



# The System of Supports for People with Developmental Disabilities

## BRIEFING REPORT

### Vision

The future system of supports for people with developmental disabilities needs to meet more of the significant and growing unmet need, respond to the shift in consumer preferences toward community integration and self-direction, and support consumers to live in, contribute to, and participate in their communities as much as possible. It will need to rely on and support shared responsibility with individuals and families. Not only are those the directions preferred by most families and consumers, but they make the most efficient use of resources. Governor Gregoire has outlined the first steps toward this vision in her policy statement: Reforming How We Care for Washingtonians With Developmental Disabilities.

### What Challenges Are in Front of Us?

The current DDD system of supports reaches only 63% of the 38,000 Washington residents with a qualifying developmental disability. About 18,000 are under age eighteen and 20,000 are eighteen or older. The DSHS ADSA Division of Developmental Disabilities (DDD) provides support to approximately 24,000 people who are living in the community. Another 915 clients (December 2009) live in one of the five Residential Habilitation Centers (RHCs).

In the next decade the number of Washington residents with a developmental disability will increase to 51,000, driven by several factors:

- The prevalence of autism spectrum disorders is rapidly increasing and is now estimated at 1:110 children (up from 1:160 ten years ago).
- Medical advancements ensure that more medically fragile children survive and need supports.
- The impacts of public education, improvements in services, community inclusion programs, and family support initiatives have allowed people to remain in their own homes.
- Individuals with Disabilities Education Act, Head Start, Child Find, and other early intervention programs have identified children in need of service, increasing demand.
- People graduating from public school expect residential supports, employment, and day services.
- The prevalence of public school graduates has not increased in recent years but early identification and personal expectations have increased the demand for public services.

Washington serves proportionately more people in institutions than most other states. Changes are needed to increase the number of clients who receive safe, high quality integrated support in the community. These changes will also free up badly needed funds to extend better support for more clients and need to be accompanied by long-term investments to gradually build a system of supports to deliver better service.

### Families, Advocates, and Consumers Point to Practical Challenges

Focus groups in 2010 involving a broad cross-section of about 100 families and self-advocates identified several areas of daily challenges:

- Getting personal care and respite help (particularly single parents and those without nearby relatives).

- Receiving medical and/or behavioral support in the community.
- Lack of community options for people transitioning from institutions.
- Caregivers planning for “what happens when I’m gone?”
- Navigating the system and learning about practical issues, such as guardianship.
- Learning how to address the unique social and learning needs of children with autism.
- Using public transportation.

## **Where Are We Going?**

To best prepare for the challenges of the next decade will require several key areas of strategic focus:

- Greater reliance (with improved supports) on families of both children and adults.
- Greater investment in locally available and community based options that help people live in their community.
- Greater investment in support directed by consumers and their families.
- Commitment to individual and family, strengths-based, assessment and service planning.
- Services that recognize family caregivers are providing support for longer periods of their lives and the caregivers are aging.
- Making added investment in community supports and focusing critical expertise currently at RHCs toward future community needs.

## **How Will We Get There?**

Budget and policy investments under consideration for FY 2012-2013 include:

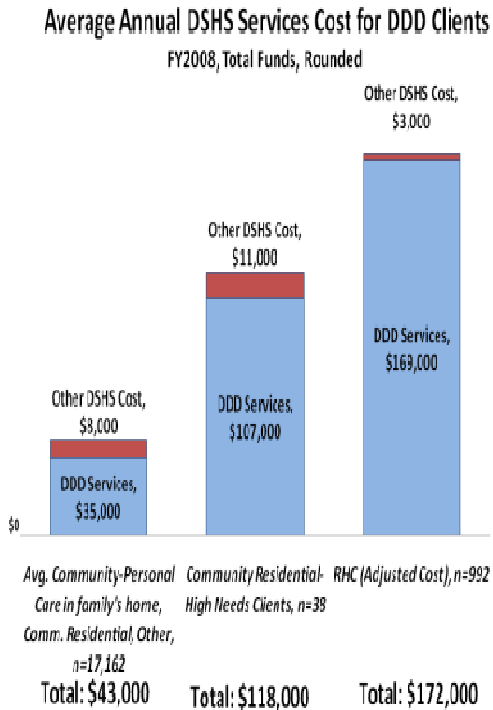
- Re-envisioning how to capitalize on expertise from RHCs to strengthen communities:
  - Expand delivery to the community of RHC professional services, including dental.
  - Use RHC health professionals to support health care worker training in DD issues.
  - Provide additional consulting to community resources by RHC specialists.
- Begin building the necessary community supports for the different needs of children, young adults, and adults:
  - Creation of state-operated short-term crisis care, affiliated with the existing State Operated Living Alternatives (SOLAs).
  - Increase in community-based respite capacity.
  - Creation of small (six bed) community-based Intermediate Care Facilities for the Mentally Retarded (ICF/MRs).
  - Expansion of intensive in-home behavioral support for children.
  - Expansion of support for people with aging family caregivers.
  - Preservation of state-only funding for family support services.
- Investment in “Critical Community Placements” as a less costly alternative for people who would otherwise drive institutional growth.
- Gradual decrease in the number of RHC beds through phased closures and transfers to community support.
- Increased staff capacity to support clients in transition from RHCs to community living.

## **Investing in the Community While Re-envisioning the Role of RHC Staff**

Determining the right capacity for the components of the DDD system of supports needs to first recognize the current and future preferences on the part of DDD consumers for community integration, inclusion, and participation. Secondly, it is important that expenditures of public funds respond to that demand by making

community options more available. A related question is how to capitalize on the staff expertise that currently exists in the RHCs. Most analyses recommend continued phased downsizing of institutions and a change in role to support communities with emergency crisis respite, community consultation and ambulatory care/clinical outreach services, focused on providing support to people with autism and/or complex behavioral and medical needs.

### While Costs Differ, People with Similar Needs are Served in All Settings



### Overlap in Level of Support Needs Exists for All DDD Clients in All Settings

The findings below are from a January 2010 study by the DSHS Research and Data Analysis Division, Assessment findings for Persons With Developmental Disabilities Served in Institutional and Community Settings. The study compared the assessments of people who recently were admitted or recently left RHCs with the assessments of people in other community settings. The study found:

- There were clients with very high support need scores served in community based settings.
- Despite differences in average support need scores between the three client groups, there was much overlap between these groups in the level of support needed in areas of basic living (e.g., home living, community living, health and safety).
- There is much less apparent overlap in the level of behavioral support needs for clients served in the three settings (institutions, community residential and other community-based), although clients with very high behavioral support needs were present in all three groups.
- There were no statistically significant differences in assessment scores between clients in Institutions and those in Community Residential programs, except for the behavior scale and some medical scale scores. However, the clients who were assessed with the highest behavioral and medical scale scores were residing in the community rather than in institutions. This may indicate that a capacity issue exists in community residential settings that support individuals with high behavioral and medical needs.

To allow for better planning and comparisons across programs an assessment of the acuity and needs of all current RHC residents is currently underway, based on a request from the Governor and Legislature.