

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

## **Executive Summary**

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

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## EXECUTIVE SUMMARY

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April 2015

## **Introduction**

This document is an overview of the findings and recommendations of the Blue Ribbon Panel. The Panel was comprised of individuals with intellectual and developmental disabilities (I/DD), family members of children and adults with I/DD and professionals with knowledge and experience in the field of I/DD. The Panel was established by Executive Order 2013-8 to:

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

## **Background**

Oklahoma, like other states, has a history of using Medicaid Waivers as a primary source of funding for services to support people with intellectual and developmental disabilities (I/DD). These Waiver services are administered by Developmental Disabilities Services (DDS) within the Department of Human Services (DHS). Currently, Oklahoma has over 7,100-people who are on a Waiver services request list, referred to as the "Waiting List" in this report. These are people of all ages who have applied for services from DDS, but will not know if they qualify until they reach the top of the list and submit the necessary paperwork for an eligibility determination. Those on the Waiting List are ranked by date of application and moved off the list as funds become available through a first come, first served approach. The list has grown over the years due to the fact that there are not enough funds to serve all who are requesting the services.

The Waiting List has become a primary focus of DDS. The Oklahoma Legislature has earmarked funds for several years, specifically for the purpose of moving people off the Waiting List. Lost in the consuming focus of working the list is the question of whether or not people's needs are being met while they wait. Data show that 75 per cent of those waiting for Waiver services receive some other type of assistance through DHS or Medicaid and that 70% have I/DD. What is unknown is the extent to which individuals receive services through non-DHS programs in the Departments of Health, Rehabilitation Services, Mental Health, Oklahoma Health Care Authority and Education. In the absence of such comprehensive service data, it was clear to the Panel that the Waiting List is a measure of insufficient program capacity but is not a reliable measure of unmet need.

## Findings

The Panel found that the intensity of the State’s effort needs to change. Currently efforts are focused on managing the Waiting List for services from one agency supporting individuals with I/DD. The focus needs to be on ensuring that individuals have a range of coordinated services from various agencies throughout their lifespan. The Panel further found that 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 relied on to support members with I/DD in the future. The Panel, therefore, organized its recommendations around three areas or “pillars” of support for families as described in the document entitled, *Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities*. Those pillars are described below.

Information and Navigation	Networking and Community Connections	Services and Goods Directed to Family Unit
<ul style="list-style-type: none"> <li>• Best practices and values within and outside of disability services</li> <li>• Accessing and coordinating community supports</li> <li>• Advocacy and Leadership skills</li> <li>• Useful information</li> </ul>	<ul style="list-style-type: none"> <li>• Family-to-Family Support</li> <li>• Self-advocacy organizations</li> <li>• Sib-shops</li> <li>• Support Groups</li> <li>• Professional Counseling</li> <li>• Non-disability community support</li> </ul>	<ul style="list-style-type: none"> <li>• Planning for current and future needs</li> <li>• Respite/Childcare</li> <li>• Adaptive equipment</li> <li>• Crisis prevention and intervention</li> <li>• Systems navigation</li> <li>• Home modifications</li> <li>• Health and wellness management</li> </ul>

## Recommendations

The Panel’s first set of recommendations are focused on the creation of coordinated services between agencies and providing necessary information to families regardless of which agency is the first point of contact. A second round of recommendations is directed toward furthering the technical and emotional support of families, revisiting the existing criteria for service access of the Developmental Disabilities Services (DDS) Waivers and identifying critical supports that will keep families engaged as long-term caregivers/support for individuals with I/DD.

A summary of the recommendations is provided below along with several strategies, which focus on better support for individuals and families and building on the strengths of the Oklahoma service systems, organizations, and communities.

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

Individuals on the Waiting List may be waiting for help that could be provided through other avenues if they knew those avenues were available to them. The Panel identified a significant need for improved information and training about community services and resources. By focusing on improving information access for both the service recipients and the service coordinators, Oklahomans with I/DD and their families can be better equipped to obtain what they need right away

The Panel recommends that the Governor create an Executive Council composed of heads of agencies providing support services to individuals with I/DD, and an Advisory Committee composed of individuals with I/DD, parents of adults or children with I/DD and individuals with professional experience regarding I/DD. The initial charge to the Council is to strengthen information access in each agency.

**Strategy #2: Provide Resource Navigation and Improve Inter-Agency Service Coordination**  
*Knowledge and Skills, Emotional Supports*

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 and expertise in identifying and obtaining services for individuals and families. 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 Panel recommends the Governor charge the Executive Council with improving the coordination of services for Oklahomans with disabilities across the life span. The improvements should include: a) strategies to provide resource navigation, b) emotional supports to individuals and families, c) strengthened service coordination at critical life points, c) a process for all agencies to regularly evaluate policies, procedures, and services, and d) simplified access for services and programs that involve more than one agency.

**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*

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

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

*Day-to-Day Needs*

The Panel believes that lifelong Waiver supports should be reserved for those with the highest support needs. Given the goal of supporting individuals and families, using the date of application for services and a “first come, first served” priority for admission 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.

The Panel recommends that the Waiting List for Developmental Disabilities Services (DDS) Waiver services be prioritized based on the individual’s and the family’s needs. To achieve that outcome the Panel recommends 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 individuals on the Waiting List. Pending applications will be reprioritized based on needs. The Panel recommends that the Governor enable the Executive Council to provide guidance to DHS related to the development and implementation of this system. The Panel also recommends 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*

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. The Panel identified barriers to accessing some 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, included employment and/or transition services, respite services, autism services, and assistive technology.



These recommendations were submitted to the Governor. On March 27, 2015, the Governor issued Executive Order 2015-17, which established the Executive Council “to continue improving the range and quality of services accessible to Oklahomans with developmental disabilities”. Members of the Blue Ribbon Panel will continue as an Advisory Committee.

