INTELLECTUAL & DEVELOPMENTAL DISABILITIES

PERCEPTIONS OF PROGRESS: 2019 WASHINGTON WORK GROUP RECOMMENDATIONS

WILLIAM D. RUCKELSHAUS CENTER
February 29, 2024

WASHINGTON STATE UNIVERSITY

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ABOUT THE WILLIAM D. RUCKELSHAUS CENTER

The William D. Ruckelshaus Center is an independent and impartial 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. The Center is a joint effort of Washington State University (hosted and administered by the WSU Provost) and the University of Washington (hosted by the Daniel J. Evans School of Public Policy and Governance). For more information, visit:
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Acknowledgements

The project team would like to thank each of the interview participants who generously shared their time and experience with us, including people who have intellectual and/or developmental disabilities, self-advocates, advocates, parents and families, guardians, direct care staff and supervisors, community-based and Residential Habilitation Center managers and administrators, researchers, association and union representatives, state agency and department staff and leaders, fiscal analysts, governor’s office advisors, and legislators.

We cannot look deeper into the different perceptions of the 2019 Workgroup report recommendations without acknowledging the core effects of structural ‘ableism’, systemic oppression and societal discrimination that people with intellectual and/or developmental disabilities experience in their lives. Self-advocates, DDA staff and care providers reminded our project team that program recommendations need to consider these and other systemic issues – and how they impact people’s successes, setbacks and resilience, while trying to live their lives with dignity, respect and independence.

Our project team hopes that these fundamental core realities will serve as a ‘north star’ as the reader reflects on this report’s context and our process recommendations moving forward – whether considering issues like crisis intervention, aging with dignity, quality assurance, case management or others, and how they connect to the real life experiences and events that are often linked to ableism and discrimination.

…. and we were also fortunate to share many joyful and positive conversations with the people we met. Thank you.

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PROJECT PURPOSE & OVERVIEW

Purpose

In 2023, the Washington Legislature asked the William D. Ruckelshaus Center (the Center) to conduct an independent assessment of diverse perceptions of the progress of the 2019 Intellectual and Developmental Disabilities (I/DD) Workgroup Report's twenty program and policy recommendations[1]. The Legislature also asked the Center to explore:

- Information about the successes and barriers related to meeting the 2019 recommendations
- Other potential issues or options for meeting the 2019 recommendations, including an Enhanced Behavioral Support Home concept
- Other state's approaches and potential innovations
- Potential emergent issues
- Recommendations for future focus groups or other convening potential between state agencies, self/advocates, parents, guardians, providers, unions, payers and/or other program partners.

Work Overview

The Center's project team held interviews and listening sessions with more than 135 people between June and November 2023[2]. The team heard a wide variety of perceptions and opinions about the progress of Washington's I/DD programs and prior 2019 Workgroup recommendations.

These perceptions were based on the experience of individuals with I/DD and self-advocates, advocacy groups, parents, guardians (relatives and professionals), direct care and other staff and leaders from community-based and Residential Habilitation Center (RHC) programs, one union, contracted and state-operated community-based providers, associations, and leadership at the Developmental Disabilities Administration (DDA), and Aging and Long-Term Support Administration (ALTSA) of the Washington Department of Social and Health Services (DSHS). The project team also heard from senior staff in the Governor's Office, university faculty, and legislators.

The interview responses were synthesized, using qualitative analysis methods and principles to identify similarities and differences, and recurring themes that are highlighted in this report's chapters.

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[1] https://s3.wp.wsu.edu/uploads/sites/2180/2019/12/2019-Ruckelshaus-Workgroup-Report-to-Legislature_Intellectual-Developmental-Disabilities-Policy-1.pdf

[2] Appendix A: Interviewee Roster

The team conducted an additional effort to identify examples of other state's I/DD program features and innovations that might be worth considering, including the Enhanced Behavior Support Homes concept. This was a high-level review and is meant to be informative, but not exhaustive.

Context

Four years have passed since the 2019 I/DD Workgroup Report was issued. COVID-19 and other external shocks have affected most people, and especially those who are often discriminated against (ableism, racism and other 'isms'), and frequently ignored by society. The project team reflected on both recent COVID-response related and diversity/belonging work, to help frame interview discussions. The team heard three important points of context:

First, recognizing COVID-19's influence on everyone involved and impacted within Washington's I/DD community. The I/DD community and support systems were particularly hard-hit by the pandemic, adding layers of trauma and isolation to an already at-risk population, their families and caregivers, and program and stakeholder[3] (partner) staff and leaders. The ability to work together to respond to the pandemic, discover collaborative strengths, and learn from the experience reflects the dedication and service of everyone who is a part of this community. Everyone is still learning. On a positive note, COVID response may have opened a window of opportunity for more open dialog and the need for more collaborative solutions that include the lived experience of people with I/DD, families, and others.

Second, acknowledging that the 2018/2019 'Ruckelshaus Workgroup' was formed from a legislatively mandated list of community and RHC advocates, unions, legislators, DDA and ALTSA officials, union representatives, the Governor's office, and fiscal staff. Although a few people with I/DD attended blocks of monthly meetings and shared their experience, self-advocates were not included on the list of participants (neither were community-based providers, guardians, and others). This resulted in an uproar from self-advocates, who felt disrespected and ignored. The project team heard that this helped further catalyze and strengthen I/DD self-advocacy in Washington state.

This project team has tried to be inclusive and respectful to all interview and listening session participants. The team valued all experience and diverse opinions heard, especially from the people most impacted by this system – people who live their lives experiencing I/DD – who are trying their best not to be defined by I/DD. On another positive note, several people felt that DDA's recent actions to be more broadly inclusive is partly due to the 2018/19 Workgroup participant limitations. Future progress around I/DD supports and services is highly dependent on hearing people with diverse opinions and needs– and including them in the solution-making process.

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[3] The term 'stakeholder' is commonly used by majority society but is considered highly offensive to some; in particular, to Tribal communities. We use the term 'partners' in this report to describe everyone with personal and/or professional experience in Washington state's I/DD system, as well as other state departments and agencies. 'Partners' does not necessarily assume a current willingness to collaborate.

Third, recognizing organizational and leadership changes over the past four years. DSHS, DDA, the Arc of Washington, People First of Washington, the DD-Council and other involved organizations have experienced leadership change over the past four years. Periods of transition can be challenging. People who have left are often missed. Change and uncertainty around relationships, focus and goals are challenging for many to work through and absorb – even if people recognize the positive opportunities and influence that may emerge. This project team acknowledges that these interviews held between June and November 2023 reflected partner's feelings at that point in time and may have evolved since then.

This Report – What it is

- This report is a synthesis of a diverse set of interviewee perceptions, opinions and understanding of progress of the 2019 Workgroup's recommendations – and include many people's thoughts around operational, cultural, and systemic strengths and gaps.
- These perceptions, opinions, and understanding helped identify positive momentum and perceived barriers to improving the lives of fellow citizens in Washington communities living with I/DD.
- This work examined relationships and trust, as they are foundational to any public program's long-term success, credibility, and resilience.
- The project team hopes that this report's findings and process recommendations will help advance collaborative processes between all I/DD partners, to build greater trust and improve I/DD supports and services.
- The content of this report is what the project team heard, with the exception of the team's process recommendations for potential future efforts. We synthesize, not editorialize.

This Report – What it isn't

- This is not a DDA 'report card' on recommendations progress– it is an assessment of diverse perspectives and perceptions of progress, to help people seek out and address root causes, systemic interrelationships and barriers, operational priorities, and potential leverage points for change – to improve Washington state's I/DD system of supports and services.
- This is not a consultant's or expert's evaluation or opinion. The I/DD programs in Washington state are complex and complicated and cannot be adequately summarized in the space or scope of this report. The project team assumes the reader is familiar with Washington state's numerous and varied I/DD supports and services programs.[4]
- This project was not a quantitative exercise - there are no numerical graphs or tables in this report. DDA has posted a comprehensive series of legislatively requested reports on

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[4] Further information on DDA's I/DD programs at: https://www.dshs.wa.gov/dda/developmental-disabilities-administration-services-programs

their website that reflect their response to the 2019 recommendations[5]. Many of those reports include quantitative information.

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[5] https://www.dshs.wa.gov/dda/publications/dda-reports

SUMMARY

This report is undeniably long! The 2019 Workgroup's report included twenty significant recommendations. Most of their recommendations link to broader and deeper issues. Those issues are at the root of I/DD operational, cultural, and systemic successes and challenges. The team heard from partners who were genuinely excited to discuss many of those issues and share their thoughts and experiences. This project team honors the diversity and intimacy of their experience. That experience informs the suggested processes to advance collective understanding and build trust to improve, reform and transform the I/DD system.

Overall Progress and Key Root Issues

If there is a general consensus, it is one of measured progress, in an often fragmented system facing significant change. This includes changes related to aging clients and caregivers, behavioral and other co-occurring conditions, individual/family demographics and cultural needs, housing stressors, and workforce constraints. COVID-19 tested the resilience of the I/DD population, caregivers, advocates and leaders across different settings and programs, and continues to have some degree of impact on many issues, including behavioral health, staffing and communications.

Participants were appreciative of legislative funding increases provided in past sessions – increases for provider rates, state-operated program capacity, housing, case management, and a variety of pilots and initiatives that address crisis intervention and stabilization needs, co-occurring conditions, and other challenges. Several advocates and DDA staff noted that deeper partnerships and a combination of program and system improvements are needed to stabilize the I/DD system, and to respond to and prepare for change.

Many I/DD professionals and administrators feel that the programs have generally worked for a majority of clients in a system that was designed in the 20th century, but is becoming increasingly pressured, trying to address the changes described above and other important factors. Others see a fragmented and underfunded system that could greatly benefit from broader coordination, less reactive focus, and more strategic direction. No one interviewed suggested that the status quo system is an acceptable alternative to address gaps, changes and constraints.

A large majority of adults with I/DD live in their family homes, and most do not receive DDA funded services, although many do receive aging services through ALTSA programs. Parents are often the caregivers – and they are aging and looking for scarce options for their loved ones. Aging clients are also a growing cohort, and the options for long-term supports and services are limited beyond existing care sites. (Fircrest will eventually open their replacement 120-bed nursing facility, which is still a contentious issue between different I/DD partners - but the pending issue is much greater than one nursing facility's capacity).

Affordable housing is a significant issue that affects large populations in Washington state and most other regions. The additional work to build, modify and maintain the types of community residential options to encourage greater independence requires significant funding and administrative efforts. These challenges compound during periods of intense housing competition and inflation.

Individuals and self-advocates have very personal perspectives of program and operational impacts on their lives. Many expressed their satisfaction and happiness with their direct care staff in their respective community-based or RHC residences and programs. Others described the tension between individual needs and wants to achieve greater independence and choice, and a system that was originally developed to focus on habilitation, health and safety. The ongoing challenge may be to achieve a balance between both. Everyone has different needs. 'Person-Centered Care' is a concept that is not yet universally defined and agreed to. Several advocates suggested using this to re-frame focus to help improve strategic direction.

People with I/DD and their families have diverse cultural backgrounds, identities and needs. Direct care staff are similarly diverse. Health disparities among people with disabilities is well studied. Self-reported health status varies – Black and Latino adults with I/DD are more likely to report fair or poor physical and mental health compared to White peers. Adults of color, including tribal members with mobility limitations are more likely to experience depression, diabetes, hypertension or vision impairment. LGBTQI+ people with disabilities are more likely to report diminished quality of life, including poor physical and mental health. Research suggests these disparities are associated with systemic issues related to multiple forms of oppression.

The population is changing, like the rest of our country, and requires flexible approaches to respect and respond to different backgrounds, identities and needs. DDA described some of their work to improve communication, collaboration and outreach efforts to align with these changes.

Increasing co-occurring conditions, including challenging behaviors and medical needs are creating further system stress. These include a range of conditions, including personality disorders, violent tendencies, suicidal ideation and acts, eating disorders, substance use disorders and less extreme behaviors. Original I/DD programs were not designed to support these and other complex disorders and behaviors. Behavioral health services are provided through the HCA/managed care and other programs. Despite significant legislative funding for community-based behavioral health services, the existing system is not structured with the knowledge or experience to respond to co-occurring conditions between I/DD and behavioral health needs. These system gaps are believed to be growing, despite the dedicated efforts of everyone working for I/DD program stabilization. On a positive note, the project team saw and heard of I/DD programs, pilots and initiatives that are adapting to focus on some of these issues. With support, these initiatives can provide lessons learned that may help to scale efforts to create significant future impact.

Many described outdated federal regulations that constrain programs from operating across habilitation, crisis intervention and treatment needs. Others spoke of state government 'silos' that dampen collaborative solutions.

Workforce shortages and constraints is a key root issue, linked to many other system complexities. Workforce challenges range widely, from sustaining staff and specialists, to creating new partnerships, para-worker and certificated classifications and possibly new programs that can address the growing changes in I/DD populations and needs. There are simply not enough training pipelines, experienced staff, and recruiting, training and retention incentives to sustain and grow the I/DD workforce to fit the changes in I/DD needs and supports. DDA is working on several new tools and processes to address some of these issues, but lower comparative wages for many direct care staff and low overall unemployment rates create broader economic competition for staff. The team frequently heard the 'McDonalds' comparison.

These key operational, cultural and systemic challenges suggest the need to build more collaborative 'muscle', to look at these root issues in new ways, and in safe spaces. Many partners described a tentative, but positive trust forming with DDA, based on their intentional efforts to reach out. Some have adopted a '*wait and see what follow-up looks like'* approach. Others noted historical and on-going conflicts between partners, sometimes based on personalities and positions. One advocate described trust in the I/DD system as '*hard to build and easy to lose*.' Leadership turnover in different organizations may offer a fresh start to relationships.

Collaboration is hard, takes time and requires a lot of joint effort. All partners should be given the opportunity to reflect on past conflict and the positive strengths they contribute to a new collective effort – as well as their willingness to work to improve communication and adapt to address shared challenges.

Specific 2019 Report Recommendations: Perceptions of Progress

Increasing the capabilities of community-residential services

Case management ratios are improving, after peaking during COVID. The team heard that the concept of a universal ratio is debatable and could benefit from collaborative efforts and education. DDA is now staffed to manage the no-paid client services caseload. A limited number of I/DD partners provided feedback on case management issues.

Caseload forecasting is one of the most complicated tools that most people admit to not understanding. The process improvements made since 2020 were misunderstood by many I/DD partners and gave rise to unrealized expectations. This issue could benefit from broader consensus around objectives, and then possible education from fiscal staff, if still needed.

State-Operated Living Alternatives (SOLA) expansion continues. It take great efforts to open SOLAs. Nearly all responses to SOLA expansion were positive. SOLAs receive all referrals to provide residential habilitation services. They make a determination of how they can support the individual based on their assessed acuity level, requested services and available program capacity.

Stabilization, assessment and intervention facility expansion is slowly happening. Lessons learned from the first Pierce County location included challenges around local zoning, which led to revising the site location. There were few I/DD partner responses on this issue.

Quality assurance efforts included focused DDA efforts for both RHC and community-based programs. A DDA report noted the commonalities and differences in quality assurance standards between programs. Self-advocates noted their perspective on quality assurance, based on positive and negative experiences. This is another area that could benefit from some degree of collaboration, education and alignment to align metrics and experience.

Conduct a rate study for community residential providers/Assess options for an alternative, opt-in rate to address challenging behaviors and other issues. DDA contracted with Milliman to conduct this study, which was due in early December 2023. The project team's interviews were completed before this report was submitted, so no I/DD partner perspectives or perceptions were heard about Milliman's published results. DDA staff and community contractors noted interest in this forthcoming report and discussed the disincentives in the current tiered rate methodology that impacts their financial status, and, along with staffing challenges, often ties to rejected referral packets. Providers also noted process inconsistencies when negotiating top tier rates and hope for increased transparency.

Increase funding for community-based overnight planned respite. This issue received unanimous feedback – everyone agrees that respite is a precious commodity, that requires more capacity for families. Many I/DD partners conflated community-based respite, RHC respite, and crisis stabilization. This seemed to be due in part to the lack of overall respite capacity in the system. The team heard that families were so eager to get any relief, that many were happy to travel to Yakima Valley School to take advantage of the service, regardless of calendar openings.

Improve Cross-System Coordination:

Ask DD Council to coordinate efforts with university assets, to develop and disseminate evidence-based practices related to co-occurring conditions. This didn't happen, for a variety of organizational and timing reasons. A following detailed chapter describes the perceived gaps in university-based I/DD experience, with a few exceptions. This is an area that would likely require intensive collaborative efforts on a larger scale, to encourage university interest and participation. Also, workforce capacity efforts would likely require newer types of university and other educational collaboration, on a much greater scale.

Expand apprenticeship opportunities by working with the State Apprenticeship and Training Council and higher education to establish medical, dental, nursing, and direct care apprenticeship programs to address systems gaps in training and workforce capacity. Partner perceptions were similar to the described university connections– that this hasn't happened. A greater workforce capacity effort (referenced above) could leverage apprenticeships across the continuum of care and supports.

Continue reforming guardianship. Guardians, parents, self-advocates, DDA staff and advocates shared a great deal of feedback on this issue, which seems to be evolving. The revised Uniform Guardianship Act and included supported decision-making issues reflect independence and goals, but also create potential client/family/guardian tensions. The relationship between guardianship concepts and supported decision-making are often unclear. Some approach the issue as a choice between one or the other. One experienced advocate suggested more education around the use and flexibility of these tools to give more decision-making authority to clients while retaining their right to ask for help when needed. Family guardians had mixed knowledge of these concepts, which suggest the need to improve tools and communication materials. It's unclear who might be responsible or willing to consider this since the courts oversee the guardianship process. Professional guardians were critical of the bureaucratic processes in the revised Act, noting significant additional administrative burden without matching compensation. Other system disconnects that are perceived to lead to unintended consequences around guardianship are noted in the later report chapter.

Prioritize funding for housing for people with I/DD. Recent collaborative efforts between DDA and Commerce, and significant support from legislators has resulted in substantial increases in I/DD funding from the Housing Trust fund and other sources. Additional housing units dedicated to I/DD residents are in process, and legislators noted continued support to ramp up efforts. DDA and Commerce have successfully created new ways of working through traditional barriers to free up red tape. DDA now has experienced staff in place to work consistently on housing issues and capacity. Partners hope these efforts will be scalable, as projected I/DD housing needs are significant. Many partners offered positive feedback on this issue.

Expand access to (RHC) facility professionals. Some partners were aware that DDA had gone through a collaborative effort with professionals and the Health Care Authority, to examine this issue's potential. The 2019 Workgroup recommended looking into possible unused capacity of professionals working in the RHCs, including dentists and hygienists, therapists, clinicians and others. The DDA/HCA collaboration resulted in a DDA report. The identified barriers seemed significant[6], and involved Medicaid regulations and related managed care organization credentialing and billing requirements. This implied significant administrative burden for all parties. Other barriers included potential collective bargaining issues and conflicts. One RHC advocate noted that Fircrest has limited excess professional capacity. If this issue becomes a strategic priority for DDA and partners, further work stages are suggested in the DDA report recommendations.

Invest in state-operated nursing facilities:

Most partner feedback was related to the Fircrest 120-bed nursing facility replacement. This is still a contentious issue with some advocates and many self-advocates. Others seem to have grudgingly accepted that this build is moving forward. As of summer 2023, the project team was told that groundbreaking was planned for Spring 2024. The broader systemic issue around aging and lack of long-term care supports and services for people with I/DD is explored in greater detail in a following report chapter.

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[6] https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/Residential%20Habilitation%20Center%20Facility%20Based%20Professionals.pdf

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

Self-advocates reminded the project team of the very real trauma and abuse that many people with I/DD experience in their lives. People need many supports and services (including crisis stabilization) from professionals who recognize their humanity, are experienced in trauma-informed care and therapies, and are cognizant of underlying structural ableism that may significantly contribute to their crisis. These complex needs create additional pressures on both people with I/DD, as well as a workforce that has capacity and experience constraints.

The redesign to implement this operational policy around shorter-term ICF status began prior to the 2019 Workgroup's report release in November 2019. Changing methods to communicate the short-term nature of ICF stays, establishing transitions teams, proactively beginning transition planning at time of admission, deepening relationships with community providers – all seemed to be implemented throughout the RHCs at different times. Partners have varying perceptions of operational consistency and effectiveness between RHCs but seem to be aware of ICF planning and transition progress.

The family mentor project is universally praised, but small. The team heard that finding qualified mentors is challenging. Three mentors are located in Western Washington, and one is on the eastern side of the state. The contract for family mentors is run through the Arc of Washington.

This program has led to a piloted peer mentor program. A self-advocate noted this peer mentor program is underfunded and is focused on parent-to-parent mentoring. She suggested more funding to support peer mentoring for people with I/DD. For example, the 'Thoughts Cost' contractor attempts to hire people with I/DD who have transitioned out of RHCs to support those still living in RHCs.

One guardian hoped that a similar program might form to help parents or professional guardians leverage existing skills and experience.

Redesigning ICF capacity to meet stabilization needs is a major issue. Washington state has had no private community-based ICFs since the early 1990s. Co-occurring conditions are increasing. Demographics and cultural needs are changing. Community behavioral health treatment facilities are being funded by the Legislature, but scarce behavioral health specialists lack experience with I/DD. Is the existing short-term ICF model capable of meeting capacity needs now and in the future?

Klamath cottages on the Rainier campus were set up during COVID and focus on short-term stay residents who have co-occurring conditions but are not in severe crisis. Much of staff effort is spent on modifying client behaviors, including coping skills and emotional regulation, to prepare people for community transition. Community-based providers seem to be accepting of referrals from Klamath. Some advocates noted their frustration with longer lengths of stay for many residing at Klamath.

The current 2024 legislative session includes bills that suggest expanding community crisis relief centers and developing regionalized coordinated behavioral health crisis response plans. If passed, will these resources include I/DD experience? Community behavioral health treatment has not been a DDA responsibility – and yet behavioral co-occurring conditions is a growing concern within the I/DD population. Does crisis response and intervention substitute for treatment? If behavioral health expansion doesn't recognize I/DD needs, won't service and support gaps increase? If Managed Care Organizations experience the same lack of behavioral health specialists with I/DD experience, how can they help to fill these gaps in state-plan services for community-based clients?

This major issue and these questions, combined with fundamental workforce capacity issues will require significant collaboration and partner agreement to address growing systems gaps.

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The process recommendations that follow in each report chapter are not meant to be finite 'work steps' – but are instead, examples and prompts to consider the need to move beyond the current system status quo, if the goal is either reform and/or transformation.

The project team recognizes that DDA and partners may be currently addressing many of these issues. This report includes a long list and wide variety of process recommendations – certainly too long a list for short-term implementation. They are meant to be suggestions for DDA, partners and legislators to collaborate and consider the interconnectedness of these 'big issues' and prioritize and sequence collective strategies to address changing needs of people with I/DD in Washington state.

Most of these process recommendations suggest building stronger partner collaboration and trust. Most of these issues are too big to attempt in small circles or silos. Building this 'collaborative muscle' does not suggest that any partner give up their core beliefs – but that parternship spaces be developed to allow for frank discussion, understanding instead of listening, and genuine collective teamwork to create options that can be jointly 'owned.'

One self-advocate summarized:
'You captured many perceptions well. It can be challenging to reflect on a well-intentioned system that means to support, yet often suppresses. The idea that individuals are not the best deciders for their own lives exists heavily with those who have an I/DD diagnosis. Intelligence is not a measure of competence.'

PERCEPTIONS OF 2019 RECOMMENDATIONS

Report Layout

These report chapters follow the order of the 2019 Workgroup’s twenty report recommendations. Each chapter reflects interview feedback on the date of that interview– which may have been as early as July 2023. Interviewee experience and perceptions may have evolved since then. Likewise, DDA efforts to hear diverse voices and collaborate has continued to evolve.

The additional section titled ‘Key Underlying Interview Themes’ highlights four major themes that represent root issues – those themes that our team heard consistently during interviews, that many believe are foundational to I/DD system reform and transformation.

Each of the following chapters include a synthesis of partner perceptions, and often include relevant quotes (unattributed). Recommendations for future collaborative processes are also included in each chapter – again, these are examples and prompts for future collaborative efforts, and not meant to be finite work-steps.

The project team also identified several examples of other state’s I/DD program ideas and innovations that may be useful to consider in Washington state. This information is included at the end of each related chapter. References are included in appendices at the end of this report.

Finally, the project team included a basic summary of Enhanced Behavioral Support Home information from other states, as one model designed to address community-based needs to support challenging behaviors. This was specifically requested by the Legislature.

1. CHAPTER ONE: INCREASE THE CAPABILITIES OF COMMUNITY RESIDENTIAL SERVICES

1a. Improve Case Management Ratios

The number of I/DD clients per Case Manager has been quite high – 75 per Case Manager is often quoted as a 'peak' during COVID. Perceptions of progress varied between community advocates, self-advocates, RHC advocates and DDA staff. All felt that legislative funding has had a positive impact, continuing to push caseload ratios closer to 1:35 over a five-year period. The current 2024 supplemental legislative session includes a DDA funding request to continue to improve case management ratios.

People living in RHCs don't technically have a Case Manager; instead, they rely on Habilitation Program Administrators (HPAs). People transitioning into community programs are assigned a Case Manager. Average ratios of 1:75 or a 1:35 goal are somewhat misleading – the diverse I/DD population has differing needs.

Several partners noted the Legislature's recent funding of additional DDA Case Managers to work through the no-paid caseload list (resulting in a larger caseload ratio for those staff).
Case management helps individuals and their families access services and covered benefits from a range of bureaucratic programs.

Case Manager turnover has been challenging. As with direct support positions, Case Managers become better at their jobs as their experience deepens. Working with people with varying and unique needs requires depth of system knowledge and communication skills, and high caseloads result in less time to spend with people. Some partners felt that it takes at least twelve months to learn the position. Several mentioned high burnout rates. Many partners noted that, while ratios have improved, managers are still overloaded, and often only see clients once a year to check eligibility. Others mentioned that individuals and families don't always report assessment information accurately to Case Managers (such as assistance with activities of daily living, or unnoticed cueing), which may not be noticed or questioned appropriately by inexperienced Case Managers. Some self-advocates noted their preference to see their Case Manager in person, and not virtually, now that COVID has waned.

One RHC advocate stated they heard that community case management ratios have improved, but that information about effectiveness has not been communicated. Several DDA staff noted that a better ratio goal is 1:18, since so much work goes into community transitions.

Some DDA staff noted that working towards a standardized ratio is challenging, given different people's range of characteristics, needs and support programs. In addition, the operational shift on the community-based side that include managed care organizations (MCOs) has compounded the complexities of case management work between state plan and waiver services.

Process Recommendations:

1. Despite COVID slowdowns and communication gaps, most who commented felt that case management ratios are improving and encouraged continued legislative funding. The complexity of the issue suggests a deeper collaborative exploration into effective ways to improve the quality of case management responsiveness and visits - and to understand and communicate different complexities in client's cases and needs as they relate to average ratios.

1b. Assess Options to Expand Forecast-Based Maintenance Level DDA Funding Adjustments for Waiver Services

Interview feedback indicated that caseload forecasting was the most complex and least understood recommendation. Legislative and Office of Financial Management fiscal staff, legislators, advocates, self-advocates and experienced DDA staff provided feedback on this recommendation. This report does not attempt to offer a primer in caseload forecasting. However, partners consistently relayed their frustration and admitted lack of understanding around different types forecasting, what each type of forecast produces, SB 5268 (2022) intent and system complexity - given the wide array of waiver programs, grants, entitlement programs and differences between financial and functional eligibility.

Fiscal staff explained differences between maintenance (base level) and entitlement forecasting (for example, for the Community First Choice Options program), and how types of forecasts do and do not apply to different community-based waivers. They also described the nuance underlying courtesy forecasts, data and other requirements, and partner expectations linking forecasts to expected funding. The project team also heard the history behind forecasting in the I/DD program, and how it has changed over time.

Most partners noted gaps in their understanding of how forecasting is done, and how it's applied. One fiscal analyst noted that prior DDA leadership had begun to focus with advocates on what they were interested in accomplishing, rather than how to navigate through forecasting complexity.

Most who responded complained that this lack of understanding led to surprises, based on SB 5268 requests. People's expectations of what would be delivered from the language differed and created confusion and disappointment. Others seemed to conflate maintenance and funding. Some said they reviewed the courtesy forecast and were confused and unhappy with the results. Others noted the added caseload forecasting complications based on the transition of state plan services to MCO networks, with a separate accounting of the waiver program populations. Fiscal staff were sympathetic and noted the need to work consistently with this information to truly understand and retain all the underlying nuance and complexity. It appeared that some advocates may have asked for forecasting and assumed it would lead to entitled funding.

Fiscal staff mentioned how a lack of underlying data and detail can impact forecasts. For example:

- not knowing how many people request but don't receive respite services;
- understanding that the forecast for supported living requires the use of the service request list (those who want waiver services, but waiver slots are unavailable) - which is not the same as caseload. There are about 150 people on the request list, which underestimates demand;
- SB 5819 funded case managers for the no-paid services caseload. About half on the no-paid service caseload list are children that get supports through schools or parental insurance. They are functionally, but not financially eligible.

Several partners suggested the need to track and communicate other data gaps, such as measuring active referrals not receiving placement.

Process Recommendations

1. It may be helpful to first gain an understanding of what different partners' interests and goals are relative to forecasting. A deeper understanding of what people really want to gain from forecasting would help inform how DDA, fiscal analysts and legislators can best plan to efficiently educate, inform and implement. Some of these interests might not require training and could be accomplished through alternative solutions.
2. DDA staff provided historical narrative that implied some degree of misalignment between a desire for waiver forecasting, budget, and legislative approval of waiver slots. Their comments suggest that this could lead to disconnects between DDA, fiscal forecasting and legislative understanding. If appropriate, fiscal staff might consider providing a basic primer to interested partners to better understand the differences between types of forecasts, their intended purpose, and realistic expectation of outcomes.

1c. Expand State-Operated Community Residential Options

State Operated Living Alternatives (SOLAs):

There are approximately 90 SOLAs in Washington, staffed and managed by unionized state employees. The general perception is that SOLAs continue to slowly increase. SOLAs receive all referrals to provide residential habilitation services. They make a determination on how an individual can be supported, based on assessed acuity level, requested services and available program capacity. Several partners noted that SOLAs also provide a safety net for those people with referrals rejected by contracted community providers.

DDA's State-Operated Community Residential (SOCR) program is proud of adopting a *'get to yes'* attitude of matching people to appropriate SOLAs. SOCR staff noted their partnership work with local health agencies, families, guardians, vocational service providers, school districts, law enforcement and others to create closer ties to support I/DD needs. Self-advocates and advocacy groups noted examples of a three-to-four-month process to wait for SOLA renovations, or to find an appropriate housemate match. The varying needs and individual behaviors in community-based settings can create significant challenges to positive and peaceful matches. Frequent moves are often stressful, but poor matches or changes in behavior can disrupt the lives of housemates.

Perceptions of the quality of life in SOLAs and relative costs vary among individuals, advocates, self-advocates, direct care staff, parents, guardians, and legislators. Some advocates feel the Legislature is too focused on SOLAs as a primary solution. Legislators continue to fund rate increases for direct care staff in most models, including SOLAs and supported living, hoping that increased wages for both state and contracted employees will help to stabilize the work force and turnover rates.

Everyone we spoke with supports wage increases. Many expressed gratitude to the Legislature for recent larger increases in wages, and some wished for more predictable and stable future increases. Several questioned whether incremental wage increases are enough to stabilize the I/DD system - including staff retention and turnover rates, as well as the ability to recruit and train appropriate levels of experience and expertise across programs as demographics, cultural and behavioral needs change over time. Partners still maintain different perceptions of costs, quality of care and acuity between SOLAs, supported living providers, RHCs and other providers.

The upfront and ongoing costs to support SOLAs was sometimes questioned by both RHC and community advocates. Beyond the costs to renovate and set up existing SOLAs, one professional guardian stated that she sees rents that exceed $900 per person in a three person SOLA and suggested that the state is paying a tremendous amount without adequate financial review, for a setting where '*the food is abysmal, yard work costs a lot of money, medicine in given in Cool Whip, maintenance is often ignored, and appliances are broken or go missing*'. She further stated that clients in SOLAs '*just sit*', and that workers do not want to work. She recommends SOLAs only if the guardian lives nearby and can frequently visit their client. This was the most negative comment the project team heard related to SOLAs.

Other clients and direct care staff described the nature and scope of positive outings, coordination with client's employer requirements, and maintaining balances of challenges and peace within the household SOLA dynamic. The project team visited several SOLAs and SOCR regional offices, and had discussions with clients, direct care staff, supervisors, and specialists.

Some felt there is a generally accepted assumption that SOLAs are in place to support people with greater behavioral challenges. A legislator repeated the hope that SOLAs would help get people stuck in hospitals out into community settings. Others suggested the need for additional assisted living models, scattered throughout communities to encourage integration. Adult Family Home operators noted a private sector desire to increase I/DD residential support capacity but feel constrained by low reimbursement rates and the widespread challenge of taking on people with challenging behaviors.

Legislators noted that although SOLAs were a positive effort to-date, the expansion of state operated community residential options has not yet scaled enough to help stabilize I/DD populations within communities. One legislator commented that, since the 2019 recommendations, five three-bed SOLAs have been funded. He noted that the SOLA program is now funded for 260 beds and has capacity to add 64 more clients. From his legislative perspective, the SOLA program is '*operating at the level that DDA can operate at - and that DDA can choose to add more funding for more SOLAs if they can find the staffing and housing capacity.'*

One self-advocate suggested the state could increase SOLAs to continue to reduce RHC size, as well as increase community capacity, since SOLAs pay staff more based on their state employee union status - and that supported living providers continue to turn down referrals of more challenging behaviors. Others acknowledged an unhealthy wage competition between different community-based direct care service programs, as well as with other service industry jobs. The 'McDonalds' and "Starbucks' wage comparisons were frequently heard.

Some DDA field staff commented that most persons are well supported by the SOLA model. Some are better off in other models, especially if they have severe disorders, or require medical attention and medication administration. They felt that the SOLA model doesn't work well for those who need much greater structure and supports in their lives. They were concerned about juggling conflicts between individual client freedom and choice, and safety issues (for example, creating a physical barrier in a busy street scenario). '*We build systems to keep people safe, but we don't always have the expertise to help people make good choices in the environment they have chosen to live in.'*

Several RHC leaders and managers spoke of a similar 'safety vs. independence' dichotomy in the ICFs. The greater push towards federal compliance with the shorter-term nature of intermediate care can conflict with community provider's willingness to accept referrals, making it difficult to quickly transition people from the RHCs into the community. Does the person feel equipped and ready for transition? Do staff agree? Is there a promising 'match' in the SOLA, supported living homes, group homes, Adult Family Homes, or other models? Is the family ready, and how much influence should the family have, when families and individuals may describe different needs and wants?

Many self-advocates spoke of their frustrations (in SOLAs or supported living environments) around this tension between independence, privacy, choice and personal rights versus health, safety, and oversight. The project team heard many stories and perspectives about excessive oversight, lack of privacy (for example, not feeling that people are able to have private phone conversations with their guardians or attorneys), and overly rigid structures relative to curfews and time constraints.

As noted, the project team also heard positive examples of community-based outings, coordination with employment needs and other positive examples. Our discussions with clients in both RHC and community-based settings reminded us that people have very individual needs and wants –and different concepts of 'person-centered care'.

DDA field staff pointed out that program tendency is to focus on client needs. Whole person care concepts generally recognize that people are more than their needs. House managers and staff try to focus on client needs and wants in the community. And communities are not always accommodating, as discrimination, ableism and nimbyism are real issues. These tensions can add to frustration and quality of life issues for clients, families, and their direct care staff.

Stabilization, Assessment, and Intervention Facilities:

Four bed crisis stabilization, assessment, and intervention facilities (SAIFs) are challenging to open. A three-bed facility in Tacoma became a temporary alternative to a planned four to six-bed facility in Gig Harbor, based on zoning and permitting restrictions and other barriers (including Housing Trust Fund requirements around non-profit site control, finding staffing for six beds, and other constraints). One DDA staff who went through the energy-intensive experience suggested focusing on three to four bed facilities moving forward, to try to avoid many of the local barriers experienced.

A great deal of work and energy clearly went into negotiations with local jurisdictions, creating a long and complicated planning process. If community crisis stabilization and intervention facilities are intended to work and scale, augment, or replace Intermediate Care Facilities (ICFs in RHCs), and reduce inpatient psychiatric or community hospitalizations of people with I/DD, process, planning and procedural changes seem to be needed.

The state continues to invest in community behavioral health supports, including a 2023 purchase and renovation of a 16-bed crisis stabilization facility in Fife, and a redesign/remodel of Cascade Community Healthcare’s crisis care treatment center in Centralia to expand adult mental health crisis stabilization services and reduce civil patient placements. The project team did not hear much about how these resources might address I/DD needs. Clinicians, some DDA staff and advocates repeated concerns about the general lack of training and capacity of behavioral health providers to understand and relate to I/DD needs and issues.

Other DDA staff suggested adding mobile services and supports, especially in rural areas. Brick and mortar supports tend to be built in more populated areas. Forks was one example of a remote rural area where the volume of crises are infrequent, but the need for access persists when crises do occur. Some spoke of the concept of movement of services around a person, as opposed to moving the person to access services. This could reduce trauma, separation anxiety from families, avoidance of long ambulance rides, and cost barriers to families to spend time in expensive cities. The project team heard a sense of hope around potential innovations in this area, although those we spoke with didn’t offer other specific examples. The team did hear that DDA is hoping to pursue mobile options. Some advocates were concerned about SAIF oversight, given their state-only funding status. ‘*Please don’t create more programs with less oversight.’*

As noted, interviewees across different organizations and self-advocates often discussed the increase in challenging behaviors – including people who are dually diagnosed with behavioral health issues. The general perception is that this population is growing, and that existing staffing in state operated and supported living models (as well as the existing behavioral health system in Washington state) may not be adequately trained to work effectively with more challenging co-occurring behaviors.

SOLA regions have hired behavioral specialists who can assist direct care staff to evaluate behaviors, design, and modify care plans. Most regions have had challenges recruiting and retaining these professionals, as they are scarce across all care continuums. SOCR has hired a retention specialist. A supervisor noted that collective bargaining agreements create less flexibility related to wages and retention.

Supported living providers and Adult Family Home leaders note they are not adequately staffed to handle these challenging behaviors. Professional capacity is limited across I/DD support programs. Client referral packets are often turned down without deeper inspection, based on cover sheets and individual's past reputations. Supported living providers shared many stories of individuals with extensive and challenging behaviors, who burned out staff and upset the agency's staffing balance, due to the disproportional attention and energy spent on one person's needs. *'The industry as a whole lacks staff.'*

Others felt that RHCs are the best current option to handle the most challenging behaviors – but the federal requirements and resulting tension to maintain ICFs as shorter-term stabilization facilities run the risk of some clients 'bouncing' between communities and RHCs (and hospitals and jails), creating greater cyclical trauma, and additional need for intervention and stabilization. The slow development timeline of community-based stabilization alternatives coupled with increasingly challenging behaviors seems to be creating a growing gap that is difficult to patch with existing services and staffing.

Intervention and stabilization are not the same as treatment services. While the Legislature has funded increases for community-based behavioral health treatment facilities, there is a general perception that this will not address dually diagnosed and behaviorally challenging clients with I/DD, if treatment staff are not adequately trained and experienced. One DDA staff noted the need to admit that not every DD client should be living in the community by themselves if they have a severe or challenging condition, and that state-operated behavioral health group training homes (the predecessor to SAIFs) or smaller units may be one solution. He also commented that it takes only one staff injury incident in a SOLA or supported living environment to lose several staff.

Many self-advocates maintain their position that community-based services would be better funded to address these gaps if the RHCs were completely shut down. Other advocates and many DDA staff felt that the ICFs are still required to support these needs, at least until a network of community crisis providers can be scaled up to meet changing needs and demand.

It is difficult to separate 2019 recommendations from the interconnected nature of the entire I/DD system's challenges, strengths, and gaps. This longer report section is one example of this interconnectivity. The short perspective is that SOLAs and smaller bed SAIFs are believed to be important community growth opportunities that are not easy to 'stand up' quickly in significant capacity. The longer view questions what demographic and behavioral changes are happening within the I/DD population, and how can Washington's overall system innovate and evolve to meet those expected changes in ways that further whole-person goals; improve inclusion, dignity, and independence; keep people safe and advance community acceptance of neighbors who happen to have I/DD.

SOLAs are not one-size-fits-all solutions. Clients have very different needs, beliefs and values around support, independence, socialization, employment, oversight, privacy, rights – like anyone else, but felt within the constraints of a system that tries to be everything to all.

Direct care staff and supervisors try to balance safety and client needs and wants – but this can change when events occur and circumstances shift. The ability of people and caregivers to negotiate this balance seems complex, and often constrained by funding limitations. Also, transferring people into different living situations can create or reignite stress and trauma, especially if people with I/DD haven't initiated the change.

Families and many guardians often live with a great deal of exhaustion, trying to navigate a complex system with sometimes limited options. Families seem grateful for increased supports and relief, but also carry strong values and opinions around what is 'best' for their loved ones. Many seem to live with the concern that their loved one's supports and preferred option (for example, families with loved ones with long lengths of stay at RHCs) may be taken away at some point.

A self-advocate described the complex guilt and tensions between people with I/DD and their families. For example, *'the feeling of being a burden on their families or feeling like a commodity within a system. The experience of being a "job", or financially supporting their families while having no funds left for their wants. Being told "no" with no recourse.'*

DDA is in the unenviable position of having to balance dozens of I/DD programs that each have their strengths and imperfections, while workforce capacity, cultural and behavioral needs, scarcity of affordable housing and other systemic and operational tensions grow. DDA leaders and staff feel they work hard as dedicated advocates for those with I/DD, without having the right to advocate for any one specific program at the expense of another. They also realize that the complexities and efforts of working with other state departments and agencies, the federal government, MCOs, and others – and the program barriers that sometimes result - are not readily recognized or understood by the greater I/DD community. One experienced advocate expressed her concern about *'the trend to put more responsibilities under DDA…foster care, employment…. it's pushing too much on DDA.'*

DDA has pilots and initiatives in process, to try to expand capacity and address system barriers, but these don't seem to be universally recognized. Some expressed hope that the shared outcomes will lead to better communication frameworks, improve transitions that mitigate stress and trauma, and strengthen options for the best use of I/DD assets in different settings.

Process Recommendations:

1. Develop a collective sense of program linkages, through the mapping of I/DD program capacity and assets, to support collaborative discussion with partners of how programs interact. Analyze differences in client acuity and other assessment metrics, where capacity

gaps exist, and how innovative pilots and initiatives are expected to address strengths and challenges from partner perspectives. Partners have different perceptions of how programs interconnect in a fragmented system. A greater collaborative understanding could lead to stronger and more evidence-based recommendations to the Legislature for policy improvement.

2. Note the related recommendations in the ‘Workforce Capacity’ sections, and the ‘Leverage ICF Capacity to Meet Crisis Stabilization Needs’ section.

Expand State Operated Residential Options – Other State’s Programs and Innovations

Community Support Services Crisis Homes – ***Minnesota***

Community Support Services (CSS) Crisis Homes provide short-term residential crisis stabilization with staff members using positive supports to help people return to successful, integrated community living. Clients are individuals with IDD who are at risk of placement in a less integrated setting and have a current residential service provider who is willing to readmit them or do not have a residential service provider who can support their immediate needs.

State Community Services (MSOCS) Residential Services – ***Minnesota***

Minnesota State Operated Community Services (MSOCS) provides support to people with complex behavioral needs that cannot be met by private community-based providers and who have been denied alternative support through private community-based providers. A state-of-the-art and highly specialized program called FACES (Friends and Community Experiencing Success) is used to plan individual support services that include community-based residential services typically provided in four-bed group homes.

Institutional Investment – ***New York***

To serve people with IDD and major behavioral challenges, New York operates two types of institutional services to provide 24-hour and all-inclusive care:

1. Developmental Center (DC)/ Small Residential Unit (SRU). DC/SRU services are delivered in a campus setting, focusing on preparing the person for return to community-based care.
2. Specialty Hospital. This facility provides intensive treatment in a rehabilitation hospital setting. It serves young adults with intense medical and behavioral needs.

1d. Expand Uniform Quality Assurance (QA) Efforts

DDA staff shared that they began designing QA planning efforts, starting with RHC efforts prior to November 2019 (for example, standard measures such as requests for admission). They then began working on community-based QA, as reported in DDA's June 2023 report[7]. Supported living program focus included program coordination and community protection.

Some DDA staff noted the challenge of comparing supported living and RHC standards, given fundamental differences in standards and goals. QA staff are assigned to each RHC. Investigators and QA units do pre-audit surveys for RHC licensure. The same isn't offered for supported living providers, SOLAs or other community-based providers. COVID put a damper on RHC audits by limiting on-site work, pushing back QA and oversight efforts.

DDA Central staff mentioned two QA-related reports, based on the expansion of QA efforts. They noted the design effort was challenging during COVID, but DDA was able to work through this process with help from statisticians and PhDs in DSHS's Research and Data Analysis division.

Both RHC and community advocates have been critical of less community-based program oversight, including Adult Family Homes (AFHs). DDA staff noted that AFHs report within DSHS/ALTSA's system. One RHC advocate noted that community-based services are not regulated enough or audited on a regular basis, questioning health and safety issues.

Self-advocates seemed to view QA based on their own lived experience. One asked for more provider accountability: '*if you get nine hours for employment, the provider shouldn't get paid until the client signs off. Are clients really satisfied? DDA is scared of turning off agencies.'* Another self-advocate maintained '*there is no enforcement through DDA, through APS, through the Ombuds. No enforcement or respect, and it's like they go and negotiate with providers….and I'm like, how are you negotiating out our individual rights and protections around abuse and neglect, when people aren't being represented or involved in that process at all*?'

Quality assurance means different things to different people, based on their own experience and perception. Some DDA staff and advocates commented that metrics are just one part of quality assurance efforts and need to be tied and applied to person-centered support concepts and actions.

One self-advocate's story may demonstrate a disconnect between QA metrics and lived experience. Her experience includes domestic violence, loss of care and changing living situations. She's in a wheelchair and needs ADL supports. She is trying to get a divorce, keeps moving, and has been hospitalized more than four times due to poor personal care services. Her husband was homeless,

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[7] https://www.dshs.wa.gov/sites/default/files/Uniform%20Quality%20Assurance%20Metrics_June%2030%20Leg%20report%206_12_23.pdf

and she was abandoned by one of her providers. Personal suffering of this magnitude is hard to explain using a QA metric – her experience questions larger systemic gaps.

Process Recommendations:

1. DDA continues to work through the design of QA metrics and concepts. QA metrics are meant to help with program oversight and compliance, improve quality of care, and achieve other program goals and objectives. Collaborative convenings (workshops or similar) between a broad range of participants and their interests might help partners question and test assumptions, create better ways to implement program oversight, and address barriers and gaps across a range of settings. The group can help DDA modify metrics over time that don't meet agreed-to program goals and principles (for example, strengthening whole person support/person-centered planning goals).

2. Encourage a culture of transparency and responsiveness. Engaging a broader group of participants as part of the design and planning process will help build trust levels and 'buy-in' between DDA, self-advocates/advocates, providers, legislators, unions, and others. Strive for a better understanding of different people's needs, wants and principles related to the intended use of quality metrics and a quality assurance structure, at both 'programmatic' and 'on-the-ground' care delivery levels. Engaging at 'upstream' planning levels can help build a quality assurance system over time that is credible, trusted and useful throughout all I/DD programs, as well as practical and easier to understand. Ensure that metrics aren't inadvertently discriminatory.

3. Many interviewees spoke of the concepts of whole-person, person-centered care, and independence. These are terms that have been increasingly used in health policy circles for many years. When questioned, many people admitted to varying definitions of these terms, without consensus. It would be helpful to have an open discussion around these terms, and what they mean to different people. Effective quality assurance design is only one 2019 recommendation that is linked to these terms – a deeper group understanding would go far to advance the conversation around redesign, for this issue and many other program principles and goals.

1e./1f. Rate Study and Opt-In Structure for Contracted Community Residential Service Providers

The 2019 Workgroup recommended an independent Medicaid rate study to evaluate the existing tiered rate structure for community-based residential care I/DD providers. Milliman was contracted, with their report due in December 2023. Our project team's interviews were completed before that due date, so this report does not include feedback on the Milliman findings. We have reviewed their report and refer to some of their general findings to add context to our interviews.

The tiered rate levels paid to community-based contractors are intended to reflect the different levels of support needs of clients. As noted, contracted community providers have the right to refuse client referrals, which often make matches for services more challenging. While everyone accepts legislative rate increases, providers feel that they're always *'chasing their tail'* when it comes to the disincentives built into the current reimbursement methodology. Rates may remain less than the costs of providing and administering the services and serving Medicaid I/DD clients. Without other significant funding streams (to subsidize lower Medicaid reimbursement) caring for those with challenging behaviors is not financially sustainable for many providers over time.

Upper rate tiers are negotiated. Several community providers noted a lack of consistency around negotiated rates –that one agency might get a vastly different rate compared to another agency with a similar client. DDA staff noted the differences in individual needs, as well as variations in relevance of requested services *('are the proposed services actual community engagement or meaningful activities?'*) There appears to be some potential for middle ground between these perspectives.

In addition, changing demographics and increasing behavioral needs questions the effectiveness of the existing rate methodology – a question that many states are asking, as tiered rates have been normalized for a long time nationwide. Milliman's rate study goes into detail, offering suggestions for modifications to the existing methodology, and future alternatives, including value-based payment trends. The rate study also notes the significant amount of administrative time and burden spent on rate negotiation at the higher, more intense tier levels.

The project team heard similar stories. One supported living contractor stated that *'only 90 percent of my costs are covered by the contracted rates. The rates cover 93 percent of direct care, but only 68 percent of administration costs. The rates do not look ahead to stabilize supported living. The rates do nothing to decrease turnover. Supported living is not really supported yet and we need to make a roadmap.'* Others relayed their concerns about the specialized staffing needs for the growing behaviorally challenged population of younger clients, and how one client's intense needs can upset their entire staffing balance in a particular geographic area. The project team heard numerous examples of the relationship between lack of behavioral specialists, staff injury and turnover, and low reimbursement rates. Several noted that nearly all the referrals that come to them involve clients with more intense behavioral needs. Will enhanced rates increase behavioral specialist capacity with I/DD experience?

One legislator questioned why Adult Family Homes (AFHs) are not the subject of more DDA focus to help fill gaps in community-based services. AFHs are a shared resource between ALTSA and DDA programs and are overseen by ALTSA. AFH rates are subject to a limited scope form of collective bargaining. AFHs are the only option (other than Adult Residential Centers) in the Basic Plus Waiver. An AFH provider relayed his concerns about rates – *'DDA pays homecare aides $20 an hour plus benefits with not Independent Provider training. The AFH model pays below minimum wage - $16.50 per hour, with expectations of expensive training. AFHs see 15,000 Medicaid residents, including people with I/DD who would otherwise be served in facilities. We have young entrepreneurs who want to open AFHs and serve those with I/DD, but the financial model doesn't work.'*

DDA received legislative funding for an AFH pilot, to pay an enhanced rate add-on for higher tier intensity levels. This pilot in Pierce County was scheduled for roll-out in September 2023, with seven contracted AFHs. A flat add-on fee of $2,500 will be paid to care for each of the 100 residents in the pilot, in addition to the base rate. Additional staff training to care for people needing behavioral interventions is included. AFH providers hope the pilot can potentially create greater AFH visibility with DDA, along with support from the Arc of Washington and different King County groups. They hope that upcoming monitoring and measurement will support AFHs as one growing part of community-based capacity to offer I/DD services and supports.

Several providers noted the connection between rates and a system that has traditionally been '*deficit-based*.' This includes the use of client assessment tools, that often focus on what people can't do, as opposed to focusing on individual strengths. These tools are used to assess needs and respective care, rate tiers and support hours. For example, the Comprehensive Assessment Reporting Evaluation (CARE), which is used by case managers to evaluate a client's functional ability and how much assistance a client will receive in community-based programs (and for those transitioning from RHCs to community-based settings). The CARE assessment was developed by ALTSA for long-term support assessments but is also used by DDA. Some questioned whether the CARE assessment adequately accounts for behavioral needs, especially given growing behavioral health challenges in the I/DD population.

Process Recommendations:

1. Evaluate, share, and discuss the prevalence and trends of co-occurring diagnoses, additional behavioral challenges, and other population changes over time across appropriate geographic regions, and demographic and cultural breakdowns. One advocate explained that the increase in school-based special education supports over the past 25+ years has resulted in an adult population with I/DD who are often better trained to handle activities of daily living, and now need more focus on behavioral challenges, employment assistance and other skills. Are the current assessment tools capable of adequately addressing these changing needs? A critical review of existing assessment tools from multiple perspectives may help and could include HCA's Department of Behavioral Health and Recovery and the Behavioral Health Administration (BHA).
2. Convene a diverse collaborative workgroup that identifies existing rate methodology incentives and disincentives. Evaluate the Milliman report recommendations as a group. Work with legislators to collectively communicate these incentives/disincentives with evidence-based and prioritized short and long-term options for improvement.
3. Build additional capacity and collaboration with the HCA, to pursue options for emerging reimbursement methodologies, that may include value-based options, demonstration and other types of waivers, new state plan amendments or other barrier-breaking methods that support agreed-to definitions of person-centered planning, whole-person supports and independence. Evaluate what other states are doing to see where trends are heading, and if other state's options are worth exploring.

Opt-In Rates for Contracted Providers – Other State's Programs and Innovations

Residential Innovation - ***Arkansas***
To serve people with I/DD and challenging behaviors, Arkansas launched an innovative program in 2019, Provider-Led Arkansas Shared Savings Entity (PASSE), to implement residential care in fully integrated settings. With the increase in I/DD and mental health conditions, this program has developed a combined and qualified provider model. Financial incentives exist for providers to deliver high-quality care at a lower cost. Arkansas pays a higher reimbursement rate (compared to other states) to service providers to intensify efforts on coordinated care.

1g. Community-Based Overnight Respite Funding

Interviewees who shared opinions about respite care were nearly universal in their opinion – the pressing need for more respite funding and capacity. The differing perspectives of what respite represented were interesting. Some chose to tie respite directly into crisis response, including increasing an at-home respite path for the many families with loved ones who are unserved in other settings. Others spoke of care giver respite from the perspective of community based and RHC care givers. Some appreciated the respite afforded through RHCs (Yakima Valley School), despite the travel requirement. One common understanding was clear – respite is perceived as a precious resource that can relieve families and care givers from their difficult and challenging work.

Is crisis response and stabilization a form of respite? Do ICFs double as crisis response/stabilization and respite-like services? Again, responses often tied back to an increase in co-occurring conditions and behavioral health needs. Several advocates warned that untrained respite care will perpetuate vicious trauma cycles. Yakima Valley School has developed significant respite experience, despite the younger age of their crisis stabilization and respite bed structure.

One advocate offered her perspective of shared family trauma. She noted the 60 percent divorce rates between parents with children with I/DD. After children age past the 21 '*cliff*', it becomes difficult to find day programs and supported employment. One parent often drops out of the workforce to care for their adult child. More and more parental caregivers are now aging themselves. Who should supports go to? This scenario potentially pits aging adults against adult children for supports resources. '*We need to give parents respite to break this chain*.' Many partners noted that respite needs are increasing as co-occurring conditions increase.

'Washington shifted resources into supported employment to prove I/DD could work. Once a child ages out of school, they have a nine-month period to get supported employment. When the recession hit (2008), we couldn't have both day services and supported employment. For a decade, there was no commitment to day services. We need both to create respite for parents. Combine waiver services. Now there are no day services to be found since they aren't properly funded.'

‘There are no crisis respite beds. You are always begging for a bed somewhere. We have been told so many times to drop the person off at the hospital. There will always be a crisis somewhere. We need 30-60 beds around the state for crisis. Those are not in residential settings or in parents’ homes or on their own with planned respite. Our agency is making a planned respite home for children, but that will be only the second home in the entire state.’

A rural provider noted that increasing local respite services could have saved adults with violent tendencies and personality disorders. They took an older child into supported living services and had to take him out of school. His parents moved away within 30 days. He aged out of childhood, but they could not keep him stabilized. He ‘*burned through staff’*, as no respite options were present – only jail. ‘*Most people think respite is for a few days. But when someone is out of control and a danger to themselves and others, there is no place for that…. we have a crisis contract, but not a great relationship with that provider. The last person we had with them had to be taken to the hospital, where he was threatening to harm himself. We can suspend services if a person is served in the hospital for that reason. The hospital released him in conjunction with another crisis provider. They sent him to a mission, where he was kicked out when he started harming staff. That person has moved on, but what a shame. We ended up pouring a ton of resources without reimbursement, putting staff at risk, plus the liability.’*

Is this just a lack of funding? Is stabilization via diversion services a form of respite? One advocate noted the links to lack of access to pre-school, day care, camp and respite. She noted that individual providers are not trained – and that untrained respite creates additional problems. How do communities end up paying when respite and crisis intervention services aren’t available? Some suggest it is too costly to provide respite at RHCs, but the need for any additional capacity is strong. There doesn’t seem to be a general consensus around the interaction (and service gaps) between respite, crisis intervention, stabilization, staffing capability and competencies.

Process Recommendations:

1. Organize a diverse participant group to map the connectivity and gaps between different definitions of respite, crisis intervention and stabilization. Evaluate the prevalence of co-occurring and challenging behaviors at all stages and points of interconnection. Estimate the costs to communities, based on individual examples. Bring legislators and legislative fiscal/OFM/WSIPP personnel into the group, to help model costs and benefits.
2. Reframe respite and crisis services from a staffing competency perspective. What are common training and experience requirements? How does YVS cross-staff between services, and how well does that work with growing behavioral needs? How can partner experience inform community-based respite potential, and what workforce and agency incentives could be created to make a significant difference in scaling services, without caregiver burnout?

Increase the Capabilities of Community Residential Services – Other State’s Programs and Innovations

The following additional out-of-state programs may be relevant to this entire chapter on expansion of community residential services:

SB962 Homes – ***California***
In California, SB 962 Homes provide a residential option for adults with I/DD and additional health care needs. These homes are operated by non-profit organizations and provide 24/7 licensed nursing supports to serve medically fragile individuals who were formerly residents of a state developmental center. Medical care providers are community-based.

Oregon Intervention System (OIS) – ***Oregon***
Oregon has developed the Oregon Intervention System (OIS) based on the Positive Behavior Support and Intervention (PBSI) framework: an evidence-based framework of practices to improve behavioral outcomes and create a supportive environment for behaviorally challenged individuals. OIS trains staff in positive behavior supports and de-escalation techniques when supporting behaviorally challenged individuals with I/DD to help produce positive outcomes and reduce the use of restrictive interventions. OIS also often provides behavioral assessments to individuals with I/DD and behavioral support needs, as well as appropriate interventions and strategies to prevent or address such behaviors.

PBIS takes a proactive and preventative approach to address behavioral challenges. It relies on data to identify behavioral trends and areas of concern. Interventions are organized into different levels or tiers based on the intensity of the support needed. PBIS places a strong emphasis on explicitly teaching and reinforcing positive behaviors to address intervention. This is done using clear expectations, visual aids, and regular reinforcement and praise for appropriate behaviors. The success of the implementation depends on consistently applying the rules across all settings and by all staff members to create a stable and supportive environment. One key component of PBIS is continuous monitoring and evaluation so that interventionists can make necessary adjustments to improve outcomes. By identifying early warning signs, PBIS can prevent crises and challenging behavior before they escalate.

Staffing Efforts – ***Ohio***
To address staffing shortages and create a more sustainable employment system, Ohio offers an increase of $1 per hour for support workers who have completed 60 hours of applicable training and worked at least two years to provide direct care to people with I/DD.

Community Crisis Homes (CCH) – ***California***
California’s Community Crisis Homes (CCH) are licensed residential facilities that provide 24-hour non-medical stabilization care for individuals with I/DD who have urgent behavior support needs and would otherwise be at risk of facility placement.

Community-Based ICF/IID – ***Texas***

Texas created community based ICFs that provide comprehensive and individualized care to clients. The facilities include physician services, nursing services, dental services, skills training, professional therapies, adaptive aids, vocation programs, and habilitation services, all with the goal to promote independence. People using this service are served in a six-bed homes or larger settings.

Family Care (FC) Homes – ***New York***

FC homes are properties owned by caregivers certified by the New York State Office for People with Developmental Disabilities (OPWDD) to provide care, support, and supervision to people with I/DD in their private homes. Clients must make a monthly payment to the homeowners. Responsibility for assisting and overseeing caregivers is shared with OPWDD or certain non-profit agencies.

CHAPTER TWO: IMPROVE CROSS-SYSTEM COORDINATION

2a./2b. Collaboration with University Assets/Expand Apprenticeship Opportunities

The 2019 Workgroup recommended that the DDC coordinate collaboration with universities, including a deeper dive into co-occurring evidence-based practices. The project team heard a variety of reasons why this didn't happen as planned. COVID hit three months after the 2019 report was submitted. In addition, changes to DDC leadership occurred during the time the Governor's office and DDA were planning their Implementation workgroup. This workgroup intended to work with participants to move the 2019 report recommendations into practice.

As noted, self-advocates and others who were not invited to participate in the earlier workgroup organized to oppose some 2019 recommendations – primarily, the 120-bed nursing facility replacement on the Fircrest campus. The project team heard that these many changes pressured advocacy relationships; the DDC asked for relief around this cross-coordination piece, given their decreased bandwidth. In the meantime, DDA continued to plan for implementation and moved forward on the 2019 recommendations. As noted, DDA had gone through their own leadership changes. By the time DDA formed workgroups to develop requested legislative reports, nearly all the DDA staff who participated in the original 2018-2019 Workgroup had moved on. This created a gap in continuity – the work underlying these many reports skyrocketed, and the staff in new positions didn't have the benefit of the context or experience with the original Workgroup members.

The project team heard common perceptions around the limitations of existing university assets. Most partners hope that our state's university systems can play a major role in developing future educational platforms to train and credential students at varying levels to create careers in I/DD. University programs have focused on research and practice around a variety of clinical and behavioral issues. I/DD and behavioral health have some common educational potential, but there are basic differences in other specialized programs. For example, traumatic brain injury, dementia and behavioral health issues all have intermittent and cognitive issues that significantly differ from I/DD. Also lacking is experience working with people who don't communicate through speech.

UW's Center for Excellence in Developmental Disabilities (UCEDD) is part of the Center on Human Development and Disability. This Center receives federal grant funding that also funds the DDC. UCEDD's core functions include professional training, technical assistance and outreach, clinical services, research and evaluation, and information dissemination. UCEDD had presented to the 2018/19 Workgroup.

The Legislature continues to fund additional educational capacity for behavioral health, but those programs (for example, University of Washington's upcoming behavioral health hospital at Northgate) do not include focus on I/DD. Several interviewees pointed to UW Medicine's focus on screening, diagnosis, and medical management. Behavioral therapy is a significant component of I/DD crisis stabilization, and a major missing educational component. In addition, the project team interviewed faculty from WSU Psychiatry – beyond a limited interest in autism, partners do not seem to be aware of potential opportunities with the I/DD community. Others noted that existing UW behavioral health planning is largely focused on Seattle and King County.

One WSU faculty member spoke of his interest in autism research, behavior analysts in other state's programs, and psychosocial interventions. He noted promising work with non-verbal autistic clients, and their development of skillsets that help them intervene with the hours spent every day on elaborate and repetitive rituals. He suggested a masters level program development if there's interest and support to develop practitioners.

A self-advocate mentioned that academics talk about '*studying people with I/DD'*, which is often an *'otherizing and dehumanizing'* experience. This can be considered another way that society unintentionally becomes oppressive. She noted many ways to train professionals in non-oppressive ways, including Open Future learning, and the LEAD program, originally launched by Kokua services at Evergreen State College.

As noted, DDA has a limited set of staffed behavioral specialists in the field to support the SOLA regions, providing training, backup and care plan support for regional clients in state-operated programs. RHCs are perceived to have the 'full menu' of supports – but even those specialized resources seem thin. RHCs are working to create behavioral response teams, and resources to provide behavior training to direct care staff.

Supported living and other community-based contractors must find their own specialized resources. Co-occurring conditions, including challenging behaviors, violent tendencies, eating disorders and personality disorders are appearing more frequently, and there doesn't seem to be a ready solution to fill and maintain staffing gaps, at all levels in most service sites. Several advocates and DDA RHC staff noted the need to create positive behavioral support plans for community-based clients. These plans outline the supports and strategies to reduce problem behavior and to teach positive skills designed to replace negative behaviors.

The team heard that newer DDC leadership, newer Arc of Washington leadership and DDA have developed some communication around university collaboration. University cultures are unique, and often follow faculty research interests – one RHC advocate felt that universities have their own focus on individual tools that address special education and disabilities and seem less involved when presented with more challenging behavioral needs. DDA staff noted that this work is a huge lift for any organization – DDC, DDA or otherwise.

It seems unlikely that universities can or should attempt to solve these issues on their own – it may take a larger investment push and set of partnerships to make meaningful progress, in the broader context of systemic health care workforce shortages, lack of training and hiring pipelines, and changes in retention tools.

Interviewees had similar opinions about apprenticeships, and often conflated them with internships. DDA staff referenced the progress creating Certified Nursing Assistant training sites at RHCs. Some noted the specific need to create apprenticeship opportunities for I/DD-mental health and crisis intervention training. *'We need to listen to the client's changing needs, or we'll be stuck with the status quo'*.

DDA has engaged with UW Tacoma's Social Work program, to explore smaller, two student practicums. One advocate suggested an option to train other professionals using RHC resources.

<u>Process Recommendations:</u>

1. Create a diverse workgroup to expand the work around this 2019 Workgroup recommendation (originally intended to disseminate evidence-based practice information). This might include identifying silos at governmental, higher education and community levels that hinder workforce development progress; brainstorming what a different system of successful workforce pipeline development and retention could look like; and determine what support internal and external partnerships would need to create scalable results, given common workforce shortages across the health care continuum.

2. Develop a multi-organizational educational workshop to pull representative deans, faculty, guidance counselors and students together from four-year universities, community colleges, technical schools and high schools across the state to learn from people with I/DD and understand their needs, and how to consider a coordinated effort to build out collaborative workforce expansion program in I/DD and related areas. Consider inviting non-traditional organizations, including philanthropy and local elected officials, as well as I/DD partners. Produce a report that synthesizes the workshop thoughts and recommendations to help support a strategic plan that educates key legislators and administrators to enable budget requests for systemic change.

3. Improve DDA communication frameworks, to engage and update partners around intent and progress of university partnerships and potential scalable workforce reforms.

Collaboration with University Assets – Other State's Programs and Innovations

Efforts in Improving Disability Competence of Health Care Professionals – ***Massachusetts***
Researchers noted the low level of disability awareness of providers and highlighted the need to prepare clinicians for quality care for adults with I/DD. The Arc of Massachusetts created an Operation House Call program in partnership with several medical schools on the east coast to address the issue. All third-year medical students receive essential skills training delivered by families with I/DD during their home visits in their pediatric rotation. This represents an experiential learning model to fill the gap in healthcare services provided to the I/DD population by soon-to-be doctors and nurses. It is estimated that families educate 600 medical professionals annually.

Another emerging program is Leadership Education in Neurodevelopmental and Related Disabilities. This program is federally funded and operated within a university system to advance workforce competence to serve people with I/DD. It prepares students from multidisciplinary clinical professions with the knowledge and experience to provide high-quality care to patients with I/DD.

2c. Continue Reforming Guardianship

Guardianship is a legally and operationally complicated and nuanced subject. People have very different and strong feelings about the historical role of guardians, how the law affects many different types of relationships, and what does and doesn't work. The project team received feedback from self-advocates, advocacy groups, family guardians, professional guardians, DDA staff (central, RHC and community-based), providers and others. Again, this report focuses on perceptions of progress heard, and does not attempt to fully explain such a complex subject.

Most of the interview conversations resulted in four general themes:

- Independence, freedom of choice and individual rights;
- Conflict and payment;
- Slow change (including Supportive Decision Making and the Uniform Guardianship Act), and
- Communication and information sharing

The first two issues can create serious relationship tensions between clients and families; clients and guardians; guardians and care givers; guardians and the courts….and the list continues. Differences in payment restrictions, based on where (and in what program) the client resides create feelings of conflict - for example, community advocate concerns about guardians keeping clients in RHCs due to guardian payment rules. DDA staff noted that a move to an AFH or a group home results in the guardianship fee coming off the top of the payment (not the case in supportive living) – and that this can create an additional disincentive to move out of an RHC.

The courts oversee the administration and payment of the guardianship program. One professional guardian complained that the newer Uniform Guardianship Act (UGA) had turned paperwork into a '*nightmare … worse than its predecessor.'* Guardians spoke of the significant amount of additional and unpaid work that is required to support clients - especially when clients move, requiring a new *'establishment of care'*. This report documents an overview of the client, including mental, physical, and financial information. When a person is transferred, the court wants to understand their physical, mental, and cognitive abilities, and what is spent on rent, utilities, recreation, medical, behavioral, transportation, participation - including social and recreational plans and how to further the individual's independence. *'Guardian reports used to take 12 hours – the new laws have increased it to 16-20 hours or more.'* Another noted the new form that came out in 2022 is repetitive and does not track well.

Several self-advocates told the project team that the concept of guardianship creates barriers to their independence. *'I used to have guardianship when I was 19 since someone thought I could not make decisions. And I did not speak up since I hate it when people put rules on me. I want to break all the rules. I do not want to have breakfast, lunch, or dinner at these times. If a person can speak for themselves and make good decisions, they don't need a guardian. It's a difficult subject since you are taking the rights away from people. It is telling people what to do and when to do it. I think it's wrong.'*

Supported decision making (SDM) is a more recent concept in its early stages in Washington state. Most interviewees supported this concept, and many don't believe that it should supplant guardianship – but instead complement it. Some self-advocates noted their desire for more infrastructure to enable SDM as the default method, as *'guardianship takes away people's rights.'*

One advocate with deep experience noted that self-advocates positively pushed to include SDM in the UGA, which was introduced in the 2018/19 legislative sessions. He has seen more and more families consider guardianship with SDM as they age as caregivers, to create a greater sense of security as they age. He noted that the interplay between guardianship and SDM creates options that can support flexibility but maintain security against exploitation – and that many people don't understand this. *'SDM can be combined with trusts, powers of attorney and guardianship to create a tailored fit that is legally recognizable.'* He recommended bringing DDA and the Office of the Superintendent of Public Instruction together to focus on age transitions, and more accurate school messaging to parents, including protection needs. He noted that DDA's 2022 report on guardianship recommended four staff to work on SDM and hoped that some form of training would emerge for individuals with I/DD, families, and professionals.

One guardian noted that the new state law is undermining guardianship. *'It is not focusing on those that need more state oversight. It is defaulting to supported decision making without court oversight. Anyone can be a supported decision maker with no oversight. When the UGA was passed, it specified preference to supported decision making.'*

Another self-advocate mentioned that he is pro-SDM, but that *'the system is going backwards. SDM has never really been implemented, not respected. Guardianship is big business, and a threat to 18 year olds still in school. People should try SDM, and only use guardianship as an exception.'* Another self-advocate noted that *'guardianship is a form of systemic ableism that is very much at odds with human rights.'* There are clearly wide differences in how these concepts relate to different people's experience and perspective.

DDA staff suggested developing legislative recommendations to make guardianship more effective, and to prevent abuse. *'Not everyone needs a full guardian. Some people are directed straight to guardianship, which often takes away their rights – and can take away their opportunities to grow and learn as a person. Gaps exist, and decision packages have not always been funded – but DDA and court recommendations align well.'*

An advocate suggested that as children age into adulthood, their special education Individualized Education Program must connect to guardianship – or at least provide a checklist that helps educate families. Families often hire expensive attorneys, creating a sizable financial burden. RHC clients often have family guardians and are naturally protective. Some community-based advocates say this is unfair, and that the client should choose. This can create tension between families and people with I/DD.

One self-advocate said that *'when I first got on SSI, one of the things they said was that I had a learning disability and that I wasn't able to make all of my decisions correctly…we tried to work with Social Security, but they kept saying, well, he has a medical disability, what makes him think? That right there tells me what it's like, and I spoke up and said, I may have a learning disability, but I'm not dumb.'*

Some see guardianship as a broken system. Others see SDM as a new way to create flexibility to address different individual needs. Some recognize that the infrastructure hasn't caught up with the legal intent. Others see a timing opportunity to correct unintended deficiencies in the newer UGA language and underlying intent. Most seem to want to reach the larger goals of strengthening independence, providing protection against exploitation, and supporting service efficiency and effectiveness.

<u>Process Recommendations:</u>

1. Form a 'five-year lookback' UGA group. Engage individuals, self-advocates, DDA staff, advocates, court and school representatives with family and professional guardians to understand common ground and differences around independence, protection, flexibility and other major program goals reflecting guardianship and SDM intent. Explore options to address known strengths and weaknesses, gaps in UGA language, SDM, and the Protective Proceedings Jurisdiction Act, school/court/DDA communication gaps, unintended consequences and legislative versus administrative requirements to implement improvements.
2. Determine how DDA, the courts, guardians and self-advocates/advocates can collaborate to simplify guardianship processes, including the development of tools and communications that help self-advocates and families understand their options when aging out of school, entering I/DD services, experiencing a change in life circumstances, or transitioning to other I/DD services.

2d. Prioritize Housing Funding for People with I/DD

A self-advocate added her perspective and context: *'Thousands of individuals with I/DD live on their own! The myth that people with I/DD cannot live without system support is inaccurate and a dangerous and ableist notion….* (many) *live on their own and have caregiving come in through ALTSA* *or DDA. Much of the time this is possible thanks to Section 8 vouchers. For families with financial independence, creative solutions have been used, such as duplexes, tiny homes, additional dwellings added to their property, and privately subsidizing rent. There are also 100 individuals who are homeless with I/DD.'*

Statewide housing affordability challenges impact many people with I/DD in different ways. The existing community-based models in Washington generally favor multi-housemate residences – either shared homes, apartments, group homes or AFHs. Residences must accommodate the needs of clients and their direct care staff. Efforts are made to balance safety and independence. Modifications are often needed to prepare a residence to meet these and other program goals. The process to bring on new real properties is slow and energy intensive. General competition in the housing market forces the I/DD program to deal with scarce supply and costly rentals, landlords who sell homes during periods of hot markets, and neighborhood '*nimbyism*'.

The project team also heard positive stories from legislators, advocates and DDA staff about recent increases in I/DD housing funding, and creative relationships between DDA and the state Department of Commerce. The state Housing Trust Fund's allocation to I/DD had shifted over time, from $3M to $5M, down to $2M, and then recently increased to $25M (with attempts to double this in a recent session to $50M). DDA staff and legislators spoke about progress around greater Commerce attention to I/DD housing needs and recognition. Some noted additional funding placed directly into DDA and ALTSA operating budgets, as opposed to the Capital budget. Others spoke of continuing legislative support for the distinct housing trust program for I/DD.

DDA hasn't traditionally received many funds from the Dan Thompson Grant – historically about $1M to $2M per year. Those funds recently increased to $50M (not all for housing). DDA provides Commerce with suggested counties and locations to build or acquire more units.

In addition, legislators were proud of the range of funding they have procured and found partners to collaborate with to build new units – for example, working with the Arc of King County to develop 30 I/DD units with Mercy Housing, I/DD set asides with the Home & Hope program, and the Kent/Des Moines 'Open Doors' program for people of color with I/DD (40 units out of 200). Legislators and DDA staff are clearly excited about building momentum for I/DD housing, to create a path to sustainable funding. It appears that prior bill attempts to find funding sources for these housing goals will continue into future legislative sessions.

DDA staff expressed excitement about hiring newer and experienced FTEs to focus specifically on housing – and strengthening cross-collaborative relationships with Commerce, legislators, and others to continue to build momentum. DDA has not been historically structured to engage substantially in housing issues. DDA noted recent success and ongoing opportunities to work with Commerce to cut red-tape and streamline existing Housing Trust Fund application processes. Also, DDA's collaboration with Commerce under the Dan Thompson grant – a first time interagency agreement with a new pathway to housing.

Self-advocates, providers, advocates and DDA staff expressed concern about one of the most significant barriers to affordable housing – that many people with I/DD have incomes well below 30 percent of the 'Area Median Income' (AMI). Rent is set at a maximum of 30 percent of people's monthly income, which creates a gap as rental revenue is lower than total operations costs, including the costs of servicing debt. In other words, client's SSI payments often cannot cover rent costs, especially in urban areas where rents have increased dramatically. A self-advocate noted that *'Poverty is required in this industry. The only three resources that may help are home ownership, ABLE (trust) accounts and healthcare for workers with disabilities. This class barrier destabilizes individuals and families.'*

Several interviewees noted that developers cannot afford to build I/DD housing in King County, or in many other locations. This and other barriers make it difficult to attract developers to build I/DD housing, unless non-profits, philanthropy, or new forms of state revenues are willing to subsidize the gap.

DDA staff relayed some history of affordable housing and supports, based on the idea of tenant supports in the 1990s, which was built for lesser needs. When RHCs started to decline, the lines became blurred between housing and supports. '*The value was in generic housing that was owned or leased by clients. DDA was advised not to become a landlord or get involved with tenant/landlord issues – but clients were completely dependent on DDA to find the housing and sustain community-based services. This created a strange imbalance – the public imagines group homes or family home care. The reality is that these different residential models have created gaps, which is why DDA is so involved in affordable housing*.'

Other barriers are evident, but not viewed as insurmountable. For example, the trend of moving away from a clustered homes concept within neighborhoods, to reduce a congregate care philosophy. Several DDA staff noted that separating homes across distances better addresses community and societal integration principles and avoids stigmatization. *'We need to integrate individuals so not all are in one wing, or not all six houses are on one street.'*

The projected housing numbers are immense. *'We have 1,400 units and added 150 units in the past year. We have a need for 10,000 units across Washington and up to 37,000 units for those not enrolled* (in I/DD). *The 10,000 are the ones we know and can target.'* Some of those 37,000 units relate to people living with their family caregivers, who represent most of the I/DD care in Washington state. These parents and family members are aging themselves, which only increases pressure on future housing and supports demand. Attracting developers is challenging, as most are busy building larger housing projects – very different from the single family home-sized model that dominates I/DD community-based housing.

Finally, some noted that housing and staffing issues cannot be separated. Building or acquiring new units requires staffing to make supports and services work. A self-advocate believes this is a myth, and that combining them results in people stuck in hospitals or with threatened housing. She noted that housing and transportation cannot be separated, as many people with I/DD cannot drive and are easily isolated.

Mitigating barriers and improving capacity requires collaboration and systems thinking around the interconnections between many factors. Increasing co-occurring behavioral health issues impacts recruiting, training, and retention of staff – and interconnected with availability of housing stock.

DDA staff noted: *'We also encourage developers to advocate for maintenance and operations of DD housing to be sustainable. If we look at permanent supportive housing, they get the capital, maintenance, and operational expenses for the program. For DD housing, our biggest partner is the Housing Trust Fund – the capital fund which lets us build. Then it's the developer's responsibility for the financial support. We need different types of housing models and solutions to meet the different client needs. So, a set-aside for group homes could be a solution for those with high needs. DDA has a state-operated group training home model* (SAIFs) *that could support the more challenging behaviors. That group training model is in the law - but doesn't exist yet. Could be operated through contracted residential providers. With four to six rooms, it would be larger.'*

Process Recommendations:

DDA produced a December 2022 report[8] (with ECONorthwest) on I/DD housing needs in Washington state. This report goes into much greater detail than our interview responses provide. The report also includes a series of detailed recommendations related to further streamlining the Housing Trust Fund application process, AMI barriers, housing strategy, housing and support service coordination, developer relationship-building, and other suggestions.

The project team heard that DDA has already internalized some of these recommendations, including hiring dedicated and experienced staff. As such, we have no specific process recommendations - other than to suggest that DDA evaluate their broader partner relationships to ensure that people are invited to engage in the process in ways that make sense to them, their interests, and the strength of achieving possible consensus. This could include hosting group sessions to provide updates on strategic housing momentum and soliciting feedback to advance and refine housing program goals and objectives.

Prioritize Housing for I/DD – Other State's Programs and Innovations

"Buy It Once" Housing Model - ***California***

Using CPP Start-Up funds, a housing developer organization (HDO; either a non-profit or a for-profit entity) may purchase real property and modify a house to meet the unique needs of consumers or may develop multiple restricted units of five or more in a multi-family project. A unit includes, but is not limited to, a studio, apartment, townhouse, or duplex. The HDO is the fee owner. The purchase must

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[8] https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/Housing%20Needs%20for%20Individuals%20with%20Intellectual%20and%20Developmental%20Disabilities%20in%20Washington%20State.pdf

be in collaboration with a California Regional Center, which is responsible for submitting housing proposals and defining the funding usage.

Office for People with Developmental Disabilities (OPWDD) Housing Subsidy – ***New York***
The OPWDD Housing Subsidy provides financial subsidy assistance to help individuals cover the costs of their housing. This assistance may help with rent, security deposits, community habilitation, environmental modifications, or other housing-related expenses. Some people may also be eligible for one time transition costs when moving into their first apartments.

2e. Expand Community Access to RHC Professionals

The 2019 Workgroup suggested that RHC professional capacity might be shared with clients living in community-based settings. Dentists and dental hygienists are a frequent example provided of community access challenges. Others noted difficult access to adult day care and speech pathology services in the community. RHCs have a deeper bench of clinicians, therapists and other specialists who are, by definition, familiar with the needs and communication styles of people with I/DD. The actual capacity of these professionals to service community clients is unclear. A self-advocate described RHCs, sheltered workshops and adult day services as '*systems of segregation'* that should be supplanted by *'person-centered community-based services – as essential for disability rights.'*

DDA developed a workgroup in 2022 to evaluate this 2019 recommendation. The workgroup included a broad roster of professionals from the four RHCs across the state – a Physician (and assistant), RN, LPN, ARNP, Psychologist, Psych Associate, Dentist, OT, PT, Speech Pathologist/Audiologist, Psychiatrist and a Dietician.

In addition to DDA staff, the workgroup also included HCA representatives and professionals from the Managed Care Organizations (MCOS – the contractors who manage services for Medicaid beneficiaries, including state plan services in community-based settings) across enrollment, provider networks, care management, behavioral health, clinical programs, and operations.

DDA produced a report of findings in December 2022[9]. The primary barriers to achieving recommendation goals were largely administrative Medicaid requirements that highlight differences between RHC and Medicaid provider rules and regulations – for example, provider credentialing and billing requirements, which could add significant administrative burden to RHCs and their practitioners. The union-affiliations of RHC professionals and collective bargaining impacts were identified as another potential barrier that would require resolution relative to practitioner workload capacity and other issues.

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[9] https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/Residential%20Habilitation%20Center%20Facility%20Based%20Professionals.pdf

This workgroup did suggest other recommendations, including the potential for telehealth-supported visits. The group noted that MCOs do not currently have sufficient networks with needed I/DD experience, and that RHC practitioner availability might increase as assumed RHC/ICF caseloads decrease over time. The report indicated a respect for deep RHC experience, and suggested recommendations that could help use that experience to fill obvious community based I/DD service gaps. The report implied that DDA would likely need to weigh the effort required to address barriers versus the potential benefits to community-based clients.

Interviewees had limited opinions on this topic. One legislator had read the report and noted that nothing had been championed yet by DDA or the Legislature. Some DDA staff were unclear about department prioritization of this 2019 recommendation. Others wondered if this was related to mobile stabilization services, and enhanced medical services. A few DDA staff thought the union affiliation and lack of realistic practitioner capacity issues at the RHCs could be major impediments to moving this recommendation forward. An RHC advocate said, '*I know that RHCs do their darndest to make sure appropriate staffing levels are pretty filled out.'*

One DDA staff questioned whether dentists could be accessed via respite care at Yakima Valley School. *'If respite is planned at YVS, could dental appointments be added at that time? Perhaps only routine cleanings and exams and some fillings, but not sedation, as its not allowed at the RHCs?'*

Another RHC advocate said that '*DDA and Medicaid need to work together with CMS on this. There is no other way to break this out. When community-based clients need a dentist, the dentist at Fircrest would have a day a week…would have to have a separate accounting form. CMS said they'd allow a certain percentage of the community (of total RHC time spent) …but never said what that percentage is. Dentists and hygienists at RHCs run in (predictable) schedules. They know what to anticipate. Would a new person from the community upset that routine? Keep the accounting and time records, add them up and see if they make CMS' allowed percentage. This issue won't change in RHCs until DDA approves it. We have one hygienist at Fircrest who is not full time. Our dentist is full time for emergencies, but not otherwise. Extractions or abscesses go to Harborview.'*

DDA staff noted: *'The biggest example are dentists. It becomes so difficult. We have fully equipped dentists at the RHC. Why can't we utilize them in the community? Find creative ways. We create barriers for ourselves!'*

Process Recommendations:

1. Engage with partners to identify different practitioner gaps in communities to evaluate the scope of access barriers. Is there some way to track community-based need and lack of access from different partner perspectives? (For example, measuring Harborview intake for advanced dental issues; polling or surveying individuals/parents/Case Managers/community caregivers to assess delayed or denied visits)?
2. If the scope warrants, partner with the HCA and MCOs to pursue the most promising (and perhaps least restrictive) recommendations from the 2022 DDA report.

3. Consider this as part of the larger issue around workforce capacity, and training existing community providers to work with people with I/DD.

Expand Community Access – Other State's Programs and Innovations

Special-Care Dental Clinics - ***Minnesota***
The Minnesota Department of Human Services operates special-care dental clinics in key regions of the state for patients whose conditions make it difficult for them to obtain dental care from other providers. Patients with developmental and intellectual disabilities, severe and persistent mental illnesses and traumatic brain injuries are eligible to receive treatment at these clinics. The clinics provide a full array of dental services, including examinations, cleanings, X-rays, fluoride treatments, fillings, extractions, root canals, partial and full dentures, and dental procedures in a hospital under general anesthesia for patients who cannot be treated in the clinic.

The Home and Community-based Services (HCS) Program – ***Texas***
The HCS program provides services to individuals with I/DD who live with their family, in their own home, in a host home care setting, or in a residence with no more than four persons who also receive services. Services consist of adaptive aids, minor home modifications, professional therapies, behavioral support, dental treatment, nursing, residential assistance, respite, day habilitation, and employment services. Service coordination is provided by the Local I/DD Authorities.

Article 16 Clinics – ***California***
People with I/DD can receive diagnostic and treatment services in Article 16 clinics, which render services within the scope of nursing, nutrition, psychology, social work, rehabilitation counseling, occupational therapy, physical therapy, speech and language pathology, and limited medical services (for example, some dental services).

CHAPTER THREE: INVEST IN STATE-OPERATED NURSING FACILITIES

As noted, the 2019 recommendation to build a 120-bed state nursing facility (SONF) replacement on the Fircrest campus subsequently became the most contentious of the Workgroup's twenty recommendations. Many self-advocates have very strong feelings and positions about shutting down the RHCs and oppose continued funding, believing that RHC funding could be better spent on additional home and community-based services to shore up gaps, support inclusion, increase independence and further other important program goals.

Some advocates have modified their interests and approaches, assuming a declining role of RHCs over time, while acknowledging that they provide some degree of a practical present role, given the gaps in community-based supports and the rise in challenging behaviors. Some long-standing RHC advocates have supported community investments, with the caveat that RHCs still provide the best match for a subset of people they believe simply cannot function in existing community-based models. Everyone has strong personal stories to share that support their long-standing positions, passions and interests – and legislators have heard many of these stories over the years.

The project team received limited feedback around perceptions of nursing facility or SONF needs, beyond the Fircrest SONF building plans. Among those that chose to comment, one theme that emerged was a general concern for the lack of collective movement on long-term care services for the I/DD Community. A legislator questioned *'What's being done about the aging of the I/DD population? Is this getting sufficient attention? Will behavioral health issues change with age? How should we plan for future I/DD aging needs as demographics change?'*

Several people the team met during RHC skilled nursing facility site visits have lived most of their lives at the RHC, including transfers internally from ICFs. Some were elderly, and others were younger with additional physical disabilities. An advocate noted that *'There's a disconnect in I/DD – it's easy to get into an RHC nursing facility, and then get stuck. The criteria to get in isn't hard, based on eligibility. There are no ICF active treatment requirements. You can get stuck at an early age.'*

The 2019 Workgroup had some limited discussion about the possibility of buying up defunct private nursing facilities in communities and were curious about the investment costs. One advocate suggested creating a progressive aging plan for I/DD, including consideration of dementia needs. She thought that using the Fircrest SONF for multiple uses might make sense in conjunction with community-based group homes (through the CORE Waiver). This could provide a positive experience with greater care and attention to Activities of Daily Living (ADLs), as well as dementia care, based on personal family experience.

Another advocate was critical of existing NFs in the community. *'NFs are worse than the RHCs….no treatment plan.'*

DDA staff and RHC advocates noted that the Fircrest SONF planning required a lot of partnership work. Site planning and the building footprint were modified, based on tree retention issues. The

City of Shoreline was a significant player throughout the process. As of our last interview dates on this topic, it sounded as if the ground-breaking could take place in Spring of 2024. DDA staff had mixed of opinions: *'I think this is an area of great achievement. The planning process with Fircrest has gone well…. having a NF on both the west and east side of the state is great….and the need for nursing services for clients is quite different from the ICF service needs.'* A legislator remarked that *'I have mixed feelings about Fircrest* (SONF). *We had to build something there but missed an opportunity. We lost the legislative battle to make that a smaller facility and put other smaller facilities across the state. If we make SOLA progress, that could be a good substitute.'*

A guardian noted that *'they are losing beds to build it* (the SONF). *They are closing Aspen. They are hot-bedding elderly persons. The SNF does not have more beds. Lakeland has capacity, but they have closures. People do better in NFs than otherwise. A person went from SOLA to the RHC because of seizures getting bad. If you get people from Rainier with challenging behaviors, there's no way the community can support that. They end up in skilled nursing.'*

The project team heard this varied feedback and concluded that I/DD aging issues seem to be in very early stages of group conversation. The intent of the 2019 recommendation was meant to open discussion around the larger issue – instead, the collective energy seemed to focus on the significant Fircrest SONF planning process. The larger issue of aging and I/DD in Washington state seems to require more intentional group discussion.

Process Recommendations:

1. Evaluate data relative to aging, ADLs, cultural differences, clinical needs, behavioral needs, and other trends and demographics to estimate the speed of I/DD population changes – towards the goal of forecasting I/DD aging capacity needs.
2. Convene a collaborative process to share current DDA and ALTSA partnership progress and existing barriers with partners around aging and I/DD issues. Form a dedicated long-term care workgroup with broad representation to explore long-term supports innovations in the U.S. that may be applied to I/DD needs, based on data results in #1 above. Explore state-operated, private, and public/private/partnership options, as well as alternative provider reimbursement strategies to consider possible options (in addition to existing capacity) to address long-term supports and service trends and needs in Washington.

CHAPTER FOUR: REDESIGN ICFs AS SHORT-TERM CRISIS STABILIZATION AND INTERVENTION

4a. Develop Infrastructure to ensure no one remains in an ICF longer than necessary

This set of 2019 recommendations included a series of programmatic changes:

- Complete DDA assessments for ICF clients
- Develop communications to ICF clients and families re: the temporary nature of ICFs
- Expand the Family Mentor Project
- Begin discharge/transition planning immediately
- Establish transition teams

The federal government's threatened and actual decertification of RHC ICF Program Area Teams (PATs) in recent years highlighted the short-term intention of ICF residency. Continuous, active, aggressive treatment requirements are intended to create a safe and properly staffed space where people can go for crisis intervention and stabilization and receive the educational and training supports needed to transition into 'less restrictive' settings. This required a significant cultural and operational shift in Washington state – historically, the long lengths of stay for many at RHC ICFs contributed to 'us versus them' ripple effects that continue to dominate some partner discussions. On a positive note, this change has created an opportunity for partners to further align between themselves and DDA, based on collective program goals and what is required to ensure federal funding match.

Gaps in community crisis options, community-based programs willing to take people with more challenging behaviors, community first responders and mental health treatment centers that understand I/DD needs, and workforce shortages (including behavioral specialists) create challenging barriers to transition options and timelines for many people.

These barriers are recognized by most partners, and many of the interview comments were related to their preferred response to these barriers – or to the level of progress made to address these cultural and operational changes. Some had praise for progress made under these difficult conditions; some had suggestions for improvement, and many expressed their frustration with the way the system backs up or leaves people in less optimal settings.

ICF Assessments

Most of the interview feedback on assessments had less to do with completion timelines, and more to do with the appropriateness of the Comprehensive Assessment Reporting Evaluation (CARE). The CARE assessment is used on the community-based service side (in part to determine needs and subsequent reimbursement tier levels for provider payment) and is also completed by the RHC as people are transitioning into community-based services.

The CARE assessment was originally developed by ALTSA's predecessor, with a focus on community-based long term supports and services. One DDA staff noted this assessment is focused on ADLs, asking questions from a deficit-based perspective. DDA staff had varying opinions on the applicability of the CARE assessment to the I/DD population. Some suggested that CARE is better than other tools but needs improvement – perhaps with a better use of comments fields.

Others suggested that DDA should move away from an ALTSA-focused tool, and develop one specific to I/DD. '*The CARE assessment fails when it comes to letting people self-direct. We have not figured out how to assess supports in a way that is not deficit-based.'* Several others noted improvements are needed to progress towards whole-person/person-centered care goals, which suggests a tool that is strength-based. One DDA staff suggested looking at California's or New York's developments in simplified and person-centered tools. The project team was told that DDA is working with an assessment group at the National Association of State Directors of Developmental Disabilities Services (NASDDDS). A guardian noted a disconnect between RHC and community-based assessment perspectives: *'RHC staff are trained to tackle the ability. Care needs are not well addressed…. it's a different view. So, these things are not always brought up when switching* (for transition*) to a CARE assessment.'*

Communicating Temporary ICF Nature to Clients and Families

A part of the cultural shift away from long ICF length of stays included communicating this temporary intent to people and families. DDA staff noted they have created a set of communications tools and FAQs that remove the older language used in the system and replaced it with messaging around stabilization and transition to community.

One DDA staff noted that '*I'm excited about the opportunity. This piece is no small feat…it's titanic. We have staff in the ICFs with amazing skills. We can use those staff for clients who need that level of care and get others back into the community. There are different ICF staff feelings. When someone needs to return to the ICF, some staff will say "he should have never left". Others feel a sense of failure, having developed relationships and tremendous progress with clients and then watching them leave. But I think most staff are excited. I think it's shifting how people see their role and how they view their purpose differently. Like the transition coordinators at the RHCs, working through transitions with clients and families. I think most people are excited and want people to live their lives to the fullest.'*

One family guardian expressed the difficulty of dealing with this transition: *'I promised on my mother's death bed not to move him away from the RHC.'* Some family guardians appreciate the positive effects of continuous active aggressive treatment requirements. Others are trying to transfer their loved ones into a SONF.

Some DDA staff and advocates criticized case managers who don't communicate the potential option for community-based services to RHC clients and families. DDA set up community fairs in 2023, to bring community providers, advocates, and the SOLA program representatives into the RHCs to speak to families and guardians. Our project team attended the Fircrest Fair and heard mixed reviews from invited partners. Most were appreciative of the opportunity to come and present their services – some were initially skeptical that they may not ultimately receive referrals and transitions.

DDA staff commented on a pilot done with nine case managers and a transitional team, to create a potential statewide transition tool that identifies the different transitions stages and progress to communicate with clients, families, and guardians. The pilot included the collective work of a therapist, psychologist, and nurses to work through the barriers that occur during long transitions.

One family guardian heard that if their loved one moved out of Lakeland, they would be unable to return. Communication is always a work in progress, and always subject to improvement.

Expand the Family Mentor Program

When Frances Morgan Haddon RHC was closed in 2011, the Roads to Community Living (RCL) grant team went to Bremerton to speak with clients and families. At that time, only two families (out of 53 clients) were interested in community-based options. The RCL team invited clients, family members and supported living providers to sit down over pizza and talk about options. They also invited families who had already moved out of Frances Morgan Haddon.

The RCL team realized the value and credibility of families hearing from other families' experience and wanted to expand the concept to other DDA services. The program became co-managed by DDA and ALTSA and included a significant number of families accessing long-term community-based supports and services. The primary goals are to ease transitions from RHCs and SNFs into community-based services, create a positive transition experience, and reduce transition stress.

As a volunteer program, families choose to work with a mentor. There is no wait list. The primary challenge is finding appropriate mentors to grow this program. The Arc of Washington runs the program (through a contract with DDA) – The Arc employs the family mentors, makes the hiring decisions (with DDA communication) and seeks out the best family matches. There are four long-standing mentors – a fifth original member retired. Three are located on the west side of the state, and one is on the east side.

The project team heard enthusiasm for the program: *'Family mentoring has been a wonderful experience for people involved. On woman found a sister at Fircrest she didn't even know she had. Huge impact. She was able to leave Fircrest and move into the community, with her 'new' sister's help. We* (DDA) *step away and let the family do their thing, and we provide supports. The Arc handles the contracts. And we have a contract with the DDC for family information.'*

One advocate suggested improving the program to attempt to train families earlier, to include positive communication around behavioral changes. She noted that, like most families, teens and early adults with I/DD often lose control and create family power struggles. She felt that earlier family mentor work might help ease these life transitions. One guardian stated a desire to create a similar program for guardians. DDA has piloted a peer mentoring program – others spoke of this with optimism.

Begin Discharge and Transition Planning Immediately/Establish Transition Teams

Some of these operational changes began prior to the Workgroup report release in November 2019, based on 2019 PAT A closures at Rainier. The project team understands that some of the funding for this transition work comes from the RCL demonstration. RCL funds can be used to provide one-on-one help to transition from RHCs into the community, as well as provide access to additional services and supports for up to one year after community transition. For example, the project team heard stories of RHC staff who kept in touch with clients after their community transitions. The team met with RHC staff who have long-standing relationships with clients and are dedicated to achieving positive outcomes.

In general, as people in ICFs reach their individual goals, information is sent to the RHC placement coordinator. The team communicates with the family/guardian that the person is ready to transition into the community. The operational documentation and placement tracking process may vary between RHCs – the project team had the opportunity to review Lakeland's process, which includes detailed stages and timing of steps to track progress, communication, momentum, and possible delays.

It appears that each of the RHCs are in somewhat different stages of transition program modifications but headed in the same direction. All have slightly different approaches and timelines related to strengthening community provider relationships. The project team visited with residents, leadership, management, supervisors, specialists, and direct care staff at all four RHCs (three on-site, one virtual visit at Yakima Valley School). We also met virtually with guardians (family and professionals relative to RHC settings). All of them team's conversations with staff indicated a genuine dedication to finding the best placement for clients, without noticeable bias towards any program. Most shared similar frustrations with the shortages of adequate staffing and specialist capacity (and turnover, retention) across programs. Many RHC staff have worked in community-based settings and programs and were able to share deep experience from a range of positions and perspectives.

All shared similar frustrations with increasing challenging behaviors, and the potential risk of transitioning some clients out of RHCs (with more specialized support needs) into community-based programs that may lack needed supports. All shared similar experiences with community-based providers rejecting offered client referral packets, due to high-risk behavior, medication complexity, or other history that might prevent a path to placement. All were able to speak to the need to plan for community transition early. Many shared similar experiences of some families and guardians who simply cannot conceive of their loved ones functioning well in community-based settings (although some have tried in the past). Some families have loved ones who have lived most of their lives in RHCs – and have expectations of being 'grandfathered into RHCs', regardless of regulations. All of this suggests the depth of the work that goes into transition planning.

The transition manager at Lakeland suggested ideas to provide additional transitional supports for individuals moving into the community – including the use of on-site facilities to gradually acclimate to the changes from RHC to community-based living. One guardian had recommended several similar options, including *'Less restrictive environments, while still having the supports they know. At Rainier, the idea was to change the old dorms into studio apartments. At Lakeland, the ideas was pre-fab homes just off-campus.'*

Process Recommendations:

1. Evaluate the CARE assessment from different partner perspectives and context. Is it an appropriate fit? Does it support the I/DD program's larger whole-person/person-centered/independence goals? Will it work for an increase in behavioral support needs? If not, should the CARE tool be modified or replaced? Would a strength-based assessment or perspective help support these goals? Does the existing transition process consistently share the RHC's broad assessment information (based on many tools) appropriately with community-based providers? If not, can process improvements be made to highlight additional context on referral packet covers and content to attract community providers?
2. Assess the value of forming regional community provider group workshops to map existing RHC transition process steps and identify real and perceived barriers to accepting community placement referrals (including, but not limited to challenging behavior issues and associated capacity/costs). Identify potential process gaps or operational enhancements that could improve placement. Identify useful and agreed-to process standardization options that minimize contractor's perception of placement process variation and ambiguity.

4b. Leverage ICF Capacity to meet Crisis Stabilization Needs

Some partners believe that the RHCs are the best current resource for crisis intervention and stabilization and seek ways to increase their capacity. Others believe that the ICF model is outdated and requires re-thinking what is possible in the community. Some noted again that without community based behavioral health treatment services, no existing model will sustain people in the community – that they will always be subjected to event 'loops', and that a crisis stabilization model focused on education and training for safety and ADLs cannot address or sustain their behavioral needs.

One legislator noted that there hasn't been much progress on crisis stabilization, and that advocates have fallen back into 'RHC closure' versus 'non-closure' positions. She also noted the consequences of transitioning too early, including lack of stability and negative ripple effects (including recidivism rates).

Some RHC staff perceived conflicts between ICF/SONF regulations and the need to address complex behaviors, as RHCs are not licensed as mental health or substance use disorder treatment facilities.

An advocate discussed a twenty-to-thirty-year history of children in special education programs who received therapies and training to address their ADLs. Those children are now adults with needs that have changed – as noted, many now have more challenging behavioral issues (for example, personality disorders, aggressive behaviors, and violence, eating disorders, suicidal ideation and acts) and medical issues that require a different set of stabilization and support skills. DDA staff noted that the federal regulations (and associated audit and review language) are based on 1960s/70s needs and have not yet caught up with the reality of these changes. Also, federal regulations direct the focus of program reviews and audits, which may also be *'out of step'* with changing needs.

Another advocate wanted to bring attention to continuing wait lists – and the vexing issue of people with I/DD stuck in hospitals (Western/Eastern or community hospitals). DDA Central sends referrals to Yakima Valley School (YVS), but their crisis beds are almost always full. People have long lengths of stay, backing up services.

DDA field staff noted that YVS crisis beds are only five years old. When clients become hard to place in the community, they can end up staying at YVS for one to five years, with high levels of staff supports. There are no active treatment requirements for these crisis beds, so there are no temporary mandates. The latest group has been at YVS for one to two years. One client left YVS, was in Spokane supported living for three months and failed, went to Eastern psych hospital for one year, and is now back at YVS. He is reportedly doing well and has returned to his '*baseline.'* YVS staff know him well, and he responds positively to them. He is apparently not an unusual example.

If family caregivers make an emergent crisis call to their case manager and there is no bed availability, they are told to call the police. YVS noted they could fill more crisis beds, as referrals stack up and they have to say 'no' – but they don't have the needed staff to expand. YVS uses the same staffing for crisis beds, respite beds and nursing facility care. Workforce shortages surface again as a root issue.

One DDA staff suggested re-configuring RHCs as centers of excellence or respite capacity. An advocate noted a need to reframe program philosophy from *'what do we have?'* to *'what do you need?'*

Rainier set up the Klamath cottages during COVID, as a concept that fits in-between hospitals and community placement. The Legislature funded Klamath with state-only funding for the current biennium. There is high demand for Klamath beds, and no active, continuous treatment protocols (due to lack of federal match).

Most Klamath residents have higher functioning skills, and don't necessarily need to learn ADLs – so staff don't need to focus their time on basic training and education. Much of the effort is spent on modifying behaviors, including coping skills and emotional regulation, to prepare people for community transition. Klamath currently provides access to '*everything needed'*, and staff speak proudly of residents '*thriving.'* Staff expressed the desire to grow Klamath but are limited by the noted workforce shortages, and the remote Buckley location. They do bring in qualified people to provide additional staff training.

Some Klamath staff hoped for future creation of a Behavioral Tech position – not necessarily requiring a college degree but trained at a slightly higher level than a GED. Could Klamath be replicated in a community-based environment? Staff suggested that it depends on the clients, as well as the supports available to address crisis in the community. Klamath doesn't admit people who are in severe crisis.

Does Klamath represent a model that might fill certain gaps between crisis intervention, co-occurring conditions, and treatment? Staff believe Klamath is worth serious consideration. They note that their work and their transition planning with their clients leads to acceptance by community-based providers. They also report that clients are happy to be at Klamath, that it's a positive place that has a short-term stay mentality, that staff enjoy less pressure, and that clients have access to what they need to stabilize and thrive. One advocate did not think that Klamath is a model that should be replicated and noted that many Klamath residents have longer-term lengths of stay – she noted that *'almost half have been there since 2021... some people are stuck there.'*

Partner comments around crisis stabilization at ICFs raise many questions. To what extent do older federal (and possibly state) regulations create site-of-service barriers and prevent crisis intervention and stabilization flexibility in RHCs and community-based services? How much have the needs of different populations with I/DD changed over time? Is the nature of service backlogs (duration, demographics, and diagnoses) changing? Are there other models, like Klamath, that might help relieve some of the backlog pressure around crisis intervention and stabilization? To what degree are such models evidenced-based, and which behavioral conditions and modalities are they best suited for? How can the system better coordinate between programs so that people don't lose scarce residence spots when they move between crisis care and community-based locations (in supported living, not just in SOLAs)? What are the most impactful training models for community-based staff to help mitigate crises before they happen?

Process Recommendations:

1. DDA has developed pilots and initiatives that are planned or already in place. It's likely that they will be monitoring early results from the SAIF program, the AFH enhanced reimbursement pilot, Klamath, and other initiatives. Consider recent behavioral health coordination efforts, including 988 call centers, regional crisis lines, public safety telecommunications, mobile rapid response teams, community-based crisis teams and designated crisis responders. Consider HCA, DOH and Behavioral Health-Administrative Service Organizations scope, scale, and willingness to partner around I/DD concerns. Plan for broad group participation, including behavioral health experts, to communicate results and feedback and solicit collaborative workgroups to explore potential scaling of promising crisis prevention, intervention, and stabilization models, regardless of location.
2. Identify federal or state regulations that are creating the most significant barriers to crisis intervention and stabilization. Consider barriers to providing behavioral treatment. Combine results with trended/forecasted data to demonstrate how barriers impact system backlogs and create adverse results at individual and program levels. Develop a collaborative strategy

with partners to share results with national associations, the Governor's office, state legislators and possibly Washington state's congressional contingent.

3. Use data results from #2 above to develop communications material to share with individuals and families, guardians, local and regional elected officials, city/county administrators and staff, tribal leadership, first responders and others to demonstrate the scope of growing I/DD and behavioral or clinical crisis concerns, and what communities can do to prepare to help with response and referrals in appropriate and culturally sensitive ways (beyond 911 or 988 service).

Crisis Stabilization and Intervention – Other State's Programs and Innovations

Step-Down Homes for Individuals Transitioning from Institutes for Mental Disease (IMDs) – ***California***
Step-Down Homes are licensed four-bed community crisis homes operated by vendors. These residential homes serve to transition people from IMDs into the community.

Stabilization Training Assistance Reintegration (STAR) – ***California***
STAR homes are five-bed crisis homes serving adolescents and adults with I/DD who need time-limited crisis stabilization services for up to 13 months.

Mobile Crisis Services – ***California***
State-operated mobile crisis teams respond in various settings with highly specialized and trained staff. These teams are designed to respond to crises promptly, assess the situation, and provide appropriate assistance, including referrals to services and resources. This includes the Crisis Assessment Stabilization Teams that work as a last resort with individuals with I/DD who continuously experience crises.

Crisis Services for Individuals with Intellectual and/or Development Disabilities (CSIDD) ***– New York***
CSIDD provides 24/7 limited-time response services and intensive interventions to people with I/DD and complex behavioral needs in structured settings to help them circumvent psychiatric hospital placements or use of emergency services. Families and caregivers may also receive services and trainings.

Intensive Behavioral Services (IB) - ***California***
Individuals with I/DD and behavioral challenges benefit from Intensive Behavioral (IB) services and interventions, including a Functional Behavioral Assessment and an individualized Behavior Support Plan (BSP) created by certified behavior intervention specialists. These intervention tools are meant to engage challenging behaviors before reaching crisis level. IB services include ongoing caregiver training to implement the BSP, as well as monitoring the BSP's effectiveness.

CHAPTER FIVE: KEY UNDERLYING INTERVIEW THEMES

In addition to responding to 2019 Workgroup report recommendations progress, people spoke to the underlying and inter-related issues that create some of the greatest challenges, opportunities, and impacts to people with I/DD. The following are the key themes and issues that emerged. Some of these most challenging issues are being worked on in a variety of ways. Some will likely require much greater policy and political support to address changing I/DD needs and population trends.

Relationships, Trust, and Collaboration

Trust is a dynamic attribute. After four years, our world, country and state are still moving through COVID-19 and its consequences. The impacts of the pandemic were (and are still) felt in disproportionate ways by underserved communities, including people with disabilities. While the many deaths (and yet unknown long-term effects) are an unacceptable outcome, there are positive stories, including stronger partnerships that emerged. Many systemic, cultural, and operational gaps relative to emergency response, public health oversight, and healthcare and social services delivery were brought to light. Some community and government relationships were strengthened through adversity, and many others were simply tested. Hopefully, lessons learned will be applied to future emergencies.

General trust in government has been declining for decades. Publicly funded health care delivery programs that are co-funded by the federal and state government (like Medicaid) require state programs to comply with complicated federal regulations. When programs are believed to be out of compliance, the changes that follow can create ripple effects that impact people's lives in major ways. The federal decertification of ICF PATs created disruptive changes in individual's and family's lives. I/DD partners and many in government worked hard with clients, families, guardians, and others to minimize that disruption and trauma. Adversity advanced some creative solutions.

There is no single I/DD program in Washington. DDA oversees many different programs for adults and children that are funded through waivers, grants, and state plan amendments. ALTSA oversees many other services offered to people with I/DD. Pilot programs and initiatives are often state-only funded. Programs cover varying types of eligibility; some support programs are deemed 'entitlement'; other community-based/state plan services are delivered by Managed Care Organizations (MCO) networks, with contract oversight from the Health Care Authority. I/DD is '*a large quilt'* of programs that target people's needs in different settings.

All these programs operate in an environment of scarcity – scarcity of funding, scarcity of staffing, and sometimes scarcity of trust and collaboration. Scarce environments can often result in negative competition, but people try to adapt and rise to the challenge to work to create joyful moments and positive change in the lives of people who live with a disability, but don't want to be defined by that disability.

People with I/DD (and those in self-advocacy roles) feel the impacts of programs on their lives every day. Direct care staff feel the challenge of supporting their clients with the daily decisions and tasks that can make their life experiences better. Families and guardians feel the pressure of balancing what is practical and what is aspirational for their loved ones and clients. Self-advocates and advocacy groups feel the pressure of championing policy that supports their constituent's needs and beliefs (which are diverse), while trying to strengthen relationships with other organizations and state government. Provider leadership feels the pressure of maintaining and improving services in a sustainable way, within this environment of scarcity. Legislators hear the stories (often the negative ones), provide funding, celebrate wins, and still sometimes wonder if their policy decisions are making a significant difference.

And DDA must oversee all these many complicated programs, and respond with empathy, dedication, sensitivity and positivity to clients and partners - while complying with sometimes conflicting state and federal regulations, and working through internal and external organizational change, inter-governmental relationships, and other short and longer-term core issues.

The good news is that the project team heard partner comments that validated what is well-known – that most people who dedicate their careers and lives to serving people with I/DD are fully invested, and resilient in their dedication to strengthen the system and improve lives. This shared universal goal creates a significant and real opportunity - to build trust and strengthen the partnerships and collaborations needed to create agreed-to solutions, while working through varied partner positions and interests, personalities, and relationship histories.

The interview responses included some of the following comments that help describe the status of many different types of important relationships:

- Some advocates noted a *'wait and see'* attitude about DDA organizational changes. Several advocates expressed hope and optimism around fresh ideas and opportunities.
- Other advocates have already spent much time and energy strengthening relationships with DDA and partners and were pleased with the direction and momentum.
- One RCH staff noted a change in client opinion: *'I'm seeing less push-back from self-advocates compared to the past. Now, some former residents speak highly of Lakeland Village.'*
- One DDA staff noted self-advocate's positive influence: *'I feel like small precedents are being set to keep progress moving forward. Self-advocates are already solution oriented. They have powerful suggestions.'*
- Advocate: '*Self-advocacy started up in the 2000s. Different groups tried to influence the system differently over time. These shifts created a natural tension with people who often can't make good decisions on their own. This created a divide between self-advocates and parents, which is in the process of being repaired. There is a natural push by self-advocates against parents at different stages of their lives. If DDA focuses on self-advocates, and not parents, they send a loud message.'*
- A self-advocate tied a lack of collaboration to negative outcomes: *'DRW (Disability Rights Washington) won't do individual cases, only class actions. APS (Adult Protective Services) does*

not do systems change or advocacy. Who enforces client's rights? Does not happen, no respect.'

- Advocate: *'Parent coalitions have become more active, have become part of local Arcs. Many good resources about dual diagnosed conditions.'*
- Advocate: *'We have the potential for a new beginning. Let's use the tools together. I'm looking for optimism.'*
- Self-advocate: *'I joined People First and Allies and SAIL because they help – they truly made me who I am, and I want to advocate.'*
- Self-advocate: *'There are lots of consent forms and disconnects with DDA, HCA, mental health, and state-only programs. I have to go above my case manager to get these done. I need easier communication to do this. I want to be part of the conversation between my supported living provider and my employment provider.'*
- DDA field staff: *'I've seen improved collaboration with the Behavioral Health Administration. Was more siloed in 1999. More issues materialized after the mental health funding cuts. On the forensic side, Trueblood called out the system for people falling through cracks – too many systems between behavioral health, medically complex and other issues.'*
- Community-based provider: '*We meet with DDA leadership in quarterly meetings. We set the agenda and discuss the issues. So, there's open dialog.'*
- Advocate: '*I've had mixed experiences* (with DDA)*. Been impressed with several people I've met through my advocacy. Everyone who works at the state level got in because they care about those with DD. But not sure why there's so much reluctance to increase access to behavioral support. Creates the biggest barrier. Most of the focus is on the caregiving workforce, and supported employment.'*
- Advocate: *'DDA Leadership needs to start showing up authentically. No current follow through with parents. They are currently following through with self-advocates who have voice. Some parent advocates carry voice forward, including parent coalitions, parent-to-parent networks, and PEACE NW.'*
- Legislator: *'DDA is doing the best they can. It's challenging, stakeholders are convinced that DDA is on the RHC side.'*
- Advocate: *'Leaders don't sit back and reflect across systems. The Arc and PEACE NW have to work across systems, so they see the interplay between organizations.'*
- Community-based provider: *'Generally we have a good working relationship with DDA and others, including Arc of WA. DDA is well aware of the issues. Feedback wise, DDA is more reactionary. Something needs to happen before they act. Instead of strategy and advocating for what needs to change. We want them to be stronger advocates for what is needed.'*
- DDA leader: '*Our collaboration and transition work with our sister agencies and organizations, starting with the HCA – escalation of issues so individuals get physical and behavioral benefits in the community, service changes and access in the community…..Klamath opening….and the PAT C closure….strong partner collaboration to support and transition people into the community....partnerships with the Behavioral Health Administration…working with discharge teams at Western and Eastern State hospitals, and other multisystem work.'*

- Advocate: '*DDA efforts have improved. Genuine, it's a learning process, some good discussions, but sometimes performative. Newer efforts to create feedback, we'll see how it's acted upon.'*
- Advocate: '*I've been dreaming about collaboration. Keeps me in this job. Think bigger picture. DDA leadership, we need a bigger place to come to and agree on where we're headed. We have the guiding values - respect for those with I/DD.'*

These are a small portion of interview comments that describe some of the complexity of inter-relationships within a system faced with significant challenges and change.

DDA central staff come from a mix of backgrounds and perspectives working with programs. As expected, staff with positions that directly and consistently interact with partners described deeper relationships. Many staff and leaders spoke of a variety of DDA cultural improvements, including more openness to hearing from a broader group of advocates, as well as new ideas resulting from organizational changes throughout the system. Most noted the direction and hope of working more closely with partners (versus '*pushing information out'*), as well as the hope of new pilots and initiatives.

DDA staff are also acutely aware of systemic barriers, linked to increased behavioral health needs, workforce capacity issues, different cultural needs, housing scarcity and the constraints and ripple effects of regulations that create system tensions and conflicts. Overall, there seems to be a sense of measured progress, within a strong push to get a lot of work done. The amount of effort that went into COVID response and reaction to the 2019 Workgroup recommendations are still fresh in people's minds – and, as several noted, *'that had a huge impact on our direction, and we're now moving on to continue our work to improve.'*

DDA field operations staff understand the operational strengths, goals, and limitations of their region's resources, and noted progress with supporting clients, SOLA staff and contracted providers. A supported living provider commented: *'We are lucky to have the relationship with DDA that we have. Locally we get really good support.'*

Self-advocates, advocates, parents, guardians, and providers have a broad range of perspectives on collaboration and trust. Those who are more intimately connected to service and support operations are acutely focused on systems gaps and operational barriers. Those with experience and greater exposure to policy work and discussions often commented on the conflicted nature between goals, needs, wants and outcomes.

The project team heard that I/DD relationships and trust take a long time to build, but a short time to damage. People crave consistency and reliability from each other. The sensitivities around I/DD supports and service impacts – which can vary daily at an individual level – make it challenging to maintain this level of expectation.

Also, some historical relationships have been partly based on the strengths of aligned and sometimes unyielding positions. These relationships are also challenging to maintain, especially when people start to diverge from those positions to attempt to move forward – which then conflicts with people's perceptions of consistency and loyalty. Personnel turnover often forces organizations to re-boot their relationships. These varied relationships and growing challenges suggest the need to build greater collaborative 'muscle' – not just between DDA and partners, but between all organizations and representative individuals.

Process Recommendations:

DDA has recently convened groups to give greater voice to self-advocates, parents, and others. DDA central leadership has taken the initiative to spend more time in the field to learn from different perspectives, and other undertakings may be in process that the project team is unaware of. Advocates, providers, and other partners tend to build 'point-to-point' relationships with each other and with DDA; while this is important, it is usually not enough to advance and grow the collaborative capacity needed to move big systemic issues. What's next? Collaboration requires a lot of work, but the positive consequences can be substantial.

Building Collaborative 'Muscle':

1. Conduct an independent assessment of the current collaborative capacity and capability of each partner organization (and other representation) to commit resources to address I/DD program and system change in Washington state (for example, self-advocates, parents/families, advocates, providers, unions, associations, guardians, DD Ombuds, DDA, BHA, ALTSA, HCA and DBHR, Commerce, OSPI, policy staff, legislators, and others, including first responders, hospitals, shelters, and jails).
2. Address the differences in collaborative capacity and capability (including cultural needs) between I/DD partners and provide training, if needed to those who wish to engage at a deeper collaborative level.
3. Design, test and implement a new facilitative process, to deepen shared understanding of key systemic, cultural, and operational challenges – that many have historically tried to address challenges from a singular perspective and strategy. Working together, focus collective capacity to start to negotiate and develop agreed-to options for solutions to seemingly intractable barriers. The interview feedback suggests that systemic focus should at least include the following interconnected key themes:
    - **Person-centered care and individual choice**. For example, how do different perceptions of person-centered care, whole person care and independence create different expectations of supports? How do different cultural needs impact these expectations, across BIPOC, tribal, LGBTQ+, immigrant, migrant, rural, generational and other populations with I/DD? What experience can other states share?
    - **The aging population of clients and caregivers**. How can the system strengthen and evolve to support people's changing needs as they age, while family caregivers are themselves aging and increasingly unable to care for their loved

ones? To what degree (and how quickly) can technology help support personal safety, or supplant care and support needs over time?
- **Co-occurring disorders**. Is the existing system and infrastructure able to support a growing range of co-occurring needs with smaller, incremental fixes? What are the deeper relationships that will need to form, at local, statewide, and potentially federal levels to match the scope and trends of these changes, and meet these growing needs? What are the disconnects between RHCs, community-based and other supports that create potential barriers to systemic care coordination and communication?
- **Workforce capacity**. Are strategies progressing to address the shifting needs of changing populations, shortages, recruiting and retention challenges, and pipeline development? If incremental rate increases struggle to sustain the current workforce, will it take a mammoth level of effort across the health care delivery and public health systems to address additional and changing needs? How can significant efforts be shared by willing partners, including development of different forms of partnerships?

Housing needs and affordability are an additional 'wicked' issue. Note that housing is reviewed in the prior chapter of this report.

Perspectives around these four significant focus areas follow.

4. Include participation of legislators, fiscal staff, and the Governor's office in varying process stages, to help build collaborative policy capacity and support for consensus-based decision packages.

This sounds wildly aspirational. It isn't. It is a lot of shared work to move everyone in the system towards a better space to have open and civil group conversations, and to reach for a deeper understanding of different perspectives of what is possible. To build or rebuild trust. And to convert these efforts into meaningful and practical options, strategies, and steps to adapt to change and improve the lives of people with I/DD in Washington state.

Improving Communication:

5. Create a new, creative, and agreed-to communication framework that strengthens collective principles, in tandem with the work noted above. Leverage existing partner communications, while building a framework that focuses on collective communication needs, transparency, feedback and accountability.

    - Ensure broad communication framework development representation.
    - Consider strengths and weaknesses of existing communication venues.

- Leverage existing meetings, with modifications, if possible, to decrease burden.
- Consider pros, cons, and belonging/equity considerations of using live, virtual and hybrid formats to address all partner's communication needs, including those who are non-verbal, have additional disabilities, or are non-English speaking.

Person-Centered Care, Whole-Person Care, and Independence

People have varying perceptions of these concepts – some in structured organizations use structured definitions. Many clients feel and internalize these concepts through their daily experience. A self-advocate noted '*Person-centered means what is going to work best. Places need to be accessible to people. It's what we want, where we want it, and how we get it.*' Similarly, DDA staff mentioned '*What this really means is meeting people where they're at. That is the challenge*.' Another self-advocate was frustrated with the lack of agreement around definition: '*People use those terms all the time. They've become meaningless. They mean different things to different people.*'

These quotes link to unintended program consequences and barriers. Many client comments referred to conflicts between health and safety program requirements, versus independence, choice, and human rights. As one DDA staff summarized: '*Custody versus independence, combined with conflicting regulations creates risk for community-based providers and other care models*.' Conflicting regulations and resulting risks impact client/client relationships, client/family relationships, direct care worker/client relationships, case manager/client/family relationships……and so on.

One advocate noted: '*Person-centered care is strength-based, but our I/DD system is deficit-based.*'

Process Recommendations:

1. The project team heard that these concepts are fundamental principles that drive missions, visions, goals, and objectives. Sharing common and different definitions of these concepts would help to deepen collective understanding of program constraints, and roles and responsibilities. Group participatory work can help move the conversation and development of shared options from health and safety OR independence, choice and human rights to health and safety AND independence, choice and human rights.
2. Work with partners to map specific regulatory barriers to downstream service and support risks, unintended conflicts, and examples of their impact using stories. Summarize for legislators for state policy reform, and for congressional members for federal reform.
3. Engage with other states making progress on novel reimbursement methodologies that incorporate person-centered concepts. Explore how they addressed their state and federal regulation constraints and conflicts.

Aging Populations

Most people with I/DD live at home with family members. Family members are aging and are looking for options to care for their loved ones. Also, as people with I/DD age, their needs change. Many partners noted that the I/DD system does not currently have sufficient options to handle the capacity or needs based on these aging demographics, beyond existing SONFs and a number of participating private nursing facilities, assisted living facilities and AFHs.

One DDA staff explained: *'The issue is elderly parents supporting adult children, sometimes for decades, without planning or a funding stream. Aging parents are the biggest concern for sustainability*.'

Also, it wasn't clear that the specific changing needs of people aging with I/DD have been identified, beyond general assumptions such as additional physical supports. Do aging needs overtake cultural differences, or do cultural differences become more important as people with I/DD age? Does a system challenged by the diverse needs of individuals become even more complicated when aging effects are considered? How can technology assist?

Aging issues were commented on least. Several legislators and advocates acknowledged the issue's importance but felt 'stuck' when trying to address it, beyond speaking to the 2019 SONF and Fircrest nursing facility replacement recommendations. Some noted the enormity of the issue, referencing similar lack of progress related to aging of the general population.

An advocate added her historical perspective on state departmental silos and their unintended consequences: '*Every other state legislative body in the U.S. decided years ago what the role of their state and their counties would be to deliver health and human services. Many states have their local counties provide or contract for services (with state oversight), and some states …. provide … with no county involvement. In Washington state …. no consistency… DDA provides most I/DD services, but employment and day services are contracted to counties. In addition, ALTSA serves people with I/DD, if they come through that door, with personal care, AFHs and other care….. and DDA provides habilitation services. You cannot receive services from both administrations. In addition, some Ombuds offices are state employees, i.e., children's services and special education; other Ombuds are county employees, like mental health, and others are private sector contracted employees (i.e., aging and disabilities). So when there is an issue like moving people out of an RHC nursing facility, the Aging Ombuds office and the DD Ombuds office were both involved with no decision on who had the lead.'*

Process Recommendations:

1. Map the existing capacity of long-term supports and services for the I/DD system and aging demographic projections. Consider ALTSA-based services, and barriers to scaling existing services to populations with I/DD, focusing on changing cultural, demographic, and behavioral needs. Consider the potential unintended consequences of department silos, lack of flexibility and impact of workarounds.
2. Model what is known about changes in needs as I/DD populations age.

3. Convene broadly representative groups to reach factual agreement on the infrastructure limitations across RHCs and existing community-based program options. Use findings to support a larger effort to address I/DD and general population aging support barriers and constraints.

The relative lack of partner comments on known aging demographics indicates a need for a more intentional discussion at all policy levels.

Co-occurring Conditions

This was the second most common underlying issue raised during the interviews and is directly linked to the following Workforce Capacity section. As noted in earlier chapters, different types of challenging behaviors are increasing, especially in younger populations. These changes directly challenge and impact the needs of individuals and family caregivers, types of needed client supports, workforce competencies, existing residence models and crisis recidivism risk. Also, these changes call out community deficits – particularly the lack of I/DD experience – related to behavioral health practitioners, first responders and healthcare providers, social service organizations and others. There are some local successes - RHCs have made some progress with their local law enforcement and others to become more knowledgeable about working with people with I/DD. Also, SOCR works to improve local relationships with first responders, school districts, health districts and others.

Increasing behavioral and medical needs affect every existing I/DD program and highlight the potential gaps in existing supports that threaten client stability. The Legislature has focused recent sessions and funding on behavioral health, but people are quick to point out that existing behavioral supports are lacking in I/DD experience. One DDA staff summed up his perception of co-occurring trends: '*Our population served has outgrown the skillset of our providers in community-based settings*.' Another said '*If I had a magic wand, I would create programs yesterday for those with dual diagnoses. That is the biggest challenge we face*.'

One community-based contractor noted: '*About 75 percent of referrals that come to us are these high need individuals. The referral process has gotten a bit better and more transparent, but we still have to read between the lines since we are gun shy about taking on a person that then throws off our entire staffing….and the need for resources when that happens*.'

One significant gap impacting client stability is the lack of community-based behavioral health treatment. DDA programs are generally focused on training for health, safety and independence-related goals, and crisis intervention and stabilization supports, but not behavioral health treatment. Beyond Western and Eastern hospitals, who should be responsible for these services, and can increased legislative funding for community treatment centers include staff training and experience for I/DD needs? Do these trends support several partner's comments that the existing system was built for an earlier time and generation with different needs than today?

Interviewees also noted DDA's positive collaboration with the HCA and BHA. For example, a process is in place to quickly elevate urgent events to the HCA, and then to the MCOs. DDA staff were pleased to be able to solve for these types of operational constraints.

RHCs are believed to proportionately have the most behavioral staff and specialists in place – and even their leadership commented on the difficulty of recruiting, staffing, and retaining people, for many reasons (many noted that although staff turnover in RHCs has dropped from COVID-level highs, direct care staff are not trained to handle many challenging behaviors). SOLA staff try to have behavioral specialists available on a region-by-region basis but encounter similar workforce capacity constraints. Community-based contractors must find the supports – and everyone is competing for the same limited number of people.

Rural areas encounter additional constraints. One advocate noted: *'We saw more remote telehealth during the pandemic. That helps with some, but not others. Not sure how well a doc or psych can evaluate a person going through a crisis. Rural hospitals try hard, but often do not have the right people for needed supports. We're seeing more crises in rural areas.'*

There simply aren't enough people becoming educated, certified, and experienced to provide all the needed supports to meet the changing needs of people with I/DD and co-occurring and challenging behaviors.

Many wanted to clarify that funding to support increasing reimbursement rates is always helpful and appreciated. Others were waiting to understand Milliman's rate study results, relative to add-on rates or methodology changes to address increasing co-occurring conditions.

The 2022 DDA report titled 'DDA Best Practices for Co-Occurring Conditions Report' noted that mental health needs in 2022 accounted for approximately half of the RHC-based population, 23 percent of people in community-residential settings, and nearly 70 percent of those in 'other community-based' settings. This data supports the common belief that co-occurring conditions are substantive, occurring in all residential models, as well as those who are cared for in their homes by families.

People hope that existing pilots, initiatives, and newer programs might help inform best paths forward. SAIFs, Klamath at Rainier, the AFH rate add-on pilot, revised ICF transition planning, family caregiver experience, self-advocate and other experience may generate collective lessons learned to help address co-occurring challenges.

Process Recommendations:

1. What are the actual trends in co-occurring conditions? Can trended data be sliced into different relevant levels or ranges of behavioral and medical needs, at more granular levels than just mental health and substance use disorders? Deliberate data analysis might yield helpful information to gain context and detail around the scope and growth of a diverse range of conditions and needs.
2. This is a national problem – other states have approached this in a variety of ways (examples documented in preceding chapters). Additional participation and discussion with national I/DD associations and other specific states would broaden discussion between DDA and Washington

state partners, including the potential value of Enhanced Behavior Support Homes (EBSH) and other interventions and therapies.
Consider hosting a regional or national summit in Washington state that brings researchers, clinicians, behavioral experts, and partners from other states together with our state's partners and potential partners to share lessons learned and participate in a co-creation process to explore options.

3. A deeper collaboration between DDA and BHA, DBHR, DOH and partners to address the roles and responsibilities of community-based behavioral treatment, to improve I/DD experience. Several advocates worried that I/DD's relatively small numbers, compared to the general population's behavioral health needs are keeping I/DD issues '*in the background*'. Consider designing different convening formats to engage partners to discuss the results from #1 above; explore the potential to re-align different agency/department strategic plans to address recent and expected future funding that impacts behavioral and other co-occurring conditions, including physical and behavioral health integration progress within the statewide Medicaid transformation waiver renewal, and more recent bills proposing regional behavioral health crisis response plans, and new community crisis relief centers.

Workforce Capacity

This was the most often noted theme in the interview discussions. Workforce capacity and constraints is a key root issue that link to most other issues. Workforce issues range widely, from sustaining existing resources, to creating new partnerships, para-worker and certificated classifications and possibly new systemic pipelines that can address the growing changes in I/DD populations and needs.

Direct care staff have changing needs, as well. Many providers and DDA regional staff noted that immigrants make up a growing and large portion of direct care workers. Many direct care staff are from Nigeria and Gambia, and spoke of a strong affinity for the work, based on family care giving culture. One provider lamented that he has seen underappreciated physicians and nurses from other countries working as direct service personnel. Providers spoke of the high degree of internal competition within I/DD for the same staff: '*We're all competing for the same people*.' Despite legislative increases, direct care rates are still comparatively low, and lack of a defined career ladders leads to turnover. In addition, the project team heard many stories about the lack of behavioral technicians and specialists.

Intelligence Quotient (IQ) will be dropped from eligibility determination in January 2025. Several people commented on the strengths and limitations of the use of IQ for determination, but many were concerned about the unknown number of new clients that might overwhelm an already strained system. It's unclear what specific impact this will have on workforce needs, including competencies, specialization and place of service. DDA attempted to seek out external research interest in studying this but found no positive response.

Several self-advocates and DDA staff imagined future technology potential to help with supports. *'There should be a way to use artificial intelligence and algorithms to assess likes/dislikes and plan a full day that's integrated…to offer therapies, jobs, hang-time with friends, instead of always asking what's available. It should be possible with assessments and qualified hours to blend services. We're currently siloed – one provider can't talk to another provider.'*

Partner perspectives around workforce concerns have been documented throughout this report. Several key questions emerged from the interview feedback – some which likely require collaborative efforts to begin to address:

- Does the existing I/DD workforce have the necessary competencies and scale to address the emerging and growing changes in the I/DD population's cultural, systemic, and operational needs? These changes include cultural competencies around different backgrounds and identities, co-occurring condition trends, rural issues and constraints, aging of family caregivers and clients, and generational shifts, among others. Most responding interviewees answered with a resounding 'no'.
- How do the existing set of I/DD programs best fit current needs, and which gaps create the greatest disconnects from known changing needs? How would potential programmatic changes impact workforce needs, from pipeline development to recruiting to training to retention?
- Based on existing and expected workforce gaps across the I/DD system, what would the most leverageable training (or cross-training) efforts look like?
- Are there other existing workforce capacity efforts (not limited to the public sector) in Washington state that can help inform I/DD gaps?
- How can I/DD workforce capacity needs gain policy momentum, when so many other workforce shortages exist across our larger system and economy? Will this require a much broader scope of effort at the statewide and/or federal levels? Are there existing federally matched or funded programs, such as demonstration waivers, grants, or other initiatives (in all sectors) that address creative ways to grow workforce capacity for underserved and changing populations? Or could workforce capacity concepts be re-imagined across a broader system and continuum beyond I/DD, to strive for greater cross-training and flexible use of direct care staff and specialists?
- How can the existing I/DD system be strengthened to create a bridge to future emerging changes and trends?
- How can technology improve the lives of people with I/DD over time, including supporting or supplanting workforce? Is existing technology focused mostly on health and safety needs, such as motion detection, smart home features, medication reminders and other features? What's on the near and mid-term horizons, with expected adoption of artificial intelligence and other improvements? What relationships with external partners need to be developed or deepened to keep people current and involved?

Process Recommendations:

1. Convene a collaborative task force to map workforce gaps across the I/DD system, and connections to operational, regulatory and systemic barriers. Consider how the effects of growing trends and changes

will impact the capacity needs and retention of existing and new types of staff and specialists. Develop options that create the greatest short and long term impact, based on the most promising investments.

2. Deeper partnerships will likely be needed to significantly address system constraints and opportunities. The project team heard that no single entity could shoulder the burden – but that a large, dedicated effort to engage organizations across education, physical/behavioral health delivery and supports, health policy, vocational training, technology, commerce, and others could work with DDA and partners to create a backbone effort to improve and stabilize workforce capacity – perhaps including cross-competency training across a range of flexible skills within the greater health continuum.
3. Consider using collaborative systems-thinking concepts and tools to help frame different perspectives, test assumptions, develop shared definitions and measurement of progress, manage existing system tensions, consider short and long term effects and unintended consequences, test program cause and effect relationships, re-evaluate system behavior, and identify small and large leverage points that can lead to most impactful change.

CHAPTER SIX: ENHANCED BEHAVIORAL SUPPORT HOMES

Introduction and Rationale

Other states have developed Enhanced Behavior Support Homes (EBSHs), to serve high-needs individuals with I/DD, co-occurring psychiatric or behavioral disorders, and dysregulated behaviors (e.g., self-injurious behavior, elopement, property destruction, or physical aggression). Some advocates in Washington state have promoted the idea of establishing state funded EBSHs, to help close support gaps based on the need for such intensive and specialized services. Some interviewees noted that this model could mitigate community-based referral rejections due to challenging behaviors.

The literature suggests that without adequate evidence-based treatments to help manage their challenging behaviors, clients can develop or intensify aggressive, disruptive, and self-injurious behavior, which may result in costly hospitalization or incarceration. EBSHs offer enhanced capacity to improve residents' behavior and facilitate self-independence in a supportive and therapeutic living environment. At the individual level, consistent treatment in these types of facilities is estimated to significantly reduce lifetime costs of care.

Several interviewees had deeper experience researching EBSHs. One noted that California EBSHs improve personal transitions by *'breaking down walls between children and adults,'* and are properly staffed to deal with difficult episodes. She commented that Washington state's current ICF system has a *'top heavy workforce'*, and that the lack of coordinated care in communities and an undeveloped supported living program workforce (re: behavioral needs) do not address growing trends. Several partners have invested deeper research efforts into California's experience, and can share with others, should the Legislature decide to pursue exploring this option.

Characteristics of EBSHs

EBSHs are residential facilities designed to provide specialized care and support for individuals with significant behavioral challenges, psychiatric conditions, and I/DD. These homes aim to create a supportive and therapeutic environment for residents to help them develop essential life skills, improve behavior, and enhance their overall quality of life. Typical features of EBSHs include:

- *Individualized Care Plans*: Each resident should have a personalized care plan, or individual program plan (IPP), tailored to their specific needs and goals. These care plans are designed in collaboration with mental health professionals, behavioral therapists, and other specialists to address the unique challenges of each resident.
- *Trained Staff*: ESBHs have staff members trained and credentialed in handling behavioral issues and providing a high level of care. These professionals include behavior analysts, therapists, counselors, and support workers who provide the necessary interventions and support.
- *Therapeutic Interventions*: ESBH residents may participate in various therapeutic interventions to address their behavioral challenges. These can include cognitive-behavioral therapy, social skills training, occupational therapy, and other evidence-based approaches.

- *24/7 Supervision and Support*: These homes offer round-the-clock supervision and support to ensure the safety and well-being of residents.
- *Skill Development*: Residents receive training and support in daily living skills, such as personal hygiene, meal preparation, money management, and social interactions, to foster independence and self-sufficiency.
- *Family Involvement*: EBSHs typically involve families in the treatment process, recognizing the importance of family support for the individual's overall well-being.
- *Community Integration*: ESBHs facilitate community outings and activities to promote socialization, leisure skills, and integration into the broader community.

California's EBSH Programs: Legal Mandates, Policies, and Requirements

California's EBSHs enroll clients who require enhanced services and supports due to challenging behaviors that cannot be managed in other types of community settings. Article 3.6, §18, of the California Constitution provides exhaustive lists of requirements for EBSH. The following paragraphs in are synthesized from this legal document:

EBSH funding comes from community placement plan funds, as appropriated in the State Department of Developmental Services (DDS) annual budget. EBSHs provide 24-hour care to adults or children with developmental disabilities and severe challenging behavior, staffed by licensed behavior technicians, and overseen by behavior specialists and psychiatric providers. This service tier supports I/DD persons with significant behavioral challenges to live safely in the community. All clients can live permanently in their EBSHs if they wish.

California law mandates that each EBSH shall have no more than four clients to ensure their privacy and safety. Each client must have their own private bedroom. Staff conduct a functional behavior assessment, engage in ongoing data collection, and develop and modify an individualized positive behavior support plan to ensure the effectiveness of interventions. Medical providers, who are on staff as part of the team, can adjust the plan as needed. Staff also provide trauma-informed care to stabilize clients and help build resilience in stressful circumstances.

If physical or mental abuse, abandonment, or any other substantial threat is identified to affect a client's health and safety, DDS requires the Regional Center to remove the client from the EBSH and provide alternative services for the individual within 24 hours.

The members of an individual behavior support team include but are not limited to a Regional Center service coordinator, a program administrator, an EBSH administrator, the client and their authorized representative, a Regional Center clients' rights advocate (unless waived by the client), a board-certified behavior analyst, and others who help develop a comprehensive and effective individual plan including nursing support, registered behavior technicians, licensed clinicians, occupational and physical therapists, and psychiatric and medical support staff.

EBSHs are certified by the Department of Developmental Services and licensed by the California Department of Social Services.

Each Regional Center has responsibility for monitoring and evaluating the services provided in an EBSH. Monitoring occurs at least quarterly. DDS ensures Regional Center compliance with their monitoring responsibilities.

EBSHs/Other States

In addition to California, several states in the US have developed behavioral health residential facilities, including EBSHs:

- **Pennsylvania** has implemented programs to support individuals with I/DD and challenging behaviors, including residential behavior support services and community living arrangements (Pennsylvania Department of Human Services, 2018).
- **Oregon** has developed community-based services and support systems for individuals with disabilities and mental health conditions, including Enhanced Care Services (Oregon Secretary of State, not dated).
- **Minnesota** has a long history of supporting individuals with I/DD and mental health needs through various residential and community-based programs. This includes behavioral and residential homes throughout the state that provide services under the behavioral health home (BHH) services program. (Minnesota Department of Human Services, not dated).
- **Texas** has been working to expand its range of community-based services and support options for individuals with behavioral challenges, including Community Living and Assistance and Support Services (CLASS; Disability Rights Texas, not dated.) and Home and Community-Based Services (HCS; Texas Health and Human Services, not dated.)
- **Massachusetts** provides community-based services and supports for individuals with I/DD and mental health needs. The state has pioneered innovative residential programs to meet the unique needs of its residents. (Massachusetts Department of Mental Health, not dated).
- **New York** has developed supportive housing and community-based services for individuals with mental health conditions and behavioral challenges (New York Office for People with Developmental Disabilities, 2022).

Appendix A: Interviewee Roster

Name	*Affiliation*
Amanda Sherry	Developmental Disabilities Administration
Amber Leaders	Washington State Office of the Governor
Amy Price	Developmental Disabilities Administration (retired)
Angela Morrison	Developmental Disabilities Administration
Annette Lormand	Developmental Disabilities Administration
Arzu Forough	Washington Autism Alliance
Bea Rector	Aging and Long-Term Support Administration
Beth Krehbiel	Developmental Disabilities Administration
Betty Schwieterman	Office of DD Ombuds; Disability Rights Washington
Blake Geyen	Self-Advocate
Brandi Monts	Washington DD Council
Brendan Arkoosh	Developmental Disabilities Administration
Bryan Way	Office of Financial Management
Charlie Weedin	Developmental Disabilities Administration
Cheryl Issacs	Guardian
Christine Rolfes	Washington State Senate (retired)
Christopher Strader	Self-Advocate
Christy Denese	Developmental Disabilities Administration
Chrystal Cummings	Developmental Disabilities Administration
Cindy Warner	Guardian
Corinna Fale	Self-Advocate
Courtney Thom	Self-Advocate
Darla Helt	PEACE NW
David Lord	Disability Rights Washington (retired)
Denise Oetinger	Developmental Disabilities Administration
David Marcus	Washington State University
Sheng Fang	Developmental Disabilities Administration
Eddie Olmos	Developmental Disabilities Administration
Elizabeth Johnston	Self-Advocate
Emily Rogers	Self-Advocate
Eric Mandt	Developmental Disabilities Administration
Eric Warwick	Self-Advocate
Ethan Strawn	Developmental Disabilities Administration
Grier Jewell	Developmental Disabilities Administration
Indian Policy Advisory Committee	Indian Policy Advisory Committee
Ivanova Smith	Self-Advocate
Jamila Taylor	Washington State House of Representatives
Jeff Carter	Friends of Rainier

Jeff Flesner	Developmental Disabilities Administration
Jessica Renner	Self-Advocates in Leadership (SAIL)
Jill Kluever	Developmental Disabilities Administration
John Braun	Washington State Senate
John Ficker	Adult Family Home Council
Josie Schindler	Self-Advocate
Julie Clark	Self-Advocate
June Robinson	Washington State Senate
Justin Maxwell	Self-Advocate
Karen Keiser	Washington State Senate
Kris Pederson	Developmental Disabilities Administration
Krista Milhofer	People First of Washington
Kurt Allen	Developmental Disabilities Administration
Laura Ryan	Guardian
Luisa Parada Estrada	Developmental Disabilities Administration
Marco Tan	Developmental Disabilities Administration
Maria Hovde	Washington State Senate
Mark Mullet	Washington State Senate
Mary Mulholland	Washington State House of Representatives
Matt Zuvich	Washington Federation of State Employees (retired)
Megan DeSmet	Developmental Disabilities Administration
Melissa Johnson	Community Residential Services Association
Micah Balasbas	Attorney
Michael Crane	Developmental Disabilities Administration
Michelle Sturdevant-Case	Developmental Disabilities Administration
Mike Gantala	Self-Advocate
Mike Raymond	Self-Advocate
Nichole Jensen	Developmental Disabilities Administration
Noah Seidel	Office of DD Ombuds; Disability Rights Washington
Paul Singer	Tri-Cities Residential Services
Pauline Nassanga-Kisembo	Developmental Disabilities Administration
Phil Diaz	Developmental Disabilities Administration
Rachel Paquin	Developmental Disabilities Administration
Randy Hauk	Community Res. Services Assoc./Community Living
Resa Hayes	Self-Advocate
Robert Schroeter	Developmental Disabilities Administration
Robert Wardell	Self-Advocate
Roger Goodman	Washington State House of Representatives
Saif Hakim	Developmental Disabilities Administration
Sam Melton	Developmental Disabilities Administration
Sandi Seaman	Developmental Disabilities Administration

Scott Livengood	Community Res. Services Assoc./Alpha SL Services
Shannon Manion	Developmental Disabilities Administration (retired)
Shaw Seaman	Developmental Disabilities Administration
Shirley Pilkey	Developmental Disabilities Administration
Stacy Dym	The Arc of Washington State
Steve Tharinger	Washington State House of Representatives
Steven Fisher	Self-Advocate
Sue Elliott	The Arc of Washington State (retired)
Tammy Neys	Developmental Disabilities Administration
Tammy Winegar	Developmental Disabilities Administration
Tatiana Armbruster	Self-Advocate
Teddy Kemirembe	Developmental Disabilities Administration
Terri Anderson	Friends of Fircrest
Tim Gerlitz	Developmental Disabilities Administration
Tim McCue	Office of DD Ombuds; Disability Rights Washington
Tom Farrow	Developmental Disabilities Administration
Tom Neys	Developmental Disabilities Administration
Tonik Joseph	Developmental Disabilities Administration
Tracy Turner	Self-Advocate
Tricia Flick	Developmental Disabilities Administration
Trinidad Orozecho	Guardian
Upkar Mangat	Developmental Disabilities Administration
Veronica Candidl	Developmental Disabilities Administration
Will Nicol	Developmental Disabilities Administration
William Sabatino	Developmental Disabilities Administration
Community-based individuals with I/DD, family members, direct care staff, supervisors, managers and specialists in Supported Living, SOLAs, and RHCs, or unsupported.	Miscellaneous[10]

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[10] Note: The project team met with others in numerous meetings but did not document names. For example, RHC visits included different individual meetings with clients, and larger group meetings with direct care staff, supervisors, and specialists.

Appendix B: Interview Questions

WASHINGTON STATE UNIVERSITY
THE WILLIAM D. RUCKELSHAUS CENTER
UNIVERSITY OF WASHINGTON

Washington I/DD Statewide Reform Progress
Ruckelshaus Center Interview Questions

Brief Overview

The 2018/19 Ruckelshaus Workgroup resulted in a set of consensus-based legislative recommendations, detailed in the November 27, 2019 report titled "Rethinking Intellectual and Developmental Disability Policy to Empower Clients, Develop Providers, and Improve Services[11]". SB 5268 subsequently communicated the vast majority of these workgroup recommendations during the FY2021/22 legislative session.

The recommendations from the 2019 report clustered around four interconnected areas:

- Increasing the capabilities of community residential services
- Improving cross-system coordination
- Investing in state-operated nursing facilities
- Redesigning state-operated ICFs to function as short-term crisis stabilization and intervention

2023 Interview Purpose and Deliverable

The Washington Legislature approached the Ruckelshaus Center to design and conduct a series of interviews between July 2023 and February 2024, to assess different partners' perception of implementation progress and successes and identify emergent issues and/or barriers that have surfaced. In addition, the Center will seek to identify other innovative related work and approaches conducted in other states that may inform progress and/or potential alternative solutions in Washington state, including an enhanced behavioral health homes concept. The Center will synthesize the results of the interviews and report on findings no later than February 29th, 2024. If appropriate, the Center will include future process recommendations for further exploratory or collaborative approaches, if productive.

Interview Approach

The Ruckelshaus Center is a university-based organization (WSU and UW) that has no stake in this process; our impartial facilitators assess the commonalities and differences between organizations' goals, visions and interests around complex public policy issues and implementation decisions– and in this case, how that relates to the progress made since the 2019 report was issued.

These interviews are semi-structured and tied to the foundational questions that follow. These questions are starting points to help frame our conversation. We look forward to your voluntary participation in this private conversation, to better understand your experience with these issues, relationships, vision, perception of strengths and weaknesses and willingness to be part of this process.

Meetings take approximately 90 minutes. While our overall goal is to identify themes, commonalities and differences, we will attribute your comments to you and your organization, unless you explicitly tell us otherwise. We always encourage open and frank conversation, to better understand your views and perceptions.
Thank you - meeting questions follow, to give you the opportunity to think about the conversation in advance.

More information about the Ruckelshaus Center is available at: http://ruckelshauscenter.wsu.edu/about/.

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[11] https://s3.wp.wsu.edu/uploads/sites/2180/2019/12/2019-Ruckelshaus-Workgroup-Report-to-Legislature_Intellectual-Developmental-Disabilities-Policy-1.pdf

Appendix B: Interview Questions

WASHINGTON STATE UNIVERSITY
THE WILLIAM D. RUCKELSHAUS CENTER
UNIVERSITY OF WASHINGTON

WA I/DD Report Recommendations Progress - Ruckelshaus Center Meeting Questions

1. *Please briefly describe your position, professional background, and organization/constituents as they relate to the I/DD program recommendations?*
2. *Which specific 2019 report recommendations have been (or are in the process of being) implemented? Do you consider each of these successful, and why/why not?*
3. *What are some positive examples of I/DD program changes since the report was issued?*
4. *What barriers have surfaced since the 2019 report was issued, and how have they impacted progress moving forward?*
5. *How would you describe your relationships with DSHS/DDA and other partners since the 2019 report was issued?*
6. *What are your priorities for remaining recommendations that have yet to be implemented?*
7. *Has your own thinking about I/DD program changes and reform evolved since the report was issued? How?*
8. *Are you aware of other I/DD program innovations that have surfaced in other states that may be worth exploring in Washington?*
9. *Focusing on process: What has worked since the report was issued? How did COVID impact the implementation timeline? What would you have changed about implementation? What would you suggest for process improvement moving forward?*
10. *Who else should we speak to with respect to these issues, beyond the initial workgroup members and guests who participated in 2018/29?*
11. *Are there other questions we should have asked? Do you have any additional questions for us?*

Appendix C: References – Other State Programs and Innovations

California Department of Developmental Services (n.d.). *Living arrangements*. Retrieved August 20, 2023, from https://www.dds.ca.gov/general/eligibility/living-arrangements/

California Department of Developmental Services (2022). *Guidelines for regional center community placement plan and community resource development plan for fiscal year 2022-23 requests*. https://www.dds.ca.gov/wp-content/uploads/2022/10/CPP_CRDP_Guidelines.pdf

California Department of Developmental Services (2017). *Guidelines for purchasing and developing permanent housing through the regional center community placement plan for fiscal year 2017-18 requests and modifications.* https://www.dds.ca.gov/wp-content/uploads/2019/02/CPP_HousingGuidelines_20190201.pdf

National Association for the Dually Diagnosed (n.d.). *IDD/MI diagnosis.* Retrieved August 21, 2023, from https://thenadd.org/idd-mi-diagnosis/

National Core Indicators. (2022). *National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD)*. https://idd.nationalcoreindicators.org/wp-content/uploads/2023/05/IPS-21-22-Access_FINAL.pdf

New York Office for People with Developmental Disabilities (2022). *OPWDD strategic plan 2023-2027*. https://opwdd.ny.gov/system/files/documents/2022/11/opwdd-2023-2027-strategic-plan-final-with-links.pdf

New York Office for People with Developmental Disabilities. (n.d.). *Types of housing*. Retrieved September 5, 2023, from https://opwdd.ny.gov/types-services/housing

Texas Health and Human Services (n.d.). *Personal-centered planning*. Retrieved September 3, 2023, from https://www.hhs.texas.gov/services/disability/person-centered-planning

Texas Health and Human Services (n.d.). Residential options for individuals with an intellectual disability or related condition. Retrieved September 3, 2023, from https://www.hhs.texas.gov/sites/default/files/documents/services/disability/residential-options-brochure.pdf

UC Davis Extension Center for Human Services (2009). *Evaluation of Senate Bill 962 pilot project – final report.* https://www.dds.ca.gov/wp-content/uploads/2019/02/WorkServices_962FinalReport_20190215.pdf

Nadeau, C. A., Glasmeier, A. K. (2018). Bare facts about the living wage in America 2017-18. Massachusetts Institute of Technology, August 30, 2018, https://livingwage.mit.edu/articles/31-bare-facts-about-the-living-wage-in-america-2017-2018.

Lezzoni, L., Rao, S. R., Ressalam, J., Bolcic-Jankovic, D., Agaronnik, N. D., Donelan, K., Lagu, T., & Campbell, E. G. (2021). Physicians' perceptions of people with disability and their health care: Study reports the results of a survey of physicians' perceptions of people with disability. Health Affairs, 40(2), 297–306. https://doi.org/10.1377/hlthaff.2020.01452

Sheryl A. Larson et al., In-home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2017 (Minneapolis, MN: Research and Training Center on Community Living, Institute on Community Integration, 2020). https://ici-s.umn.edu/files/aCHyYaFjMi/risp_2017.

Kalb, L. G., Beasley, J., Caoili, A., & Klein, A. (2019). Improvement in mental health outcomes and caregiver service experiences associated with the START program. American Journal on Intellectual and Developmental Disabilities, 124(1), 25–34. https://doi.org/10.1352/1944-7558-124.1.25

Ohio Department of Developmental Disabilities. (2021). Competency-based training and longevity add-on. https://dodd.ohio.gov/about-us/training/training-policies/competency-based-training-longevity-add-on

Appendix D: References – Enhanced Behavioral Support Homes

C.A. Const. art. 3.6, § 18. Retrieved July 16, 2023, from https://casetext.com/statute/california-codes/welfare-and-institutions-code-wic/division-45-services-for-the-developmentally-disabled-4500-4885/chapter-6-development-and-support-of-community-facilities-and-programs-4670-46981/article-36-enhanced-behavioral-supports-homes-468480-468487

Pennsylvania Department of Human Services. (2018). Individual Support Plan (ISP) manual for individuals receiving targeted support management, base funded services, consolidated or P/FDS waiver services or who reside in an ICF/ID. https://www.dhs.pa.gov/providers/Providers/Documents/ISP%20manual%20for%20Individuals%20with%20ID.pdf

CA Department of Developmental Services. (n.d.). Enhanced Behavioral Supports Homes. Retrieved July 16, 2023, from https://www.dds.ca.gov/general/eligibility/enhanced-behavioral-supports-homes/

Disability Rights Texas. (n.d.). *Texas home and community-based supports and services.* https://disabilityrightstx.org/en/handout/texas-home-and-community-based-supports-and-services/#Community_Living_and_Assistance_and_Support_Services_CLASS

Forough, A. (2021, September 1). **Enhanced Behavior Supports Homes (EBSH): A new support tier for individuals with developmental disabilities and significant challenging behaviors. https://washingtonautismalliance.org/enhanced-behavior-support-homes/**

Gallagher, E., Barr, O., & Taggart, L. (2014). How can community residential services effectively support adults with intellectual disabilities who present with challenging behavior and/or mental health problems? *Austin Journal of Nursing and Health Care*, *1*(1), 1-3.

Ganz, M. L. (2007). The lifetime distribution of the incremental societal costs of autism. *Archives of Pediatrics & Adolescent Medicine*, *161*(4), 343–349. https://doi.org/10.1001/archpedi.161.4.343

Massachusetts Department of Mental Health (n.d.) *DMH child, youth, and family services overview:* A brief overview of services offered by the Department of Mental Health https://www.mass.gov/service-details/dmh-child-youth-and-family-services-overview

Minnesota Department of Human Services. (n.d). *Behavioral health home services.* https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/minnesota-health-care-programs/behavioral-health-home-services/

New York Office for People with Developmental Disabilities. (2022). *Strategic plan: 2023-2027*. https://opwdd.ny.gov/system/files/documents/2022/11/opwdd-2023-2027-strategic-plan-final-with-links.pdf

Oregon Sectary of State. (n.d.). *Aging and people with disabilities and developmental disabilities – Chapter 411*. Department of Human Services. https://secure.sos.state.or.us/oard/viewSingleRule.action?ruleVrsnRsn=89512

Texas Health and Human Services. (n.d.). *Home and community-based services (HCS).*
https://www.hhs.texas.gov/providers/long-term-care-providers/home-community-based-services-hcs