# PUBLIC TESTIMONY SUMMARY

# I-900 STATE AUDITOR'S PERFORMANCE AUDIT:

# Developmental Disabilities in Washington: Increasing Access and Equality (July 31, 2013)

As Heard by the Joint Legislative Audit & Review Sub-Committee on I-900 Performance Audits on August 14, 2013

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# Title: Developmental Disabilities in Washington: Increasing Access and Equality

## **Audit Scope and Objectives:**

SAO reports that this audit assessed Washington's Developmental Disabilities Program, evaluating it against national benchmarks, to answer two key questions:

- Does Washington's program provide effective services for people with developmental disabilities?
- What steps can Washington take to improve its Developmental Disabilities Program?

SAO indicates it evaluated Washington's program using state and national data, as well as interviewing clients, family members, and other stakeholders. SAO says it compared the number of people Washington serves, how it serves them, and its expenditures to national data; matched client assessment results and residential setting information with expenditure data to learn how Washington serves clients with various needs and the costs associated with those services; and reviewed employment support outcome data, including the number of people served, hours of participation, and monthly wages by person. SAO also says it compared Washington's results for National Core Indicator outcome measure surveys to other states' results.

SAO reports that it also reviewed policies, procedures, and other documents, conducted interviews, and held ten small group discussions.

# **SAO Findings:**

#### Access to Services

 Many eligible people and their families do not receive services from Washington's Developmental Disabilities Program, effectively creating a system of "haves" and "have-nots."

## **SAO Findings** (continued)

#### **Service Delivery**

- Most clients receive services in community settings appropriate to their needs, but Washington maintains segregated institutional housing for some.
- Washington relies heavily on its Residential Habilitation Centers (RHCs) for services that can be better provided in the community.
- The real gap in crisis care and a perceived gap in respite care has led to a reliance on RHCs for both services.
- Washington could do more to support people with disabilities by developing additional community-based resources.

# **Funding**

- Washington does not adequately fund services for people with developmental disabilities, and funds are not distributed equitably.
- Washington maintains costly residential service options for some clients while spending less on others.

# **Quality of Services and Results for Clients**

- Washington routinely measures its program results against performance benchmarks.
- Those receiving services report positive results and high levels of satisfaction.
- Washington is a national leader in employment services, but we found that the overall hours worked are low, and where clients work and what they do varies by county.

#### **SAO Recommendations:**

To better balance funding inequities and reduce the waitlist for services, SAO recommends that: The Legislature set policy that directs the Developmental Disabilities Administration to develop strategies to maximize using cost-effective service options. Strategies may include:

- Reducing the number of Residential Habilitation Centers.
- Expanding crisis stabilization and emergency respite services in the community, relying less on Residential Habilitation Centers for these services.
- Providing resources to build peer support networks in the community to aid clients and their families with such needs as transportation, respite, and day activities.

The Legislature set policy to reduce the number of eligible people awaiting services:

- Set targets for how much to reduce the waitlist by when. SAO provides three funding scenarios to reduce the waitlist over six years.
- Direct the Administration to develop strategies and a budget proposal for prioritizing the people waiting for services by their needs. The proposal should include funding for case resource managers for people on the waitlist and for collecting information on the services people need, the level of support they require, and how urgent their needs are.

To improve its employment program, the Administration should:

• Provide financial incentives to counties to encourage equal access to integrated, individual employment for clients regardless of where they live in the state.

Agency Responses in Audit Report?	Yes, beginning on page 35.
Legislative Action Requested?	Yes; the first two recommendations are to the Legislature.

## **Agencies Testifying:**

The Department of Social and Health Services (Evelyn Perez, Assistant Secretary, Developmental Disabilities Division)

The Office of Financial Management (Ryan Black, Budget Assistant)

## **Summary of Testimony from Audited Agencies:**

The report's findings and recommendations will assist us to provide quality support for individuals with developmental disabilities and their families. We agree with the findings and appreciate the recognition that DSHS faces resource challenges in supporting individuals who are on the waitlist and who do not receive support from our Administration. We support efforts to increase individualized employment for people with developmental disabilities, and we have made some progress in implementing assessments that recognize individuals with more needs require more hours. This is an improvement over prior years when we used flat funding. We also recognize this is not a cost-neutral proposition. We do know the benefit is great once a person is employed, becomes more independent, and has reduced need for a job coach. In the long run, the support needs are less expensive.

This audit illustrates the challenges of providing cost-effective service options in times of limited and constrained resources. While some of the policy recommendations are directed to the Legislature, we realize OFM and the executive branch have a role, and we look forward to working with the Legislature to address these issues.

# **Other Parties Testifying:**

Emily Rogers, Self-Advocates in Leadership
Darla Helt, Washington State Parent Coalitions
Sue Elliott, The Arc of Washington State
Ed Holen, Washington State Disabilities Council
Julianne Moore, Washington Federation of State Employees
Matt Zuvich, Washington Federation of State Employees

# **Summary of Testimony from Other Parties:**

Ours is a large coalition of folks with developmental disabilities who are interested in shaping public policy. The members of our group could get behind many of the recommendations in the report; however, there is opposition to the recommendation about the employment program. Employment providers already get paid a lot of money. There is a concern that more money does not necessarily equal more jobs. DSHS should increase contract monitoring for counties, and the county contracts should include specific outcomes that are consistent statewide, with the goal of folks having jobs.

Our coalition represents the family members of those who are receiving these services, and we are the 60 percent who are at home taking care of these individuals. We support the recommendations in much of the audit. We request that respite options be increased within the community setting so that it provides a more user-friendly option for our loved ones and for the families trying to access those services. We ask that you support the recommendation about crisis stabilization. We encourage you to look at the recommendations and continue to work

toward serving those on the non-paid services caseload. We like the idea of the peer-to-peer network.

We are a nonprofit organization that advocates for people with developmental disabilities. Unfortunately the findings in the two I-900 reports did not come as a surprise. We have shared with you for years that we have an under-funded, broken system in our state. It's a complicated system where the counties administer day employment and the state does the rest, and oftentimes families do not know the entry point to use. We need funding to expand community respite, to begin addressing the waiting list, and to provide additional case managers. While it is a difficult decision, we need to consider further consolidating the residential habilitation centers.

We do not support the finding about giving counties additional financial incentives. If the Administration did a better job of contract monitoring and used outcome-based contracts, this would be another way to hold the counties and providers accountable. We need to change the statute so that people can get more than one day-service at a time. We also want to make sure other family members besides parents can receive respite and to change the training requirements for respite providers.

Ours is a federally funded organization in the state to provide advocacy and capacity-building recommendations and activities. For two years, our focus has been on the no-paid services caseload. Based on our review, people on the no-paid services caseload look no different than people on the paid services caseload. We are grateful that last session the Legislature provided some money allowing an estimated 1500 people to receive respite and related services coming off of the no-paid services caseload.

We are excited about several of the policy areas pointed out in the study. To enhance access to services, it's important to examine eligibility and the process to determine eligibility. We think services should be based on need, not on crises. We could look at providing incentives so that families set aside maybe their own resources to plan for the future needs of their sons and daughters. We are hopeful for action in the next session to support these families.

I work for a residential habilitation center, and I represent Action DD, an advocacy group for people with disabilities. This study is another blueprint to continue attacks on the residential habilitation centers (RHCs). The idea that people who live in RHCs are segregated is not true. People who live in RHCs are part of their communities. I spend time volunteering for people who are not in RHCs, and a lot of these people never leave their homes. I also spend time with people who do get services but who do not get enough services in the community, trying to keep them safe. A report released last year noted that people out in the community are not safe. We need to look at this holistically, looking at the whole system.

The cost of care is going to be the same, no matter the setting. The people with high acuity needs who need hours of nursing care a day are getting 24 hours in an RHC, while the most you can get in the community is 20. The people who live in the RHCs are the three percent of the DD population who are profoundly disabled. Most of them have lived there for 20 or 40 years. These are their homes. We who work in the RHCs have advocated for the RHCs to become centers of excellence to help people in the community stay in the community.

It's true that there is not enough crisis respite, and it should be available across the state. Many people drive to Yakima Valley School to get competent respite. They have tried the other choices for respite, and they come to Yakima Valley School and the other RHCs where the families don't have to worry that the care will be inadequate, and they know their family member is safe. You get that care from state employees because they are long-term in their jobs, they do

get adequate salaries, and they get health insurance, which is a big issue for workers earning minimum wage.

We appreciate the observation in the audit that it is the lack of resources that drives the size of the waiting list. It would require a significant investment for the Legislature to address this. Based on a court decision, people with developmental disabilities have a right to choose where they want to be, and the state has a responsibility to help them get the services they need. We are concerned about the continued effort to downsize, consolidate, and close the RHCs, which are a vital component of the safety net for these people. RHCs could play a bigger role in serving the unserved. With changes, people in the community could access the dentistry, the med help, and the occupational therapy services that are already in the RHCs. There would have to be a waiver to allow that to happen.

We agree that there is not enough respite care. It is true that most people with developmental disabilities are being served in their homes, and that may be the best place for them to be. We add that, over a lifetime, the caregivers in the home get tired, and the needs of the loved one may change. Sometimes the needs may become so acute that they need to be in a place where they can have care all day.

The situation we are always put in is to compare the costs in the community to the costs in an RHC. This audit talks about a daily rate or a per-year rate that may include staff care, but there are costs on top of that coming out of Medicaid/Medicare that still impact the State General Fund. Those costs need to be included if the General Fund is what we are looking at. At the same time, the rate for an RHC bed looks high, but it is an all-inclusive price (food, shelter, durable goods, occupational therapy, etc.). The audit also doesn't mention the 54 percent federal reimbursement at the RHCs.