

 BLOOM WORKS

Washington State Complex Hospital Discharge Discovery Sprint

Research and Recommendations

Bloom Works, LLC

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Executive summary

Washington State has a range of service gaps and challenges in supporting youth and caregivers of youth with complex behavioral health-related needs, particularly in moments of crisis. At the same time, there are many initiatives in motion working to better meet the needs of these youth.

As part of [Washington Thrivings](#)' process to develop a statewide strategic plan for Prenatal-through-Age-25 Behavioral Health, Bloom Works conducted a discovery sprint to identify opportunities to improve complex hospital discharge outcomes with a core research question of: **How might we better support youth with complex behavioral health needs and their caregivers as they reintegrate into their communities after a hospital discharge?**

During our research, we spoke with a total of 35 people in 1:1 or group engagements. We did this to gain a holistic understanding of what people directly experiencing these issues need and what infrastructure could support this work. Those we talked with included youth, caregivers, system partners, agency representatives, and behavioral health providers.

Key findings

From these conversations, we heard many pain points about the process as a whole, identified by youth and caregivers with supplemental perspectives from providers. Key findings include:

1. Youth with complex behavioral health needs have limited access to care that meet their and their caregivers' holistic needs.
2. Washington state emergency departments are not always designed to support behavioral health crises.
3. Youth and caregivers often do not feel ready for or have support to navigate services after discharge.

These findings are further detailed in the "[Process pain points](#)" section of this report, which includes a [process map](#) representing major pain points for youth and caregivers across their journey from initial behavioral health crisis to post-discharge care.

All perspectives we spoke to also highlighted [systemic barriers](#) that influence the delivery of services, including:

1. Behavioral health cuts across many different systems, expertise, and needs.
2. Fragmented entry points and services lead to fragmented support.
3. The care that youth and caregivers receive reflects system constraints, rather than youth and caregiver needs.
4. Lack of services within the continuum of care.
5. Lack of cohesion and coordination of efforts leads to frustration and mistrust for all perspectives.

To represent an example of the range of services a youth and caregiver may need to navigate as part of discharge planning or other assessments of needs, we developed a [navigating systems map](#).

Recommendations

We developed three high priority recommendations the state should focus on, each with multiple sub-opportunities to tangibly address the overarching needs in this space. These recommendations are framed to address three primary findings that are essential to developing a strategic roadmap, informed by need.

Because our research has provided varied levels of visibility into the feasibility and effort needed for each opportunity listed, we have summarized our proposed next steps for Washington Thriving in a separate, [“Suggested Next Steps”](#) section.

Recommendations to improve complex hospital discharge outcomes:

[Recommendation #1: Increase opportunities to assess and serve holistic needs for improved behavioral health care](#)

[1.1: Understand holistic needs consistently across entry points](#)

[1.2: Offer comprehensive discharge planning and post-discharge supports for successful reintegration to community](#)

[Recommendation #2: Build out the continuum of care at all levels of intervention to inform a longer-term roadmap](#)

[2.1: Expand and enhance mobile/local crisis stabilization and treatment offerings](#)

[2.2: Increase in-home services and options for ongoing non-crisis supports](#)

[2.3: Create step up/step down options: partial, short-term, and intensive outpatient](#)

[2.4: Expand in-state residential treatment and/or therapeutic schools](#)

[2.5: Ensure unique needs and populations are designed for within all levels of the continuum of care](#)

[Recommendation #3: Develop a cohesive, strategic approach informed by data collection](#)

[3.1: Align efforts and available data to focus on populations with unique needs and significant system impact](#)

[3.2: Strengthen mechanisms for quality management across programs and services](#)

Next steps and future research

Given the range of opportunities, the urgency of addressing complex hospital discharge, and the highly interrelated nature of the three recommendations, we have outlined [suggested next steps](#) that Washington Thriving can take to move forward with all recommendations. Within the next year, if staffing and funding permits, Washington Thriving should collaborate with relevant stakeholders to review our recommendations and:

- Determine 1-3 high priority or high impact needs to assess and/or address.
- Identify opportunities with existing programs and services to collect meaningful data on need, services, and funding in order to better assess need and inform the longer-term roadmap.

- Create useful and usable documentation on existing programs as part of this effort to inform future work.
- Proactively and publicly demonstrate a roadmap and proposed next steps.

Based on the conversations we had, we identified some high priority additional research opportunities to further explore. The following are our suggested [topics for future research](#):

- Better understand when, how, and why youth become dependents of the Washington Department of Children, Youth, and Families (DCYF) in these behavioral health crisis cases and how to best ensure youth and their caregivers access support through DCYF.
- Better understand how school districts, special education, the Developmental Disabilities Administration (DDA), and other relevant stakeholders can support youth and their caregivers in accessing therapeutic schools (particularly for youth who have intellectual and developmental disabilities and/or are non-verbal).
- Explore upstream interventions for intellectual and developmental disabilities through special education that may support behavioral health.

Introduction

As part of [Washington Thrivings'](#) process to develop a statewide strategic plan for Prenatal-through-Age-25 Behavioral Health, Bloom Works conducted a discovery sprint focused on complex hospital discharge needs. In our research, we aimed to understand both the youth and caregiver experience around emergency department discharge from a behavioral health-related visit and the provider and systems-side landscape. From the insights gained across these perspectives, we propose areas of opportunity to improve access to behavioral health services for youth and the caregivers of youth with complex needs.

To identify opportunities to improve complex hospital discharge outcomes, we sought to understand our core research question: ***How might we better support youth with complex behavioral health needs and their caregivers as they reintegrate into their communities after a hospital discharge?***

Improving supports for youth and caregivers of youth with complex needs after a behavioral health-related hospital discharge is aligned with the vision of the [Children and Youth Behavioral Health Work Group](#) (CYBHWG): “that each and every child, youth, and young adult – and their parents or caregivers – has the behavioral health services and supports they need, where and when they need them, across the full continuum of care.”

Research methods

To understand the challenges and opportunities for better supporting complex behavioral health-related hospital discharge across Washington state, we sought out and spoke to:

- Youth aged 13-21 who have gone to an emergency department for a behavioral health-related crisis 2 or more times in the last 4 years and/or were discharged post-evaluation while their caregivers still had safety concerns.
- The caregivers of the above-described youth, to learn about the caregiver’s experience navigating the emergency department process and supporting their youth in reintegrating into their communities post-discharge.
- Youth representation across Autism Spectrum Disorder (ASD) and Intellectual and Developmental Disability (IDD) comorbidity and level of verbality, due to how this comorbidity often contributes to additional challenges in accessing services.
- Youth with comorbid needs across behavioral health needs (including complex mental health diagnoses, ASD, IDD, Substance Use Disorder (SUD), psychosis, learning disabilities) and safety concerns observed by their caregivers (including risk of danger to self and others, general safety concerns, inability to self-regulate, and inability to manage self-care).

We also sought out professionals who support youth ages 13-18 and their caregivers with the process of discharging from a behavioral health-related inpatient stay by:

- Supporting in the discharge process and care coordination/connecting youth to the next step of care (i.e., discharge planning, social workers).

- Supporting youth and caregivers as members of their care team (i.e., physicians, primary care providers, nurse practitioners, etc.).
- Supporting youth and caregivers post-discharge or outside of inpatient programs (i.e., psychiatrists, mental health counselors, etc.).
- Supporting youth and caregivers in crisis response (i.e., mobile response teams, designated crisis responders, etc.).

We generated 3 core interview guides (or sets of questions) for each participant group in our discovery sprint. Our guide for providers was adapted based on the provider type we were talking to. When we say “provider,” we use it as an umbrella term to cover: **system partners, agency representatives, and behavioral health providers.**

To find our youth and caregiver participants, we created and broadly shared a screener survey to identify who to talk to.

Across our research, we spoke with a total of 35 people in 1:1 or group engagements. All participation was voluntary, and youth and caregivers were compensated with pre-loaded Visa cards at a rate of \$80 per hour of their time. When we conducted interviews with participants, we shared our consent protocol and emphasized that questions were optional and participants could decline to answer or end the engagement at any time. We also developed a participant memo summarizing the findings and recommendations in this report that we sent out to participants at the end of our project.

Participant demographics

The following diagrams depict our participant demographics, split into two groups:

1. Youth and caregivers
2. Providers

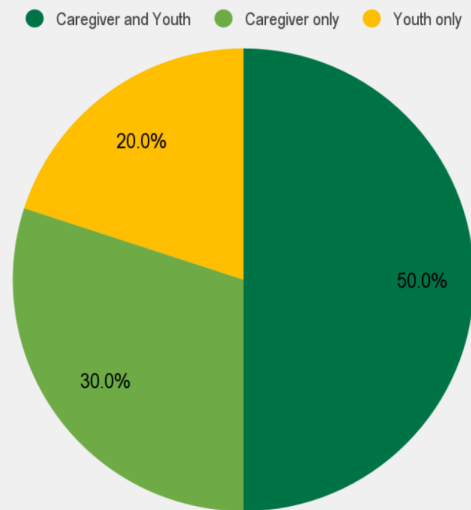
Youth and Caregivers

15 Participants

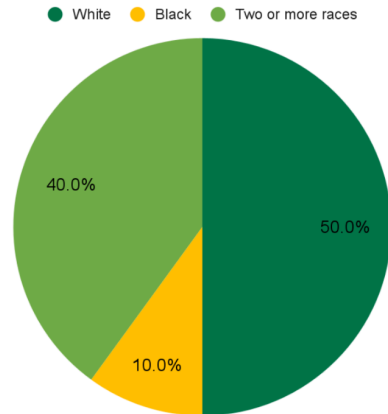
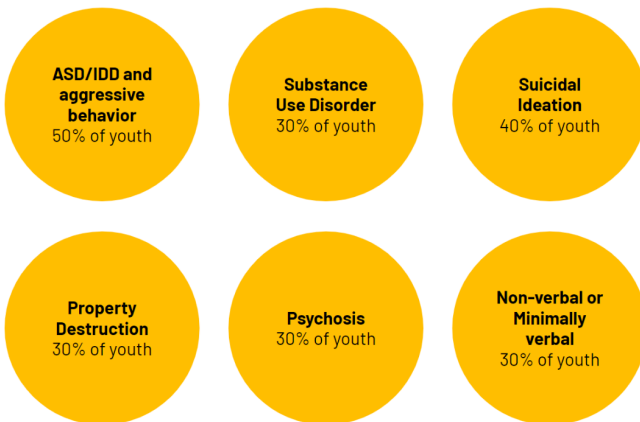
8 Caregivers

7 Youth

Conversation breakdown



Demographics of youth represented



The youth represented in our conversations were ages 14-18+

Demographics of caregivers represented



Providers

- 20** Participants
- 11** System Partners
- 6** Agency Representatives
- 3** Behavioral Health Providers

Conditions Mentioned



Key findings

What we've learned

Process pain points

These process pain points were identified by youth and caregivers, with supplemental perspective from providers (which encompasses system partners, agency representatives, and behavioral health providers).

1. Youth with complex behavioral health needs have limited access to care that meet their and their caregivers' holistic needs

- Due to the need to travel long distances, in-crisis transportation to care can be dangerous and traumatic.
- Emergency departments are mostly set up for acute crisis stabilization, not long-term support. There is a lack of services that youth can otherwise go to during and prior to a crisis.
- Caregivers have no or limited options for non-crisis respite.

2. Washington state emergency departments are not always designed to support behavioral health crises

- A crisis is a snapshot in time and does not provide emergency department staff with a clear picture of the issue or what long-term supports are needed.
- Mental and behavioral health is not treated as seriously as physical health.
- Hospital staff can be significantly injured when treating youth they aren't equipped to serve.
- Hospital environments are inherently traumatizing to youth and may exacerbate behavioral health challenges and behaviors.

3. Youth and caregivers often do not feel ready for or have support to navigate services after discharge

- There is a strong desire for a clear action plan at discharge that outlines each step in the continuum of care.
- Youth need support systems, especially when transitioning from "no/low demand" treatment centers to home and school.
- Services aren't designed around holistic youth and family needs and often have variable quality.
- Piecemeal services create navigation and access challenges for both caregivers and providers.

Process Map

This process map represents major pain points for youth and caregivers across their journey from initial

behavioral health crisis to post-discharge care. The arrow at the top of this map shows that this is often a cyclical process for most youth and caregivers. The “fast-forward” section represents the in-hospital part of the journey, which was out of scope for this study. Supplemental perspective from providers is shown at the bottom of the map.

This map is **not comprehensive of all pain points experienced**. It is meant to illustrate the pain points with the most saturation across the audiences we spoke to during this research.



- Key:**
- Gray:** Steps of the journey (dotted lines indicate steps that happen for some, but not all)
- Yellow:** Youth pain points
- Red:** Caregiver pain points
- Orange:** Challenges unique to specific populations
- Purple:** Additional perspective from providers, partners and agencies

Visit this link to download and view a higher resolution version of this image: [Process Map](#).

Systemic barriers

These system needs were identified by all perspectives that we spoke with (youth, caregivers, and providers).

1. Behavioral health cuts across many different systems, expertise, and needs

Given the complexity and interrelated needs of behavioral health, coordinated provider collaboration and/or a holistic assessment of needs is essential to successfully support youth and their caregivers.

2. Fragmented entry points and services lead to fragmented support

Varied funding sources, agency responsibilities, and needs assessments result in piecemeal, siloed support that fails to comprehensively address all of a youth's needs.

3. The care youth and their caregivers receive reflects system constraints, rather than youth and caregiver needs

Decisions on discharge, services, and treatment often reflect funding, insurance coverage, availability of beds, the entry point, etc., rather than need. This often leads to unmet needs and/or youth "recycling" through services.

4. Lack of services within the continuum of care

While care coordination is a critical support, all perspectives emphasized that without services at all levels of care that youth and their caregivers can access, coordination isn't enough to meet the need.

5. Lack of cohesion and coordination of efforts leads to frustration and mistrust for all perspectives

While there are many efforts to address systemic needs and provide care, the lack of cohesion across and visibility to all stakeholders leaves many duplicating work or missing opportunities for support.

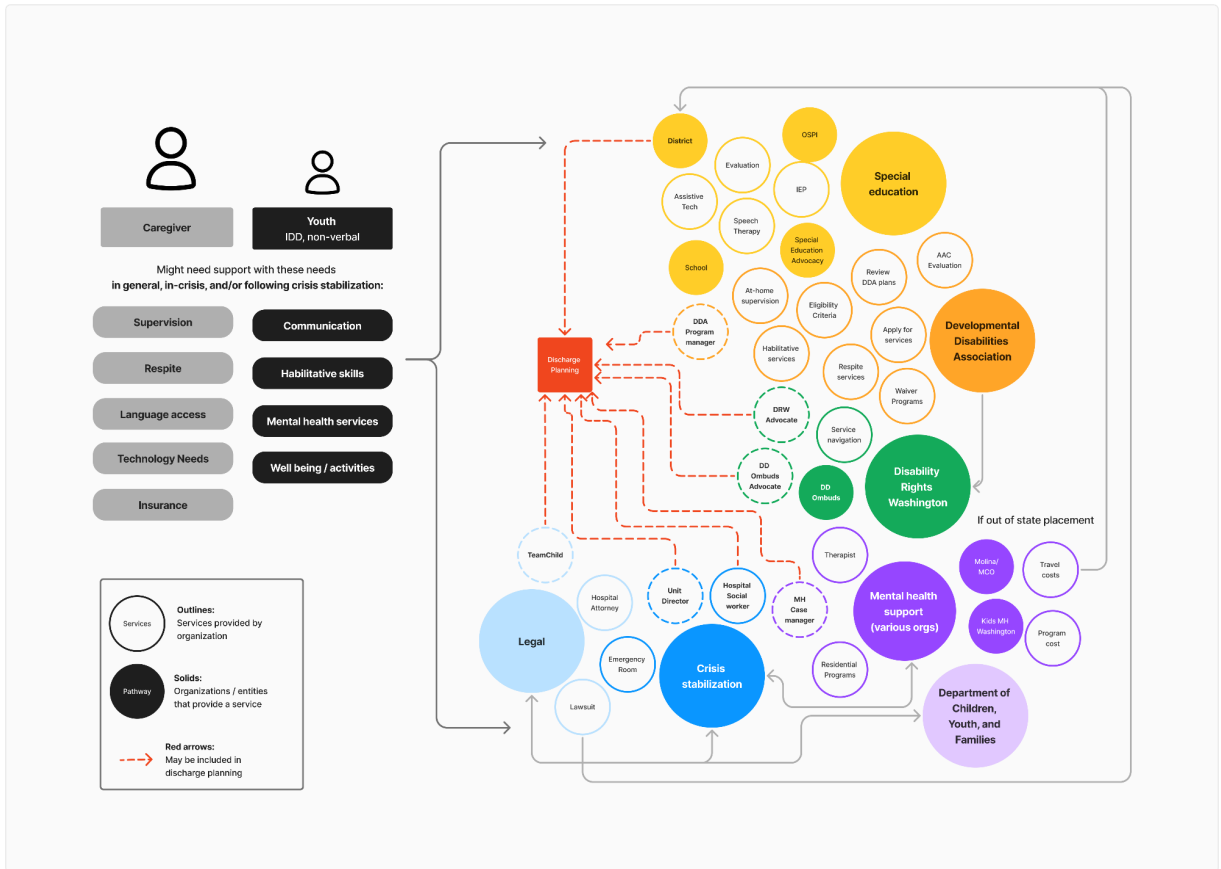
Navigating Systems Map

This systems map represents an example of the range of services a youth and caregiver may need in general, in crisis, and/or following crisis stabilization.

This diagram is **not comprehensive of relevant services or organizations**. It intends to demonstrate the variety of paths through which youth and caregivers may need to navigate to have their needs assessed, be offered services, receive care coordination, and/or receive services.

This diagram aims to highlight the range of perspectives and organizations that may be needed as part of discharge planning, or other assessments of needs, to help youth and their caregivers access "holistic" care that reflects their needs.

The demonstrated complexity reflects existing fragmentation in funding and agency responsibility; **it does not represent the desired experience of stakeholders**.



Visit this link to download and view a higher resolution version of this image: [Navigating Systems Map.](#)

Recommendations

These recommendations are for Washington Thriving to advance as part of their annual legislative agenda and strategic plan. These recommendations are framed to address three primary findings that are essential to developing a strategic roadmap, informed by need:

1. Existing **needs assessments currently reflect the perspective and role of the provider**, not the holistic needs of youth and caregivers. As a result, there isn't currently an accurate understanding of the holistic needs essential for youth and their caregivers to be successful with behavioral health.
2. The **lack of services at all levels of care** leaves emergency departments and residential treatment as the solution that caregivers often seek and request. As a result, there isn't currently an accurate understanding of which services or interventions are actually needed or impactful.
3. The previous findings, paired with the **lack of cohesive data and documentation of services**, prevents a comprehensive understanding of need, scale, and the impact of interventions. As a result, there isn't currently an accurate and comprehensive understanding of the need, scale, and impact of interventions to inform a strategic roadmap.

Given the above-described current state of systems, the scope of Washington Thriving, and the urgent need to address complex hospital discharge in Washington state, we have developed three high priority recommendations, each with multiple opportunities to address the overarching need while building a strategic roadmap.

Because our research has provided varied levels of visibility into the feasibility and effort needed for each opportunity listed, we have summarized our proposed next steps for Washington Thriving in the [Suggested Next Steps](#) section.

Recommendations overview

Recommendation #1: Increase opportunities to assess and serve holistic needs for improved behavioral health care

[1.1: Understand holistic needs consistently across entry points](#)

[1.2: Offer comprehensive discharge planning and post-discharge supports for successful reintegration to community](#)

Recommendation #2: Build out the continuum of care at all levels of intervention to inform a longer-term roadmap

[2.1: Expand and enhance mobile/local crisis stabilization and treatment offerings](#)

[2.2: Increase in-home services and options for ongoing non-crisis supports](#)

[2.3: Create step up/step down options: partial, short-term, and intensive outpatient](#)

[2.4: Expand in-state residential treatment and/or therapeutic schools](#)

[2.5: Ensure unique needs and populations are designed for within all levels of the continuum of care](#)

Recommendation #3: Develop a cohesive, strategic approach informed by data collection

[3.1: Align efforts and available data to focus on populations with unique needs and significant system impact](#)

[3.2: Strengthen mechanisms for quality management across programs and services](#)

Recommendation #1: Increase opportunities to assess and serve holistic needs for improved behavioral health care

The ways that youth and their caregiver's needs are assessed reflect the perspective and purview of their "entry point" to services. While it is reasonable that particular services are designed to assess and serve particular needs, this can lead to highly fragmented or incomplete assessments of needs. For example, with emergency departments as a primary entry point, assessments are focused on acute stabilization and may not provide youth and their caregivers with the holistic supports and services needed for ongoing success post-discharge.

Alternatively, if youth with intellectual and developmental disabilities are being assessed by a behavioral health provider for their mental health, other essential needs for communication, habilitative skills, etc., may not be considered. The lack of holistic assessment of needs impacts the system in 2 critical ways:

- 1) Youth and their caregivers may not gain access to all the supports and services needed to be successful in their behavioral health care.
- 2) Given the possible incomplete assessment and access to services, it is more difficult to assess the efficacy of existing services.

Washington Thriving should work toward increased opportunities for holistic assessment through various entry points to services to ensure that youth and caregivers are more likely to receive the supports they need and have their needs more accurately assessed.

All perspectives shared that "step down" programs would best support youth and their caregivers in the transition from the 24/7 supervision of emergency departments or residential programs to home settings. We've outlined these gaps in the continuum of care in [Recommendation #2](#).

Opportunity 1.1: Understand holistic needs consistently across entry points

Based on our discussions with youth, caregivers, and providers (which encompasses system partners, agency representatives, and behavioral health providers), "holistic" refers to these 3 primary needs:

- 1) Assessment of urgent needs vs. ongoing needs
- 2) Interdisciplinary perspective beyond behavioral health
- 3) Access to technology, language services, etc.

In order to provide youth and caregivers with the supports they need to be successful, Washington Thriving should identify ways to take into account different entry points when assessing the holistic needs of youth and their caregivers.

Finding 1.1A: Providers typically assess immediate needs in a crisis, rather than considering ongoing needs

- There are often non-crisis needs that are essential to behavioral health and well-being that may not be addressed because they are not assessed as part of a crisis response, or are viewed as “preventative” if they occur outside of the crisis. Since a crisis is a snapshot in time, it may not provide hospital staff with a clear picture of the issue, which makes it difficult to appropriately care for the youth experiencing the crisis.
- The emergency department’s primary focus of acute crisis stabilization does not always account for the on-going behavioral health needs that repeatedly lead to crisis:

“You have to be extremely honest in your answers. In this very moment, it may be ok. What was it like 10 minutes ago? You need to let them know that. They’re basing all of the services you can get off this snapshot. You need to be more honest about what your daily life is like.”

- Caregiver describing giving a friend advice for navigating an emergency department

“The doctor refused to give any psychotics or meds – it was egregious neglect. I tried to tell them he needed a sedative, hadn’t slept, was out of his mind and the doctor refused to give him any meds...We know enough to say he has a prescription for adderall and that’s why he tests positive for meth. We know to tell them that. He doesn’t have a substance problem. Seemed like the ER doctor wasn’t trained in mental health.”

- Caregiver describing an experience with her youth experiencing psychosis

“We have so many people who are only in the early intervention non-crisis space, and they have no idea what to do when someone is in crisis...So many people [only work in response to] crisis and have no idea what to do when people are happy.”

- Provider

Finding 1.1B: Assessing holistic needs that influence behavioral health, such as academic and habilitative needs, is critical to early interventions and ongoing support

- A provider offering a multidisciplinary approach shared that the supports needed often aren’t therapeutic in nature, and can only be understood by bringing together a team who know the youth well:

“Had a kid who cycled through every system you can imagine. [Through a multidisciplinary team], we learned that this kid was struggling with not having school. [Once resolved with the school,] we haven’t seen that kid since. The response wasn’t clinical, wasn’t a diagnosis, wasn’t a medication. It was having someone in the community knowing the kid and making a recommendation that works.”

- System partner

"There remains long waitlists for [services to assess needs] so I see kids get put on medications super young and they don't get the support to evaluate how they're working/not."

- System partner

"Autism - it's a disorder. It's something you're gonna live with for the rest of your life. Whether you have the coping tools or not. But the earlier we start just like with drugs and alcohol guys, it's about prevention. What can we do at a younger age?"

- Caregiver speaking about the need for applied behavior analysis therapy in schools at a younger age

Finding 1.1C: Needs assessments should consider any additional barriers that may limit youth and caregivers' ability to access services, such as technology and language

- Intensive Children's Long-term Inpatient Program (CLIP) facilities, like the Child Study Treatment Center (CSTC), are difficult to access for some youth. A caregiver shared their experience with the application process to CSTC. Before being admitted, they felt like they needed to exhaust all available resources:

"It's a 40-page application and reams of evidence to provide... There are often lengthy waitlists to even get a bed at [CSTC,] which speaks to why we sat in the emergency room for 6 weeks, but I've seen families wait 6 months. So we were lucky that it was only 6 weeks."

- Caregiver

"They might have [undiagnosed] mental health needs but because they are [non-verbal and thus] not able to verbalize their mental health needs/feelings/desires, that's being ruled out. [So] they aren't [diagnosed, which blocks them from] accessing essential services with assumptions that they can't have feelings, can't be depressed, etc. because they don't have the ability to communicate it."

- Agency partner

- Also consider how we give youth access to ensure their services are comprehensive. For example, Augmentative and Alternative Communication (AAC) devices are often tied to schools:

"They're also taking away their language and a lot of instances when they leave school. AAC devices are seen as a school device, not a device given to the child. When you step out of

school and have no way to communicate, it's frustrating because they take away your ability to use words."

- Agency partner

- Communications around services need to be easy to understand and navigate. Existing documentation is so confusing that it exacerbates the issue and prevents caregivers from accessing care:

"When a child is determined eligible for services, there's a notice sent out to families. The document is very complex and not user-friendly. It's hard for us to even understand."

- Agency partner

"[Because communication from state agencies is not] succinct, clear, and actionable, families often give up somewhere along the way and then don't get resources they need while the child is young, and then they grow up and don't have services they need."

- Agency partner

Opportunity 1.2: Offer comprehensive discharge planning and post-discharge supports for successful reintegration to community

Discharge planning is typically the responsibility of the hospital and thus reasonably reflects the responsibility and purview of the hospital. However, we consistently heard from all perspectives that there are many needs to consider that may go beyond the typical responsibility and perspective of a hospital. By not accounting for these needs, youth and caregivers may wind up with a patchwork of services, rather than a comprehensive discharge plan.

Putting together services piecemeal creates navigation and access challenges for both caregivers and providers. When providers, agencies, and system partners are aware of each other's work and where they may overlap in care, youth and caregivers will feel more supported and less stressed about trying to piece fragmented services together.

Youth and caregivers also often do not feel ready to navigate services after discharge. There is a strong desire for a clear action plan that outlines each step in the continuum of care. Youth need support systems, especially when transitioning from "no/low demand" treatment centers to home and school.

Finding 1.2A: Discharge decisions and planning processes can be abrupt and leave youth, their caregivers, and providers feeling unprepared for discharge

- Our research participants expressed the suddenness and impact of discharge decision making:

"These discharges also might be abrupt - maybe a week's notice that they don't meet medical necessity to stay."

- Agency partner

"I didn't think there'd be any trauma from [waiting to learn about discharge], but the period of time is the trauma. It's like a sentence in prison—at the end of the day I couldn't leave... They don't tell you the date you're going to leave. They gave me a letter at the 8th week, but they don't tell you the date. They told me the night before. It was the first time I really cried, tears of joy."

- Youth in treatment for substance use disorder

- When caregivers experience multiple weekly meetings with a large care team of hospital staff and advocates, they grow frustrated and nervous going into these discharge planning sessions:

"I would call them our "weekly hell meetings" because I would go into it with my knees shaking and just knowing that I had to stand toe-to-toe with people that were going to tell me no."

- Caregiver

- While a caregiver refused discharge because she was waiting for a bed in Florida to open for her youth, there was a case built to take custody of her youth due to neglect:

"So they came in and talked to [Youth]. Somehow said they got his consent, which I still don't understand how, when he is unable to give consent of that nature. They never talked to me ever. Nothing was done with it for a couple of months, and so the hospital and I continued our weekly meetings. And I got a spot and a date for [Youth] to go to [another state.] Two days after I got the final word on him being able to go, I was served documents. The lawyer went ahead and filed the dependency petition for the State to take custody of [Youth]."

- Caregiver of a nonverbal youth

- The age of consent for services is 13 in Washington state, and it often leaves youth and providers to navigate these situations independent of caregivers:

"Until we can get the child to sign a consent, we're only working with the kid or the hospital. If they're under 13, we're going to do our very best to pull in the kid and the parent. I would say 30% of kids are willing to say, yeah, absolutely I'll sign this so that we can pull the parents in."

- Provider

Finding 1.2B: Caregivers, schools, and other community supports need to be part of a youth's plan to reintegrate

- Various factors play into a youth's difficulty in reintegrating back into their communities after complex behavioral health-related hospital visits:

"Integrating back into school was also difficult. I had to get back to get into my normal and realize it wasn't everybody else's normal (and also not my normal)...just took time. I kept more to myself after [the crisis], didn't talk much, no specific urge to socialize with other people or participate in class. What could have maybe helped would be to have better connection with counselors at my school. I felt like the counselors I worked with weren't very understanding because they themselves/their children didn't experience it the way I did, so they didn't have much knowledge on that subject."

- Youth

"As a person of color, it was difficult to go through. There were not many Black people at my school and if they were, they weren't that helpful or interested in communicating about that."

- Youth

- One youth we spoke to didn't return to work for significant period of time after being discharged from the hospital so they had to quit and re-apply to get re-hired at their job:

"It felt important that I take off as much stress as possible and give my brain some time to recover."

- Youth

- One youth we spoke to felt uncomfortable with teachers asking them about their hospitalization upon return:

"It felt like this isn't your place, you're my teacher, you're supposed to be giving my math worksheets, I don't want you asking me about my health or offering me help beyond the bounds of what your job is. It felt really unprofessional and violating."

- Youth

"Was weird to readjust to things again. Big thing I noticed was hospital food...can't find the word...but it resets my whole gut biome and it was hard to eat food because food wasn't seasoned [was only allowed salt and pepper in the hospital] so I had stomach issues for about three weeks. Otherwise, it was about getting used to/having certain freedoms while in the house and getting used to medications."

- Youth

Communication between parents and [youth] should be daily when you know you're leaving. You're in your best state of mind... [I had most success when] I had the most communication with [my parents] and understood the most whether it was being discharged or to go to the next program. It helped the most when I had the best understanding of what the future was going to look like."

- Youth

I think kids should have a way to present their reason for why they should go home. There was never an instance where my mom was going to take my opinion into account.

- Youth

"Referral to a family therapist would have been nice...Not just 1:1 with [the Youth], but to look at the family structure and teach us how to deal with him being in crisis...he has two older sisters and they were never involved, but they should have been involved; they've been good supports for him. I wish someone had helped facilitate that. It's helpful to have somebody else talk to the family as a whole and say 'ok these are things that are working'."

- Caregiver

Finding 1.2C: Post-discharge, caregivers are often left on their own to conduct significant research, reach out to providers, and coordinate access to services

- Almost every caregiver we spoke with mentioned that leaving the hospital after a behavioral health crisis meant immediately acquiring a huge research project (like calling endless lists of providers and programs), all while desperate to find help for their child and being turned down, ghosted, or waitlisted one by one:

"[I feel an] overwhelming sense of "I don't know how to help my kid." I'm lost, I don't have direction, and now I have to buckle down and do a huge research project to find some help/programs."

- Caregiver

"No one helped us navigate financial piece. The first medical bill [was] \$22,000 WITH good insurance [Regence] and it was still outrageous. Just a hospital bill."

- Caregiver

"I had to take months off to help him get through this. If you don't know what to ask or you don't have someone who's on it or knows your family, good luck to you."

- Caregiver

Finding 1.2D: Caregivers need resources and support to take care of themselves so that they can best support their youth and caregiver after discharge

- Caregivers' needs are often forgotten or left behind despite being humans also experiencing trauma and who are ultimately responsible for the youth's care:

"They give you a lot of instructions in discharge on how to care for your child, but no one tells you how to care for yourself as a parent. There's a lot of guilt and shame around having a child who struggles with chemical dependency or mental health needs or both, especially when they're actively suicidal/coming home from a suicide attempt. Parents should get some information on programs/self care."

- Caregiver

"The most egregious to me was [specific hospital]. They would want me to sign a piece of paper that required me to recreate a hospital environment in my home. [Youth] was self-injuring inside the hospital with a piece of plastic. I was expected to remove all knives, all glass out of picture frames...if my child isn't safe in a room with a piece of glass, how is my child safe in the community?"

- Caregiver

Recommendation #2: Build out the continuum of care at all levels of intervention to inform a longer-term roadmap

Urgent behavioral health needs are a key barrier to assessing global and holistic essential needs when supporting youth with complex hospital discharge. All participant perspectives shared that the limited availability of low, mid, and high intensity services results in longer boarding in hospitals and discharge decisions that don't reflect the needs of youth and their caregivers. This leads to less successful transitions out of the hospital and contributes to recidivism. For example, a youth who is non-verbal and discharged without returning to a full school day may become frustrated and aggressive without access to communication technology.

Without support for supervision, the caregivers of this youth may have to miss work or return to the emergency department to stabilize the escalating crisis. Given these gaps in the continuum, it is difficult to accurately determine the scale of need and the impact of various levels of intervention, when youth and their caregivers do not have consistent access to different levels of care.

Although residential treatment programs were a frequent request of youth, caregivers, and providers, it is unclear whether this request is:

1. A reflection of residential treatment being the best therapeutic fit,
2. If it's the only existing type of program that offers the types of services needed (safety, ongoing supervision, etc.), or
3. If it's a reflection of current awareness and understanding of the function of different treatment options.

"Folks are shocked that there isn't therapy done in an acute inpatient setting...what they're seeking isn't what it is."

- Community provider

Given this ambiguity, the opportunities below identify where lower levels of care might be introduced more quickly while developing a quantitative understanding of high-need/high-impact residential facilities. While Washington state has moved away from institutionalization, the current lack of lower-level services paired with the lack of in-state facilities drives reliance on out-of-state residential placements. This introduces logistical challenges while exacerbating reintegration needs that still require development of low and mid level services.

Opportunity 2.1: Expand and enhance mobile/local crisis stabilization and treatment offerings

Washington state has recently launched increased mobile and local crisis stabilization offerings as a key path to services. All perspectives shared that:

1. Expanding these services to more regions can play a role in preventing future behavioral health crises, and
2. Enhancing these services to consider long-term stability, rather than just crisis stabilization, may mitigate crises and provide more meaningful opportunities for early intervention.

Finding 2.1A: Traveling to services during crisis and emergency department settings can exacerbate crises

- The experience of transporting a youth in crisis can be difficult and dangerous, especially if the nearest or most effective treatment center is far away:

"I got into my vehicle by myself with him in the back seat. He banged his head the whole time and was screaming and yelling...it took about an hour and a half to get there. It was a pretty scary drive. He kept trying to grab at me. Tried to bang my head while I was driving, but we got him there... When we got there, security came out. He immediately started coming at me. Security pulled me aside, took him in his wheelchair and put me in another room."

- Caregiver of youth with autism spectrum disorder, intellectual and developmental disabilities, and who is minimally verbal and aggressive

- Caregivers of youth in crisis may be turned away from the hospital if the hospital is not equipped to serve the youth:
 - One caregiver told us that they attempted to take their son to a local hospital in their county, but the hospital was not equipped to accommodate him and recommended they return home to call the county crisis line. So, the caregiver returned home and called the crisis line themselves. The crisis services provided 48 hours of support, but then said because the youth was non-verbal, they couldn't provide additional support. The caregiver had to then transport their youth to a hospital that would accept the youth.
- Caregivers need to be made aware of options for crisis response:
 - Organizations like Kids' Mental Health Washington are working to ensure that caregivers and their youth are aware of options like county crisis lines by partnering with school districts to introduce their program.

Finding 2.1B: Mobile/local crisis teams may benefit from training and resources for ongoing stabilization and treatment rather than just crisis stabilization

- Mobile or local crisis response can be a key entry point to services. Providers emphasized that these services would benefit from expanding toward access to treatment, rather than just initial crisis stabilization:

"There's no "treatment" at all in the word "stabilization"...parents are sick of the word "stabilization." [Mobile crisis response teams] take a kid for a few hours and then say they're "stable"."

- Agency partner

"Those teams need better training, and they need to have more of "what's the objective here" and it needs to not be "to get out of crisis." It needs to be more about staying stable."

- Provider

- Mobile and local crisis teams present an opportunity to offer the holistic needs assessment outlined in [Recommendation #1](#).

Opportunity 2.2: Increase in-home services and options for ongoing non-crisis supports

All perspectives shared that caregivers often don't have the supervision support needed to realistically attend to the needs of their youth post-discharge. This is particularly true in situations where "step down" programs aren't available, or when students aren't able to return to school for the full day. Caregivers struggle with the necessary supervision for the safety of their youth and themselves while also maintaining other responsibilities like employment. Thus, in-home services may be one "lower effort" opportunity to increase safety in less restrictive settings.

Finding 2.2A: In-home supervision is needed post-discharge and on an ongoing basis to support youth and caregivers with modified school schedules, maintaining employment, etc.

- Youth with chronic conditions such as suicidality or aggressive behaviors may need long-term supervision. This can be a barrier for caregivers, especially working caregivers:

"In-home supports would have been helpful. A hospital liaison connected us to [therapy and counseling provider], but they were terrible. They only provided 15 hours of help a month. WISE told us that [Youth]'s needs was not a forte of theirs. We basically use WISE for medication management. They give me a slight break for like an hour."

- Caregiver

- Caregivers may be able to access in-home supports through Behavior Rehabilitation Services (BRS), the Department of Children, Youth, and Families (DCYF), Wraparound with Intensive Services (WiSe), and the Developmental Disabilities Administration (DDA), but all perspectives shared that these services can have long waiting lists, convoluted eligibility and application processes, and that caregivers are often unaware that these services are available to them.

Finding 2.2B: Respite centers are critical to supporting all caregivers, but may be particularly valuable for single caregivers

- We spoke with a single caregiver (of a youth with complex behavioral healthcare needs) who had a personal health emergency. The caregiver needed to take themselves to the hospital, but didn't have a place to drop off their youth that would understand how to care for the youth:

"We need an emergency drop off facility. For when parents or caregivers are having an emergency and they need some help with kids like ours. You can't just call a babysitter. It's not that easy. It's dangerous actually to just expect a random person to be able to come in and know what to expect from your child. Somebody's gonna get hurt if you do that."

- Caregiver of youth with autism spectrum disorder, intellectual and developmental disabilities, and who is nonverbal and aggressive

Finding 2.2C: Youth and caregivers need access to non-crisis interventions to build skills over time

- Upstream interventions like non-crisis supports are a key need. While there are some organizations providing these services, these supports often have unsustainable funding sources or limited options for reimbursement through insurance. Providers shared a range of opportunities to better support youth and caregivers outside of crisis:

"People need to know there's places you can go where you don't need to be in crisis, or need a referral."

- Provider

"Yeah, ABA [Applied Behavior Analysis] therapy. We need more of it. We don't have enough providers in the State. And also it's pretty stringent access. You have to have an autism diagnosis in order to get ABA therapy. But there's lots of kids who would benefit from ABA, who don't have an autism diagnosis because a lot of kids who have intellectual and developmental disabilities don't have autism."

- System partner

"ABA [Applied Behavior Analysis] is the only thing I know of where you can tackle a lot of different domains, but people don't need the level of ABA the state is doing and there's no other system."

- Provider

- System partners described that accessing the habilitative supports for youth with intellectual and developmental disabilities are particularly difficult and often accessed separately from mental health supports.

Opportunity 2.3: Create step up/step down options: partial, short-term, and intensive outpatient

All perspectives shared the need for additional "step down" services to support youth with transitions post-discharge so they maintain the progress achieved in treatment. While our conversations were focused on "step down" as it relates to hospital discharge, all perspectives shared that these same services would additionally be beneficial as "step up" services for more significant interventions.

Finding 2.3A: Interim supports are needed to help youth and caregivers be successful as youth transition from no/low demand contexts to the higher demands of home, school, and community

- Youth, caregivers, and providers spoke to the abrupt transition that occurs for youth and their caregivers without interim support services:

"[There needs to be] more of a gradual step-down. I would go from going there every single day for 8 hours a day to never going back again. I wish you would go from 6 hours a day to 4 hours and then 3...it's just an abrupt change."

- Youth

"The emergency department is a stable place for a minute, but then what happens?"

- Provider

- When asked about one thing they would change to improve their discharge experience, a youth with autism and psychosis said:

"Easier and cheaper access to step down levels of care...a lot of people aren't ready to just go back to society after being in such severe crisis."

- Youth

- A youth we spoke to mentioned wanting an in-between level of care post-discharge.

- They said Intensive Outpatient (IOP) Services would have been too high a level of care, but needed something for a couple weeks, either with the same clinicians from the unit or satellite staff. They mentioned wanting multiple points of contact per week with someone who's aware of the situation (e.g., 15 minute Zoom calls).
- For various reasons, and because there is no interim care, sometimes youth spend excessive time or get “stuck” in the hospital, which hurts their treatment progress:

"How behavior changes while they're in hospital is a huge part of this - see patients stabilize in first weeks. The longer they're in hospital unnecessarily, their behavior tanks."

- Provider
- State-Operated Living Arrangements (SOLA) were often referenced as an example of a “step down” program where youth are able to successfully discharge with appropriate supports. They have an appropriate staff ratio, get to reintegrate in their community, and have a safe space to de-escalate:

"In the SOLA home, he has the sensory space where there are padded walls, protective glass, no door, and a google home that is locked up that has the ability to play soothing music."

- Caregiver

Finding 2.3B: The lack of step up/step down options may exacerbate the need for “boarding” in hospitals, residential placements, or “recycling” through services

- Caregivers and providers shared that, without sufficient supports outside of hospitals or residential placements, school districts may refuse to let students return to school:

"[There needs to be] a plan for discharge from the hospital [and also a plan] to discharge from residential settings. Gets tricky when coming back from residential to the home. A lot of schools don't feel equipped to handle the aggressive kids. When a school won't take a kid back then some parents will try homeschooling or other options. Often[, these parents get] overwhelmed and end up losing their jobs. Snowballs into a lot of issues."

- Provider

"[There are] lots of kids who can't return to [their] community because they don't have one of the essential services, which is school services. [What may happen is the] school team has said they can't meet their needs, [which leads to] families who have “chosen” to home school."

- Agency partner

Opportunity 2.4: Expand in-state residential treatment and/or therapeutic schools

All perspectives shared the need for increased in-state residential treatment programs and/or therapeutic schools. While the lack of services available for less restrictive levels of care make it difficult to assess the full need and scope of residential placements, the limited residential options within the state lead many caregivers to have to board their youth out-of-state, leverage emergency departments for interventions that the departments aren't intended to support, or lead to "boarding" their youth in hospitals until other options become available.

Finding 2.4A: In absence of residential programs, emergency departments are serving as the path to safety and stability which is detrimental to youth, caregivers, and providers

- Hospitals are set up for acute crisis stabilization, not long-term support, but without long-term facilities or other entry points to services, emergency departments continue to a common path to services:

"I feel like there's a huge disconnect...the reality of it is you have to meet this criteria to access this level of service. And now this is the conflict of the "why" - why kids are boarding, why kids are coming to the hospital. Because what [the parent and/or the youth want or need] doesn't exist, or [they] don't meet criteria for it, or nobody is going to pay for it. So, I think that that contributes to the complexity a lot of times to what we see as crisis because guess what? The family gets to define their crisis...and it doesn't translate to what crisis services may be able to triage or what an inpatient stay or emergency stay might be able to do for you and your families."

- System partner

- Emergency departments often aren't equipped or staffed to manage aggressive behaviors as part of a behavioral health crisis, highlighting the need to provide appropriate services elsewhere:

"We had a youth in our emergency department that had a very complex presentation...co-occurring diagnoses...ended up spending about 6 weeks there...from a healthcare perspective, it had various system impacts. It resulted in multiple staff injuries, it resulted in hundreds of thousands of unreimbursed costs to our hospital, and...the moral injury that it caused to our team and our staff was just unheard of...when you think about a kid who needs predictability, stability, all those things, it was not able to be provided. He was in a place with no windows, no access to human contact, no consistency, anything like that. Once...we were able to get him discharged, from a systems lens, it really highlighted the challenges and silos that were happening in our pediatric behavioral health lens."

- System partner

"[When hospitals and community stakeholders came together,] the thing that we recognized the most was, when these complexities arise, [hospital abilities] are limited. In order to be able to move forward, we are going to have to engage the community in a different way. [We] really leaned into the sentiment that...while we're in various systems, we're all facing very similar challenges, very limited resources, and [need to] pull this together to rally around our kids."

- System partner

- Emergency departments' sterile settings can also further exacerbate crisis and are inherently traumatic:

"[Youth] thought people were putting substance in his food and drink for mind control... got to critical mass and were going to take him to a facility with cameras and do experiments...When you go to the emergency room, it looked like the room that delusion said it would look like when he reached critical mass."

- Caregiver

"In the hospital, youth are undergoing trauma... We have hospitals that are declining to let them use an iPad because they don't want to allocate the money. Kids are bored and don't have basic things they're used to having in the community."

- Agency partner

Finding 2.4B: The lack of residential or therapeutic schools for youth with autism spectrum disorder, intellectual and developmental disabilities, or who are non-verbal, leads to many caregivers seeking out-of-state placements

- For programs that primarily rely on cognitive behavioral therapy (CBT), being verbal is essential to participation. This means non-verbal youth are ineligible for most facilities in Washington state because the vast majority of them employ CBT in their treatment plans:

"I have been looking for a facility for him for probably 3 to 4 years now...you throw in an autism diagnosis, and then the fact that he's nonverbal, and he was pretty much an automatic "no" from a lot of places due to them using cognitive behavioral therapy as their main form of treatment. So, if you can't comprehend or talk back, then their program's not going to work for you."

- Caregiver of a nonverbal youth with autism spectrum disorder

- A caregiver shared that when they finally found an out-of-state facility for their youth, they were shocked by how many other youth at that facility were from Washington state:

"There are probably at least 15 kids from Washington state in this program [Bancroft Children's Residential Program in New Jersey]...Shows why Washington needs to change and have behavioral facilities for these kids. We shouldn't have to send them 2300 miles away."

- Caregiver

- A caregiver of youth with intellectual and developmental disabilities and autism spectrum disorder who was nonverbal and aggressive shared her experience with making the decision to abandon her son at the hospital:
 - She felt they were not prioritized and then pushed out by the hospital. Her son's comorbidities make him difficult to place in a residential facility and too dangerous to take back home. The youth was in and out of hospital placements for 20 months before he was able to be placed at [a residential habilitation center] through the Developmental Disabilities Administration (DDA).

"What would have been nice would be not having to abandon your child at the hospital to get what they need. There is no program [or] pathway in the state for these kids."

- Caregiver

- A caregiver shared with us how tedious and disheartening finding care for their autistic and nonverbal youth was:
 - They called every facility on the list given to them at discharge and were rejected from one after another. Then they started moving their search out of state, placing themselves on as many waitlists as they could manage. It was only by accident (through literally calling the wrong number) that they finally landed on a treatment facility in [another state] that could accommodate their youth's needs.

Finding 2.4C: Out-of-state treatments introduce many logistical challenges and barriers to long-term stability

- When youth are sent out-of-state to receive care, they are further isolated from their communities and their caregivers, making it harder for them to reintegrate back into their communities after treatment:

"[We] have children come back [from out of state residential] after making great gains in their skills or reduction in behaviors that maybe sent them there. But if the parent isn't tied to that, they don't know anything other than the child who went away and don't have the supports needed."

- System partner

"The family needs to be engaged; when you're putting kids in inpatient, sleeping elsewhere for a long period of time, the family gets used to not having that stress/challenge and the youth gets used to not having to work things out with family."

- System partner

- One caregiver we spoke to had to coordinate an airlift to get their youth to a treatment center across the country because they can't fly commercial due to their behavioral needs. Despite all the effort that went into preparing for that transport (sleeping in the hospital the night before, packing, making hotel reservations, coordinating with the treatment facility, etc.), the airlift pilot showed up, saw the youth was aggressive, and refused to fly him. Turns out, there was some miscommunication through the school district who coordinated the airlift:
 - The hospital administrator filed a complaint against the district that day and helped the caregiver set up a GoFundMe to raise money to re-book everything on their own (as they were under time pressure to make the opening at the treatment facility).
 - On the second airlift attempt, they did make it on the plane but the caregiver still had to deal with their youth getting aggressive while in the air, when they landed to refuel, and when they arrived at the facility. The caregiver ended up staying for a week to get their youth all set up (with new doctors, coordinating with local hospitals, new clothes, etc.) as they couldn't bring much on the plane.

Opportunity 2.5: Ensure unique needs and populations are designed for within all levels of the continuum of care

As part of building out the continuum of care, Washington should consider the unique needs, populations, or comorbidities that are struggling to be served within existing supports. The lack of services for these needs contributes to seeking highly restrictive levels of care through out-of-state placements or the "recycling" of youth through crisis response.

Finding 2.5A: Providers shared that there are key populations that don't have sufficient support at different levels of care to meet their unique needs, particularly for neurodivergent youth

- Unique populations that we heard about in our research include:
 - Youth with intellectual and developmental disability and/or who are aggressive:

"Kids with intellectual disabilities are primarily the ones that get stuck at the hospital with aggression because they can't be discharged home safely. The aggressive kids often don't meet criteria...Kids that don't meet criteria for inpatient admission end up staying for longer than 5 day[s]...When a kid doesn't meet criteria they don't get paid for that stay. [The hospital] eats the cost."

- Provider
 - Youth who have co-occurring or chronic behaviors:

"[For] kids with chronic suicidality or chronic aggressive behavior supervision is a long term issue...The continuum of care is not where it needs to be for kids with suicidality."

- Provider

"Substance use and mental health residential exist, but not together. Need residential for co-occurring disorders and services across the continuum of care."

- Provider

"He's never fit easily into these programs. [The treatment center] said they could handle mental health and addiction but they didn't know what to do with him...they put him in a house down the road from everyone else. It's always been a challenge to get that combination of help that you need. He doesn't fit the common ASD [Autism Spectrum Disorder] spectrum. Nothing has been a good fit, including school."

-Caregiver of youth with autism spectrum disorder, intellectual and developmental disability, substance use disorder, and psychosis

- Youth who are victims of human trafficking:

"Kids that are victims of human trafficking are at a high risk and we don't have a good plan for them...Human traffic victims are at high risk of death"

- Provider

Finding 2.5B: There is a need for culturally-responsive supports

- Programs and services need to be sensitive, aware, and relevant across cultures:

"In my experience, it's very rare for a young person to refuse services if we provide kids with information and culturally relevant services that meet them where they're at and serve their needs. Most of the time, they want those services."

- System partner

"There are race and identity and belonging issues that do come up with the mental health and family support for transracial adoptees – when the parents' attitude about how the young person "doesn't conform" to the ways they have parented their other (white) children, or attachment related issues when the parents really need to unpack how much the difference in how their child looks (hair is different, body shape, etc.) impacts their empathy and support for the child who is not white, and how that child is being supported to love their entire self."

-System partner

"If the hospitals are not seeing these families [from various cultures and communities] often, [the question becomes] about whether that is because they have other ways to support them – or whether they are so isolated that they never get the level of support actually needed."

-System partner

- We heard that these specific cultures and communities may not have existing culturally-responsive supports:
 - Black
 - Spanish-speaking
 - Southeast Asian and Pacific Islander
 - Transracial adoptees
 - LGBTQ2SIA+

Recommendation #3: Develop a cohesive, strategic approach informed by data collection

With this recommendation, we emphasize the need to build cohesive, data-informed, and accessible systems to understand the systemic needs behind complex youth behavioral health-related crises. There are many initiatives underway to address the topic of youth complex hospital discharge in Washington state. In some communities, initiatives have seen a lot of success and were eventually funded to scale statewide. Other communities are just starting to develop how they might respond to burning issues. However, there is no central group looking across the state to think about a data-informed strategy to coordinate across these disparate efforts, leading to silos, confusion, potential duplicity of work, and misuse of time that could be better spent elsewhere.

Additionally, to build out a robust and comprehensive statewide system, the state must ensure that the services and supports that do exist are providing quality services for individual needs and are accessible to the youth who need them.

Opportunity 3.1: Align efforts and available data to focus on populations with unique needs and significant system impact

Washington state should develop standardized documentation and data related to initiatives addressing complex behavioral health youth crises. This can help improve crisis responses by displaying where the needs are, what types of needs exist, for what demographics of youth the gaps are most prevalent, and the level of urgency. Continuing on without centralized systems and data can lead to further fragmentation of treatment, gaps in attempted wrap-around services, and/or failures to comprehensively identify and respond to the needs of youth in our system.

Finding 3.1A: The providers we talked to often highlighted the impact of the current lack of cohesion across existing efforts

- When youth have conditions such as intellectual and developmental disabilities or if they are non-verbal, a portion of their needs and services are assessed through separate agencies like the Development Disabilities Association (DDA), Special Education Services, etc.
- We heard from multiple providers (encompassing system partners, agency representatives, and behavioral health providers) that the existing system is fragmented and siloed, with multiple efforts running in tandem that often ask others' for time or don't know about each other:

"I come to this conversation with a lot of frustration about the silos of what's happening in this space."

- System partner

"Solutions could include braided services to wrap around kids. We're all so siloed, there's no place connecting all the needs and serving them all at once."

- Agency partner

"People are depending on the system to take it all on. We're not working together to take it on collectively and having everyone do their part to help this person across time."

- System partner

- We heard from multiple providers that this work is best done by supporting youth and caregivers within their communities, and they worry the state's approach may not be effectively community-based:

"How are we guiding people in their community in being part of their community? In our state, we've compartmentalized a lot of things."

- Provider

"There's power in relationships... What works in [one county] isn't what will work in [another region. Services seeing success] were not built to respond to broken systems. The state tries to scale up in ways that work for the state...we cannot continue to do work that way."

- System partner

"I have been part of multiple multidisciplinary[, community-based] teams in different states...[Comparatively,] there aren't always clear objectives and goals for where [Washington state is] going."

- Provider

- There are already efforts underway to try to achieve this opportunity by aligning and informing existing efforts with data-informed methodologies, but even those efforts sometimes overlap and are not aware of one another.
- The state is lacking data transparency. It's unclear where and what data already exists, which adds difficulty in determining a comprehensive strategy for what opportunity is most urgent to address. There is data being collected, though, and a key starting point would be to centralize existing data being collected by various agencies and providers.

Finding 3.1B: Specific populations have unique needs that should be designed for and prioritized given their impact on the system

Across our desk research and conversations with youth, their caregivers, and providers, we identified a few demographics of youth and caregivers who have needs not well understood or responded to by the system who in turn add strain to the system due to its inability to meet their needs. When we say “unique” here, we are referring to a specific combination of demographics, lived experience and/or behavioral health needs that add complexity to how these groups must be served:

- Youth with the most unique needs to design for include those who:
 - Have intellectual and developmental disabilities (IDDs), are non-verbal, or have selective mutism
 - Have the combination of IDDs and Autism Spectrum Disorder (ASD)
 - Experience IDDs and ASD co-occurring with aggressive behavior
 - Have a substance use disorder co-occurring with mental health needs
 - Are Black, Indigenous, or people of color (BIPOC)
 - Have caregivers of a different race or culture

- Caregivers with the most unique needs to design for include those who are:
 - Single caregivers
 - Live in rural communities without nearby hospitals or providers that fulfill their youth’s needs
 - Are Black, Indigenous, or people of color (BIPOC)
 - Have adopted children of a different race or culture

Opportunity 3.2: Strengthen mechanisms for quality management across programs and services

Youth experiencing complex behavioral health-related crises need care that is responsive, individualized, and affordable. By nature of the circumstances, these youth may experience difficulty in interaction and self-regulation while in crisis, and require specialized knowledge and care for their crisis management and response. But our systems lack specific training or supports for providers to give dedicated care to these youth, leading to potential further trauma, distrust in systems, and poor standards of care for behavioral health needs.

Finding 3.2A: Care for complex behavioral health patients is not standardized across the state, including hospital staff training

- Many caregivers we spoke to were frustrated when hospital staff told them they were being discharged because their youth was “stable.” But when pressed, hospital staff have not been able to give a clear definition of what that means.

“How do you know when you’re stable? How do you define stable?”

- Caregiver

"The word "stable" means too many things for too many people. [A hospital may] send home a kid who's "stable" with continual suicidal ideation. Taking home a kid who still wants to kill themselves is scary and doesn't feel like the definition of stable."

- System partner

- Services can be highly variable, which leads to lack of consistency and effectiveness of care:

"[Some wraparound services have] been a game changer for a lot of families, but it's incredibly variable and personality-driven."

-System partner

- One caregiver we spoke with recalled their youth's first psychosis episode/crisis, which was also their first hospitalization as an adult. The caregiver shared that the emergency department rooms exacerbated the youth's delusions, leading the caregiver to have to carefully negotiate and advocate for a different space at the next hospital:

If I show any emotion, they're going to think I'm a hysterical parent. I use everything I can to be taken seriously – he's not going to harm himself or others... [I] convinced them to put him in a regular room.

- Caregiver

Finding 3.2B: Mental and behavioral health receive less state care and attention than physical health

- Mental and behavioral health stigmas exist nationwide and manifest in various ways in our communities and healthcare systems. Commonly, physical health needs are taken more seriously than mental and behavioral health needs:

"If you leave the ER [emergency room] with stitches or break your leg, they call you to check in and ask how you're doing. The odd thing is, when your child is experiencing a [behavioral health] crisis, they do not do that. But you'd think that's one of the most important things you can do as a follow up. Check in with people and learn how they're doing and what they might need."

- Caregiver

"[Parents may] believe mental health to be a kid's problem. There are not appropriate supports to help parents change their parenting strategies and provide the healthcare needs for their kids."

- System partner

Finding 3.2C: Services are differently available based on insurance type

- Providers and caregivers spoke to both real and perceived care limitations due to complexities around insurance coverage:

"We don't have Medicare, we have private insurance. I think out of the 3 or 4 [providers] around, only 1 took private insurance...We did the whole application. [It took] a month or 6 weeks [to get a response] and he didn't get in. To this day I don't know why."

- Caregiver with a child experiencing psychosis

"Because there's just not services, and especially if you have state insurance, because not all of us can afford ABA [Applied Behavior Analysis] out of pocket. You definitely get pushed down that list and get forgotten about."

- Caregiver

"With commercial insurance, they can limit [caregivers' and youth] access to in home supports."

- Provider

"For kids who are verbal and don't have the intensity of behavior we're talking about, there's a significant difference in [the continuum of care] between Medicaid and no coverage because families covered by Medicaid get WISe [Wraparound with Intensive Services]."

- System partner

"People are surprised to learn and don't believe that, on Medicaid, you have more access [to behavioral healthcare services] than off [of Medicaid]."

- Agency partner

Suggested next steps

Given the current state outlined in our [Recommendations](#) section and the urgent need to improve supports for complex hospital discharge, any next steps toward the recommendations should address:

- The **lack of an accurate understanding of the holistic needs** of youth and their caregivers
- The **lack of data and documentation on existing needs, services, and funding**
- The need to **repair trust with youth, caregivers, and stakeholders**

Recommended approach

We recommend the following approach in order to repair trust and demonstrate progress with impacted youth, caregivers, and stakeholders:

Within the next year, if staffing and funding permits, Washington Thriving should collaborate with relevant stakeholders to:

1. [Determine 1-3 high priority or high impact needs to assess and/or address](#)
2. [Identify opportunities with existing programs and services to collect meaningful data on need, services, and funding in order to better assess need and inform the longer-term roadmap](#)
3. [Create useful and usable documentation on existing programs as part of this effort to inform future work](#)
4. [Proactively and publicly demonstrate a roadmap and proposed next steps](#)

Note that these are not separate activities, but interrelated tasks that should be completed together. These activities are a critical first step to building out the services outlined in the recommendations. Also note that “building out” a service likely means expanding or enhancing an existing service.

1. Determine 1-3 high priority or high impact needs to assess and/or address

Determining a limited set of high priority needs can help focus Washington Thriving’s initial effort, particularly independent of new legislation or funding. Defining this limited set of needs can help align relevant stakeholders on the direction of a roadmap and create greater clarity around how different agencies, efforts, and programs can better align toward common goals.

Given the range of needs to address and the current limited scope of data, we recommend the following approaches to determining high priority needs:

1. **Prioritize one group or need that uniquely impacts the system.** We recommend that group to be **youth with intellectual and developmental disabilities (IDDs) or comorbidity of IDDs, non-verbal, and aggressive behavior**. In our research, this group was consistently identified from all perspectives as a population that Washington state is struggling to serve. As a result of this gap in their care, their behaviors can be damaging to themselves, their caregivers, and providers. Various providers and systems partners also indicated that youth “boarding” in hospitals might disproportionately reflect youth with these comorbidities.

2. **Identify opportunities for data collection within existing programs that can help clarify the needs and scale of the chosen population.** Although we may not have a quantitative understanding of the scale of the chosen population, relevant system partners may be able to provide data. Potential partners include:
 - a. The Developmental Disabilities Association (DDA)
 - b. Disability Rights Washington
 - c. Seattle Children's
 - d. Kids' Mental Health Washington
 - e. The Department of Children, Youth, and Families (DCYF)

2. Identify opportunities with existing programs and services to collect meaningful data on need, services, and funding in order to better assess need and inform the longer-term roadmap

A primary piece of feedback from providers was that there are many relevant efforts happening in the state to address these issues, but it isn't always clear what oversight there is for aligning these efforts. As an example, various system partners expressed questions about how the Washington Thriving and Bloom Works Discovery Sprint related to the 1580 Task Force effort and report, and/or previous reports written on the topic (by the Health Care Authority, Disability Rights Washington, etc.). As a result, many perspectives shared feeling frustrated with the duplicated effort and wanting greater clarity on how there can be a more cohesive approach to progress. Given the range of system partners, providers, and efforts in this topic, we recommend:

1. **Collaboratively defining the data points** (and possible sources) needed to inform high priority needs
2. **Collaboratively identifying existing programs or services that allow Washington Thriving and relevant stakeholders to collect meaningful data and test key hypotheses** about needed services in the recommendations such as:
 - a. More holistic understanding of needs
 - b. Impact of different interventions

There are currently multiple entry points to services that already offer the potential for more holistic assessment of needs and to assess the impact of different interventions. Below are programs that could be considered as paths to collecting data on existing need and impact, or for piloting modifications to programs to assess the impact of introducing more holistic assessment or varied levels of care. These are programs that were referenced with varying levels of detail in our research. There are likely many other relevant programs that stakeholders can help identify.

Note that these possible steps may be activities that are already planned for these programs and organizations, but given our level of visibility into these efforts we are still documenting what feels relevant based on our research.

For each of these possible starting points, **Washington Thriving should identify opportunities for more holistic assessment that addresses the opportunities in [Recommendation 1](#) and the cohesive oversight for data collection in [Recommendation 3](#).**

- **1580 Task Force:** This interdisciplinary team is already working to identify opportunities to more successfully move high-need cases out of hospital “boarding.” Consider investigating:
 - How this approach is impacting the on-going stability of youth.
 - Learnings about the holistic set of needs that youth and their caregivers need served and factors that may lead to youth “boarding.”

- **Kids’ Mental Health Washington:** This organization is already working closely with the state to “scale up” the Pierce County model to other regions. Kids’ Mental Health Washington relies on a highly local and community-based approach that offers multiple avenues to more holistic needs assessment. Consider investigating:
 - The impact of Kids’ Mental Health Washington’s partnership with school districts in Pierce County to make youth and their caregivers aware of their services prior to a crisis.
 - Kids’ Mental Health Washington offers multidisciplinary team assessments to understand the holistic needs that youth and their caregivers have from those who know them best. Understand the needs surfaced through these multidisciplinary assessments and implications for possible early intervention.

- **Molina Healthcare Discharge Planning Program:** Molina Healthcare offers 30 day support post-discharge to members of their Managed Care Organization (MCO) based on high risk for readmission to help ensure youth and their caregivers don’t return due to a lack of support. Consider investigating:
 - Key impacts of this service: e.g., the number of youth that maintain stability, the number of youth that return to the hospital, and the supports needed to help youth and their caregivers maintain stability.
 - Understand the algorithm for assessing readmission risk.

- **Behavior Bridges:** Offers non-crisis oriented support for youth who are neurodivergent and their caregivers, including caregiver and provider training for preventing mental health and behavioral health crises. The program also partners with emergency services to ensure that there’s an appropriate connection with the hospital. Consider investigating:
 - Impacts of non-crisis supports for neurodivergent youth and caregivers.
 - Impacts of partnership with emergency services.
 - Crises mitigated through these upstream interventions. The Behavior Bridges program asks for input on whether their services are helping reduce behavioral health crises.

- **Additional programs that have been referenced for consideration by various stakeholders:**
 - Disability Rights Washington
 - Seattle Children’s Psychiatric Urgent Care Clinic
 - Lake Burien Transitional Care Facility

- Center of Parent Excellence
- Youth and Young Adult Housing Response Team
- A service example from New Jersey:
 - Voluntary care coordination for caregivers for youth ages 13 and up, regardless of youth's participation in services (New Jersey trip attendees can provide additional context for this program)

Data collection should be aggregated across programs where possible to give a more comprehensive understanding of needs and the impacts of services.

Washington Thriving should prioritize investigations that stand to give the most holistic understanding of the need and intervention. For example, if the 1580 Task Force or Kids Mental Health Washington Pierce County program are best equipped to connect youth and their caregivers with holistic services, these are better opportunities for data collection and pilots than introducing a new holistic needs assessment in a hospital that can't connect youth and their caregivers to a broad range of services.

3. Create useful and usable documentation on existing programs as part of this effort to inform future work

Given the lack of documentation of existing programs and services, a critical first step is to collaboratively begin building useful and usable documentation. Initial documentation should be created as it supports the other tasks outlined above, but can later be used to support a broad range of internal and public needs.

Washington Thriving and relevant partners should be able to use these documents to understand the existing service landscape and identify gaps and opportunities. Initial documentation should include the following:

- Services that are currently available at the state, local, Non-Governmental Organization (NGO), and private levels
- Entry points that lead people to those services (e.g. the Developmental Disabilities Administration, Disability Rights Washington, legal groups, etc.)
- Funding source and insurance per service use

Documentation will be useful and usable if it:

- Uses visuals to succinctly introduce key information and relationships
- Allows viewers to easily understand the relationship between data points
- Is easily editable by multiple parties
- Allows viewers to progressively view more detailed information

As more robust documentation is built, Washington Thriving can extend and adapt these documents to serve a broader range of audiences and needs by:

- Breaking down services by:
 - Need (behavioral health, disability, etc.)
 - Group (LGBTQ2SIA+, autism spectrum disorder, chemically dependent, blind, etc.)
 - Geography
- Making available for use by youth, caregivers, and providers seeking services

4. Proactively and publicly demonstrate roadmap and proposed next steps

As part of building trust with relevant stakeholders and establishing a cohesive vision for this work, Washington Thriving should make key roadmaps, materials, and actions publicly available on an ongoing basis. As part of the Washington Thriving strategic planning effort, they should consider developing and sharing a visual roadmap that communicates short- and long-term goals to set expectations for improvement. These public materials should:

- Summarize key learnings and needs from Bloom Works Discovery Sprints and other Washington Thriving efforts.
- Indicate collaboratively-developed possible next steps that reflect youth and caregiver perspective.
- Be clear and accessible for youth, their caregivers, and providers.

Topics for future research

In our research, there were a few topics that were raised that feel highly critical to address but would require additional research to understand more fully. We are highlighting these topics below as recommendations of future topics for research. We have provided a summary of relevant insights we heard in our current research to help set context for future investigations.

1. Better understand when, how, and why youth become dependents of the Washington Department of Children, Youth, and Families (DCYF) in these behavioral health crisis cases and how to best ensure youth and their caregivers access support through DCYF.

As part of understanding complex hospital discharge, we had conversations to understand how youth might become dependents of DCYF in relation to caregivers “abandoning” youth in hospitals. This is an extremely complex topic that goes beyond what we could understand in a limited set of interviews. However, we want to surface some of the major themes that we heard in service of future research given the potentially significant impact of DCYF involvement for these youth and their caregivers.

How youth may become dependents of DCYF within complex hospital discharge:

- Many caregivers have the impression that their children can or will be taken away by DCYF if they refuse to take their children home from the hospital
- A non-profit legal group may be called in by hospital attorneys or hospital social workers to work with youth when their caregivers have “abandoned” the youth
- Hospital attorneys may file with DCYF on behalf of youth
 - Some hospitals have attorneys that may be more frequently filing on behalf of youth
- Law enforcement may also file with DCYF on behalf of youth
- If a court orders youth as a DCYF dependent, DCYF must comply

Other rationale for involving legal teams in complex hospital discharge:

- A non-profit legal group may be called in by hospital attorneys or hospital social workers to work with youth when the communication between the caregivers and hospital have become “adversarial” from the perspective of the care team and other hospital staff
- A non-profit legal group may often be requested in order to “put pressure on” to help youth access services they may otherwise have been denied through DCYF or the Developmental Disabilities Administration (DDA)
 - The priority is providing the youth and family with the services they need to be successful. They prioritize helping youth understand the services that are available to them and finding the culturally competent services that will help them be successful

Role and impact of DCYF Involvement:

- DCYF is intended to serve youth and their caregivers in cases of neglect or abuse. Many of the youth and caregivers involved in complex hospital discharge constitute abuse and neglect when caregivers do not think they can maintain a safe setting for youth due to the instability of the young person. It is

unclear if DCYF involvement is the solution to these conditions, particularly if they result from the lack of services available in the state

- DCYF may be an avenue to voluntary services for youth and their caregivers
- DCYF may be an avenue to other services for youth, which may incentivize caregivers and legal teams to take this path
- When a child is in DCYF custody in relation to complex hospital discharge, DCYF assumes the responsibility that the caregivers had and navigate trying to help the youth access services
- DCYF has to navigate the same set of services that were (or were not) available to the family. If Washington is lacking in critical services within the continuum of care, DCYF is not uniquely able to connect youth to services, and may struggle with the same challenges as caregivers attempting to access services. As a result, DCYF isn't necessarily better positioned to help youth and their caregivers access services
- Many shared that placements with DCYF can be traumatic and add to the complexity of behavioral health issues

Considerations for future research:

- Given that DCYF may not be better positioned to help youth access services, and that being in DCYF care can be traumatic, how might Washington Thriving help mitigate the likelihood that hospital attorneys or law enforcement unnecessarily file for DCYF?
- Why are hospital attorneys pursuing DCYF as a solution to complex hospital discharge?
 - In one conversation with a provider we learned that when youth "board" for safety concerns, but don't meet medical necessity for behavioral health services, the hospital is responsible for the cost of the youth's stay because it isn't covered by insurance. How might the financial responsibility of "boarding" contribute to how hospitals make decisions around youth?
- Are there cases where filing with DCYF has helped youth access necessary services?
 - If so, how might Washington Thriving identify opportunities to help youth and their caregivers access these services without DCYF involvement?
 - Is filing for DCYF needed as a mechanism to access services?
 - We have heard in many conversations throughout these sprints that the reputation of DCYF is a barrier for providing direct services because caregivers fear interacting with the agency will lead to their youth being taken away
 - In other sprints, we learned that there are DCYF services that may be delivered through other providers to mitigate the fears associated with the agency
 - Are there opportunities to improve how youth and caregivers can access DCYF services they're entitled to without the legal or traumatic consequences of the current process?
- How might Washington Thriving help youth, caregivers, and providers better understand the role of DCYF and clarify when or how DCYF is an appropriate path in complex hospital discharge?
 - Feedback in conversations suggests that the misinformation around DCYF may exacerbate the negative dynamics between youth, caregivers, and hospitals.

2. Better understand how school districts, special education, the Developmental Disabilities Administration (DDA), and other relevant stakeholders can support youth and their caregivers in accessing therapeutic schools (particularly for youth who have intellectual and developmental disabilities and/or are non-verbal).

We heard many perspectives speak to the complexity of accessing services for youth with autism spectrum disorder (ASD), intellectual and developmental disabilities (IDDs), and who are nonverbal given this population's prominent representation in the topic of complex hospital discharge. We have surfaced specific gaps in the continuum of care for these populations within the recommendations but want to separately highlight the unique challenges that may arise with therapeutic school placements. Note, that these challenges may be true in any instance where a student accesses services through Special Education, but the primary example we heard about was specific to IDDs.

- In one example a family shared, the family sued the school district in order for the youth to access the appropriate therapeutic school setting. Because the youth has IDDs and is non-verbal, they aren't eligible for most programs in Washington state, the family sued the district to provide their youth access to a therapeutic school through the Individuals with Disabilities Education Act.
 - Due to the lack of services in Washington state, this meant the family had to find a therapeutic school placement out of state, which led to an additional lawsuit covering the costs of travel to bring the youth to the placement, as well as family visits, etc. Note, that "travel costs" here include not only the cost of the family, but arranging multiple non-commercial flights due to the aggressive behavior of the youth.
 - The family understood the options available to them through work with a special education advocacy group
- This process was extremely costly and stressful for all parties involved and required the cost and time resources of multiple lawsuits to arrange the appropriate services for the youth
- A subject matter expert shared that this legal process may not be uncommon for districts who have youth whose needs are likely difficult to serve in the existing education settings and thus require costs that greatly exceed what's anticipated within Special Education funds
- Various perspectives shared that it's also extremely difficult for caregivers of youth with IDDs to access relevant services through DDA, special education, and other providers

Considerations for future research:

- Given the extreme costs associated with therapeutic schools, and the lack of therapeutic school options for IDD, etc in Washington state, how might Washington Thriving identify opportunities to better support youth, their caregivers, and school districts in navigating therapeutic school placements independent of building new programs?
- If the access to services is the result of the lack of cohesion and fragmented responsibilities of key organizations such as special education, school districts, DDA, HCA, etc – how might Washington Thriving alleviate the "hot potato" that occurs with youth and their caregivers in these situations?
 - For example: Are there ways to make state funding more immediately accessible to school districts in these cases to cover the cost of therapeutic placements to prevent the tension between districts, youth, and their caregivers?

- Ex. making safety net funds available more easily
 - In the example provided, the lawsuits served the function of forcing the district to “pay” for the therapeutic school, in spite of not having the funds to support that ask. How might the state support with funding in these cases that may reflect state rather than district-level infrastructure?
- Washington Thriving can investigate the following to better understand the role of legal action in this process:
 - Do districts have the funds via special education to cover the costs associated with therapeutic schools, particularly out of state?
 - How are caregivers made aware of their options for legal action in these situations? What are the costs associated with this for the family and district?
 - How often are districts subject to legal action to gain access to educational services that caregivers are entitled to via special education?
 - Are there other situations where caregivers take legal action against districts to gain access to education services they are entitled to?
 - What is the “cost” and frequency of the legal processes? How can this inform our understanding of the scale of this problem?

3. Explore upstream interventions for intellectual and developmental disabilities through special education that may support behavioral health.

Given the prominence of IDD in the complex hospital discharge population, we had many discussions which pointed to the need for earlier supports and interventions for youth with IDD. Part of the challenge described is that given that assessments for behavioral health are focused on behavioral health rather than holistic needs, in many cases youth with IDD have significant needs for their wellness that aren't being assessed or served. Below are examples of specific ideas that were raised for potential prevention or early intervention for youth with IDD. Note that these supports may currently be accessed through various paths such as special education or DDA. Washington Thriving should investigate:

- How to make Augmentative and Alternative Communication (AAC) evaluations accessible
 - If youth don't have access to AAC technology outside of school it can be an extremely frustrating experience for the youth that contributes to aggressive behavior
 - Lack of access to communication technology may also contribute to youth being ruled of services if they aren't able to verbalize their needs
 - Schools and districts may need access to technical assistance for AAC: local schools need the ability to call in and receive technical assistance
 - The Office of Superintendent of Public Instruction (OSPI) offers a Special Education Technology Center that districts pay into. However, it can be difficult to access this through safety net funding
 - Existing requirements make it difficult to cover coaching for technical assistance under these models
- Use of Applied behavior analysis (ABA)

- A system partner shared the perceptions that Washington has a bias for leaning on applied behavior analysis (ABA). This can lead to caregivers being persuaded to take a youth out of school for ABA, or used as an alternative to (vs. in addition to) other mental health services
 - They expressed concerns that ABA may not address communication or other key skill building because it is being viewed with the medical model, rather than looking at the whole person
- Other providers shared that ABA may be over-relied on in Washington state
- Providers expressed that ABA may be relevant to populations outside of ASD, but the limited set of providers that can offer this intervention mean that it can't be extended to those other populations