

Continuum of care for youth and adults with developmental disabilities

Second Substitute House Bill 1394; Section 10; Chapter 324; Laws of 2019
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Continuum of Care for Youth and Adults with Developmental Disabilities

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Executive summary

On May 9, 2019, Governor Jay Inslee signed in to law Second Substitute House Bill 1394 (SSHB 1394). Section 10 required the Health Care Authority (HCA) and the Department of Social and Health Services (DSHS) to:

- Consult with the following partner agencies and organizations
 - Department of Health (DOH)
 - Department of Children, Youth, and Families (DCYF)
 - Representatives from providers serving children’s inpatient psychiatric needs from Seattle, Spokane, and Tacoma
 - Representatives from behavioral health and developmental disability service providers
 - Representatives from developmental disability advocacy organizations - including individuals and families of individuals who need or receive behavioral health and developmental disability services.
- Provide recommendations relating to short-term and long-term residential intensive behavioral health and developmental disability services for youth and adults with developmental disabilities and behavioral health needs who are experiencing, or are in danger of experiencing, barriers discharging from inpatient behavioral health treatment received in community hospitals or state hospitals.

Below are the topics we address in this report, along with a few key recommendations of the workgroup. This list is not comprehensive. To see our full list of recommendations please refer to the workgroup recommendations on page 6 of this report.

Topic 1: The separate needs of youth and adults.

- Key recommendation: Create a path for DDA clients to own homes or rent from an organization who specifically manages housing for this population.

Topic 2: Services necessary to support the youth or adult, their family, and the residential service provider in preparation for and after discharge.

- Key recommendation: Fund the addition of provider types such as psychiatrists or psychiatric Advanced Registered Nurse Practitioners (ARNP) to the physician assistance line (PAL) to improve capacity on the help line.
- Key recommendation: Expand training to families and foster families.

Topic 3: Establish staffing and funding requirements that provide an appropriate level of treatment for residents in facilities, including both licensed mental health professionals and developmental disability professionals.

- Key recommendation: Create short-term (up to 90 days) transitional community based facilities with statewide accessibility to deliver stabilization services using a therapeutic model to support youth and adults.



Topic 4: How to successfully transition a youth to adult services without disruption.

- Key recommendation: Add an adult ABA program, other behavioral health therapies and remove limitations on some medical services.

The recommendations in this report are the result of a substantial collaborative effort between multiple system and stakeholder representatives. HCA and the Developmental Disabilities Administration (DDA) first consulted with the State Developmental Disabilities Ombuds and the Developmental Disabilities Council (DDC) for recommendations on how to proceed in collaboration with the required entities to gather feedback and identify consensus to make recommendations. This group then met with the larger group and over the course of four two-hour meetings gathered feedback and met consensus on the recommendations that will best address the issues. Subsequent meetings were held with additional stakeholders identified in the legislation to identify recommendations on how to improve services for people with developmental disabilities in Washington State.



Background

Today, the service system for supporting individuals with developmental disabilities is not meeting the needs of those with both an intellectual or developmental disability, and a behavioral health condition. The situation is most acute for individuals with challenging health and behavioral needs, that require support and services well beyond what can be provided in the home or a supported living environment. There simply is not enough capacity and qualified providers in the system to provide for these higher levels of need.

This situation is difficult for parents and care providers who are unable to provide the care needed on their own. This is when we see families and individuals in crisis. With no viable alternatives to access the therapies and support needed to be successful in lower levels of care, these individuals end up in our community or state hospitals. Once hospitalized, the road to being discharged is a lengthy one that unnecessarily consumes community resources.

HCA and DSHS have developed a number of responses to improve coordination and track the issues surrounding the discharge process. These include:

- A centralized tracking system, established by DSHS, that is populated by regional staff with the goal of better understanding at the statewide level scope of those hospitalized and ready for discharge, discharge barriers, and lengths of stay.
- Complex case staffing to close gaps and barriers preventing timely discharge is occurring routinely with regional DSHS staff and HCA.
- On-going collaboration with the Washington State Hospital Association (WSHA) and Hospital systems to share perspectives and realities of potential barriers and solutions that would reduce the length of inpatient stays.
- HCA receives reports from participating hospitals regarding their difficulty to discharge patients. Then HCA staffs organizes calls with Managed Care Organization (MCO) care management staff on the clients reported from the hospitals.
- Ongoing coordination with DCYF to improve transition timeliness for youth aging out of foster care and who need long-term services and supports from DDA.



Barriers and gaps

Individuals with intellectual and developmental disabilities who are Washington Apple Health eligible have access to all of the services available to other Washingtonians and may have access to additional services depending on their program eligibility through DDA. While a wide variety of treatments and services are available, barriers may prevent adequate access such as:

1. Washington state lacks a continuum of care for individuals aged 20 and under with autism or another condition who may be experiencing self-injurious or assaultive behaviors and require intensive behavior treatment that is grounded in applied behavior analysis principles. The model design provides four fluid levels of care. “Fluid” meaning any level can be accessed depending on severity of need and as need changes the child can move from one level to the other, whether needing an increase in intensity of service or ready for a decrease in intensity.
 - a. Level one is the most intensive level of care and is provided in an inpatient setting.
 - b. Level two provides partial hospitalization.
 - c. Level three provides community center-based day programs Level four provides service in the private residence or a clinic setting. Services delivered in these settings are a covered Apple Health benefit, but are sparsely available for those with severe behavior issues.

Although inpatient services are a covered benefit for Apple Health, the inpatient care model is not available in our state and as a result, families are accessing inpatient level of care for their child out of state. A complete continuum of care preventing unnecessary hospitalization would require a designated inpatient setting. Partial hospitalization is neither an Apple Health funded benefit or available care in our state. Partial hospitalization settings and a strengthened community model should be located strategically around the state to support access. The components of each program should be designed and directed by an expert in the delivery of intensive behavior services, such as the Seattle Children’s Autism Center. The Applied Behavioral Analysis (ABA) benefit will continue to ensure the appropriate level of care support is provided to the child and family during the transition back to the private residence or community residential setting.

2. Many behavioral health and other healthcare providers may not have training or experience treating people with intellectual and developmental disabilities.
3. Providers with an interest in gaining training and experience to expand their scope of practice to serve people with intellectual and developmental disabilities have limited educational or practicum resources available.
4. Youth and adults with developmental disabilities are often unable to find a provider and living arrangement to meet their needs when discharging from a hospital. A number of challenging factors limit developmental disability residential provider capacity. Housing availability is limited and costly. There is a workforce shortage of direct support professionals. Providers are not able to pay wages that are competitive in their communities and there is not a strong career path for the workers that want to remain in the field.
5. Apple Health rates are insufficient for a practice to depend primarily on Apple Health. Additionally, the low rates make it challenging to take time off to attend training or participate in other non-billable activities.
6. People dually diagnosed with both an intellectual or developmental disability, and a mental health condition need skilled family and/or staff to support them successfully in the community. Whether the individual is living on their own, with family, or in a residential setting, training is essential to the stability and longevity of the living situation. The curriculum in the basic training for the Home Care Aid Certification needs to provide better information for supporting people with intellectual and



developmental disabilities. Many elements of the training are valuable, but additional standards are necessary to support the wide array of need of those with intellectual and developmental disabilities. Training for families is also necessary. Families are the expert on supporting their loved one, but helping them gain skills and alternative support modalities is important for the support situation to remain sustainable.

7. Youth transitioning to the adult system experience a dramatic change in service delivery. In addition to school services stopping at age 21, Early and Periodic Screening, Diagnostic and Treatment (EPSDT) coverage ends and youth that may have received Wraparound with Intensive Services (WISE), ABA, nutrition, occupational therapy, speech therapy and physical therapy may stop receiving the service or have lower benefit limits.
8. Youth transitioning from the foster care or voluntary placement system may no longer have residential supports and can become homeless. In the past, starting to transition about six months before the end of foster services was sufficient to find a long-term residential provider and get other services set up. As other barriers to accessing needed services (i.e. service capacity limits, limited number of qualified providers, low reimbursement rates for needed services, etc.) have increased, six months has become insufficient. More transition planning time is necessary for the transition to adult services to be successful.
9. Data in the healthcare and social service system to further identify barriers and gaps and help analyze the effectiveness of changes is limited.



Workgroup recommendations

The workgroup made recommendations for both youth and adults to support the person or person’s family and residential provider in preparation for and after discharge. This includes in-home behavioral health and developmental disability supports that may be needed after discharge to maintain stability. Recommendations were also made on how to transition a youth successfully to adult services without service disruption.

Table 1 – HB 1394 sec. 10 (1) Recommendations

Workgroup Recommendation	Short-term Services	Long-term Services	Hospital Discharge for youth or adults	Transition to Adult Services
<ul style="list-style-type: none"> Develop the continuum of care for the treatment of autism and self-injurious or assaultive behaviors: inpatient hospital setting partial hospitalization program (PHP) and community center-based care for intensive behavioral assessment and treatment, including training to caregivers. Creating inpatient beds for youth and adults with self-injurious or assaultive behaviors and prevent the need to receive this specialized inpatient treatment out of state. Adding the PHP setting followed by the transitional step to community centered-based care would complete continuum of care available to people with intellectual and developmental disabilities. Access to this intensive behavior treatment is often of limited availability for people with intellectual and developmental disabilities. A new setting designed to deliver psychiatric and other specialized behavioral treatment creates capacity that does not currently exist in Washington. This frees up acute hospital beds and gets specialized treatment to those who need it. PHPs serve people with chronic mental illness treatment needs, which leads to repeated hospitalization when their symptoms interfere with daily responsibilities and lead to impaired functioning in the community. Services resemble a highly structured, short-term hospital inpatient program except there is no 24 hour care, participants return home each evening. PHPs provide more intense 	✓		✓	



treatment than outpatient day treatment or psychosocial rehabilitation.				
<ul style="list-style-type: none"> • Develop alternative behavioral treatment modalities for individuals with intellectual and developmental disabilities in both the psychiatric residential treatment facility settings and behavioral health community based settings. Access to care depends on providers having a mechanism to provide treatment. Currently, many behavioral healthcare providers do not have the training in modalities that have shown efficacy in treating those with intellectual and developmental disabilities. 	✓	✓	✓	
<ul style="list-style-type: none"> • Fund the addition of provider types such as psychiatrists or psychiatric Advanced Registered Nurse Practitioners (ARNP) to the physician assistance line (PAL) to improve capacity on the help line. • Improving capacity for behavioral health treatment requires existing psychiatric care providers have access to assistance when needed. Implementation of a funding mechanism to help psychiatric providers expand their skill set and scope of care will improve care statewide in both the hospital setting and the community. 	✓	✓	✓	✓
<ul style="list-style-type: none"> • Prioritize funding for housing. • Without a home, improved treatments and expanded capacity of long-term supports cannot be implemented. The Department of Commerce Housing Trust Fund program has shown great success in building affordable housing built to meet the needs of people with intellectual and developmental disabilities, when given sufficient and targeted funding. Prioritization of this funding for people with intellectual and developmental disabilities is necessary to meet demand for housing. Those with intellectual and developmental disabilities have few options. High housing costs make it extremely difficult for providers of supported living to find housing in a timely fashion. This can lead to continued hospitalization without a need. 		✓	✓	✓



<ul style="list-style-type: none"> • Provide funding to supported living residential providers to employ housing specialists. • The housing market is complex. Special expertise is needed to find and modify housing, work with property owners, builders and housing authorities, expertise provided by housing specialists. Direct funding for housing specialists or an enhancement to the administrative rate for this will ease this burden for supported living providers. 		✓	✓	✓
<ul style="list-style-type: none"> • Create an enhanced rate for Medical or Behavioral Health providers with a Developmental Disabilities certification. An existing model to replicate is the ABCD dental model. Paying more to providers who expand their scope of practice will result in better care earlier. Currently, individuals with intellectual and developmental disabilities struggle to find a behavioral health provider willing to provide services. Incentivizing providers to expand their scope of practice will result in better care, earlier and help head off crises. 	✓	✓	✓	
<ul style="list-style-type: none"> • Continue funding the \$150,000 allowed in FY 20-21 and increase the allotment in FY 22-23 by an additional \$150,000 for Project Echo model. • This model provides training to health care professionals who would benefit from learning appropriate interventions and specific technics for providing services to a person with autism and developmental disabilities. Project ECHO for autism and developmental disabilities disseminates evidence-based diagnoses and treatments to increase access to health services for people across the state. The focus group for the first ECHO model is aimed at those behavior health providers who provide outpatient behavior health services, including WISe. This model has proven to be extremely popular and valuable for providers. Continuing this critical, cost effective model and expanding the training to other focus provider groups will help close many gaps identified by the workgroup. Increasing the ECHO model funding can serve to assist in training of other provider types working with the ID/DD population (see A.2, A.7, A.8, and A.9). 	✓	✓	✓	



<ul style="list-style-type: none"> • Increase training for in-home care providers. • The current Home Care Aid curriculum and testing standards is built around the basics of personal care. Additions to the current curriculum to focus on the unique support needs of people with intellectual and developmental disabilities are needed. Supporting people with complex needs in their family home longer is possible with sufficient resources. 		✓	✓	
<ul style="list-style-type: none"> • Expand training to families and foster families. • Families know their family member better than anyone but building an enhanced skill set around the unique support needs of people with both intellectual and developmental disabilities and behavioral health diagnoses is key to making the transition out of an acute hospital setting or out of foster care successful. Other options for training including building a peer support network similar to that available for Substance Use Disorder treatment. Receiving training and support from experts who have real life experience can help make training meaningful and relatable. 	✓	✓	✓	✓
<ul style="list-style-type: none"> • Increase flexibility for training delivery. • For both direct care workers and the health care work force, training is essential. Delivery of the training needs to be flexible to accommodate the needs of business who must staff homes and care settings around the clock. Training can be more accessible with expansion of online training opportunities and increasing the number of trainers available to deliver in-person training. 			✓	
<ul style="list-style-type: none"> • Recruit new providers and expand existing provider capacity for long-term community based residential supports. • Current provider capacity is limited. The support needs of people with intellectual and developmental disabilities have become more complex. Individuals entering service have needs that can be supported in the community but are intense and require agencies to focus efforts by accepting a smaller number of new clients into service than they have in the past. Funding 		✓	✓	✓



is needed to recruit and help new providers start services in Washington. Development of new providers is essential to building sufficient capacity.				
<ul style="list-style-type: none"> • Increase reimbursement for Apple Health providers of all types including behavioral health, healthcare, and social service. • Create tiered or enhanced rates to pay more for services to individuals requiring a higher-level care by healthcare and social services providers. 	✓	✓	✓	✓
<ul style="list-style-type: none"> • Collect data across healthcare, behavioral health and social services and analyze data to identify what leads to timely discharge and good outcomes. 	✓	✓	✓	✓
<ul style="list-style-type: none"> • Create an automatic mechanism to pay DDA residential providers costs to start services for new clients. • Bringing in clients with exceptional needs has higher start-up costs than is typical. Individuals that are new to service need enhanced supports. Currently, providers need to make a request for each new client entering service. Streamlining and standardizing this process will support providers bringing in new clients. 		✓	✓	✓

Table 2 – HB 1394 sec. 10 (2) Recommendations

<ul style="list-style-type: none"> • Establish staffing and funding requirements that provide an appropriate level of treatment for residents in facilities, including both licensed mental health professionals and developmental disability professionals.
<p>Issue: When a hospitalized youth or adult no longer needs medically necessary treatment in an acute care hospital or treatment facility, there often remains a need to transition care, while individualized, long-term habilitative services are developed. DDA clients do not currently have an interim, discharge setting providing a transitional residential option while a long-term residential option is developed.</p>
<p>Workgroup Facility Recommendation</p>
<p>Create short-term (up to 90 days) transitional community based facilities with statewide accessibility to deliver stabilization services using a therapeutic model to support youth and adults. The transitional facilities will provide non-acute short term enhanced community supports and facilitate access to behavioral health and medical care. Clients will continue to access outpatient medically necessary state plan benefits based upon identified need. Individuals who have complex physical and behavioral health care needs, who are discharging from a hospital or treatment facility and experiencing barriers to discharge, may</p>



receive the greatest benefit from accessing this service. The facility model will include direct support professionals with the training and expertise to support individuals with co-occurring disorders.

At full implementation, the DDA contractor(s) will have capacity to provide short-term, transitional supports to 18 clients in 6 facilities. A daily rate of \$1,056 will enable the contracted provider(s) to employ staff with expertise to deliver behavior supports and coordinate with community health providers. A decision package has not been submitted.

Table 3 – HB 1394 sec. 10 (3) Staffing and Funding Model

Grand Total	FTE	State	Federal	Total
FY22	2.0	3,679,000	3,526,000	7,205,000
FY23	2.0	3,679,000	3,526,000	7,205,000
21-23 Biennium	2.0	7,358,000	7,052,000	14,410,000

Service Costs	FTE	State	Federal	Total
FY22	-	3,523,000	3,412,000	6,935,000
FY23	-	3,523,000	3,412,000	6,935,000
21-23 Biennium	-	7,046,000	6,824,000	13,870,000

Staff & Related Costs	FTE	State	Federal	Total
FY22	2.0	156,000	114,000	270,000
FY23	2.0	156,000	114,000	270,000
21-23 Biennium	2.0	312,000	228,000	540,000



Table 4 – HB 1394 sec. 10 (3) Recommendations

<ul style="list-style-type: none"> Additional considerations for successfully transitioning youth to adult services without service disruption. 				
Workgroup Recommendation	Short-term Services	Long-term Services	Hospital Discharge for youth or adults	Transition to Adult Services
<ul style="list-style-type: none"> Add an adult ABA program, other behavioral health therapies and remove limitations on some medical services. Creating in the Apple Health program an adult WISE program, an ABA adult benefit and removing benefit limits for therapies and nutrition will promote stability for adults with intellectual or developmental disabilities. The needs of those receiving these services do not change when they turn 21. Continued treatment availability is necessary for continued healthy outcomes. Providing these supports in the community for those over 21 will result in better outcomes so that people are more likely to continue living at home with families or are more successful in long-term residential supports. Closing service gaps that occur when EPSDT ends will help youth transition to adult services. 	✓	✓	✓	✓
<ul style="list-style-type: none"> Increase provider rates. Board Certified Behavior Analyst rates are insufficient to develop sufficient provider capacity to meet the needs of all youth that would benefit from ABA services. Increasing provider rates to sufficiently cover cost and overhead, including an incentive pay, for those specially trained to provide services to a child demonstrating aggressive self-injurious behavior or on others and build provider capacity is necessary to serve children and youth as they transition to adult services and to prevent unnecessary hospitalization. Additionally, consideration of expansion of this service to adults, through an adult Apple Health benefit must take into account building provider capacity. 		✓	✓	✓



<ul style="list-style-type: none"> • Fund community activities. • Youth supported in Voluntary Placement Services receive up to \$171 per month for costs associated with community activities. Staying active and building connections in the community is a core part of adult residential habilitation services. There is not a mechanism at this time for clients to receive support for costs associated with these activities. When individuals do not have the funds to be active, transition from youth to adult services or from the active life of the school years to the end of school can be challenging and lead to increasing needs for behavioral healthcare support. 		✓	✓	✓
<ul style="list-style-type: none"> • Increase flexibility of rate structure in Supported Living. • Voluntary Placement Services provides for a second, higher benchmark for a program manager position in each house. This second benchmark creates a career path for VPS workers. Supported living agencies do not have the same flexibility within the existing rate structure. Adding a second benchmark or other mechanism for an enhancement in Supported Living could help agencies retain staff and turn direct care in supported living into a career path. 		✓		✓
<ul style="list-style-type: none"> • Continue to strengthen programs that provide access to school transition programs that connect youth to work opportunities by the time of high school graduation. • This is important for all individuals with intellectual or developmental disabilities. Stable employment can make the transition to the adult world more successful and is especially important for youth transitioning from foster care to adult services. 		✓		✓
<ul style="list-style-type: none"> • Continue to analyze data on employment rates for youth transitioning to adult DDA services to inform policy decisions to improve employment outcomes. • Employment is an indicator of success in the transition to adult life. Youth in foster care are 		✓		✓



less likely to graduate high school and more likely to be unemployed. Special attention to data on employment outcomes for these youth can indicate successful transition to adult services.				
<ul style="list-style-type: none"> • Align policies between voluntary placement services, foster care, and adult residential services. • Create policies specifically for transition age youth services. Transitioning from youth to adult services can be challenging when a person suddenly moves from youth services built around a shared parenting or foster care model to an adult services model with very few or no restrictions. 		✓		✓
<ul style="list-style-type: none"> • Start transition planning from Voluntary Placement Service (VPS) and foster care to DDA adult services 1-2 years prior to the anticipated transition age. • Individuals eligible to be clients of DDA only have case managers if they are receiving a paid service. To bridge the gap for those who do not have a case manager additional staff is necessary to provide case management for all youth in foster care beginning at age 16 with smaller caseloads than the typical 1:75 ratio. 		✓		✓



Table 5 – HB 1394 sec. 10 other recommendations

Workgroup Recommendation	Short-term Services	Long-term Services	Hospital Discharge for youth or adults	Transition to Adult Services
<ul style="list-style-type: none"> Other recommendations relating to short-term and long-term residential intensive behavioral health and developmental disability services for youth and adults with developmental disabilities and behavioral health needs who are experiencing or are in danger of experiencing, barriers discharging from behavioral health treatment received in community hospitals or state hospitals. 				
<ul style="list-style-type: none"> Incentivize training to crisis and emergency responders around people with intellectual and developmental disabilities. Our first responders are on the front lines serving people in their community with intellectual and developmental disabilities and behavioral health needs. Understanding de-escalation techniques can reduce unnecessary use of jails or hospitals and reduce the trauma associated with that. 	✓		✓	
<ul style="list-style-type: none"> Create a path for DDA clients to own homes or rent from an organization who specifically manages housing for this population. DDA clients who utilize residential supports rely on the rental market for homes. Depending on the needs of the clients sharing the home, there may need to be modifications such as adding ramps, widening doorways or hardening surfaces. The clients may have little rental history and limited income. Property owners may perceive this as an unnecessary risk in such a competitive market. Provider owned homes are not permissible in the supported living program due to conflicts of interest. Increasing home ownership or creating a non-profit to develop and purchase housing could be worth exploring if this helps mitigate current barriers to accessing affordable housing. 		✓	✓	✓
<ul style="list-style-type: none"> Use market research to determine pay for direct support professionals working in DDA residential settings and incorporate automatic rate increases to make 		✓	✓	✓



<p>employment in DDA residential services competitive.</p> <ul style="list-style-type: none">• The legislature has made solid steps in improving funding for supported living services. There is still work to be done though. The last funding increases made it possible for providers to pay minimum wage in their respective communities. This is not a competitive wage. The work of the direct support professional is challenging and essential. Stability in the settings that provide long-term supports requires that the wages attract staff to provide quality care. Paying higher wages will result in less turnover and increased stability in the care that individuals receive.				
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Appendix A

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Appendix B

Additional resources

<https://www.hca.wa.gov/assets/program/essb-6032-behavioral-health-services-state-plan-3-5-19.pdf>

<https://www.hca.wa.gov/assets/program/access-behavioral-health-services-children-report-20191126.pdf>

https://www.nationalcoreindicators.org/upload/core-indicators/NCI_DualDiagnosisBrief_Oct072019.pdf

https://www.nationalcoreindicators.org/upload/core-indicators/NCI_DataBrief_MAY2014_ADDENDUM_04_20_15.pdf

https://www.nasmhpd.org/sites/default/files/TAC.Paper_.7.IDD_.Final_.pdf

