

REPORT TO THE LEGISLATURE

**Rethinking Intellectual and Developmental Disability Policy to
Empower Clients, Develop Providers, and Improve Services**

Engrossed Substitute House Bill 1109, Sec. 203(2)(e)(i)
November 27, 2019

Introductory Letter	1
1. Community residential services: It's time to mind the gap	
2. Cross-system coordination: It takes a village	
3. State-operated nursing facilities: A sound model in a state of disrepair	
4. Federal funding for state-operated intermediate care facilities: The future hangs in the balance	
A. Background	4
1. Community residential services	
2. Overview of residential habilitation centers	
3. The successful closure of Rainier PAT A	
B. Ruckelshaus Workgroup Recommendations	8
1. Increase the capabilities of community residential services	
2. Improve cross-system coordination	
3. Invest in state-operated nursing facilities	
4. Operate intermediate care facilities as a short-term intervention	
C. Conclusion	11
D. Ruckelshaus Center Addendum	13
E. Appendices	17
1. Paid residential services for adults	
2. Adult residential service information by setting	
3. Distribution of DDA Clients by Paid Residential Service Showing Average Daily Rate in Fiscal Year 2018	
F. Glossary	20
G. Acknowledgements	21

Dear Legislators,

In 2018, we accepted the Legislature’s invitation to discuss how to provide appropriate services for individuals who currently reside in residential habilitation centers.¹ We came together on behalf of diverse constituencies and we hold divergent views. The William D. Ruckelshaus Center (WSU and UW) provided us with both process design and neutral facilitation, guiding us through nearly two years of cautious deliberation and consensus building. We have created this consensus-based vision to transform the continuum of care for people with intellectual and developmental disabilities (I/DD).

Our report abstains from philosophical reflection and focuses instead on how to meet each client’s needs through a person-centered, legally sound, and federally funded service delivery system. Our recommendations address both state-operated facilities and community-based supports because each exists in relation to the other.

The first step toward transforming the continuum of care for individuals with I/DD requires substantial investment in community residential service options. Recognizing that the system as a whole will not succeed if it fails any individuals—including those with complex behavioral needs—immediate and substantial investment in state-operated community residential options should be the Legislature’s first priority.

If acted upon, the recommendations contained in this report will expand the capabilities of community residential services, strengthen state-operated nursing care, improve cross-system coordination, and reduce the risk of federal divestment from intermediate care facilities.

Our Ruckelshaus workgroup recommendations are predicated on the following findings:

1. Community residential services: It’s time to mind the gap

Around a single fact swirls a wider crisis—Washington lacks appropriate community residential services for individuals with I/DD. This shortage prevents people from living more independently and amplifies the threat of federal divestment from state-operated ICFs. This report explains how to improve cross-system coordination, retool state-operated nursing services, and address state-operated intermediate care facilities. However, these recommendations will fail to achieve their promise without immediate investment in state-operated and contracted community residential services. The workgroup recommends that the Legislature examine options (i.e., caseload forecasting) to more accurately project demand for DDA waiver services and provide funding that is predictable and aligned with caseload demand. Recommendations, Section 1, details the necessary investments.

2. Cross-system coordination: It takes a village

People with I/DD are people first. Like all humanity, some develop dementia, some require help understanding the full weight of the questions they face, and some endanger themselves or others. But unlike most others, these individuals face systems that assume their intellectual or developmental disability overshadows their other characteristics. All too often, professionals and paraprofessionals mistakenly assume that disability, not a mental health condition, individual preference, or the natural aging process, explains the whole. The resulting treatment—whether

¹ Engrossed Substitute Senate Bill 6032, Sec. 205(2)(g)(i).

medical or otherwise—is often marked by missed connections and poor outcomes. Recommendations, Section 2, addresses many of these issues.

3. State-operated nursing facilities: A sound model in a state of disrepair

The state-operated nursing facilities occupy buildings that have reached, or will shortly reach, the end of their useful lives. The services delivered in these buildings are essential and approximately 256 individuals depend on them.² The Y-shaped buildings that house the Fircrest nursing facility raise immediate concern. Recommendations, Section 3, describes the necessary next step.

4. Federal funding for state-operated intermediate care facilities: The future hangs in the balance

It is probable federal regulators will decertify one or more additional state-operated intermediate care facilities within the coming biennium. Of the five that existed this time last year, one was ordered closed after federal regulators stripped its certification and withdrew funding. Of the four that remain, one is currently denied federal funding for new admissions due to treatment gaps and safety violations, and another is out of compliance with active treatment requirements. Recommendations, Section 4, explains how to redesign state-operated ICFs to meet short-term crisis intervention and stabilization needs.

Thank you for the opportunity to recommend a series of steps that, if taken together, will transform the developmental disabilities continuum of care. We believe that these recommendations chart the course toward a brighter future for Washingtonians with I/DD, their families, and our state as a whole. We hope you agree.

Sincerely,

The Honorable John Braun
State Senate

The Honorable Karen Keiser
State Senate

The Honorable June Robinson
House of Representatives

The Honorable Chris Corry
House of Representatives

Terri Anderson
Friends of Fircrest

Jeff Carter
Friends of Rainier

Matt Zuvich
Washington Federation of State Employees

Lindsey Grad
Service Employees International Union

Sue Elliott
Executive Director
The Arc of Washington State

Julia Bell
Council Chair
Developmental Disabilities Council

² State-operated nursing facility census in October 2019.

Evelyn Perez
Assistant Secretary
Developmental Disabilities Administration

Bill Moss
Assistant Secretary
Aging and Long-Term Support Administration

Amber Leaders
Senior Health Policy Advisor
Office of the Governor

A. Background

1. Community Residential

Of DDA's 48,422 clients an overwhelming majority—71% as of July 1, 2019—live with and receive support from a parent or other relative.³ As clients age, their support needs increase; as the relatives who support them age, the support they are able to provide typically declines. Many clients who are presently served in their own home or in a relative's home will require publicly financed residential services later in their lives.

Approximately 6,400 clients reside in DDA-funded home and community-based residential settings. Although the majority of community residential providers are contractors, state-operated programs play a vital role for individuals with complex behavioral needs.

Current participation in DDA residential programs does not reflect true demand. The current model of forecast-based maintenance level funding for DDA waiver services is limited to contracted community residential services and does not recognize that caseload demand for home and community-based services continues to exceed funded waiver capacity.

Appendix 1, *Paid Residential Services for Adults*, provides a brief narrative description of the primary paid residential services. Appendix 2, *Adult Residential Service Information by Setting*, is a simple reference guide that compares variables across settings.

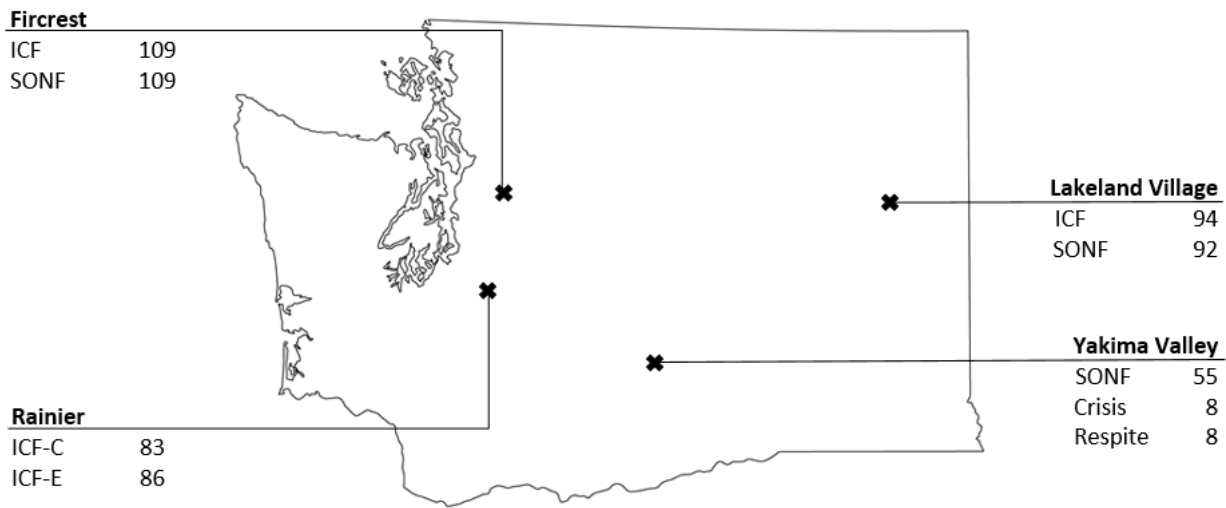
2. Residential Habilitation Centers

DDA operates four residential habilitation centers (RHCs) for individuals with I/DD. Each of these centers has a unique campus and composition: Fircrest and Lakeland each contain a state-operated nursing facility and an intermediate care facility; Rainier houses two intermediate care facilities; and Yakima Valley is a single state-operated nursing facility, plus an eight-bed respite facility and an eight-bed crisis stabilization program. In sum, the four RHCs include a total of seven separately certified long-term facilities—three state-operated nursing facilities (SONFs) and four ICFs. ICFs are primarily teaching facilities where the goal is to help clients develop skills they need to live in a less restrictive setting.

Residential care models vary in their cost and state-operated intermediate care facilities are the most expensive publicly funded care model for adults with I/DD in Washington State. Of DDA's approximately 48,422 enrolled clients, 372 reside in a state-operated ICF. The majority of the current demand for ICF services comes from legacy families whose loved ones have resided in an RHC for a decade or longer.

³ Developmental Disabilities Administration 2019 Caseload and Cost Report, page 14.

Residential Habilitation Center Census by Certified Facility in October 2019⁴



Total census: 644

For decades Washington’s ICFs were stable with respect to federal funding—but this is no longer true. The Great Recession led to cuts in RHC staffing and deferral of millions of dollars for physical plant maintenance that have not been fully restored. These cuts might have been survivable, but a stricter enforcement posture from the federal regulators led to broader and more fundamental citations against Washington’s ICFs, denial of payment for new admissions, special agreements in lieu of immediate termination of certification, and ultimately the decertification of Rainier PAT A in 2019.

As the legal landscape changed, the Department responded with a multifaceted strategy that included hiring two national consulting firms, adding staff, establishing a statewide quality assurance unit, and providing extensive on-site technical assistance. Despite these efforts, state-run ICFs continue to face considerable risk of federal divestment.

At the heart of this risk are issues related to federal active treatment requirements. Under federal law, intermediate care is available only for individuals in need of, and receiving, active treatment services. Active treatment refers to a continuous, aggressive, and consistently implemented program of specialized and generic training, treatment, and health or related services directed toward helping the client function with as much self-determination and independence as possible.⁵ The demanding nature of these federal requirements has resulted in citations for gaps in active treatment as short as 20 minutes.

Table 1 identifies each RHC, its constituent facilities, and their pertinent Medicaid certification history.

⁴ Data collected on October 28, 2019

⁵ <https://www.medicaid.gov/medicaid/ltss/institutional/icfid/index.html> (Accessed October 25, 2019).

Table 1: Medicaid Certification History by Facility

Campus	Facility Type	Certification History
Fircrest	Intermediate care facility	Decertified 2018 Reinstated 2019 Condition-level deficiency 2019 Next survey by January 2020
	State-operated nursing facility	Certified Next survey by November 2020
Lakeland	Intermediate care facility	Denial of payment for new admissions Next survey by May 2020
	State-operated nursing facility	Certified Next survey by June 2020
Rainier	Intermediate care facility A	Decertified March 6, 2019 Closed September 30, 2019
	Intermediate care facility C	Decertified 2018 Reinstated 2019 Next survey by June 2020
	Intermediate care facility E	Decertified 2018 Reinstated 2019 Next survey by January 2020
Yakima Valley	State-operated nursing facility	Certified Next survey by June 2020

The workgroup recognizes that there is a national trend away from large state-operated ICFs. In addition, other states with existing state-operated ICFs have noted similar problems complying with federal active treatment requirements.

3. The Closure of Rainier PAT A

On March 6, 2019, the Centers for Medicare and Medicaid Services notified the public that Rainier School PAT A (one of Rainier’s three ICFs) had been involuntarily terminated from participation in the federal Medicaid program. Termination was due to noncompliance with the conditions of participation for active treatment and governing body. CMS further stated that federal funding for the PAT would cease in thirty days.

DDA appealed the determination and negotiated a settlement agreement. The agreement guaranteed continued federal funding to the PAT through September 30, 2019, provided that the Department

satisfied certain conditions as it completed the work necessary to transition all PAT A residents to other appropriate settings. The Department fulfilled its obligations and closed PAT A on September 30 with federal funding intact.

Following these moves, DDA interviewed clients and their families about their experience. While many people expressed frustration with certain aspects of the transition process, such as how they were notified, 91% of respondents reported being happy with the new service setting. There were numerous comments such as, “I was so worried, but I now believe this will be the happiest years of his life,” and “I was sure she was going to be really harmed in this process, but I was wrong and I am seeing her laugh and smile for the first time ever.” No one interviewed expressed a feeling that the individual who had moved was worse off.

Table 2 identifies the residential setting chosen by each PAT A resident. Two PAT A residents died prior to transition.

Table 2: Rainier PAT A Moves by Residential Setting⁶

Chosen Residential Setting	Individuals Who Moved
State-Operated Supported Living (SOLA)	32
Contracted Supported Living	10
Lakeland Village	20
Fircrest	12
Adult Family Home	4
Family Home	1
Rainier (Program Areas C and E)	5
Total	84

“This outcome data is remarkable,” says Assistant Secretary, Evelyn Perez, “because the average age of the individuals was 65 and the average length of time they had lived at Rainier was 45 years.”⁷ DDA leadership intends to use insights from the successful closure of Rainier PAT A to inform future transitions.

⁶ Data collection began March 1, 2019 and was updated October 1, 2019

⁷ Average age and average length of stay data from *Procedures Recommendations for RHC Downsizing or Closures*, October 2019.

B. Ruckelshaus Workgroup Recommendations

1. Increase the capabilities of community residential services

- a. **Improve case management ratios.** Case management connects people to the services they need and helps them navigate community resources. Currently the standard ratio for a general caseload in Washington State is 1:75. Nationally, the average size for a general caseload is 1:31.⁸ The workgroup recommends that the Legislature appropriate funds sufficient to ensure a general caseload ratio of 1:35. Reducing case management ratios will also improve cross-system coordination and the facility discharge process.
- b. **Assess options to expand forecast-based maintenance level funding adjustments for DDA waiver services.** The workgroup recommends that the Legislature develop and examine options to more accurately project demand for DDA waiver services and provide funding that is predictable and aligned with caseload demand. The DDA no-paid services caseload includes many clients who may be eligible for paid DDA services but are not receiving them due to the capped funded capacity of DDA waivers. The caseload may not exceed the funded cap, which is defined by legislative appropriation, and per-capita cost adjustments are made for currently enrolled waiver clients. The current model of forecast-based maintenance level funding for DDA waiver services is limited to contracted community residential services. An option to consider is including state-operated living alternative services in the forecasted maintenance level funding. The current model does not recognize that caseload demand for home and community-based services continues to exceed funded waiver capacity.
- c. **Expand state-operated community residential options.** The current community residential network lacks sufficient capacity to meet existing and anticipated demand. State-operated community residential capacity should be expanded to accommodate individuals with complex behavioral needs, including those leaving state-operated ICFs and state psychiatric hospitals. The Legislature should invest in expanding the following state-operated residential models.
 - 1) State-operated living alternatives (SOLA). SOLA is the state-operated supported living option. SOLA has proved indispensable in successfully transitioning behaviorally and medically complex individuals from state psychiatric hospitals and state-operated ICFs to the community. The success of the PAT A closure was made possible in large part by the recent SOLA expansion.
 - 2) Stabilization, assessment, and intervention facilities.⁹ These four-bed facilities will provide stabilization services for individuals with complex behavioral support needs, including crisis intervention and stabilization. The beds will provide an alternative to hospital stays while an appropriate long-term placement is secured. The Legislature should fund the creation of six additional stabilization, assessment, and intervention facilities. If funded, the Department will establish these facilities in local communities across Washington State with particular emphasis on communities that are currently underserved.

⁸ Case Management Supporting People with ID/DD: Indications of a New Frontier of the Workforce Crisis, available at https://www.aaid.org/docs/default-source/default-document-library/bogenschutz.pdf?sfvrsn=f18e3621_0. Accessed November 8, 2019.

⁹ Previously “state-operated behavioral health group training homes”

- d. **Expand quality assurance efforts.** As contracted and state-operated community residential programs expand, it will be necessary to increase quality assurance infrastructure to monitor growth and service delivery. To ensure the greatest possible utility and consistency in residential programs, it will be necessary to develop uniform quality assurance metrics that are applied across community residential settings, intermediate care facilities, and state-operated nursing facilities. Creating this infrastructure would increase DDA’s ability to deliver technical assistance. The framework for this work is largely in place within the Department’s systems.
- e. **Conduct rate study for contracted community residential service providers.** The State should conduct a rate study to determine future rates, and enhanced rates when appropriate, for contracted providers. Feedback from contracted providers consistently indicates that they are unable to recruit and retain sufficient numbers of skilled direct care professional under the current rate.
- f. **Assess options for an alternative, opt-in rate structure for contracted supported living.** Under such a model, contracted providers could receive an enhanced rate for serving individuals with complex behavioral needs,¹⁰ completing additional training, and submitting to additional monitoring.
- g. **Increase funding for community-based overnight planned respite.** Overnight planned respite is an essential service for helping to prevent clients and families from entering crisis. The workgroup recommends increasing the number of funded respite hours available to clients and the number of respite beds statewide.

2. Improve cross-system coordination

- a. **Ask the Developmental Disabilities Council (DDC) to coordinate collaboration efforts.** Coordination should occur among: DDA; the DDC; University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) at the University of Washington; Washington State University’s Floyd College of Medicine; the Pacific Northwest University of Health Sciences; and any additional relevant stakeholders. The purpose of this collaboration should be to develop and disseminate evidence-based best practices related to serving individuals with co-occurring I/DD and mental health conditions. The intended audience is families, clinicians, first responders, and other direct care professionals.
- b. **Expand apprenticeship opportunities.** There is a shortage of medical and direct care professionals who have received specific training related to working with individuals with I/DD. The existence of state-operated facilities and community residential settings creates apprenticeship opportunities. The workgroup recommends that the Legislature work with Washington State’s Apprenticeship and Training Council, colleges, and universities to establish medical, dental, nursing, and direct care apprenticeship programs that would address gaps in provider training and overall competence.

¹⁰ Subject to reasonable limits to ensure the safety of the client, the providers, and the public.

- c. **Continue reforming guardianship.** Not every person with an intellectual or developmental disability needs a guardian; however, many individuals with I/DD do not receive the decision-making support they require to live as independently as possible. Our workgroup supports ongoing stakeholder workgroups regarding the implementation of the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act.
- d. **Prioritize funding housing for people with I/DD.** Inability to access affordable housing often prevents individuals with I/DD from living in the least restrictive setting appropriate for them. For example, there are DDA clients who have been accepted by a supported living provider who is ready to meet their needs; however, the client is unable to obtain affordable housing and therefore remains in a more restrictive setting than necessary.
- e. **Expand access to facility professionals.** Enable professional staff at the state-operated ICFs to provide State Plan benefits to individuals who reside in the community. The Legislature should direct DDA to work with the Health Care Authority and Washington State’s managed care organizations to establish the agreements necessary for clients who live in the community to access DDA’s facility-based professionals to receive care covered under the State Plan. If feasible, these agreements should enable facility-based professionals to deliver services at mobile or brick-and-mortar clinical settings in the community.

3. Invest in state-operated nursing facilities

- a. **Continue to invest in state-operated nursing facilities.** There is widespread consensus that individuals with I/DD achieve better clinical outcomes and have a better overall quality of life in state-operated nursing facilities than they do in privately operated nursing facilities.
- b. **Rebuild Fircrest’s nursing facility.** Recognizing that the buildings that currently house the Fircrest nursing facility have reached the end of their useful lives, the Legislature should appropriate sufficient funds for the Department to construct a 120-bed replacement facility on the Fircrest campus. Given the condition of these buildings and the time it takes to construct a new nursing facility, funds should be appropriated and design work begun immediately. This investment is also necessary to facilitate the transformation of the state-operated ICFs into a short-term intervention model as described in Section 4 below.

4. Redesign state-operated ICFs to function as short-term crisis stabilization and intervention

- a. **Develop infrastructure to ensure no one remains in an ICF longer than necessary.**
 - 1) **Complete DDA assessments for ICF clients.** The DDA assessment determines the level of support a client needs, which is essential in planning for a move to a community residential setting. All ICF clients should be assigned a case manager and receive a DDA assessment at least annually and any time a significant change is identified.

- 2) **Clearly explain to ICF clients and their families the temporary nature of ICFs.** Many ICF residents and their families and guardians are under the impression that ICF placement is intended to be permanent. DDA should inform these individuals that ICFs deliver continuous, aggressive active treatment in order to facilitate successful placement in a less restrictive setting. This communication should also include an explanation of continuous aggressive active treatment and its eligibility implications.
 - 3) **Expand the Family Mentor Project.** DDA currently funds the Family Mentor Project through the Roads to Community Living grant. This program should be expanded to the level necessary to immediately connect each client in a state-operated facility with a family mentor.
 - 4) **Begin transition planning immediately.** Because the purpose of an ICF is to support the client to live successfully in a less restrictive setting, discharge planning should begin immediately and include clear descriptions of all placement options and their requirements.
 - 5) **Establish transition teams.** Each ICF should establish a transition team consisting of a Referral Coordinator, a Regulatory Compliance Coordinator, and a Person-Centered Planning Coordinator. If created, this infrastructure would increase the ability of ICFs to serve as a short-term intervention to best address the behaviors or other support needs that prevent the individual from living in a less restrictive setting.
- b. **Leverage the resulting ICF capacity to meet crisis stabilization needs.** Redesigning state-operated ICFs from a long-term care model to a short-term crisis intervention will create the necessary crisis stabilization capacity.

C. Conclusion

Washington State's current practice of operating ICFs as a long-term care model imperils their Medicaid certifications and leaves many individuals dependent on a costly service with an uncertain future. Striving toward a six-month average length-of-stay in state-operated ICFs will accelerate skill acquisition by galvanizing facility staff and focusing families on the specific habilitation needs that prevent each client from living in a less restrictive setting.

Discharging clients who are ready to live in a less restrictive setting substantially reduces Medicaid decertification risk and—in the event of decertification—the number of lives disrupted and dollars lost. Such work will only be possible, however, with considerable short and medium-term investments in community residential services, state-operated nursing services, and cross-system coordination.

The workgroup understands that Senators Keiser and Braun, Representatives Robinson and Corry, and representatives from the Governor's office and DDA intend to work together around implementation of the enclosed workgroup recommendations. Table 3 identifies each recommendation that requires an appropriation and indicates the Legislative session in which the Ruckelshaus workgroup recommends the Legislature appropriate funds. An arrow indicates an ongoing expenditure.

Table 3: Appropriation Timeline for Implementing Recommendations

Item	Recommendation	2020	2021	2023
B.1.a.	Improve case management ratios		→	→
B.1.b.	Assess residential forecast options		→	→
B.1.c.	Expand SOLA	→	→	→
B.1.c.	Expand stabilization assessment and intervention facilities		→	→
B.1.d.	Increase quality assurance		→	→
B.1.e.	Conduct rate study for contracted community residential		→	→
B.1.f.	Assess options for alternative rate structures		→	→
B.1.g.	Increase respite funding		→	→
B.2.d.	Prioritize funding for affordable housing		→	→
B.3.a.	Continue investing in state-operated nursing facilities		→	→
B.3.b.	Rebuild Fircrest nursing facility	→	→	→
B.4.a.	Assess and case manage ICF residents		→	→
B.4.a.	Expand Family Mentor Project	→	→	→
B.4.a.	Establish transition teams		→	→

THE WILLIAM D. RUCKELSHAUS CENTER

UNIVERSITY OF WASHINGTON

Intellectual/Developmental Disabilities – Residential Habilitation Center Workgroup 2019 Workgroup Process Summary and Neutral Recommendations

The William D. Ruckelshaus Center is a neutral resource for collaborative problem solving in the State of Washington and the Pacific Northwest, dedicated to assisting public, private, tribal, non-profit, and other community leaders in their efforts to build consensus and resolve conflicts around difficult public policy issues. It is a joint effort of Washington State University hosted and administered by WSU Extension and the University of Washington hosted by the Daniel J. Evans School of Public Policy and Governance. For more information, visit:

www.ruckelshauscenter.wsu.edu

PROJECT AND FACILITATION LEAD:

Kevin Harris, Ruckelshaus Center -Senior Facilitator/Health Policy

Assistant Professor

kevin.harris2@wsu.edu

WILLIAM D. RUCKELSHAUS CENTER

Hulbert Hall, Room 121

Pullman, WA 99164-6248

-and-

901 Fifth Avenue, Suite 2900

Seattle, WA 98164-2040

DISCLAIMER

The following summary was prepared by the William D. Ruckelshaus Center, a joint effort of the University of Washington and Washington State University whose mission is to act as a neutral resource for collaborative problem solving in the State of Washington and Pacific Northwest. University leadership and the Center's Advisory Board support the preparation of this and other reports produced under the Center's auspices. However, the key observations contained in this Addendum are intended to reflect the statements and opinions of the DD-RHC workgroup, and the recommendations are those of the Center's team. Those observations and recommendations do not represent the views of the universities or Advisory Board members.

Summary - Background, Process and 2019 Workgroup Progress

In 2018, the Legislature requested that the DSHS/Developmental Disabilities Administration engage the William D. Ruckelshaus Center (the Center) to structure a collaborative workgroup process and provide neutral facilitation services around pressing Residential Habilitation Center (RHC) and intellectual/developmental disability (I/DD) issues.

The Ruckelshaus workgroup consisted of diverse and historically conflicted organizations, including representation from four advocacy groups (from RHC and community-based perspectives) and two unions, as well as the Governor's office, four legislators, DSHS/DDA, and DSHS/ALTSA. In addition, the workgroup was supported by non-partisan fiscal staff from the House and Senate, as well as the Office of Financial Management. At times, clients with I/DD from both RHC and community-based settings were invited and joined workgroup meetings to share their views and stories.

Many of the issues identified in the original 2018 authorizing proviso language were described in the main body of the Ruckelshaus workgroup's January 1, 2019 report to the Legislature. The 2018 workgroup efforts included mostly short-term, consensus-based recommendations. The Legislature subsequently authorized more than \$172 million to address recommended investments in community and RHC-based supports and services. These included expansions of SOLAs and wage rate increases for community-based providers, among other program supports. The workgroup had also recommended continuing their facilitated work in 2019 on the longer-term issues they had identified in the January 2019 report – including how RHCs should 'fit' within the I/DD continuum of support and services, especially under continued CMS compliance challenges around ICF services.

Facilitated workgroup meetings restarted in the spring of 2019, and continued into November. As before, the workgroup met monthly for full-day facilitated meetings to develop a consensus-based vision for the I/DD continuum. The Ruckelshaus Center again used traditional collaborative processes to help the workgroup build capacity towards consensus, including shared principles, productive inquiry, diverse thinking exercises, data evaluation and subgroup breakouts. At times, guests from government agencies and university departments were invited to inform the workgroup about germane issues and relevant work.

The workgroup continued throughout 2019 to build collective trust to reach consensus around an I/DD vision for continuum improvement, as well as specific legislative, departmental and stakeholder recommendations to:

- Re-design the intention and operationalization of intermediate-care services over time, from an 'aging in place' legacy within RHCs to shorter-term crisis intervention and stabilization supports and services (through the use of smaller, regional state-run facilities), intended to move people into less-restricted settings once stabilized;
- Invest in necessary and appropriate community-based service and support capacity, to allow the above re-design to effectively work. The workgroup clearly feels the urgency of timing this capacity build-out (including investment in the above recommended smaller, regional facilities) against the continuing CMS threat of further RHC/ICF decertification activity);

- Build upon and improve quality assurance efforts, to explicitly measure the effectiveness, success and warning signs of the ICF transitions noted above, as they relate to individual's well-being, progress and independence;
- Invest in necessary state-operated nursing facility services and supports, including capital investments, to achieve needed capacity and ensure appropriately trained personnel, as individuals with I/DD age;
- Increase respite capacity;
- Improve cross-system coordination, including a variety of recommendations around training providers and first responders to properly address co-diagnosed I/DD, mental health and substance use disorders, as well as leveraging existing trained experience at both RHC and community-based settings, and
- Mitigate federal ICF decertification risk, while maintaining the highest degree of federal matching funds possible.

The attached workgroup report expands each of these areas in greater detail, and offers a legislative timeline that 'stages' each recommendation that requires fiscal appropriation.

As noted, the workgroup worked hard in 2018 and 2019 to achieve consensus – both a vision for a lifelong continuum of supports and services to achieve independence for those with I/DD (and their families and guardians), as well as specific recommendations, plans and a timeline to help the State of Washington achieve these goals. This consensus effort included putting aside nearly 40 years of disputes and conflict – advocates remarked in several of the last workgroup meetings that they *'had never achieved this degree of progress in the past'*, that *'I can't believe how much time and energy was wasted over past conflict'*, and *'It's remarkable that we were able to finally come together to address these issues as a group'*.

Recommendations

The following Ruckelshaus Center recommendations are limited – the workgroup has detailed many of the upcoming steps that will help to achieve the noted vision and I/DD continuum improvements. These few following recommendations are offered in both the spirit and positive impact of continued collaboration:

1. DDA might encourage hosting small workgroup forums to seek collaborative guidance, when needed around:
 - Client/family communication improvements;
 - Continuing improvement on quality assurance metrics;
 - Best use of expanded CARE assessments across sites of service and relative to independence goals, and
 - Development and implementation of transition team approaches and individual/family transition needs.
2. DDA might work collaboratively with diverse partners to develop or leverage existing I/DD outcomes (and process) metrics/measures that can realistically be measured and interpreted. The Ruckelshaus workgroup discussed several existing association-related measure sets that may be useful. In addition, it may be helpful to include metrics that evaluate the success of

increased ICF-to-community placements, as well as identify and perhaps strive to mitigate the frequency of crisis ‘events’.

3. Strengthen higher education relationships with DDA and diverse partners. The workgroup’s recommendations include the DD Council’s willingness to take responsibility for reinforcing some of these relationships. A natural degree of cultural disconnect currently exists between I/DD academic research and state program practices. Higher education is willing and eager to help bridge that gap – but some preliminary work to identify and define design and implementation value on the programmatic side will be required.

Appendix 1

Paid Residential Services for Adults

Supported living occurs in a home owned or leased by up to four clients. Clients receive support from contracted service providers. Support varies from a few hours a month to 24 hours a day, depending on the client's need.

Private nursing facilities provide 24-hour support to clients who require nursing facility level of care. Clients receive support from contracted service providers.

Assisted living facilities provide 24-hour adult residential care services in a home-like environment for seven or more clients. Enhanced care includes intermittent nursing and medication administration.

Adult family homes provide 24-hour care for two to six clients. The provider owns or leases a home in the community and offers meals and personal care, and may also offer nursing or specialized mental health care.

Group homes provide 24-hour instruction and support to two or more adults. The provider owns the facility and clients pay for room and board.

Alternative living provides up to 40 hours a month of support to a client living in their own home. The support is provided inside and outside the client's residence.

State-operated intermediate care facilities provide 24-hour support to promote client independence and teach clients skills they need to live in a less restrictive setting. Support is provided by state employees.

State-operated nursing facilities provide 24-hour support to clients who require nursing facility level of care. Support is provided by state employees.

Private intermediate care facilities provide 24-hour support to promote client independence and teach clients skills they need to live in a less restrictive setting.¹¹

Community protection provides 24-hour supervision to clients who live in a supported living environment and pose significant risk to others.

SOLA is state-operated supported living. It occurs in a home occupied by up to four clients. Support is provided by state employees and varies from a few hours a month to 24 hours a day.

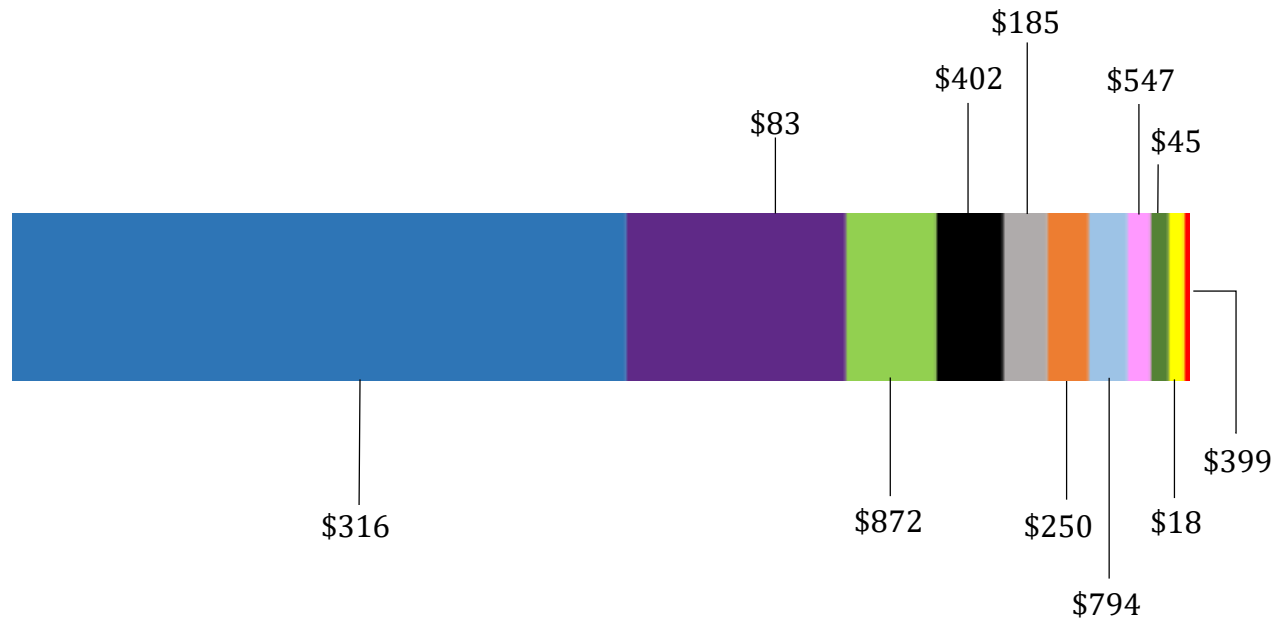
Companion homes support a client in the provider's home where 24-hour support is available

¹¹ At the time of this report only one privately operated ICF exists in Washington State.

Appendix 2
Adult Residential Service Information by Setting

Setting	Age	Support available	Funding	How are food, rent, and utilities paid?	Who owns or leases the living space?	How many clients share the living space?	Will the client have a private bedroom?
Adult Family Home	18+	24-hour availability	State Plan	Participation	Provider	Up to 6	Possibly
Alternative Living	18+	40 hours per month	Waiver (Core)	Client funds	Client	1	Yes
Assisted Living (Adult Residential Care)	18+	24-hour availability	State Plan	Participation	Provider	Per license	Possibly
Companion Home	18+	24-hour availability	Waiver (Core)	Room & board	Provider	1	Yes
Group Home	18+	24-hour availability	Waiver (Core)	Participation	Provider	2-12	Typically
Intermediate Care Facility—private	18+	24 hours	State Plan	Participation	Provider	Up to 16	No
Intermediate Care Facility—state operated	16+	24 hours	State Plan	Participation	Provider	Up to 8	Possibly
Nursing Facility—private	18+	24 hours	State Plan	Participation	Provider	Per license	Possibly
Nursing Facility—state operated	16+	24 hours	State Plan	Participation	Provider	Up to 18	Possibly
SOLA	18+	Up to 24 hours	Waiver (Core or CP)	Client funds	Client	Up to 4	Yes
Supported Living	18+	Up to 24 hours	Waiver (Core)	Client funds	Client	Up to 4	Yes
Supported Living—Community Protection	18+	24 hours	Waiver (CP)	Client funds	Client	Up to 4	Yes

**Appendix 3
Distribution of DDA Clients by Paid Residential Service
Showing Average Daily Rate in Fiscal Year 2018**



- Supported living
- Adult family homes
- State-operated intermediate care facilities
- Community protection
- Private nursing facilities
- Group homes
- State-operated nursing facilities
- SOLA
- Assisted living facilities
- Alternative living
- Private intermediate care facilities

GLOSSARY

Active Treatment

A continuous, aggressive, and consistently implemented program of specialized and generic training, treatment, and health or related services directed toward helping the client function with as much self-determination and independence as possible.

Centers for Medicare and Medicaid Services (CMS)

The federal agency within the Department of Health and Human Services (HHS) chiefly responsible for Medicare and Medicaid policy.

Crisis Stabilization

Short-term support to a person experiencing behavioral health issues that may put them at risk of hospitalization or institutionalization. A client may receive crisis stabilization services in a state facility or a specialized community setting.

Intermediate-Care Facility

A residential teaching facility where clients develop skills they need to live in the least restrictive setting possible.

Program Area Team or PAT

A separately certified facility within a residential habilitation center. A PAT may be either an intermediate care facility or a state-operated nursing facility.

Residential Habilitation Center (RHC)

A residential facility operated by DDA for individuals with I/DD or other similar conditions. Each RHC campus may contain separately certified intermediate care facilities, a state-operated nursing facility, or a combination of the two.

Respite Care

Short-term, intermittent care to provide relief for a person who lives with a client or is the client's primary care provider. A client may receive respite care in their home or another setting.

State-Operated Living Alternative (SOLA)

A state-operated supported living service. Typically this model involves multiple people sharing a residence with additional support provided based on each individual's assessed need.

State-Operated Nursing Facility (SONF)

A nursing facility operated by DDA for DDA clients.

Supported Living

Residential services occurring in a home owned or leased by up to four clients. Clients receive support from contracted service providers. Support varies from a few hours a month to 24 hours a day, depending on the client's need.

Acknowledgements

This report and the Ruckelshaus workgroup consensus recommendations would not have been possible without the contributions of the following people: Debbie Roberts, Charlie Weedon, Mick Pettersen, and Chantelle Diaz (DSHS Developmental Disabilities Administration); Jeremy Norden-Paul (Developmental Disabilities Council); Michele Alishahi and Maria Hovde (Senate Ways & Means Committee staff); Mary Mulholland (Office of Program Research, House of Representatives Committee staff); and Bryce Andersen (Office of Financial Management).