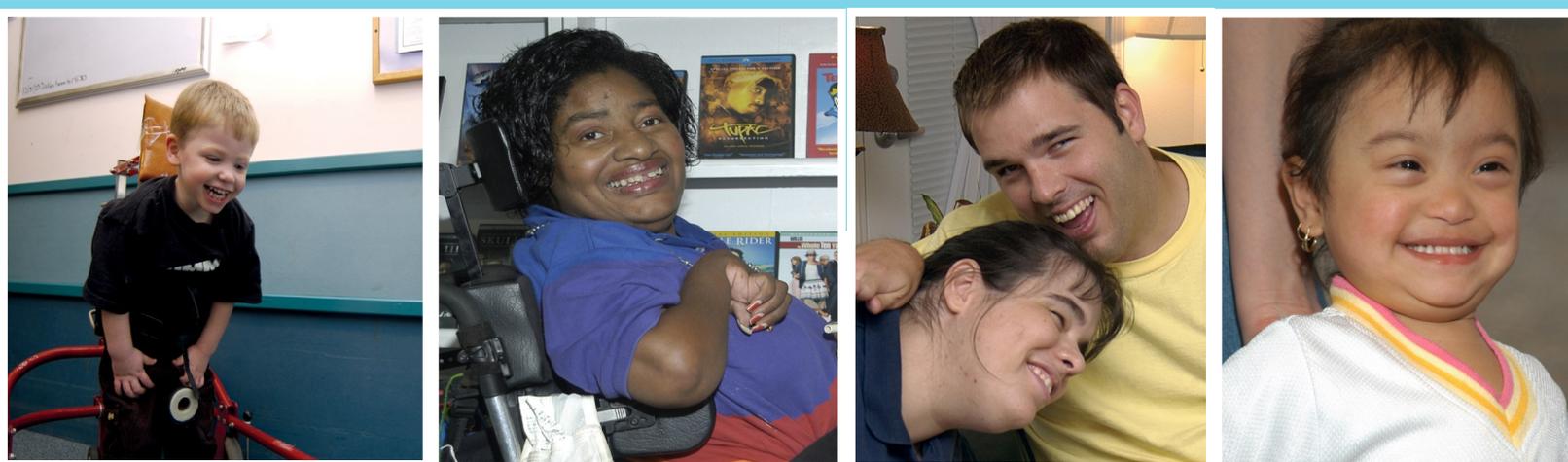


Governor's Blue Ribbon Panel for Developmental Disabilities



**Recommendations to the Honorable Mary Fallin
Governor of the State of Oklahoma
April 2015**

This document was compiled and edited by the Center for Learning and Leadership, which is a collaborative initiative of the University of Oklahoma Health Sciences Center, sponsored by the OU College of Medicine, with support from the U.S. Administration on Intellectual and Developmental Disabilities grant number 90DD0685.

Recommended citation. R. Percival, M. Fenrick and the members of the Oklahoma Governor's Blue Ribbon Panel on Developmental Disabilities(2015). *Governor's Blue Ribbon Panel on Developmental Disabilities: Recommendations to the Honorable Mary Fallin*, Center for Learning and Leadership/UCEDD, Oklahoma's Federally Designated University Center for Excellence in Developmental Disabilities Education, Research and Service, University of Oklahoma Health Sciences Center, OU College of Medicine, publication no. #CE010113.

**Governor's Blue Ribbon Panel
for Developmental Disabilities**

**Recommendations to the Honorable Mary Fallin
Governor of the State of Oklahoma**

April 2015

Table of Contents

Panel Members and Staff

Introduction

Background and Historical Perspective

Strategy #1: Strengthen information access

Strategy #2: Provide resource navigation and improve inter-agency
service coordination

Strategy #3: Provide family-to-family support to individuals and families
who are currently on the Waiting List or who apply for waiver services.....

Strategy #4: Assess the needs of families currently on the Waiting List

Strategy #5: Build capacity of services and supports outside of those
provided through the Developmental Disabilities Services waivers

References

Appendices

Executive Order 2013-8

Executive Order 2015-17

**THE OKLAHOMA GOVERNOR'S BLUE RIBBON PANEL
WAS CREATED BY EXECUTIVE ORDER 2013-8**

- To develop a comprehensive plan to support individuals with intellectual and developmental disabilities (I/DD) and their families;
- To address the state's growing wait list of thousands of individuals requesting community services from Developmental Disabilities Services; and,
- To research and analyze best practices for the comprehensive delivery of high quality services to Oklahomans with intellectual and developmental disabilities.

Blue Ribbon Panel Members

Jim Nicholson, Chair

Former Director
Developmental Disabilities Services

Wanda Felty, Vice Chair

Parent
Center for Learning and Leadership

Robin Arter

Sibling, Parent - Duncan
Ability First, Inc.

Dee Banta

Self-Advocate - Tecumseh
Oklahoma Self-Advocacy Network

René Daman

Oklahoma Autism Network

Deborah Decker

Parent - Norman

Representative Jason Nelson

Oklahoma House of Representatives

Kim Osmani

Ex officio
Oklahoma Department of Rehabilitation
Services

Senator Greg Treat

Oklahoma State Senate

Ann Trudgeon

Ex officio
Oklahoma Developmental Disabilities Council

Mike Upthegrove

Self-Advocate - Norman

Nancy Ward

Self-Advocate - Oklahoma City
Oklahoma People First

Blue Ribbon Panel Staff

Katie Altshuler

Governor's Office

Cody Inman

Governor's Office

Melissa Fenrick

Center for Learning and Leadership

Rose Ann Percival

Center for Learning and Leadership

INTRODUCTION

The Governor's Blue Ribbon Panel for Developmental Disabilities was created by Executive Order 2013-8 and met during the period of May 2, 2013—March 27, 2015.

The Panel's recommendations were presented to the Governor in two sets. The first set was finalized in January 2014 and the second set, which built upon the first, was presented in March of 2015. The underlying rationale for both sets is summarized in the Panel's first key findings:

The Panel finds that the intensity of the state's effort needs to change from managing the Department of Human Service's list of requests for one program to support individuals with intellectual and developmental disabilities (I/DD) throughout their lifespans to a range of coordinated services from various agencies including, but not limited to, the Departments of Education, Rehabilitation Services, Mental Health and Substance Abuse Services, Human Services, the Regents of Higher Education, the Health Department and the Oklahoma Health Care Authority. The Panel further finds the most essential component to meeting individuals' needs is to provide effective, meaningful, and timely support to their families and caregivers. Declining revenues and the challenges of staffing out-of-home living arrangements mean that families will be increasingly relied upon for supporting members with developmental disabilities in the future.

The Panel's initial recommendations focus on:

- 1) the creation of coordinated services between agencies and
- 2) providing necessary information to families regardless of which agency is the first point of contact.

The second set of recommendations is directed toward:

- 1) furthering the technical and emotional support of families;
- 2) revisiting the existing criteria for service access of the Developmental Disabilities Services (DDS) Waivers; and,
- 3) identifying critical supports that will keep families engaged as long-term caregivers/ support for individuals with I/DD.

BACKGROUND and HISTORICAL PERSPECTIVE

The creation of the Home and Community-Based Services Waiver program in 1981 enabled people with intellectual and developmental disabilities (I/DD) to receive a broad array of services without being required to leave home to live in an institution. Initially the program, which was funded by the Centers for Medicare and Medicaid (CMS), was limited in size by tying enrollment to the number of institutional beds in the state and by making services optional rather than required. At the time, this program was hailed as an innovative alternative to institutionalization. Unfortunately, the program contained seeds for significantly inadequate coverage in the future.

As states initiated community-based waiver programs, the problems within the authorizing federal legislation became obvious. The institutional-bed formula penalized states that had limited their use of institutions in favor of community services. There also were so many more individuals with I/DD living outside of institutions that they could never be covered using the institutional-bed requirement. The growing discontent over the requirement eventually led the CMS to drop the formula. States could expand enrollment in waiver programs provided they had the appropriated funds to meet the Medicaid matching requirement.

However, the state dollar matching requirement has continued to be a limiting factor for enrollment in the waivers. CMS requires that states have dedicated funding up front before they will approve additional slots in the waivers and that all the approved slots be served within each five-year waiver authorization period. On top of the enrollment limitations, managing the waivers requires substantial administrative support, including case management, quality assurance monitoring and financial oversight.

This administrative complexity and funding requirements have been a hallmark of the Home and Community-Based Waiver Services program and have resulted in the growth of waiting lists nationally. The Kaiser Family Foundation reported 317,000 persons with I/DD waiting for waiver services in 2011. The focus of advocacy groups and federal oversight agencies has been to decrease the time individuals spend waiting, and in some cases, to secure additional funding through lawsuits and settlement agreements.

In Oklahoma, the 7,100-person Waiting List has become the primary focus of Developmental Disabilities Services (DDS) within the Department of Human Services (DHS). The questions asked by policy-makers, legislators, parents, advocates and self-advocates are: How many people are waiting? How many applications are being worked? How fast are people getting off the list? How many new people are being served? How quickly are the appropriated dollars being used? The most critical measure of the program's effectiveness has become whether there is a net reduction in the list over a given period of time.

Lost in the consuming focus of working the Waiting List is the question of whether or not people's needs are being met while they wait. Data show that 75% of those waiting for waiver services receive some other type of assistance through DHS or Medicaid. Some families decline waiver services in order to continue receipt of the DHS Family Support Assistance Program. Some children on the list are below the age for service eligibility. At least some individuals are on the list due to the long waiting period rather than to a current need for waiver services. What is unknown is the extent to which individuals receive services through non-DHS programs in the Departments of Health, Rehabilitation Services, Mental Health, and Education. In the absence of such comprehensive service data, it is clear to the Panel that the DDS Waiting List is a measure of insufficient program capacity, but is not a reliable measure of unmet needs.

The Panel finds that the intensity of the state's effort needs to change from working a list of requests for one program from one agency to supporting individuals with I/DD across the life span through well-coordinated services from every agency. The Panel further finds that the most essential component to meeting the needs of individuals is to provide effective, meaningful, and timely support to their families and caregivers. Declining revenues and the challenges of staffing out-of-home living arrangements mean that families will be increasingly relied upon for supporting members with developmental disabilities in the future.

In March 2011, a group of national leaders in the field of developmental disabilities met for the Wingspread Conference. The result of that meeting was a document entitled, "Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities". The document identified three critical areas of support for families:

- **Knowledge and Skills** - Information, education, and training on best practices within and outside of disability services, accessing and coordinating community supports, and advocacy and leadership skills.
- **Emotional Supports** - Connecting and networking a family/individual with others, including parents of people with disabilities, self-advocates, siblings, and guardians for mutual support.
- **Day-to-Day Needs** - Services and goods that are specific to the daily support and/or caregiving role for the person with developmental disabilities, such as planning for current and future needs, respite, crisis prevention and intervention, systems navigation, home modifications, and health management (Hecht & Reynolds, 2011).

The Panel used these three areas to frame strategies our state can use to better support individuals and families. These strategies build on the strengths of our service systems, organizations, and communities.

Strategy #1: Strengthen Information Access *Knowledge and Skills*

The Panel identified a significant need for improved information access and training about community services and resources, both formal and informal. Those needing better information include individuals, their families/caregivers, and professionals who interact with them. From formal presentations made by family members at Panel meetings and the Panel members' personal experience with families, we learned that many families find the process of identifying, locating, and applying for services across an array of different agencies and organizations difficult. Some people do not know what to ask for or whom to ask. Information access is particularly challenging in rural areas of the state. The Oklahoma DDSD Waiting List Study Follow Up (Fullerton, 2013) surveyed 71 family members on the DDSD waiver services Waiting List about this issue and others. Of those surveyed, 73.2% indicated they needed help getting services and 77.5% indicated they needed help accessing the system.

How This Strategy Leverages Oklahoma's Resources

By focusing on improving information access for both service recipients and service coordinators, Oklahomans with I/DD and their families can be better equipped to obtain both formal services and informal community resources that can meet needs right away. Individuals on the Waiting List may be waiting for help that can be provided through other avenues if they knew those avenues were available to them. Professionals and families should have ways to continually increase their knowledge about what resources and services are available.

Due to the lengthy wait, many families are advised to add their child or family member to the DDS Waiting List regardless of current need or potential eligibility. This future time focus may mean less time is devoted to searching for solutions for current needs. One result is creating the perception that the waivers are the only truly effective solution for families and that once the wait is over, all needs will be identified and met. While DDS waivers do provide some unique services, many services can be obtained elsewhere through other agencies or generic community resources. Our focus should be on finding ways to improve the quality of life for individuals and families right now and not accepting that such a life must wait for services from one program at some point in the future.

It is important to note that not every individual can get their needs met without waiver services. Some have high support needs which cannot be met through generic community resources nor by the State Medicaid Plan. Others no longer qualify for services for children. When they reach the ages of 18-21, a number of childhood services end. These services include the Family Support Assistance Payment (FSAP), Early and Periodic Screening, Diagnosis

and Treatment (EPSDT), Supplemental Security Income-Disabled Children’s Program (SSI-DCP), Tax Equity and Fiscal Responsibility Act (TEFRA), and school-based services.

Recommendations

The Panel recommends the Governor create an Executive Council of heads of agencies providing support services to individuals with I/DD. The council should also include representation from knowledgeable service applicants and consumers. The council’s initial charge should be to strengthen information access in each agency by:

- Increasing knowledge about disability services and community resources for professionals interacting with the public in all agencies.
- Increasing access to information about disability services and community resources for Oklahomans with disabilities and their families.
 - ⇒ Equipping professionals to provide broad disability service information to individuals and families at the point of intake at each agency.
 - ⇒ Supporting regular resource training to families and self-advocates in different parts of the state.
 - ⇒ Improving information access via agency websites, and/or creating a disability information web portal, to provide comprehensive information about services and resources in an easy-to-understand manner that is helpful to families who are navigating systems on their own.
 - ⇒ Sending useful, comprehensive information about available services and community resources to all people on the waiver services Waiting List. The information should be tailored to the area in which the individual lives.

Strategy #2: Provide Resource Navigation and Improve Inter-Agency Service Coordination

Knowledge and Skills, Emotional Supports

One area of concern is the scarcity of information about programs and services across agencies and communities and the lack of resource navigation. Individuals intent on getting on the DDS Waiting List may ask for or receive little information about ways to meet needs immediately. Currently there are no service coordinators within state agencies dedicated to providing resource navigation. “Resource navigation” is used here to encompass services among all agencies and community resources.

Another barrier the Panel identified is the lack of service coordination between human

service agencies. When families apply for one service, they often have other needs that might be met by another agency. Sometimes families are told to go elsewhere but not given enough information to understand what to ask for and from whom. Additionally, some programs have application processes that involve more than one agency. Without effective communication between the different agencies and between agencies and the applicant, the process can be extremely complicated, long, and confusing.

How This Strategy Leverages Oklahoma’s Resources

Resource navigation could meet current needs for individuals and their families on the Waiting List and others with I/DD who are not yet on the Waiting List. Improving information access is a good start, but resource navigation would also provide expertise in identifying and obtaining services for individuals and families. By having resource navigation available, Oklahomans could have help finding solutions to improve the quality of life for their family member now instead of simply waiting for waiver services. Results from the Oklahoma DDSD Waiting List Study Follow Up (Fullerton, 2013) confirm this need. Of the 71 respondents, 90.1% indicated that having a professional help them figure out the service and resource system would benefit their family.

Resource navigators, particularly if they are family members themselves, could also provide emotional support and refer families to appropriate support groups, self-advocacy groups, and networks. The opportunity to talk with someone who has first-hand experience and who speaks in non-professional terms can be invaluable to families. Having the opportunity to learn how to advocate for services and build leadership skills can also be invaluable to individuals with disabilities and their families. Resource navigators could help families leverage organizations and groups who provide these supports by connecting people to them.

Improving inter-agency service coordination would increase positive outcomes for individuals and families for two reasons. First, when they are applying or receiving assistance for one service or program, the professional or agency has an opportunity to meet other needs. Second, when they are applying for a service that involves more than one agency, it can help them obtain the service faster and more easily.

The Panel recommends the Governor charge the Executive Council with improving the coordination of services for Oklahomans with disabilities across the life span by:

- Strengthening service coordination at critical life points, including early intervention to school-based services, school to work, and post education through the adult lifespan.

- Establishing a process for all agencies to utilize regular evaluation and assessment of policies, procedures, and services so that updates and improvements are made in a timely manner.
- Simplifying access for services and programs that involve more than one agency.
- Developing strategies to provide resource navigation services to Oklahomans with disabilities to meet needs and provide emotional supports to individuals and families.

Strategy #3: Provide family-to-family support to individuals and families who are currently on the Waiting List or who apply for Waiver services.
Knowledge and Skills, Emotional Supports, Day-to-Day Needs

Over the past two years, the Panel has repeatedly heard that parents of a child recently diagnosed with a developmental disability are frequently in a state of shock when confronted with the fact that their family’s life has irrevocably changed. They not only have to learn about their child’s condition and its impact on the family’s future, but also have to navigate a very complex service environment. Both the emotional well-being and the service environment the child experiences are heavily influenced by the parents’ resilience and coping skills, making parental support a critical endeavor. As a leading Oklahoma parent advocate stated, “the parents’ challenge is to get through the grief and emotion and to start actively managing their child’s disability”.

Oklahoma has a rich heritage of neighbors helping neighbors, and this is especially true in the field of developmental disabilities. The first generation of community service providers, group homes, and workshops was the result of parents taking the lead to form small non-profit agencies to serve their communities. Support groups throughout the state help parents raising children with specific disabilities, such as Down syndrome and autism. In 2001, the parents and professionals who developed the *Individuals with Autism and Their Families Oklahoma Plan*, recognized that the first need of every parent who learns his or her child has a disability is another parent to help them process their shock and grief, and to begin to take action to support their child. This initial contact offers emotional support to parents, but also serves as their first resource in learning to navigate a complex service environment. Supporting families in the early stages of learning about their child’s disability also provides the opportunity to assist them in creating a framework for supporting their child that is not solely dependent upon programs, but that incorporates family, friends, and readily available community resources.

Rather than leave this critical parent-to-parent connection to chance, the Panel believes there

needs to be a deliberate statewide effort to link parents and caregivers to each other. This effort would assist families in creating a meaningful life for their child as well as navigating services and programs.

How This Strategy Leverages Oklahoma’s Resources

This strategy reiterates the need for effective resource navigation and emotional support for Oklahomans. Creative solutions for everyday challenges and plans for a meaningful life, often come from talking with other parents and caregivers. Establishing a way for state agencies to actively connect parents and caregivers is an effective and cost efficient way to support families. This strategy capitalizes on the many family support resources available and provides parents and caregivers with knowledge and skills necessary to access a variety of resources to find solutions. It also provides emotional support and guidance from experienced parents and caregivers who have developed the skills of finding and managing formal and informal supports, and can offer the perspective of another parent/caregiver.

Recommendations

The Panel recommends that the Governor acknowledge statewide family-to-family networks and the developmental disability-specific networks as the critical “first contacts” for parents and guardians receiving a diagnosis of their child’s developmental disabilities. These networks will provide assistance in identifying and connecting to resources and supports that the child may be able to access to meet immediate needs.

Where these networks currently receive state funding, the Governor assigns the Office of Management and Enterprise Services to provide oversight of agencies’ budgetary planning to ensure existing funding is maintained.

As resources permit, the Governor will request the Office of Management and Enterprise Services to support new and additional funding for these networks. The Governor charges the Executive Council with taking the necessary regulatory steps to create an automatic referral process to the statewide family-to-family networks for parents and guardians who apply for services at the agencies represented on the Executive Council.

Strategy #4: Assess the needs of families currently on the Waiting List. *Day-to-Day Needs*

The Panel’s primary focus was centered on ways the Waiting List could be prioritized based on the individual’s and the family’s needs. For the past three years DDS has received an annual appropriation of \$1 million to reduce the Waiting List. For each of the past three years, DDS worked approximately 350 applications. The Waiting List remains unchanged at approximately

7,000 individuals. While individuals on the list are invested in their date of application, as that date places them in the order of service selection, a much more specific indicator of when they will be served is the rate at which applications are worked. At a rate of 350 applications per year, it will take 20 years to work the current list, assuming a \$1 million annual increase.

Given the goal of supporting individuals and families, the use of “first come, first served” as the criteria for admission to the Waivers is counter-productive. The person with the next date may have no significant unmet needs, while the person whose date is years behind may have great need. Failure to address more significant needs could result in emergency services at an increased cost.

It is the Panel’s opinion that DDS waiver services must be used for individuals whose needs cannot be met through existing formal or informal supports available to them through DDS non-waivered services, other agencies, or other community resources. The Panel believes a needs-based prioritization is necessary to serve the state’s population of individuals with developmental disabilities in an equitable manner. Of particular interest to the Panel are those strategies utilized by Missouri, which include the use of a Prioritization of Need (PON) document to rank how much support or assistance the individual needs. It is worth noting that Pennsylvania attempts to capture expected future needs as part of their service and budgetary planning.

Current emergency admission criteria for waived services is based on the direst circumstances related to the health and safety of individuals and their primary caretakers. This policy leaves addressing levels of serious but not dire circumstances to the accident of application date. Even in an environment of scarce resources, a system that prioritizes need, and provides services accordingly, would further the mission of maintaining families as caregivers. The Panel recommends the criteria for expedited DDS waiver services be amended to take into account the age of the applicant, the age of the caregiver, the medical condition of the caregiver, and significant life events.

How This Strategy Leverages Oklahoma’s Resources

The Panel recognizes that many individuals and families have waited for services for years and expect to eventually receive Waiver services if they meet the eligibility requirements. However, the Panel also recognizes that many put their family members’ name on the list because someone told them they should. They are unclear about what they are applying for and what needs can be met once they qualify for services. Furthermore, the application date and the ability to meet minimum eligibility requirements do not reflect an individual’s needs.

- The Panel believes establishing a system to prioritize needs is a more effective and

responsible way to provide services. The Panel also believes that lifelong waiver supports should be reserved for those with the highest support needs. Improving access to and the quality of other supports and services would address the needs of all other individuals and their families. The Panel felt serving those according to the date of application caused greater hardships and challenges to people with I/DD and their family. Prioritizing the Waiting List and amending expedited criteria also will help prevent negative outcomes for families in crisis or on the brink of a crisis.

Based on statements from legislators and others in policy-making positions, appropriations might be more consistent if the justification for the request painted a picture of those who would be served. Dates of application, by themselves, do not communicate an urgent need for funding.

Recommendations

The Panel recommends that:

- The Governor’s Office and the Oklahoma Legislature provide directives to the Oklahoma Department of Human Services (DHS) to implement a needs-based selection criteria for persons on the waiting list, prioritizing pending applications. The application date may be used to establish priority of service within a need category, but the use of application date as the sole determinant of non-emergency services will be discontinued.
- The Governor enable the Executive Council to provide guidance to DHS related to the development and implementation of this system. The services of the Executive Council’s member agencies should be identified as key elements in reducing the demand for Waiver services.
- DHS describe the level of need of individuals to be newly served in its annual appropriation request for funding to reduce the Waiting List.
- DHS modify administrative rules so that expedited criteria include:
 - ⇒ the advanced age of caregiver, the advanced age of applicant,
 - ⇒ certain medical conditions of the caregiver or applicant, and
 - ⇒ loss of employment by the primary caregiver due to having to provide support at home to the family member with Intellectual/Developmental Disabilities (I/DD).
- DHS create an automatic referral process to connect individuals and families applying for DDS services, including those currently on the list, to statewide family-to-family networks.

Strategy #5: Build capacity of services and supports outside of those provided through DDS waivers.

Knowledge and Skills, Day-to-Day Needs

Another focus of the Panel’s discussions was the identification of gaps in services and supports for individuals and families, and ways to fill those gaps. By identifying services and supports that could meet needs outside of those provided through the DDS Waivers, the true need for the Waivers becomes clearer.

It is important to make a distinction between true gaps in service and supports – meaning there are little to no resources – and gaps that exist only because of barriers in accessing resources. For instance, many caregivers need a respite from their caregiving responsibilities and/or need to have a paid caregiver to perform some of the daily caregiving duties. According to the DDSD Waiting List Follow-Up Study (Fullerton, 2013), 38 percent of respondents identified respite as one of the top five services needed. There are a number of respite programs and personal care services provided through programs other than the DDS Waivers. However, the Panel identified barriers to accessing these programs, including challenging application processes and complex eligibility requirements. If these barriers were removed, families would have improved access to respite and in-home care services that are not dependent on receiving Waiver services.

Services and supports identified by the Panel in need of expansion, rather than simply improved access, include employment and/or transition services, autism services, and assistive technology. These supports are particularly important to expand as a strategy to assist individuals and families at critical life points to ensure individuals with I/DD can achieve meaningful lives.

How This Strategy Leverages Oklahoma’s Resources

If DDS Waiver services are reserved for individuals with the highest needs and most urgent situations, our state must increase the capacity of other services and resources that individuals and families need to plan for meaningful lives. The Panel finds that these services and resources are particularly important for youth preparing to make a transition from secondary education to work or further education and for young children with autism. Transition and employment services are essential to ensure that individuals with disabilities have opportunities to work, and to ensure that parents are able to retain employment after the child completes high school. Services for children with autism are important to increasing independence and decreasing the need for lifelong services.

Improve Access to Respite Voucher Programs

Currently there are a number of respite voucher programs for which caregivers of individuals with I/DD may qualify. These programs include the DDS program, the DDS Marriage Initiative program, the SSI-DCP program, the Aging Services (AS) program, and the Lifespan Respite Grant program. Each has its own application process and eligibility requirements, making application to respite programs difficult to navigate. While Sooner SUCCESS has recently become the point of contact for the Lifespan Respite Grant program, each program is coordinated separately. The Panel feels this barrier could be removed and replaced with a centralized application process. The application process could utilize web-based application submission on the DHS website, as well as becoming a single contact point for all respite programs. Because there is a large amount of duplicate information in the applications for each program, the Panel recommends that a single application be used to capture the necessary information to determine the program(s) for which a caregiver would be eligible.

Finally, the Panel recommends expanded eligibility for certain caregivers. Currently recipients of the Family Support Assistance Program (FSAP) cannot receive respite vouchers through the DDS program. It is the Panel's request that caregivers of two or more children with intellectual or developmental disabilities in the home be eligible for DDS respite vouchers. As the additional FSAP monthly payment for more than one child with a disability in the home is \$50 per child, it seems reasonable to allow this group of caregivers to receive respite vouchers.

Recommendations

The Panel recommends that access to respite programs be improved by:

- Simplifying application through the creation of a single, centralized web-based application process.
- Funding a full-time position specifically to assist caregivers navigate the respite application process.
- Opening the DDS respite program to recipients of the FSAP with two or more children with disabilities in the home.

Improve Access to Personal Care Services

Personal care is a service that is provided to an individual who is unable to care for personal needs, such as toileting, bathing, feeding, or food preparation. In Oklahoma personal care is available to SoonerCare members as part of the Oklahoma Medicaid State Plan. The Centers for Medicare and Medicaid Services (CMS) stated that under EPSDT (Early and Periodic Screening, Diagnosis and Treatment, a Medicaid entitlement program for children), personal care is a required service that must be provided to children when medically necessary.

There is a general perception that personal care services are for older adults only, making it difficult for caregivers of children with disabilities to apply. The two main entry points to make application are the ADvantage Care Line and local DHS county offices. The ADvantage Care Line is administered through DHS Aging Services and is a Medicaid Waiver program for older adults and people with physical disabilities. Because the vast majority of inquiries are for older adults, there seems to be confusion among DHS employees taking calls from parents attempting to apply for personal care services for their children. The Panel feels this problem could be solved by DHS workers statewide receiving additional training on eligibility for personal care services for children.

Additionally, the Panel learned DHS policy requires that all personal care applications meet the Aged, Blind, and Disabled income limit before the application is processed to determine medical eligibility. We believe this policy seems to have been created to manage the state personal care program without consideration of the CMS requirements for this treatment.

Recommendations

The Panel recommends that:

- The Governor instruct DHS and the Oklahoma Health Care Authority (OHCA) to create a seamless process for children applying for personal care services that would not restrict the medical necessity determination due to the income limit guidelines created by DHS policy.
- The Governor instruct DHS to modify administrative rules to assure compliance with CMS regulations regarding EPSDT, which requires personal care as a treatment option when medically necessary.
- DHS create staff training to assure understanding of personal care services for children with I/DD.
- The Governor instruct the Executive Council to create a statewide process to increase awareness for families and staff of both OHCA and DHS on the availability of personal care services for children and adults with I/DD when needed.

Expand Transition and Employment Services

The Panel invited Dr. Jim Martin, Endowed Chair of the Zarrow Center for Learning Enrichment and Professor of Special Education at the University of Oklahoma, to discuss strategies to improve post-secondary outcomes for students with I/DD. Through discussions with Dr. Martin, several strategies were identified: 1) writing Individualized Education Plans (IEP) that guide the student school personnel toward a positive transition into a meaningful community life after high school; 2) teaching skills associated with post-school success, including job skills;

3) providing students opportunities to explore interests; and 4) teaching self-determination skills, such as involving students in their IEP meetings.

In order to support transition planning, our state must provide a systematic way to provide best practice information and technical assistance to educators and schools equipping them to utilize these strategies. The need for expansion in this area requires training and support for school personnel and other professionals who engage students with I/DD and their families to prepare for living in the community. The Panel members emphasize that effective transition and employment planning must begin informally as early as possible. In addition to being essential for the student, effective transition planning enables parents and caregivers to continue to be employed themselves once the student completes high school.

Additionally, the Panel members discussed challenges related to accessing available services and supports for employment and post-secondary transition. The Panel feels it is of particular importance to increase collaboration between DDS, the Oklahoma Department of Rehabilitation Services (DRS), and local schools in order to increase awareness and utilization of DDS and DRS services among students with I/DD. These services include school-to-work transition services (DRS) and the Community Integrated Employment program (DDS). Because DRS and DDS work together to provide on-going employment supports for individuals with I/DD, the Panel feels this process should be clarified for students, families, and professionals.

Another important component to effective transition is assistive technology that can help individuals communicate and perform job-related tasks. The Panel recommends the expansion of assistive technology services, including services that assist school personnel in the selection and use of assistive technology.

To support an outcome of employment, benefits planning and counseling is essential. The Oklahoma Work Incentives Planning and Assistance Project is operated statewide by the National Center for Disability Education and Training at the University of Oklahoma/Norman. This project provides individual counseling to assure that important benefits such as Social Security Income, Social Security Disability Insurance, and Medicaid-provided health care coverage are not “lost” as wages are earned.

The panel recognizes that individuals achieve better employment outcomes when both “hard skills” (those required to accomplish specific job tasks) and “soft skills” are learned. Soft skills are general or social skills, such as communication skills, interpersonal skills, time management skills, problem solving skills, and work ethic. If systems of services and supports do not recognize and teach such skills, employment will remain a challenge for people with I/DD.

The Panel recognizes that employment immediately after high school is not obtainable for every student. For parents who need and want to continue employment once their child

completes high school, day programs may be an appropriate option. However, the Panel believes strongly that day programs should focus on a goal of community-based employment. Standards must be developed for all DHS-contracted day programs. These standards would require day programs to provide job skills training and opportunities for individuals to explore job and volunteer interests.

Finally, the Panel recognizes that the path to employment does not need to rely on specialized, formal services. Employment service agencies, temporary agencies, and other human resource organizations can provide support and assistance, regardless of an individual's disability.

Recommendations

The Panel recommends that transition and employment services be increased by:

- Better equipping school personnel to utilize transition services and plan for meaningful lives for students with I/DD after they graduate. Strategies could include:
 - ⇒ Standardizing training related to teaching and supporting students with I/DD .
Training would include specialized instruction on:
 - 1) writing IEPs to support employment,
 - 2) teaching “hard” and “soft” employment skills,
 - 3) helping students explore interests, and
 - 4) teaching self-determination skills.
 - ⇒ Providing on-going information and training related to transition and employment services available through cross training of agency personnel, professional development for school personnel, families and caregivers, and community providers.
 - ⇒ Training and supporting IEP teams to discuss and write meaningful transition plans that lead to stable, wage-earning employment.
- Better equipping providers of employment services on how to best support young adults with I/DD.
- Providing ongoing training to community providers, schools, agencies, and families on effective and evidenced-based practices for preparing youth with I/DD for community employment, including generic private employment organizations.
- Providing ongoing training to community service providers regarding service coordination between DRS and DDS, long-term supports available through Community Integrated Employment (CIE) services and requirements for obtaining CIE contracts with DDS.

- As resources permit, the Governor will ask the Office of Management and Enterprise Services to support additional funding for expansion of CIE services to meet the increasing demands as efforts such as Employment First and Workforce Innovation and Opportunities Act (WIOA) continue to encourage and support competitive employment.
- DDS requiring that each community provider with a DDS contract, obtain a CIE contract to further encourage and support integrated employment.
- Enabling the Executive Council to develop strategies to increase collaboration between agencies represented on the Council. Strategies could include:
 - ⇒ Increasing collaboration between all state agencies related to the delivery of pre-employment training and employment services to individuals with I/DD. Increased collaboration is particularly important between DRS, DDS, and the Oklahoma State Department of Education.
 - ⇒ Increasing awareness of transition and employment services and programs available among individuals, family members and professionals.
- Increasing awareness about benefits planning and assistance programs that assure needed benefits are protected.
- Increasing assistive technology training and support services (see below).
- Developing standards for day programs in order to utilize them as employment training programs. Standards would include requirements to provide job skills training and opportunities for individuals to explore job and volunteer interests.
- At Career Technology centers, expanding service capacity in vocational training programs for students with disabilities with a focus on statewide and “vocation diverse” programming, to include:
 - ⇒ Placing students with disabilities in credit-bearing programs that can culminate in a certificate, a trade license, or Associate of Applied Science (AAS) degree.
 - ⇒ Educating families and special education teams that Career Technology centers maintain staff that can attend Individualized Education Plan (IEP) meetings and contribute to transition plans.
 - ⇒ Initiating transition planning for students likely to use Career Technology training by the ninth grade.
 - ⇒ Ensuring students, their families, and employers participate in short- and long-term evaluations related to Career Technology services to assure the efficacy of their programs.

Expand Autism Services

The need for services for individuals with autism and other developmental disabilities was another theme within Panel discussions. Between 1999 and 2013 there was an 80.7% increase in the number of children ages 3-21 receiving special education services under the category of autism. This does not include the increased number of children in the SoonerStart Early Intervention Program who have a suspected or confirmed diagnosis, or children or adults outside the public education system. With the increased prevalence of autism, there is a greater need for access to evidence-based interventions for children and adults with autism across the state. The July 2014 CMS guidance memorandum on autism services states that a plan amendment is “strongly encouraged to articulate the state’s menu of services for autism spectrum disorders (ASD) treatment.” This guidance also outlined that states’ obligations under EPSDT to include medically necessary services for the treatment of autism. These services can be included under the categories of: 1) other licensed practitioners, 2) preventive services, and 3) therapies. The Panel recommends that Oklahoma’s Medicaid State Plan be amended to outline services that will be provided through EPSDT for children with ASD. The coverage of autism services under Medicaid will require careful planning to ensure that effective, evidence-based interventions are provided by appropriate practitioners. The Panel recommends that the Executive Council prioritize the tasks of determining what autism services our state will cover and who will be authorized to provide those services.

Additionally, the Panel recognizes the importance of expanding programs that build the capacity of parents to meet the needs of their child with autism versus programs that focus primarily on building the child’s skills through services provided by professionals. Research indicates that behaviorally-based parent training results in better maintenance and generalization of child skills, increases parent optimism about their child’s future, increases the number of hours of intervention a child receives, and is cost effective. Parent training models that build family capacity are an effective way to increase the availability of evidence-based interventions to children across Oklahoma in a cost effective manner.

As mandated in Senate Bill 135, the Oklahoma Autism Network has developed and evaluated a model program, called “ConnectedKids,” which teaches parents behavioral and developmental strategies to improve their child’s social communication skills. Evaluation of the program completed in 2014 showed that parents can effectively learn and implement the strategies in the home and community, resulting in improved child skills and a positive effect on family relationships.

Recommendations

The Panel recommends that the Governor empower the Executive Council to expand and improve autism spectrum disorder services by:

- Expanding the availability of evidence-based services to children with autism and their families across the state through the following actions:
 - ⇒ Implement the July 2014 CMS guidance.
 - ⇒ Amend the Medicaid State Plan to describe the autism services to be provided to children under the age of 22.
 - ⇒ Determine the Medicaid practitioners authorized to provide autism services.
 - ⇒ Increase pre-service training and professional development among school personnel and other service providers regarding evidence-based interventions for individuals with ASD.
 - ⇒ Expand cost-effective intervention models, such as “ConnectedKids”, that support children with ASD by building capacity of parents and caregivers to meet their child’s needs in natural environments.
 - ⇒ Develop a plan for statewide implementation of the “ConnectedKids” program within SoonerStart, which focuses on teaching parents strategies to support their children with ASD in natural environments.

Improve Access to and Expand Services for Assistive Technology

Assistive Technology is an umbrella term that includes assistive, adaptive, and rehabilitative devices (both low and high tech) for people with disabilities, and also includes the process used in selecting, locating and using such technology. Assistive Technology promotes greater independence by enabling people to perform tasks they were formerly unable to accomplish, or had great difficulty accomplishing, by providing enhancements to, or changing methods of interacting with, the technology needed to accomplish such tasks.

The Panel recognizes that access to, and selection and use of assistive technology for individuals with I/DD and their families is critical. Too often, the term “assistive technology” connotes high-tech, expensive equipment such as power wheelchairs and augmentative communication devices. In fact, pencil grips are assistive technology, and “off the shelf” items like iPads can be easily modified with applications like speech readers to provide a relatively low-cost solution for communication. Professionals and families must become more aware of the many types of technology, including low-tech, free or low cost, and “generic” technology.

Some technology remains high-tech and expensive. Although some professional development and device loan programs are available across the state to assist individuals and their families, there is a lack of consistent decision-making and equitable access and use. The Panel recommends the expansion of assistive technology services in our state, including services that help families and professionals select, use, and pay for appropriate assistive technology for individuals with I/DD.

To support planning for assistive technology needs and to recognize how those needs change across the lifespan, our state must consistently provide training and technical assistance, and must mentor professionals and families so they have access to strategies and tools that will enhance their capacity to support the use of assistive technology by individuals with I/DD's. On-site mentorship and technical assistance is a vital element that is currently missing across service delivery systems. The Panel members recognize that assistive technology assessment and implementation requires on-going decision-making. Such decision-making and planning should begin in early intervention and continue into adulthood. Parents and caregivers must have adequate information upon which to make decisions about current and future assistive technology needs.

Because multiple state agencies are involved in assistive technology decision-making and payment, the Panel recognizes the need for increased collaboration to ensure consistency and to identify gaps and redundancies in both services and payment.

Recommendations

The Panel recommends that the Governor charge the Executive Council with expanding and improving assistive technology access, decision-making, and use by:

- Increasing competency-based assistive technology (AT) training for early intervention programs, schools, agencies, support services personnel and families. Training should include but is not limited to:
 - ⇒ Procedures for AT assessment;
 - ⇒ Decision-making in the consideration and acquisition of appropriate AT;
 - ⇒ AT device knowledge and use;
 - ⇒ High-tech and low-tech options;
 - ⇒ Emerging technology;
 - ⇒ Computer software and “smart phone” applications;

- ⇒ Implementation strategies to support successful use of AT in various settings, e.g. home, school, and work;
 - ⇒ Payment for AT; and
 - ⇒ Evaluation of the effectiveness of AT use.
- Increasing pre-service assistive technology coursework for professionals who work with individuals with I/DD (such as educators, occupational therapists, physical therapists, speech-language pathologists, behavior analysts, nurses, child development specialists).
 - Increasing the use of short-term loan programs provided through organizations such as ABLE Tech, Oklahoma Assistive Technology Center, Centers for Independent Living, and the Oklahoma Durable Medical Equipment Reuse Program as a routine part of the selection process to ensure decision-making is data-driven prior to purchase of AT.

REFERENCES

- Individuals with autism and their families Oklahoma Plan (July 2002). Retrieved from: http://www.okautism.org/okplan/documents/Oklahoma_Plan_Attachments_7.29.02.pdf
- Centers for Medicare and Medicaid Services (September 2014). Medicaid and CHIP FAQs: Services to address autism. Retrieved from: <http://www.medicaid.gov/Federal-Policy-Guidance/downloads/FAQ-09-24-2014.pdf>
- Centers for Medicare and Medicaid Services (June 2014). EPSDT - A guide for states: coverage in the Medicaid benefits for children and adolescents. Early and periodic screening, diagnostic and treatment (EPSDT). Retrieved from: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Downloads/EPSDT_Coverage_Guide.pdf
- Fullerton, A. (2013). Oklahoma DDSD waiting list study follow-up study.
- Hecht, E. & Reynolds, M. (2011). Building a national agenda for supporting families with a member with intellectual and developmental disabilities. Retrieved from: [www.http://supportstofamilies.org](http://supportstofamilies.org)
- Ingersoll, B., & Dvortcsak, A. (2010). *Teaching social communication: A practitioner's guide to parent training for children with autism*. New York: Guilford Press.
- Koegel, R.L., Bimbela, A., and Schreibman, L. (1996). Collateral effects of parent training on family interactions. *Journal of Autism and Developmental Disorders*, 26(3), 347-359.
- McConachie, H., & Diggle, T. (2006). Parent implemented early intervention for children with autism spectrum disorder: A systematic review. *Journal of Evaluation in Clinical Practice*, 13, 120-129. doi:10.1111/j.1365-2753.2006.00674.x
- Oklahoma Autism Network. (2014). *ConnectedKids: Training parents to use sevelopmental and behavioral strategies with their child with autism spectrum disorder*. Oklahoma City, OK: Oklahoma Autism Network.
- Strauss, K., Mancini, F., & Fava, L. (2013). Parent inclusion in early intensive behavior interventions for young children with ASD: a synthesis of meta-analyses from 2009 to 2011. *Research in Developmental Disabilities*, 34, 2967-2985.

APPENDICES



Mary Fallin
Governor

FILED

MAR 27 2015

OKLAHOMA SECRETARY
OF STATE

EXECUTIVE DEPARTMENT
EXECUTIVE ORDER 2015-17

By Executive Order 2013-8, I established the Governor's Blue Ribbon Panel for Developmental Disabilities (Blue Ribbon Panel), which was tasked with developing a comprehensive plan to support individuals with developmental disabilities and their families in acquiring reliable, high-quality care. This Blue Ribbon Panel, comprised of individuals with developmental disabilities, their family members, and professionals from developmental disability-related fields, is scheduled to sunset on April 1, 2015. Much important work, however, remains unfinished.

It is for this reason that, I, Mary Fallin, Governor of the State of Oklahoma, pursuant to the authority vested in me by Sections 1 and 2 of Article VI of the Oklahoma Constitution, hereby create an executive council of State officials (Executive Council), which shall be composed of the individuals designated in Section A, below. The Executive Council is hereby authorized, with the support and guidance of an Advisory Committee as established in Section B, below, to continue improving the range and quality of services accessible to Oklahomans with developmental disabilities.

More specifically, the Executive Council shall coordinate and improve the information tools that key State agencies make publicly available regarding existing developmental disability services and community resources (hereinafter referred to as "resources"). As part of this initiative, the Executive Council shall: 1) provide for the regular, periodic dissemination of information about resources to individuals on the waiver services request list that are specifically-tailored to each individual's need; 2) develop and implement resource training programs that are designed both for State workers to employ at the point of intake, and for families and self-advocates to access, more generally, throughout Oklahoma; and 3) improve the ease-of-use and prominence of information on State agency websites concerning resources, including the potential creation of a uniform disability information web portal. In addition, the Executive Council shall analyze how best to prioritize the waiver services request list so that need and urgency of care, and not just date of application, are considered in the ordering of the list.

The Executive Council, however, is by no means restricted from considering and recommending implementation of statutorily authorized State agency action(s) on unanticipated issues critical to the developmentally disabled community, or from championing necessary statutory amendments to me or the Legislature, where appropriate.

A. The Executive Council shall be composed of the following State officials:

1. The Chief Executive Officer of the Oklahoma Health Care Authority (OHCA), or his or her designee;
2. The State Superintendent of Public Instruction (Superintendent), or his or her designee;
3. The Director of the Oklahoma Department of Rehabilitation Services (DRS), or his or her designee;
4. The Commissioner of the Oklahoma Department of Mental Health and Substance Abuse Services (ODMHSAS), or his or her designee;
5. The Chancellor of the Oklahoma State System of Higher Education (Chancellor), or his or her designee;
6. Director of the Oklahoma Department of Human Services (DHS), or his or her designee;
7. The Secretary of Health and Human Services, or his or her designee; and
8. The Secretary of Education and Workforce Development, or his or her designee.

The Chair(s) of the Executive Council shall rotate on an annual basis, with the DHS representative serving as Chair in 2015; the OHCA and ODMHSAS representatives serving as co-Chairs in 2016; the Superintendent and Chancellor representatives serving as co-Chairs in 2017; and the DRS representative serving as Chair in 2018. Administrative support for the Executive Council and its Advisory Committee, as is deemed necessary and appropriate to ensure compliance with this Order, shall be provided by the State agency of that year's designated Chair; except that, OHCA shall be exclusively responsible for providing administrative support in 2016, and the Chancellor shall be exclusively responsible for providing administrative support in 2017.

B. The Advisory Committee shall be comprised of the ten (10) non ex-officio members of the Blue Ribbon Panel. The Executive Council is hereby authorized to appoint, as it deems necessary, replacements for any vacancies that arise on the Advisory Committee; however, in no event shall the Advisory Committee include less than six (6) members. The Advisory Committee's composition shall remain restricted to individuals with developmental disabilities, parents of adults or children with developmental disabilities, and individuals with professional experience regarding developmental disabilities. Advisory Committee members shall not be compensated for their services, but may be reimbursed for reasonable expenses incurred in the performance of their duties in the same manner as provided State employees by the State Travel Reimbursement Act.

This Executive Order shall be distributed to the Secretary of Health and Human Services, the Secretary of Education and Workforce Development, and all of the State officials designated to serve on the Executive Council in Section A, above, who shall cause the provisions of this Order to be implemented.

IN WITNESS WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Oklahoma to be affixed at Oklahoma City, Oklahoma, this 27th day of March, 2015.

BY THE GOVERNOR OF THE STATE OF OKLAHOMA



MARY FALLIN

ATTEST:


Acting Assistant SECRETARY OF STATE



Mary Fallin
Governor

FILED

MAR 05 2013

**OKLAHOMA SECRETARY
OF STATE**

**EXECUTIVE DEPARTMENT
EXECUTIVE ORDER 2013-8**

I, Mary Fallin, Governor of the State of Oklahoma, pursuant to the power vested in me by Sections 1 and 2 of Article VI of the Oklahoma Constitution hereby establish the Governor's Blue Ribbon Panel for Developmental Disabilities.

The Panel shall consist of ten (10) members with both the director of the Department of Rehabilitation Services ("DRS") and the director of the Oklahoma Developmental Disabilities Council serving as two (2) additional ex-officio members. The members shall be appointed by and serve at the pleasure of the Governor. The Governor shall also select the chair of the Panel who will then select a vice-chair. The Panel shall include the following members: individuals with developmental disabilities, parents of adults or children with developmental disabilities, and individuals with professional experience regarding developmental disabilities.

The purpose of the Panel shall be to develop a comprehensive plan to support individuals with developmental disabilities and their families, to address the state's growing wait list of thousands of individuals requesting DDSD community services, and to research and analyze best practices for the comprehensive delivery of high quality services to Oklahomans with developmental disabilities. The Panel shall also act in an advisory capacity to the Governor on all issues related to providing community services for individuals with developmental disabilities. The Panel shall submit an annual report to the Governor regarding its findings and shall sunset on March 5, 2015.

Administrative support for the Panel, including, but not limited to, personnel necessary to ensure the proper performance of the duties and responsibilities of the Panel, shall be provided by the Oklahoma Department of Human Services.

This Executive Order shall be distributed to the Secretary of Health and Human Services and the Oklahoma Department of Human Services, who shall cause the provisions of this Order to be implemented.

046000

IN WITNESS WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Oklahoma to be affixed at Oklahoma City this 5th day of March, 2013.

BY THE GOVERNOR OF THE STATE OF OKLAHOMA



MARY FALLIN

ATTEST


SECRETARY OF STATE

1907

A digital copy will be available at:
www.ouhsc.edu/thecenter

