

GO Project's Summary of the House Interim Committee on Human Services and Housing Informational Meeting regarding Intellectual and Developmental Disabilities Eligibility and Services on January 11, 2018

Update by Lilia Teninty, Director of the Office of Developmental Disability Services (ODDS):

Lilia reported on the current status of the agency's actions to reduce spending in this current two-year budget cycle by \$12 million general fund dollars on top of the \$30 million general fund cut the legislature imposed in the 2017 session:

- \$1.3 million general fund savings has been identified from a reduction of maintenance contracts and rent subsidies in Community Integration Project (CIP) homes. It is important to note that this will not impact the Fairview Housing Trust Fund.
- The Oregon Needs Assessment (ONA) tool has been developed; and will be used to create service level groups to help inform service authorization amounts and rates. The ONA has been piloted but is going through additional reliability reviews.
- ODDS is working with case management entities (CDDPs and Brokerages) to create dedicated assessment staff positions to administer the ONA. The State understands that this extra staffing model is not included in the current funding agreements and is working to make adjustments. ODDS will conduct training on the ONA to train assessors once the validation process is complete.
- This initiative to revise the assessment and service planning process will change many of the procedures and processes used by ODDS, Service Coordinators, Personal Agents, provider agencies, individuals, and families. ODDS will work to develop a communication strategy, informational materials, online and other types of training. The final assessment tool and new planning process will require approval from the Centers for Medicare & Medicaid Services.
- ODDS has contracted a strategic planning facilitator to work with stakeholders on developing a strategic vision for the DD service system. ODDS expects the resulting strategic plan will support additional steps to improve services while containing overall cost.
- ODDS also plans to review the current eligibility Oregon Administrative Rule 411-320-0080 to ensure that the intent of the federal statute and rules are clear and consistent. ODDS will evaluate how Level of Care criteria aligns with the federal requirements and new DSM-5 diagnoses, as well as clarify and add definitions of terms as required.
- Unless the legislature removes the budget cut requirement, ODDS may be forced to make changes to eligibility criteria that would shut the door to services for some families! ODDS was directed to change its federal waivers so the State could begin to change enrollment criteria and place caps on the number of children who could access in-home services. If CMS approval is received and the change is implemented by July

2018, it would only save an estimated \$360,000 in general funds this biennium and \$2.7 million general funds in the following biennium.

These changes would begin in July of this year by capping the number of children who could access DD Services and conclude in October 2019 when children whose parental income exceeds Medicaid income criteria would be forced back into system where out of home placement would be primary option if a child needed support.

The costs to the systems and to families would be higher in the end. It was estimated that the average cost of children's in-home services is only \$2,000 per month; whereas foster care costs \$5,000 monthly and children's group residential care is approximately \$11,000 per month per child.

Lilia noted that while implementing the K Plan has increased expenditures, families now have access to the needed supports and services to remain at home, and that while there are more children accessing services, the numbers will begin to level out.

Testimony from Leslie Sutton, Policy Director for the Oregon Council on Developmental Disabilities:

Leslie began her testimony with the statement that "Oregon is strongest when all people, no matter their age, have supports they need to be members of their community. This includes supporting families to raise their children in stable and loving homes."

She reminded legislators that "In 2013, the Oregon legislature enacted a statement of values in Oregon law to ensure that Oregon's IDD program prioritizes services that support community integration, self-determination and provide assistance to families who raise their children experiencing developmental disabilities at home. ORS 427.007(1)."

Ms. Sutton noted that the State's attempt to find savings by creating waitlists and then eventually barring some children from services because of their parent's income exceeds Medicaid poverty levels constitutes a philosophical change in DD services that will have lasting social and economic ramifications for children, their families and whole communities.

"We question whether long-term sustainability can be achieved by cutting people out of services. Removing access to services has costly, long-term consequences to children, families and our community. These children and families will still need services and will be forced into crisis, isolation and then into programs that are more expensive and less appropriate to meet their needs." Leslie explained.

She concluded her testimony with this statement: "These traumatic consequences will have a lasting impact on children, families and communities. This is exactly what we have sought to avoid by putting strong values in Oregon law. Rather than making changes to eligibility now, it seems a more prudent course of action might be to allow the caseloads to plateau in 2019 as forecasted and give sustainability measures already underway time to stabilize program costs so that Oregon children experiencing DD continue to have opportunities to access supports and succeed in our communities."

Testimony from Dianna Hansen, Director of the Central Oregon Disability Support Network:

Dianna's testimony provided a clear and realistic view of what access to services means for families like hers. "DD services provide families with in-home supports such as behavior supports to help a family prevent or react to different behavior crisis, personal support workers, relief care and access to the Oregon Health Plan. Many of these supports cannot be accessed except through DD services. They are a critical lifeline that helps to hold families together."

She explained to the legislative committee that the Oregon Health Plan gives coverage as a primary or secondary form of medical insurance for children who are eligible. Dianna shared that access to OHP is incredibly important to so many families who otherwise would spending thousands of dollars each year for co-pays, deductibles and medical needs not covered by private insurance.

In addition to sharing her own family's story, Dianna shared two other examples from families she's worked with:

"For one single mother whose 10 year old daughter was living in a state residential facility, DD services meant they were able to bring her home and back into her community and enroll her back into her neighborhood school with her peers and siblings. At home they were able to access personal support workers and a behavior specialist to assist with skills training, some technology to assist with communication, a few home modifications to make the home a safe place to be and relief care to give that Mom an occasional break or night away to get a full night's sleep."

"For another family, DD services means being able to access behavior supports when they were at their wits end, not knowing where to turn and if they could continue to keep their child at home. They were able to access therapies and medical support they were not able to afford without OHP, and having the help of a personal support worker so when they go out as a family they can give attention to all their children instead of just the one with the highest needs. It means this family can focus on their entire family now and their future together."

Dianna reported that if either of these families lost DD services, they would no longer be able to support their children at home and their children would be placed in a residential facility at a much higher cost as well as loss to the families and their communities.

She went on to say that "For our communities, if families lose access to DD services it would result in higher demand for police, medical, emergency room and educators for crisis support. Families will be torn apart as they will not be able to support their children in the community home and be forced to send their children to a residential facility."

Dianna reminded the legislative committee that Oregon's old DD system didn't offer families much support unless they were willing to say they could no longer care for their child safely at home. "Many parents, children and families are still traumatized because they were so desperate for support that they signed a document saying they could not care for their own child. Let's not take a step backward by forcing families into this corner."

She continued, "Our old system also meant when kids turned 18, and could access DD services, they likely needed more support than they may have if they were well supported, and stable, in childhood. We are in a new era of providing proactive support to families with children – where they don't have to enter crisis in order to get support – it makes me wonder what kind of adults with DD this generation could raise if they were well supported from the start."

Dianna noted that, "Effective supports that help a child have typical life experiences will result in adults with DD who are active and engaged in their community and who are able to leverage integrated supports. They will be better connected and more likely to find meaningful jobs, they will be engaged with community resources that decrease the burden of support on state funded services. Effective support from the start can change the trajectory for kids."

She wrapped up her emotional testimony with a powerful statement, "Oregon is stronger when people have the supports they need to live and work. For many families the lifeline supports that allow them to remain a family are DD services. The threat of losing these services or not being able to access the services when they need them has many families panicked."



Video of this Informational Meeting can be accessed with this link:
http://oregon.granicus.com/MediaPlayer.php?clip_id=24356