home.
- Safety in schools – bullying.
- Safe public transportation.
- Safety for people with developmental disabilities that walk a lot or have to walk home late at night.
- Public places that claim to be accessible but aren't actually accessible. (Ex: Norman's sidewalks)

**Question 2: What safety resources or supports are currently available for people with developmental disabilities in Oklahoma?**

- Thinkability (Duncan) – Residential services and independent living skills development for people with disabilities that allow them to be somewhat independent.
- Independent Opportunities, Inc. (Broken Arrow)
- Oklahoma Self-Advocacy Network (OKSAN)
- Aging Services has safety resources that support accessibility in housing, including home repairs and home assessments. They also support respite and caregiver services.

**Question 3: What safety resources or supports are missing for people with developmental disabilities in Oklahoma?**

- Attendees would like to see stronger requirements for law enforcement training.
- All first responders should be trained to recognize and successfully communicate with people with intellectual or developmental disabilities.
- Accessible public places and transportation.

**Question 4: What are your greatest concerns about abuse, neglect or exploitation for yourself or other people with developmental disabilities?**

- What happens when a caregiver can no longer care for you?
  - There are a number of concerning long-term care issues and concerns.
- Families are concerned about putting their family members in an intermediate care facility because they do not have control over their care. Families are nervous that abuse and exploitation may be a larger issue in an ICF.
- Mental health – How do you reinforce and teach good behaviors?
- There is a fine line between advocating for someone when you think that they are being taken advantage of and allowing them to make their own decisions, especially if they are living alone.

- Peer pressure and bullying, especially for more susceptible kids. Online bullying is becoming a bigger issue.

**Question 5: What supports or resources are available to help prevent abuse, neglect or exploitation for people with developmental disabilities in Oklahoma?**

- Crisis Intervention trained officers (CIP) trains police officers to handle cases where there are mental health concerns. They are trained to deescalate tense situations.
  - The DDCO did make a binder of flip cards to help with these trainings.
- Sibshops train and connect family members with resources to better support their families.
- Respite (Although limited availability.)
- OKSAN's sexuality training and resources. The conversation about abuse, neglect or exploitation was not happening with self-advocates before these trainings.

**Question 6: What supports or resources to help prevent abuse, neglect or exploitation are missing in Oklahoma?**

- There are not a lot of resources for adult siblings who become caretakers.
  - Guardianship information is limited and often unclear.
- Safety and abuse prevention trainings for family members.

**Question 7: How can the Council help improve supports and advocacy for the prevention of abuse, neglect or exploitation of people with developmental disabilities?**

- There needs to be more trainings for families and professionals to start the conversation. Abuse, neglect and exploitation are uncomfortable topics (especially when it is related to a sexual nature), but the conversation needs to happen.

**Question 8: If the Council were to create trainings for parents or self-advocates related to these issues, what specific topics should be included?**

- Cyber security – How to be safe online. For families – How to safely setup devices.
- For online bullying – Parents need to be prepared and educated about cyber and text security and how to best monitor their children's safety.
  - Is this a topic that OKSAN can include in one of their trainings for self-advocates?

**Question 9: What community organizations need additional training to better support people with developmental disabilities who have experienced abuse, neglect or exploitation?**

- Direct service providers need to have specific trainings about the topics of abuse, neglect and exploitation.
  - The topic of neglect needs to be specifically discussed when it comes to elderly care and assistive living situations.

**<u>Question 10</u>: Do you know of any programs that are successfully addressing the issues of abuse, neglect or exploitation?**

- The Canadian County Sheriff's Office holds parent forums about children, technology and internet vulnerability. They share information with parents about how to be responsible and protect their family members online.

**<u>Question 11</u>: If you had the opportunity to create any program to better support the safety of Oklahomans with developmental disabilities, what would you do?**

- It would be great to create a series of special-topic training "sessions" for families and professionals to directly address these hard topics.

## 8/4/2020 – McAlester and Southeastern Oklahoma

**12 Attendees**

**Question 1: What supports and services have been successful in helping you and your family to live your best lives?**

- School services have been good at providing resources, including occupational and physical therapy.
- Systems of Care – Counseling and mental health care.
- Pervasive Parenting Center
  - Resource center for people with developmental disabilities and their families.
    - Only covers four counties.
    - Resources and services: IEP advocacy – Works with local schools
      - IEP and parent rights training
      - Job skills and transition resources and training
      - Peer mentoring in schools to defend against bullying.
  - Early Access partners with the Center.
- Oklahoma Community Action Centers

**Question 2: What supports or services for people with developmental disabilities are missing?**

- There are not a lot of options for ABA therapy.
- Even if you qualify for physical therapy supports, there is only one contractor therapist in the area.
- Transportation is limited.
- There are not a lot of group homes or individual living homes.
- There is a lack of childcare and adult day options.
- There is limited housing for adults with developmental disabilities.
  - Limited housing options with adequate accessibility options.
  - It is especially hard for adults who are unemployed or are not received Social Security.
- Services and supports aren't always up to date.

**Question 3: What barriers to equal opportunities have you or your family encountered?**

- There is a lack of resources and services. It is a long drive to get to any medical specialists.
- There are very few childcare options, and even fewer options for centers that will take children with developmental disabilities.
  - Families have to become a one-income family so that someone can stay home.
- Technology gap and limited connectivity – Has only been exasperated with COVID-19.
- Services and supports are missing or inadequate for people aged 21-65.
- Lack of adult day services and recreational opportunities.
- Lack of employment opportunities.
- There is trouble in finding respite services.

- It is hard to connect with the developmental disability community due to distance, and Zoom is not really “disability friendly.”

**Question 4: How can the Council better support a more inclusive community in southeastern Oklahoma?**

- There is no Oklahoma People First in far southeastern Oklahoma. (The chapter in Ada is not currently active.)
- Self-advocacy and peer-to-peer supports could go a long way in the area.

## 8/5/2020 – Employment
**18 Attendees**

**Question 1: In your opinion – why aren't more people with developmental disabilities working?**

- People are not exposed to the dream or reality of being able to get a job and work.
- There are misconceptions from employers about the abilities of a person with a developmental disability.
  - The word "disability" has a negative stigma.
- Families don't think the person can work, or don't want them to work.
- People get boxed into certain job categories and don't have the opportunity to do meaningful work.
- People don't want to work fulltime because they risk losing Social Security or state benefits.

**Question 2: What supports and services are available to help people with developmental disabilities prepare for, and find, meaningful employment?**

- DRS has the ability to work with people with developmental disabilities get supported employment with a job coach.
  - The amount of job coaches available are limited.
  - If someone works with a job coach, they will receive diminishing supports over time.
  - What keeps employers from dropping employees once they no longer have the support of a job coach?
- If a person is unable to get a job or find employment supports, they may be able to become a trained volunteer. While this would be unpaid, it would allow people to find more meaning in their lives and allows them to develop skills as a volunteer. These skills could help someone find meaningful employment in the long run.
- Workshops are available on a limited basis but may become more unreliable because there has been an increase in ADA complaints against some of the workshops in the state.

**Question 3: What transition supports and services are available to help people with developmental disabilities prepare for meaningful employment?**

- There tends to be a lack of long-term planning by families for their children post-high school.
- How can we get schools to include transition planning into a student's IEP earlier, rather than waiting until the end of high school? This would be enhanced by person-centered planning.
- There are very few options for transition from high school into a job placement.
  - Skills development opportunities are also limited.
  - There are some career tech trainings available, but then you still have to go through the application and hiring process to try to get a job.
    - It is still hard to get and keep meaningful employment.
- Project Search – A job training program that is a combination of classroom employability skills instruction, career exploration, and on-the-job training and support for students with developmental disabilities.

- The program is run by the Department of Rehabilitation Services, in association with schools and host businesses.
- The program helps prepare students with developmental disabilities for competitive employment in a variety of host businesses.
- Oklahoma's Project Search program is only available in the Oklahoma City-area and Enid.

**Question 4: What employment supports or services are missing in Oklahoma?**

- Even when working with the Department of Rehabilitation Services, it is hard to get a consistent career counselor or consistent support.

**Question 5: What services or supports would help people with developmental disabilities find and keep meaningful jobs?**

- For people who are interested in self-employment or starting their own business, DRS does have some supports, but it can be a lengthy process.
- For people who are able to work with a DRS counselor, the counselor will help create an individualized plan for employment.

**Question 6: What barriers to equal employment opportunities have you or your family encountered?**

- Employers won't give people with developmental disabilities the chance to work.
- When people are able to get employment, it is often in menial labor jobs. Often, people are taking those jobs out of necessity, rather than choice.
- Internships are often only open to college students.
- People with developmental disabilities have trouble even having the opportunity to develop the important job skills that they need to get meaningful employment.

**Question 7: What is your greatest concern about on-the-job supports or services for people with developmental disabilities in Oklahoma?**

- Employers need more awareness about ADA accommodations. And, the state needs to take more responsibility for spreading awareness and upholding those accommodation requirements.
  - The ADA language about reasonable accommodations is vague, and the vagueness allows employers to say that the accommodations are an undue hardship.

**Question 8: What organizations need additional training to better support meaningful employment opportunities for people with developmental disabilities?**

- Department of Labor
- The Society of HR Managers
- OK-APSE
- Small Business Associations
- Rotary Clubs

- Community service groups

**Question 9: Please share any successful programs that have positively supported people with developmental disabilities prepare for and find meaningful employment.**

- ABLE accounts help people with developmental disabilities plan for and save money for the long term.
- Family Employment Awareness Training (FEAT) can help raise expectations that employment is possible.

## 8/6/2020 – Oklahoma Panhandle and Northwestern Oklahoma

**8 Attendees**

**Question 1: What supports and services have been successful in helping you and your family to live your best lives?**

- Sooner SUCCESS is a resource available in the Enid area, but there are not many resources closer to the panhandle.
- Oklahoma Family Network supports resource centers.
  - The resource centers cover a broad geographical area, but it is hard to justify additional presence and resources when people are so sparsely spaced.
- Individual Placement and Support (IPS) has a Center for Behavioral Health in northwestern Oklahoma with one employment specialist.
- Project Search is available in Enid through a partnership with Integris Hospital.
  - Project Search is only available for seniors in high school in the Enid public school district. Students at other schools are not eligible for the program.
  - There aren't any other transition or job training programs.

**Question 2: What supports or services for people with developmental disabilities are missing in northwestern Oklahoma?**

- Some families go to Kansas to get resources.
  - Going to Guyman is a far drive for some families, and transportation is hard to find, even with Sooner Ride.
- Counseling and mental health services.
- Family and parent support groups are limited.
- For special medical care, families may have to drive hours.
- Connectivity and technology issues – Internet is expensive, and technology is limited.
  - Even with lower quality internet connectivity, telemedicine has been a big help for families in the far reaches of rural Oklahoma during the COVID-19 pandemic. There is concern about how to convince insurance companies to continue to support telehealth options after COVID-19.
- Transition resources and supports are hard to find. There is limited guidance for families with school-aged children.
  - Transition research and planning decisions are often left up to families who have been provided few resources about their options. Schools and doctors do not aid in the process much.
  - When families try to work with DRS, they find that there is a lot of turnover, and DRS employees and job coaches are spread thin because they are covering such a big area.
    - Follow-through tends to be a big issue. Families must be extremely proactive.
  - Life skills are not taught in school.
- SoonerStart is a good early intervention provider, but supports are still limited because case workers have heavy caseloads and cover wide areas of the state.
  - Due to limited SoonerStart employees, there are delays getting referred to physicians or specialists. Once referred, it is then on the parents to call the doctor to setup and intake appointment.

  - The long process means that parents need to be better educated about resources and services available. Parents need to be empowered to advocate for themselves and their family members.

- It is a challenge to find good medical providers.
  - Older, rural doctors tend to be stuck in their ways and may not know what resources are available to families. Head Start and school programs tend to become advocates for families.
  - There is a lot of turnover of doctors in rural areas, making it difficult to have stability in medical care and support.
  - It is hard to find pediatric services. It is particularly difficult to find psychologists for children.
  - There are limited medical specialists and resources in Enid.

- It is hard to transition to adult doctors when children turn 18. There is very little support for the transition from doctors or the medical community. And, it takes a lot of time and research to find the right doctor for you and your family.

- Dental services are not available for children who need sedation.

- There are a limited amount adult service providers and adult group homes.

**Question 3: What barriers to equal opportunities have you or your family encountered?**

- There are limited resources available in the schools for students and their families.
  - There is a lack of special education teachers (or any teachers that have been trained to work with children with developmental disabilities).
  - There is limited long-term planning for children with developmental disabilities.
    - School counselors don't sit down with families and students until the eighth grade to fill out the OLAP and start planning for a student's future trajectory.

- Schooling options are tricky with COVID-19. Each district or school has different options (virtual, in-person, hybrid).

- Childcare options are really limited, especially for families with children who have intellectual or developmental disabilities.

- Social, community recreational events are geared towards younger people rather than adults.

- Recreational options are only available in Enid.
  - There are small groups that do Special Olympics, but it is still rare.

- Transportation – Public transportation options are limited and expensive.
  - Sooner Ride won't always drive siblings or other family members to medical appointments. If people are unable to get a ride from Sooner Ride, they can apply to mileage reimbursement.
  - Sooner Ride is transitioning to allow siblings to be brought to medical appointments, if needed. This helps parents who have struggled finding childcare in the past. Families must still provide car seats.

**Question 4: What is your greatest concern about health or wellness supports/services for people with developmental disabilities in northwestern Oklahoma?**

- It is exceedingly hard to find good doctors in the rural areas. And then, once you find a good doctor, you may not be able to keep them because there is a high rate of turnover of doctors in rural areas.

- Guardianship
  - Information and resources need to be more accessible for families. Early planning would be great, but most families don’t know where or when to start planning.
  - Some planning is available when families do an IEP, but parents usually just take whatever information is given to them. They usually don’t know about life course planning or person-centered planning.

**<u>Question 5</u>: How can the Council help improve supports and advocacy for people with developmental disabilities in northwestern Oklahoma?**

- More information sessions or trainings for parents, families and self-advocates would be great.
  - Resources are usually more difficult to share because families are so spread out in the rural and frontier areas of the state.
  - If internet connectivity gets enhanced, families would benefit from more virtual trainings and resources.
- Both Oklahoma People First and OKSAN are not visible in the region. The Council should help to make more connections between these groups and the families in northwestern Oklahoma and the panhandle. Virtual developments from COVID-19 and Zoom trainings could help to support more connections in the more rural areas of the state.
- How can the Council support families advocate to insurance companies so that they will continue to cover telehealth appointments when COVID-19 is over?
  - Telehealth appointments are being done successfully in other states.
  - Telehealth capabilities help both families and providers.

**<u>Question 6</u>: What organizations need additional training to better support people with developmental disabilities?**

- Teachers, school administrators and district leaders would benefit from continuing education units about early intervention, how to best support students with developmental disabilities throughout their educational career, person-centered planning, and preparing students and families for the transition out of high school.
- Professionals who provide routine community services (like DHS workers or local courts)
- Medical doctors and mental health specialists
- Dentists
- Leaders of places of worship and other community leaders.

**<u>Question 7:</u> Please share any successes or program models that have positively supported inclusivity and best lives for people with developmental disabilities.**

- Virtual family and peer support groups have been really beneficial for families in more rural areas.
- Service-learning programs in schools to create more inclusive environments for students with developmental disabilities. Intentional peer to peer connections help the larger community. It helps to start mindset changes. (The Deer Creek high school program was noted as an example.)

**<u>Question 8</u>: If you had the opportunity to create any program to better the lives of Oklahomans with developmental disabilities and their families, what would you do?**

- There is currently an attempt to start a rural health project that is grant funded. The project's goal is to get more high quality doctors and to provide health education and community health workers in order to support families in those rural areas.

## Council Member Input Session

**Question 1: What do you think that the Council was most successful at over the past five years?**

- The Council has been successful at advancing self-advocacy skills development.
  - The Council has helped to build a strong set of self-advocate leaders. This is particularly related to OKSAN.
- The Council has done a good job at keeping connected with our community partners and have successfully kept engaged with those partners.
- YLF – Skills and social connections have helped to create more community relationships and leaders.
- In partnership with the DD Act partners – The Waiting List Caucus has gotten more support, and additional funding was granted by the Legislature to help shrink the Waiting List.
- START, a Council-sponsored seed project, has helped to bring more collaboration of organizations throughout the state and has led to increased awareness.
- Person-centered thinking and charting the life course trainings began with the Council and has now moved throughout the community in Oklahoma.
  - The Department of Education has started to use person-centered planning in IEPs and conversations about planning for the transition for students when high school ends.
  - There has been more Charting the Life Course ambassador trainings.
  - Person-centered thinking has become a part of the culture in Oklahoma and continues to imbed the ideas across the state.

**Question 2: What would you like to have seen the Council do over the past 5 years that was not done?**

- A detailed orientation and more training for Council members.
  - This could include a DD Act review and NACDD Council member training.
- More outreach to underserved and unserved populations across the state.
  - This would include expanding partnerships and reaching out in more creative ways. Working with partners would also allow the Council to build upon and enhance existing programs without rebuilding the wheel.
  - It was noted that 73% of people with intellectual or developmental disabilities are unknown to the system.
- More transition resources and trainings. There doesn't seem to be standardized information for families across the state.
- More partnership with the Brain Injury Alliance to increase awareness of traumatic brain injuries and outreach programs.
- We would like to see the Council take a more active role and closer look at how contracts are doing.
  - We need to make sure that our contractors are following through on what they said they are going to do.
  - There should be more emphasis on the long-term sustainability of projects. We do not want to see contractors come back with a project that has already been done with a new name.
  - Contractors need to be more accountable.
  - A good example of a sustainable program is Sib Shops. There is continued community support.

**<u>Question 3</u>: What is your greatest concern about health or wellness supports/services for people with intellectual or developmental disabilities in Oklahoma?**

- The limited availability and support of direct support staff.
  - How do we spread awareness of the job opportunity and encourage people to go into the field?
  - We need to find creative solutions to building capacity and training for direct support specialists.
  - This should be a partnership effort with the Redlands Partners.
- There seems to be a big push for more managed care and facility care options. There is a growing number of ICFs across the state.
- The long-term support model is too heavily dependent on natural and family supports.

**<u>Question 4</u>: How can the Council better support or strengthen state-wide advocacy and self-advocacy efforts over the next 5 years?**

- The Council would like to see more focus on healthy living and nutrition.
- We would like to explore ways to keep young self-advocates involved (in addition to YLF). Oklahoma People First is good, but it is mostly an older group of self-advocates.
  - Would like to look into the possibility of a mentor program to get the younger self-advocates involved with OKSAN and OK People First.
  - Student First – How do we encourage chapters in schools? This program could help to start training people with developmental disabilities to be more active and effective self-advocates.
  - Students should be included in their IEP meetings and plans.
  - Get young people, their families, and the schools all actively involved in IPE planning at an early age. This will allow families prepare for the transition after high school.
- The Council should continue to expand the idea of person-centered thinking across the state. These ideas should start when children are in school with person-centered planning.

**<u>Question 5</u>: How can the Council better support a more inclusive community across Oklahoma over the next 5 years?**

- How can we expand awareness and community inclusion across more areas of the state?
  - Church and community leaders need more awareness to encourage acceptance and inclusion.
- Transportation – How can we encourage and train people with developmental disabilities to use public transportation?

**<u>Question 6</u>: What organizations would benefit from additional training to better support people with developmental disabilities?**

- More CLEET trainings
- School safety and resource officers

Developmental Disabilities
Council of Oklahoma

# *2022 – 2026 Five Year State Plan*

## Goal 1: Advocacy and Self-Advocacy Skills Improvement

Individuals with developmental disabilities and their families will be skilled and empowered advocates and leaders in individual and systems change advocacy.

***Objective 1:*** *Annually through 2026, 150 individuals with developmental disabilities will be trained by self-advocate leaders to be resilient, strong and effective self-advocate leaders. (Self-Advocacy Objective)*

***Objective 2:*** *By 2026, Oklahoma's self-advocacy organizations will be strengthened through increased participation of individuals with developmental disabilities in culturally diverse and cross-disability leadership coalitions.*

***Objective 3:*** *Annually through 2026, at least 10 self-advocates and 10 family-advocates will obtain leadership positions of their choice on key boards, councils and committees that take up issues for people with developmental disabilities and their families.*

***Objective 4:*** *Annually through 2026, 50 individuals with developmental disabilities, their families and professionals will be educated about systems change advocacy and the tools to use to effectively educate community leaders and policymakers about issues that impact people with developmental disabilities and their families.*

### EXPECTED OUTCOMES GOAL 1

Oklahoma will have an educated and trained advocacy base that will provide leadership in Oklahoma on issues related to developmental disabilities.

Oklahoma will have an increased number of leaders with developmental disabilities serving on key boards, councils and committees that take up issues related to developmental disabilities.

## Goal 2: Good Lives Across the Lifespan

Individuals with developmental disabilities, their families and caregivers will have increased access to quality, long-term, individualized supports and services across the lifespan in the home and community of their choice.

***Objective 1:*** *By 2026, 250 Oklahomans with developmental disabilities, their families, community leaders and other professionals will be trained and educated on the Person-Centered Thinking and Supporting Families Community of Practice principles.*

***Objective 2:*** *By 2026, 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.*

***Objective 3:*** *By 2026, 150 families and caregivers of children with developmental disabilities will have increased knowledge and understanding of the tools, resources and support systems to begin to prepare for, and develop, person-centered plans as early as a child's diagnosis to allow them to prepare for transitions across the child's lifespan.*

***Objective 4:*** *By 2026, 50 Oklahomans with developmental disabilities will have increased opportunities to develop independent living and life skills that will allow them to lead self-directed and self-determined lives.*

***Objective 5:*** *By 2026, 50 individuals with developmental disabilities, their families and caregivers will have increased knowledge and understanding of the supports and resources to help them plan and prepare for life when their caregiver is no longer able to provide care.*

### EXPECTED OUTCOMES GOAL 2

Oklahomans will regularly use Person-Centered Thinking and Supporting Families Community of Practice principles as they plan for transitions across the lifespan. Individuals with developmental disabilities, their families and their communities will work together to support person-centered planning so that all Oklahomans are able to live their best lives and accomplish their personal goals.

## Goal 3: Community Awareness and Inclusion

People with developmental disabilities and their families will experience increased inclusion and integration so that they may fully participate in all aspects of the community.

***Objective 1:*** *Annually through 2026, the Developmental Disabilities Council will educate Oklahoman communities and community leaders about developmental disabilities so that people with developmental disabilities and their families will experience increased inclusion and support in the community and will be empowered to live their best lives.*

***Objective 2:*** *In collaboration with Oklahoma's DD Network, the Developmental Disabilities Council will provide technical assistance and education to 20 state- and local-level decision makers annually about public policies and procedures that affect people with developmental disabilities and their families. (DD Network Collaboration Objective)*

***Objective 3:*** *By 2026, 150 service professionals in rural and frontier areas of Oklahoma will have increased awareness and training about how to best support people with developmental disabilities and their families. (Targeted Disparity Objective)*

***Objective 4:*** *By 2026, an increased number of children, youth and students with developmental disabilities will receive individualized supports and services in inclusive and integrated settings that will allow them to foster and reach their potential.*

***Objective 5:*** *By 2026, individuals with developmental disabilities will have greater opportunities for meaningful friendships and relationships, recreation activities and social inclusion in their communities.*

***Objective 6:*** *By 2026, employers, community leaders, family members and the wider community will have an increased understanding about the benefits of having individuals with developmental disabilities participate in the workforce and volunteer activities.*

### EXPECTED OUTCOMES GOAL 3

Individuals with developmental disabilities and their families will have a community support system that will help them to live their best lives.

Policymakers will have the information they need to positively impact people with developmental disabilities and their families.

The Developmental Disabilities Council of Oklahoma wants to hear from you. Your

ideas will make a difference as we dream about what our vision is for persons with intellectual and developmental disabilities (I/DD) and their families for the next 5 years. Thank you for helping us by filling out this survey.

**Demographic Questions**

Please check below to tell us who you are. Check all that apply.

- ☐ Person with an I/DD
- ☐ Parent
- ☐ Grandparent
- ☐ Guardian (not biologically related)
- ☐ Child of
- ☐ Sibling
- ☐ Spouse
- ☐ Other family member

Does a family member with I/DD live with you?

- ☐ No
- ☐ Sometimes, but not all the time
- ☐ Yes, or most of the time
- ☐ Prefer not to say

What is the age of the person with I/DD (you or your family member with I/DD)? If you have more than one family member with I/DD, you may check more than one box.

- ☐ Age 0-13 years
- ☐ Age 14-20 years
- ☐ Age 21-25 years
- ☐ Age 26-54 years
- ☐ Age 55 or over
- ☐ Prefer not to say

What is the gender of the person with I/DD (you or your family member with I/DD)? If you have more than one family member with I/DD, you may check more than one box.

- ☐ Female
- ☐ Male
- ☐ Prefer not to say
- ☐ Prefer to self-describe:

What is the race or ethnic background with I/DD (you or your family member with I/DD) ? Check all that apply.

- ☐ White
- ☐ Black or African American
- ☐ American Indian or Alaska Native
- ☐ Hispanic/Latin (o) (a) (x)
- ☐ Asian
- ☐ Native Hawaiian or Pacific Islander
- ☐ Unknown
- ☐ Prefer not to say

How would you describe the community of you or your family member(s) with I/DD? If you have more than one family member with I/DD, you may check more than one box.

- ☐ Urban (medium or large city)
- ☐ Suburban (outside the city)
- ☐ Rural (fewer people and more open spaces than urban or suburban areas)
- ☐ Don't know
- ☐ Prefer not to say

What is your zip code? AND/OR – add a map that is divided up (NE, NW, SE, SW, Tulsa metro, OKC metro)

**Services & Supports**

1) What do you think are the three (3) most important issues for people with I/DD in Oklahoma right now? Check up to 3.

- ☐ School
- ☐ Employment
- ☐ Housing
- ☐ Transportation
- ☐ Money and finances
- ☐ Planning for the future
- ☐ Knowing their rights
- ☐ Self-Advocacy
- ☐ Knowing what services and supports are available
- ☐ Getting the services and supports they need
- ☐ Getting good medical care
- ☐ Technology to help them do the activities they want
- ☐ Living more independently
- ☐ Helping people with disabilities move out of institutions
- ☐ Doing more activities they like

☐ Having friends and meaningful relationships
☐ Being more a part of the community
☐ Other (please describe):

2) What type of services and supports do you or your family member with I/DD currently receive? Check all that apply.

☐ Medicaid Waiver services
☐ Help from a family member or friend who isn't paid
☐ Technology
☐ Public school
☐ Nursing Facility)
☐ Group home
☐ Help in the family home
☐ Help in own home
☐ Vocational Rehabilitation
☐ Day program
☐ Don't know
☐ None
☐ Other help (please describe):

3) If your family receives more than one paid service and support, do they work well together?

☐ No
☐ Somewhat
☐ Yes
☐ Family member only receives one paid service
☐ Family member does not receive paid services
☐ Don't know

4) Who helps your family member(s) with I/DD with daily activities? Pick the box that most applies to their situation.

☐ A family member or friend
☐ A paid service provider
☐ A school or day program
☐ No one helps, but help is needed
☐ No one helps them, because they do not need help
☐ I don't know
☐ Other (please describe):

5) Does your family member with I/DD currently receive enough support to do what they need and want to do?

☐ Yes, my family member has what is needed
☐ No, my family member needs a little more help

- ☐ No, my family member needs a lot more help
- ☐ No, my family member needs more help almost all the time
- ☐ Don't know/doesn't apply to me

**Technology**

Some people can participate more in their communities with technology. Examples are iPad, voice-activated e-mail, screen readers, eye-gaze sensors, apps.

6) Do you or your family member with I/DD have the technology they need to participate in the community?

- ☐ No
- ☐ Somewhat
- ☐ Yes
- ☐ I don't know enough about what technology might be helpful
- ☐ Don't know/doesn't apply to me

7) If you said no to the question above, what other technology is needed?

**Education and Learning**

8) Please tell us about your family member's school activities. Check all that apply in each row.

- ☐ High School Certificate
- ☐ High School Diploma or GED
- ☐ Some College classes
- ☐ College Degree
- ☐ Job Training
- ☐ Day Program
- ☐ Recreation Classes
- ☐ Don't know
- ☐ Doesn't apply

Which did they finish?

Which do they take now?

Which do they want to take in the future?

9) Does/Did your family member's school do a good job of preparing them for adulthood?

- ☐ No, a big change is needed
- ☐ Some change is needed
- ☐ Yes, it's about right, no change is needed

- ☐ Don't know/doesn't apply

10) How can schools prepare students better for adulthood?

11) Does/Did your family member’s school do a good job of preparing them to have a job or go to college?

- ☐ No, a big change is needed
- ☐ Some change is needed
- ☐ Yes, it's about right, no change is needed
- ☐ Don't know/doesn't apply to me

**Jobs and Money**

12) How important is it to you or your family that the person with I/DD be paid at least minimum wage ($7.25 an hour) for employment?

- ☐ It is very important
- ☐ It is somewhat important
- ☐ It is not important to me
- ☐ Don't know/doesn't apply

13) Do you or your family member with I/DD work at a paid job?

- ☐ No
- ☐ Yes
- ☐ Don't know/doesn't apply

14) How important is it to your family member with I/DD to have a paid job? Why is it important or not important?

15) If you or your family member with I/DD does NOT have a job, do they have help to find a job?

- ☐ No
- ☐ Yes
- ☐ Don't know/doesn't apply

16) If you or your family member with I/DD DOES have a job, is this a job they want?

- ☐ No
- ☐ Yes
- ☐ Don't know/doesn't apply

17) If you or your family member with I/DD DOES have a job, do they earn minimum wage ($7.25 per hour) or more, and work with people with and without disabilities?

- ☐ No
- ☐ Yes
- ☐ Don't know/doesn't apply

**Health and Well-Being**

18) Do you or your family member with I/DD have friends and caring relationships with people other than support staff and family members?

- ☐ No, my family member only has relationships with staff and family
- ☐ My family member has one friend/relationship other than staff and family
- ☐ Yes, my family member has several friends/relationships with people other than staff
- ☐ and family
- ☐ Don’t know/doesn’t apply to my family member

19) Are you or your family member with I/DD able to see a doctor when they need to? Check all that apply.

- ☐ No, they do not have insurance
- ☐ No, they cannot afford a doctor
- ☐ No, they do not have a doctor to go to
- ☐ No, they cannot get to the doctor because of a lack of transportation
- ☐ Sometimes
- ☐ Yes
- ☐ Don’t know/ doesn’t apply to my family member

20) Do you think most emergency personnel (police officers, firefighters, E.R. staff) know enough about working with individuals with I/DD?

- ☐ No, they need a lot more training
- ☐ They need some more training
- ☐ Yes, it's about right
- ☐ Don't know

**Self-Advocacy and Leadership**

Self-advocacy means that individuals can speak up for themselves, know their rights, and advocate.

21) How do you or your family member with I/DD learn about personal rights? Check all that apply.

- ☐ From family
- ☐ At school
- ☐ From other self-advocates
- ☐ At meetings and conferences
- ☐ From the Developmental Disabilities Council of Oklahoma (DDCO)
- ☐ Other advocacy organizations
- ☐ He/she doesn't know about rights
- ☐ Don't know/doesn't apply to my family member

22) What would help you or your family member with I/DD to be a better self-advocate? Check all that apply.

- ☐ Training about self-advocacy
- ☐ Knowing other self-advocates
- ☐ Meetings and conferences about self-advocacy
- ☐ Self-advocacy practice at school
- ☐ More information and training on the issues important to people with I/DD
- ☐ Transportation to events and meetings with leaders
- ☐ More opportunities to advocate at the state, local, and federal level
- ☐ Don’t know/doesn’t apply to my family member

23) What would help you or your family be a better advocate on I/DD issues? Check all that apply:

- ☐ Training on advocacy
- ☐ Knowing other advocates and self-advocates
- ☐ Meetings and conferences about advocacy
- ☐ More information and training on disability issues
- ☐ Transportation to events and meetings with leaders
- ☐ More advocacy events
- ☐ Don’t know/doesn’t apply to me

**Home**

24) Do you or your family member with I/DD have the kind of housing they need?

- ☐ No
- ☐ Yes
- ☐ Don't know/doesn't apply to my family member

25) How would you describe where you or your family member with I/DD lives? Check all that apply.

☐ In own home or apartment
☐ With one or more family member(s)
☐ With one or more roommates(s)
☐ On own (without roommates)
☐ In a non-family member's home
☐ With one or two other people with disabilities
☐ With 4 to 15 people with disabilities (including my family member)
☐ With 16 or more people with disabilities (including my family member)
☐ Doesn’t have a regular place to stay
☐ Don't know/doesn't apply

26) Do you or your family member with I/DD choose where they currently live?

☐ No, they didn't have a choice
☐ They had some input but someone helped them choose
☐ Yes, they chose on their own
☐ Don't know/doesn't apply to my family member
☐ 27) Did your family member with I/DD choose who they live with?
☐ No, they didn't have a choice
☐ They had some input but someone helped them choose
☐ Yes, they chose on their own
☐ Don't know/doesn't apply to my family member

28) How could housing for people with disabilities be better in your community?

**Transportation**

29) How often does your family member with I/DD have the transportation to get where they want and need to go?

☐ Never
☐ Hardly ever
☐ Sometimes
☐ Most of the time
☐ Always
☐ Don't know/doesn't apply to my family member

30) How could transportation for people with disabilities be better in your community?

**Family Support Services and Advocacy**

Many individuals with I/DD live with their families. These families may need services and supports (e.g. respite, family peer services, case management, natural supports) to meet the needs of their family member with I/DD. Families should also have the opportunity to be meaningfully involved in policy and decision making at all levels.

31) Does you or your family have services and support?

☐ Limited or no services or supports
☐ Some services or supports
☐ Yes, we have all the services or supports we need
☐ Don’t know/doesn’t apply to me and my family

32) Do you or your family have the support you need to plan for the future?

☐ No, we need support to plan
☐ We have some support
☐ Yes, we have about the right support
☐ Don’t know/doesn’t apply to me and my family

33) Do you or your family have enough opportunities to be involved in advocating on public policy issues and decisions related to people with I/DD?

☐ No opportunity to be involved
☐ Some opportunity to be involved
☐ Yes, enough opportunity to be involved
☐ Don’t know/doesn’t apply to my family