

# Transition-Age Youth and Complex Behavioral Health

Research and Recommendations

Bloom Works, LLC
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## Discovery Sprint Final Report: Transition-Age Youth and Complex Behavioral Health

#### **Contents**

Tra	Insition-Age Youth and Complex Behavioral Health	1
	Executive summary	4
	Suggested next steps	6
	Acknowledgements	7
	Research scope and approach	7
	Background and scope	7
	Who we interviewed	9
	Transition-age youth at a glance	9
	Key TAY milestones	10
	<u>Charlie's story</u>	11
	Recommendations	12
	The fragmented WA BH landscape	12
	3 Key ways to understand prevention	13
	Recommendations overview	13
	Recommendation 1. Help TAY and their support networks understand needs, navigate services, and coordinate care.	14
	Recommendation 2. Provide TAY-centered services at the appropriate level, across the continuum of care.	23
	Recommendation 3. Enable providers to work with TAY effectively and at the level that is needed.	30
	Conclusion	36
	Appendix: Charlie's story	37

## **Executive summary**

This report presents the recommendations from the discovery sprint that Bloom Works conducted August to October 2024, aimed at improving behavioral health access and outcomes for transition-age youth (TAY). Our goal is to provide insights for the <u>Children and Youth Behavioral Health Work Group (CYBHWG)</u> and <u>Washington Thriving</u> as they work to improve behavioral health from prenatal through age 25.

In collaboration with the Health Care Authority (HCA), we explored the perspectives and needs of:

- Transition-age youth (TAY) with complex behavioral health experiences as they navigate the behavioral health system
- Parents/caregivers
- Direct service providers
- Professionals who oversee the systems that organize and deliver these services

Based on that research, we offer these findings and opportunities:

Overarching recommendation: A TAY-centered behavioral health system designed with and for youth that addresses their specific needs. While the TAY age range group spans a range of experiences, the critical life milestones and developmental stages they share highlight the need to recognize them as a distinct population within the system. Current services are often geared toward either children or adults, leaving thousands of TAY without the appropriate care and support they need. To address this gap, it's essential to adopt a more TAY-centered approach.

**Recommendation 1.** Help TAY and their support networks understand needs, navigate services, and coordinate care.

Help TAY and their support networks understand needs, navigate services, and coordinate care.

#### Findings

- **Finding 1.A**. The systems that TAY must navigate often assume strong executive and physical functioning, which can create barriers to access and engagement.
- **Finding 1.B**. A diagnosis can be life-changing, but not everyone gets one, or they may not get it when they need it most.
- **Finding 1.C**. TAY are more likely to engage with programs and services where they feel accepted.
- Finding 1.D. TAY are more likely to thrive when they have natural supports or a trusted adult in their lives, but not everyone has access to such resources. In their absence, direct service providers frequently step in to fill the gap.

#### Opportunities

- Opportunity 1.1. Increase access to peer support for TAY as part of behavioral health services and Community-Based Organizations.
- o **Opportunity 1.2.** Share guidance for providers on working with TAY
- Opportunity 1.3. Normalize TAY behavioral health through targeted marketing efforts.

- Opportunity 1.4. Provide guidance for TAY family, caregivers, and support networks on navigating behavioral health needs.
- o **Opportunity 1.5**. Evaluate the expansion of existing resource lines.

**Recommendation 2**. Provide TAY-centered services at the appropriate level, across the continuum of care.

#### • Findings

- Finding 2.A. Because of high demand and limited resources, many services focus on treatment, instead of prevention that could ease the strain on both individuals and the healthcare system.
- **Finding 2.B**. More care options exist for people with high-intensity needs than for those with middle- to lower-intensity needs, creating a counterproductive incentive for health conditions to worsen before getting treatment.
- Finding 2.C. Gaps in services create breaks in care for TAY. At 18, many TAY lose benefits, age out of programs, or get dropped from Medicaid without their knowledge, disrupting their care and setting them back.

#### Opportunities

- Opportunity 2.1. Offer providers guidance on how to promote safe and trustworthy services to TAY.
- Opportunity 2.2. Build out private insurance high-intensity wraparound services to have parity to Medicaid.
- o **Opportunity 2.3**. Build out Medicaid-funded mid-intensity wraparound services.
- Opportunity 2.4. Help Medicaid enrollees navigate the transition from household to individual Medicaid at age 19.

**Recommendation 3**. Enable providers to work with TAY effectively and at the level that is needed.

#### Findings

- <u>Finding 3.A</u>. Providers for TAY struggle with unstable funding and complicated insurance, leading to shortages that disrupt programs and stifle consistent service.
- Finding 3.B. Workforce shortages are common in behavioral health, especially in Washington. Poor working conditions and low pay increase turnover, pushing providers into private practice and limiting access to services for TAY.

#### Opportunities

- o **Opportunity 3.1.** Increase funding for outreach, navigation, and care coordination.
  - Potential first step: Map out existing funding streams that can resource this work
  - Potential first step: Assess existing data to help understand the effectiveness of current funding and identify where more resources are needed.
- Opportunity 3.2. Streamline the funding process and requirements to ease burden on providers.
- Opportunity 3.3. Integrate funding opportunities across behavioral health agencies for a simplified provider experience.



■ Potential first step: Redesign communications about provider funding.

#### Suggested next steps

Given the broad scope of this discovery sprint, this report highlights a range of opportunities to improve the experiences and outcomes of TAY with complex behavioral health needs. Some of these are long-term goals that, while essential for sustainable change, will take time to achieve because of the need for legislative action, budget shifts, or multi-sector partnerships. Below are key opportunities we recommend prioritizing to address urgent challenges and lay the groundwork for achieving the long-term goals tied to the three overarching recommendations in this report.

- Opportunity 1.2. Share guidance for providers on working effectively with TAY. Building trust with TAY is crucial, and one key step is offering tips on how providers can clearly and effectively discuss complex but essential topics, such as TAY's options, rights, and confidentiality within behavioral health services.
- Opportunity 1.5. Evaluate the expansion of existing resource lines, like Teen Link. Our top recommendation for helping TAY navigate behavioral health challenges and services is to increase access to individualized, personal peer support. While this may be a longer-term goal, Washington Thriving and state agencies should act now to assess which existing resource lines and public information services can be scaled and adapted to better meet the needs of TAY. These resources already exist in various forms, and improving their effectiveness could provide immediate support.
- Opportunity 2.5. Help Medicaid enrollees navigate the transition from household to individual Medicaid at age 19. This transition may be resulting in coverage lapses for many Medicaid families in Washington. Washington Thriving should advocate for durable solutions like extending the transition age to 26 and implementing auto-enrollment. While these changes may require federal or policy action, the State can take immediate steps by enhancing communication and providing clearer guidance to enrollees about the transition—efforts that can be implemented within the current policy framework.
- 3.1.A. Catalog the existing funding and programs that can resource TAY outreach, navigation, and care coordination work, including the source of the funding, how providers access it (e.g., grants, contracts, billable/reimbursable), what criteria apply, how many providers can access it, how much funding is available, and how the provider's accountability is evaluated. Any expansion of funding for this critical work needs to start with greater shared understanding for how funding currently works.
- 3.3.A. Redesign communications about provider funding to better promote funding
  opportunities across agencies, and more effectively guide organizations in understanding
  requirements and applying for funding. This would be a quick win within the existing
  environment of multiple funding portals and differing application processes across
  agencies, while the State makes progress on integrating those funding opportunities and
  streamlining the process for providers.

### Acknowledgements

This work is driven by the compassion and brilliance of youth and young adults, their parents and caregivers, and subject matter experts, all working together to improve outcomes for transition-age youth.

Despite incredible obstacles, the people with lived experience who shared their stories have achieved better outcomes than many of their peers, thanks to the support they received. We're grateful to amplify their voices here. We recognize that many young people still lack the resources or connections needed to thrive.

We want to acknowledge the tremendous efforts of healthcare providers, direct service professionals, community advocates, and legislative officials who work to improve conditions and outcomes for youth, young adults, and the people that support them.

We also want to express our gratitude to partners who helped us connect with research participants, including transition-age youth, parents/caregivers/people in support roles, providers, and subject matter experts.

## Research scope and approach

Discovery sprints are short, ultra-focused research projects designed to quickly understand a challenge and identify actionable paths forward. This approach is ideal for exploring why certain issues exist, understanding current processes, identifying root causes, and uncovering opportunities to address them. Given the timeframe, discovery sprints cannot solve historically systemic issues or answer all questions on a topic — often they generate additional questions for further exploration.

#### Background and scope

Over 8 weeks between August and October 2024, Bloom Works conducted a discovery sprint We gathered data from desk research and participant interviews. We worked closely with the co-chairs of Washington Thriving and sprint champions from the Health Care Authority (HCA), with regular check-ins to ensure alignment and gather feedback.

Early on, interviews with subject matter experts and stakeholders revealed several key challenges:

Services are not well designed for transition-age youth (TAY): Few services are TAY-specific. Existing services for children or adults are often poorly adapted for youth and young adults, and this results in environments that do not feel welcoming or accessible. For example, children's settings that look and feel like childcare spaces with toys and games for littler kids may feel uninviting to TAY, and services that require early morning appointments may be impractical for many youth and young adults.

**Gaps in specialized and integrated behavioral health services**: Stakeholders highlighted the significant shortage of services for complex or targeted needs, including residential programs. We also repeatedly heard about the lack of integrated and well-coordinated

services to address behavioral health needs, such as substance use treatment interconnected with underlying mental health issues.

**Stigma and mistrust**: Behavioral health issues and seeking treatment are stigmatized among many youth and young adults. Past negative experiences with the system — which can include criminal legal system involvement — have compounded that mistrust.

**Need for non-clinical supports**: Some stakeholders highlighted that TAY can benefit from non-clinical programs like art therapy or social groups, which provide behavioral health support without requiring a formal diagnosis (recognizing that art therapy can be considered a clinical service, depending on the qualifications of the provider). But because a diagnosis is often necessary to secure program funding and reimbursement, few non-clinical programs exist and are underfunded.

**Navigational challenges**: TAY and their families face difficulties in finding reliable, trusted information, and have challenges navigating the behavioral health system. It is difficult for anyone to navigate a highly complex, fragmented system like behavioral health, especially at the developmental stages of youth/young adulthood.

**Systemic factors and need for wraparound services**: Systemic factors, including race, income, migrant status, geographic location, past trauma, and housing access, exert a profound influence on the behavioral health of TAY. Many who access services are also struggling with housing, food access, and employment, which need to be addressed for meaningful results.

**Inconsistent touchpoints**: As young people approach adulthood, they are less connected to institutions like K-12 schools and pediatricians, and have fewer access points to vital service and support hubs.

**Missed opportunities for successful early intervention**: Intervening early can ease the need for more intensive services later. K-12 schools are widely acknowledged as opportunities for upstream intervention, particularly for addressing mental health needs before they escalate to substance use as self-medication and to help students without resorting to punishment, which can prevent criminalization as they grow older.

**Behavioral health is often not treated with the same importance as physical health:** Due to a combination of stigma, funding issues, and a lack of understanding how behavioral health impacts overall well-being, within our healthcare system mental and behavioral health are generally given lower priority. For example, the rollout of the new DSM-6 is delayed in a way that experts say would be unacceptable if it were related to physical health fields like cardiology.

These initial insights helped us develop the following guiding question, which shaped the scope for the remainder of the discovery sprint:



How can the State of Washington improve the experience for youth and young adults with complex behavioral health needs by creating a more integrated approach that addresses service gaps and is designed with their direct input to meet their needs?

#### Who we interviewed

We interviewed 22 people across three categories:

- People who are or were recently transition-age youth (which we defined as ages of 15 and 26).
- People in support roles of transition-aged youth, like families, parents, guardians, or community members.
- People who are direct service providers or otherwise have subject matter expertise in the broader system.

## Transition-age youth at a glance

"My two operating principles that I would like to offer are curiosity and gentleness. We might not see eye to eye, but we can be curious about each other's experience in a way that builds empathy and understanding. Like, I would love to know you and I would love it if you would know me."

Transition-age youth

The term "transition-age youth" or TAY spans a wide spectrum of people and experiences. A TAY may face complex behavioral and physical health challenges, lack of access to resources or support, or other challenging scenarios:

This list provides examples of the challenges a TAY may face. It is not comprehensive.			
Behavioral health	Physical health		
<ul> <li>Addiction</li> <li>Depression, anxiety</li> <li>Developmental disorder (e.g., ASD, ADHD, learning disability)</li> <li>Dissociative Identity Disorder (DID)</li> <li>Other neurodivergence</li> <li>Serious mental illness (e.g., psychosis)</li> </ul>	<ul><li>Physical disability</li><li>Medical conditions</li></ul>		
Access to resources	Scenarios		
<ul> <li>Housing</li> <li>Food</li> <li>Material goods (e.g., clothing, furniture)</li> <li>Transportation</li> <li>Education</li> </ul>	<ul> <li>CPS/foster care/family separation</li> <li>Gang involvement</li> <li>Legal system involvement</li> <li>Abuse</li> <li>Racism/sexism/ableism/phobias</li> </ul>		

<ul> <li>Employment</li> <li>Pet care</li> <li>Child care</li> <li>Internet/Technology</li> </ul>	<ul> <li>Bullying</li> <li>Persecution</li> <li>Trauma</li> <li>Stigma/bias</li> <li>Loss of a loved one</li> <li>High-risk behaviors (e.g., drug use, gambling, sexual behavior)</li> <li>Pregnancy and parenting</li> <li>Recently immigrated (documented/undocumented)</li> </ul>
Access to support	
<ul> <li>Access to a trusted adult (parent, guardian, friend)</li> <li>Insurance or payment (e.g., Medicaid, private insurance, out of pocket)</li> </ul>	

Any one of these factors can create significant challenges and disruptions for TAY. Many of the people we spoke with faced several of these challenges at once, forcing them to grow up quickly as they worked hard to manage their behavioral health and maintain basic stability. While these challenges are not unique to TAY, this stage of life can make them especially difficult, as young people are often encountering these obstacles for the first time and are often expected to navigate them independently, with little guidance. Their experiences during this period are likely to shape their expectations and understanding for years to come.

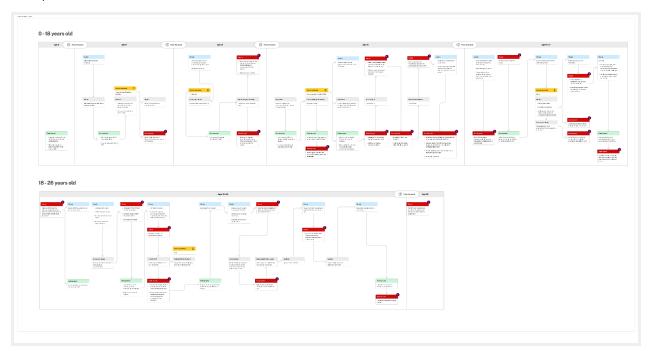
#### **Key TAY milestones**

Within the broader journeys of TAY, we identified common milestones marking significant shifts in their experiences and responsibilities:

- **Ages 0 to 12:** Early childhood experiences influence a young person's outlook and future outcomes.
- **Age 13:** In Washington, youth gain the ability to make certain medical decisions without parental consent.
- **Age 16**: Youth can apply for a driver's license, potentially gaining greater independence.
- Ages 18 to 21: At 18, youth under their family's Medicaid plan are reclassified as independent and may lose coverage and their access to healthcare. They may also age out of youth-serving programs and services, leading to gaps in care as they transition to adult systems. At 21, youth in foster care can exit the foster care system, while some can remain eligible for extended foster care benefits.
- **Age 26:** Youth covered by a parent or guardian's private health insurance may lose coverage, necessitating new arrangements for their healthcare.

#### Charlie's story

To illustrate the experiences of the young adults and families we spoke with, we created a journey map (<u>Appendix A: Charlie's story</u>), a visual tool that outlines key events over time and how these events affect everyone involved. This journey map centers on Charlie, a transition-age youth, and their parent, Sarah.



#### Ages 0 to 9

Early on, Sarah observes behaviors in Charlie that remind her of a cousin diagnosed with Autism Spectrum Disorder (ASD), making her question if Charlie may also have ASD. In school, Charlie struggles with reading, and the teacher suggests testing for learning disabilities. Sarah requests that the evaluator test Charlie for ASD as well, but the results are inconclusive. Instead, Charlie is diagnosed with a language-based learning disability.

#### Age 14

As Charlie enters high school, they start to develop high levels of anxiety, at times unable to leave the house. Around the same time, Charlie is diagnosed with a tic disorder. Sarah finds a language specialist for Charlie but grows frustrated when the specialist focuses solely on the tic disorder, without considering how anxiety may be a contributing factor.

#### Age 15

When it's time for Charlie's school accommodations to be reassessed, Sarah again requests that the evaluator test Charlie for ASD. This time, Charlie receives the diagnosis, providing both Sarah and Charlie with some relief and answers. However, Sarah still struggles to fully understand and manage Charlie's behavior in context with their other diagnoses.

Sarah finds a therapist for Charlie, but the therapist's child-centered approach, which includes using puppets, alienates Charlie, who feels patronized. After several tries to find someone suitable, they eventually connect with a therapist who has pride flags in their office. This helps create an inclusive environment, and Charlie feels safe.

During this time, Sarah begins to feel overwhelmed. Her husband does not take Charlie's symptoms seriously or play an active role, leaving Sarah to manage most of the responsibility. She also feels isolated, as friends and family don't seem to understand what she is going through.

#### Ages 16 to 17

As Charlie approaches 16 and 17, their anxiety and depression worsen, culminating in a suicide attempt. Sarah takes Charlie to Children's Hospital, the only facility that accepts people with ASD. After discharge, Charlie enters a day program for treatment, surrounded by peers with similar needs. Sarah also participates in training and peer support groups but eventually withdraws, finding the stories of other parents too triggering of her own difficult experiences.

#### Ages 18 to 25

At age 18, Charlie ages out of the day program, leading to a gap in care. They enroll in community college and move into subsidized housing, but over time, they struggle academically and drop out, returning home. This setback exacerbates Charlie's feelings of failure, worsening their depression and anxiety.

When Sarah discovers that Charlie is self-harming again, she takes them back to the hospital. This time, Charlie is placed in an adult psychiatric ward with individuals experiencing severe mental health challenges. The experience escalates Charlie's symptoms into a psychiatric emergency, resulting in a 72-hour mental health hold.

Sarah spends countless hours on the phone searching for a safe discharge option for Charlie. Eventually, she secures placement in a mental health facility with a group home component.

#### Conclusion

While the full journey map provides more detailed insights into Charlie and Sarah's experiences, this overview establishes the context for the recommendations that follow.

#### Recommendations

#### The fragmented WA BH landscape

The behavioral health system for TAY involves many agencies that support young people's diverse needs. While the HCA Division of Behavioral Health and Recovery (DBHR) is the lead agency for behavioral health in Washington, other key players include:

- Department of Children, Youth, and Families: Mmanages child welfare, juvenile rehabilitation, and foster care
- Department of Commerce: Addresses youth homelessness

- Department of Health: Oversees behavioral health licensing and healthcare data infrastructure
- Department of Social and Health Services: Runs programs for developmental disability, vocational rehabilitation, and psychiatric care
- HCA Medicaid/Apple Health: Provides insurance for low-income residents
- Office of the Insurance Commissioner: Regulates private insurance
- Office of the Superintendent of Public Instruction: Influences school-based behavioral health and special education

In our discovery sprint, we found that these agencies are not always aligned in strategy and priorities, with limited shared understanding of roles, funding, and programs. This fragmentation shows up in siloed reports and recommendations that aren't fully used or even known across the system. Reports we referenced in our desk research include:

- Adolescent and Young Adult Health Youth Advisory Council Report (DOH, 2022)
- Aged Out: How We're Failing Youth Transitioning Out of Foster Care (Think of Us, 2022)
- Safe and Supportive Transition to Stable Housing for Children and Youth (HCA, 2021)
- Access to Behavioral Health Services for Children and Youth (HCA report to state legislature, 2022)

As we present the recommendations in this report, we acknowledge that meaningful improvements to the behavioral health system for TAY will require a more unified vision and greater inter-agency collaboration.

#### 3 Key ways to understand prevention

- 1. **Prevention in its simplest form:** This means stopping problems, issues, or hardships before they begin.
- 2. **Prevention as early intervention:** This approach focuses on providing timely treatment before symptoms or problems escalate. It's important to note that prevention should not mean trying to "fix" or "prevent" disabilities, as everyone, including individuals with disabilities or complex behavioral health needs, deserves acceptance as they are.
- 3. **Prevention of further issues from untreated behavioral health problems:** This focuses on avoiding the negative consequences that can arise from not addressing mental/behavioral health issues. It connects to larger systemic problems, such as the school-to-prison pipeline and the challenges faced by foster youth as they transition to adulthood who have disproportionately worse outcomes than their peers from traditional households.

#### Recommendations overview

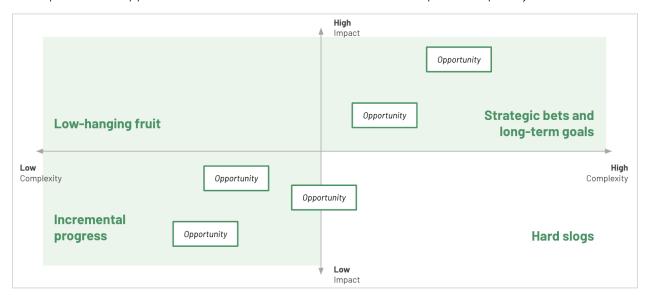
We outline findings and opportunities within three broad recommendations:

1. **Recommendation 1.** Help TAY and their support networks understand needs, navigate services, and coordinate care.

- 2. Recommendation 2. Provide TAY-centered services at the appropriate level, across the continuum of care.
- 3. **Recommendation 3.** Enable providers to work with TAY effectively and at the level that is needed.

Our aim for opportunities is to give Washington Thriving options to consider in shaping a strategic plan that includes TAY-centric behavioral health. Each set of opportunities contains short-term and incremental opportunities for action, as well as long-term strategic bets.

We've plotted the opportunities for each recommendation on an impact/complexity matrix:



This matrix helps to prioritize action by comparing two aspects of an opportunity:

- **Impact:** How beneficial would it be, including how many people could benefit, and to what extent
- **Complexity:** How challenging it would be to implement, including:
  - How many partners/organizations would need to be involved
  - What resources would be required
  - To what extent would policy or legislation need to change

Recommendation 1. Help TAY and their support networks understand needs, navigate services, and coordinate care.

Finding 1.A. The systems TAY must navigate often assume strong executive functioning, which can create barriers to access and engagement.

"I would tell myself to, you know, also not be afraid to unmask, you know, if you can. It's a lose-lose scenario: unmasking and unnecessary masking. It's kind of what put me in the autism burnout situation in general."

#### Transition-age youth

This TAY describes the pressure of masking — a continual hiding of their true self to fit in. Masking is anxiety inducing for anyone, but for people who are neurodivergent, it piles even more burden onto their cognitive load, making burnout more likely.

Executive functioning includes skills like planning and prioritizing, focusing on tasks, and managing emotions. It enables people to know what, when, and how often to do something. When a person has executive dysfunction, they may need to expend more energy and carry a higher cognitive load to complete seemingly "small" tasks by neurotypical standards.

One of these seemingly "small" tasks is searching for and finding the right therapist, who then can take a TAY's payor source (e.g. Medicaid, private insurance) and finally, is accessible to get to through a TAY's transportation options.

"Usually for me it's like a several month process where, like, I get on psychology today and I kind of think about it. I leave the tabs open, kind of set out the vibes in the back of my mind. And then like, three months later when I'm like, 'Oh, shit, I should have gotten a therapist three months ago and now I'm in crisis. I'm gonna call, you know, and make an appointment.' So I think that that's kind of how we all generally find our therapist."

Transition-age youth

The lack of available resources to find support, such as a therapist in the example above, reflects the struggle many TAY face in seeking help, which often leads to an avoidable crisis as this TAY describes.

For neurodivergent TAY, transportation is often another major barrier to seeking and receiving treatment, getting to work and school, or feeling the I freedom to move and live their life. Buses and trains are available, they can be overwhelming due to crowds, noise, and strong smells that may trigger sensory overload. This leaves driving as the best alternative but it's expensive and traditional driver's education can increase anxiety instead of helping. For example, films like Red Asphalt create fear, which can prevent neurodivergent youth from obtaining their licenses. If a transition-aged youth (TAY) can't get around independently, their parent or guardian often has to drive them, which adds extra stress, as seen in Charlie's situation with their caregiver Sarah.

On a systemic level, a lack of transportation makes it hard for TAY to get to school or work, leading to absences, then possible expulsion or job loss. These challenges can hurt their long-term financial and social well-being, potentially pushing TAY toward risky behaviors as they struggle to fit into society.

With this in mind, it's critical to promote education and empathy to better understand what is going on beneath the surface of TAY behavior.

"They get up super early, get dressed, look awesome, get there, get outside the door and then I don't know why, they don't know why, they can't quite walk in...! send the staff sometimes to say 'Hey, I'm out here. Any questions you want to ask? You got this!' It's just like that last little piece."

Direct service provider/subject matter expert

The direct service provider speaks to the crucial need to consider that behavioral health challenges like executive dysfunction are not laziness or a lack of effort — indeed these false assumptions stigmatize and exacerbate behavioral health struggles for those with lived experience. Instead, it's about grappling with real, often invisible challenges that can make everyday activities feel daunting. Despite the effort put into getting ready — waking up early, dressing well, and making plans — many TAY still find themselves unable to take that final step of actually entering a space. This highlights the anxiety that can accompany social situations and the importance of support in managing behavioral health, which in turn, stresses the importance of provider availability and their own well being.

# Finding 1.B. A diagnosis can be life-changing, but not everyone gets an appropriate evaluation leading to an accurate diagnosis, or they may not get it when they need it most.

Many TAY shared that they received a diagnosis in their early adulthood, often after years of feeling overwhelmed without understanding why. Getting a diagnosis helped clarify their experiences, making them finally feel empowered.

"I will say that I think for OCD, the diagnosis has been so helpful. Part of the treatment is just understanding what's happening, you know, and having information to fall back on because OCD thrives on doubt. But if you have good information from someone that you can trust, it can help alleviate some of that doubt."

Transition-age youth

Per one TAY, understanding they have OCD is crucial to their treatment itself, which allows them to challenge the doubts that OCD generates. It's like having a map when navigating a difficult terrain: knowing what to expect can significantly reduce anxiety. This person highlights that reliable information serves as a support system, enabling them to cope more effectively, which echoes the <a href="Youth Advisory Council's recommendations">Youth Advisory Council's recommendations</a> for plain language education from their providers about their conditions, and treatment options. For this young adult, a diagnosis is not just a label; it's a

crucial step in their healing journey. It provides them with the tools to understand their condition, manage their symptoms, and seek out the help they need, making it a transformative experience.

However, the process of getting a behavioral health diagnosis can be overwhelming, making it even harder for transition-aged youth (TAY) to manage work and school.

"I wish that it was easier to get diagnosed. **It's something that we've probably always known, but we couldn't get help for it until the diagnosis.** But we didn't have the means to, like, actually go and get tested and the waitlists are astronomically long. So I think that it's an issue of accessibility — both availability of providers as well as cost."

Transition-age youth

This young person highlights two main challenges in getting a diagnosis: accessibility and cost. For services to be truly accessible, they need to be widely available, easy to find, and have low barriers to entry. It's important for services to consider how a person's health conditions might affect their ability to seek help, rather than expecting them to be at a level of wellness that would prevent them from needing assistance in the first place.

For TAY who are uninsured, have been removed from Medicaid, have aged out of programs like extended foster care, or are in any circumstances where they are without basic benefits for social determinants of health, the costs associated with diagnostic evaluation and treatment are prohibitive. Even for those who do have insurance and financial resources, the expense is still significant, such as higher-intensity services that can involve costly residential treatment or require TAY to go out of state for help they cannot find locally.

"In any state, in any city in the nation, there's somebody who's struggling who needs some extra support, whether they've been diagnosed or not. But there's an awful lot of people who have been diagnosed and they've raised their hand and they've said, 'This is the kind of help I need,' and why are we not willing to listen to that and to give them the help that they're telling us they need? In fact, sometimes they're punished for that."

Direct service provider

This provider not only describes the large unmet need for diagnosis, but they also reflect on some of the problematic aspects of diagnoses that contribute to the difficulty receiving one:

• **Subjectivity:** Diagnosing mental health conditions often relies on patient self-reports and clinician observations, which can vary widely. Two doctors might interpret the same symptoms differently, leading to different diagnoses for the same individual.

- **Cultural bias:** Many diagnostic criteria are based on Western cultural norms, which may not apply to individuals from different backgrounds. For instance, certain behaviors considered symptoms of a disorder in one culture may be seen as common in another.
- Overlapping symptoms: Aside from subjectivity, many mental health conditions share similar symptoms, making it harder to distinguish between them. For example, anxiety and depression often co-occur and can manifest similarly, complicating diagnosis and treatment.
- **Stigmatization:** A diagnosis can carry a stigma, leading to discrimination or negative perceptions. Someone diagnosed with depression might face judgment in their workplace, impacting their social and professional life.
- **Diagnostic criteria changes:** The criteria for diagnosing mental health conditions can change over time as new research emerges. What was once classified as a disorder may be re-evaluated and removed from diagnostic manuals, leading to confusion and inconsistency in treatment.
- Access to care: Not everyone has equal access to mental health resources, which can lead to underdiagnosis or misdiagnosis. Individuals in underserved communities might not receive appropriate evaluations, resulting in untreated or improperly treated conditions.

Tying back to Charlie and Sarah's story, Sarah saw signs of ASD when Charlie was young. Despite seeking an evaluation, doctors told her Charlie didn't have ASD; years later, after many untreated symptoms worsened, Charlie finally received the correct diagnosis, all of which highlight several issues with the diagnostic process.

Despite these complexities with diagnoses, they serve several important functions. They help patients and healthcare providers understand each other, which is crucial for creating effective treatment plans. Additionally, without a diagnosis, providers often can't get paid for their services, underscoring the need for diagnoses to access care. Simplifying the diagnosis process, especially to address its challenges, is essential for both transition-aged youth (TAY) and the providers who assist them.

## Finding 1.C. Transition-age youth often thrive in programs and services where they feel accepted and understood.

"I would love it if there were exposure to a bunch of different ways to live and like possibilities to find ways to manage mental health that work for you."

Transition-age youth

TAY report a need to be seen as individuals, with options to explore diverse ways of living and approaches to mental health that best suit them personally. This sentiment challenges ableism — the societal pressure to conform to a narrow definition of "normal." For many, striving to meet these unrealistic expectations can worsen feelings of isolation or co-occurring mental health struggles

like depression and anxiety, making it even harder to create and maintain stability. People need the freedom to be their full selves, with their behavioral health conditions validated.

Instead, our current systems make it increasingly difficult for TAY to advocate for themselves. Even when they do, it can be met with harsh responses:

"I checked myself into [a facility] because I didn't feel like I could keep myself safe. I experienced really awful treatment there, and **their med provider laughed at me when I suggested that my meds were having negative interactions with one another.** Ultimately I quit all of my medicines and decided to handle things on my own."

Transition-age youth

Given the significant effort to find support (whether navigating transportation, dealing with sensory overload, or a general overcoming of stigma), this youth expended their energy while in crisis — only to be ridiculed by an older adult whose job was to help. This type of response both escalates the current scenario TAY are working through and deters them from seeking help in the future.

In contrast, positive experiences can make a significant difference:

"My therapist was very good at explaining the function that different emotions serve. She taught me that it's not just panic, but it's panic that is trying to serve as sort of a protective thing. So just the educational aspect on its own was really stabilizing."

Transition-age youth

For this young person, their therapist's skill in appropriate, effective communication helped them to understand their emotional and cognitive reactions so that they feel stabilized and empowered — the impact of youth-competent care. Per the <u>Youth Advisory Council</u>, such care includes understanding the developmental stage of youth, using relatable language, and fostering a supportive environment where young people feel heard and respected.

A direct service provider echoed this need for rapport, emphasizing that effective care depends on the ability to connect with young people. Without this connection, the chances of youth feeling comfortable and genuinely participating in their care diminish significantly:

"If we don't have that rapport, we can't be the most effective humans we can be for the people we are serving. We have to have an understanding of how to be an approachable adult. It's a verb — we have to practice and have to be engaged and intentional about how we show up with young people. If you aren't doing that, the chances of youth being present with you or

getting anywhere with the young person or getting genuine responses from the youth don't feel likely."

Direct service provider

Finding 1.D. TAY are more likely to succeed when they have natural supports or a trusted adult in their lives, but not everyone has access to such resources. In the absence of these supports, direct service providers frequently step in to fill the gap.

"In 2022, I was living in my car for a year and before that there were various different situations. I tried a bunch of different stuff. I did all the things, I was on all the lists. I kept showing up to various places... Then over the winter I ended up in San Diego for a while. I was able to get into a parking lot to stay at when nothing else had worked out. I've finally figured out that as an unaccompanied homeless youth I could qualify for [benefits] and, yeah, I did all that stuff by myself."

Transition-age youth

"I literally just got off the phone with a TAY sleeping in her car right now outside of a McDonald's while she's supposed to be on bed rest. I told her, 'Go to the fucking hospital! You need to go to the hospital!' Her parents said that they would take her in but they haven't been caring for her at all, yelling at her, doing the whole abuse thing. So she's in her car and I don't even work with her anymore. I haven't worked with her for two years. She's contacted me several times over the years because we [providers] become those supports for people over time. This assumption that parents are going to give that is just not, it's not real."

Direct service provider

The young person's story highlights the isolation that many TAY feel. Their mental health needs often stem from lack of support, and while services exist to help, these services frequently depend on having that support in place. Without it, TAY experience more delays in getting their needs met, worsening the issue they are seeking help for.

The direct service provider shared a similar concern: gaps that arise when TAY lack natural supports. Service providers often step in to fill these gaps, but when their formal roles end — due to issues like funding and workforce shortages — TAY can find themselves even more isolated. Many times, providers continue to offer help informally, but with the high turnover and short operations for many direct services, most TAY in circumstances like the client living in the McDonald's parking lot would have no one to call.

#### **Opportunities**

From these findings, we identified opportunities for action: to provide TAY and their support networks with coordinated, stigma-free support that empowers everyone to address their needs and access services and resources.

Opportunity 1.1. Increase access to non-clinical peer support for TAY.

What this solves for: Peer support is essential to help TAY make informed decisions either before engaging with services, or alongside the services they're already receiving, through a trusted, personal connection. While peer support roles currently exist within Medicaid-billable clinical services like WISe – which are valuable and should remain part of these programs – a significant unmet need exists for non-clinical peer support that is independent of a specific service or program. This could be because resources and funding for peer support are limited, and also potentially because the structures and roles for non-clinical, service-independent peer support roles are in short supply. Washington Thriving should explore ways to expand non-clinical peer support roles and provide the funding and program structures necessary to enable this vital work.

Related: Opportunity 3.1. Increase funding for outreach, peer support, and care coordination

**Impact:** High considering the number of potential TAY with BH needs that could benefit.

**Complexity:** Medium/High • as some infrastructure for peer support roles is already in place (e.g., billing codes, peer counselor certifications through the SPARK youth network). However, expanding non-clinical peer support may require new/additional funding or new infrastructure, such as billing codes for services not covered by Medicaid and data flow systems.

#### Opportunity 1.2. Share guidance for providers on working effectively with TAY.

**What this solves for:** Providers (especially those new to working with TAY) can have a challenging time building trust. Guidance on how to relate to TAY — how to communicate, show respect, acknowledge their agency — will help providers offer more effective care. It is particularly important for providers to communicate in a such a way that helps TAY understand complex issues like their options, rights, and confidentiality in behavioral health services. Guidance could take the form of:

- Trainings for provider staff
- Webinars
- Recorded videos
- Published content on the web
- Content provided to Teen Link and other resource lines

**Impact:** Medium/High considering the potential scale of TAY that behavioral health providers serve in Washington.

**Complexity:** Medium/High considering that guidance might need to be created or endorsed by experts or professional associations, and that managed care organizations (MCOs), professional associations, or insurance companies might need to be involved in distributing artifacts.

#### Opportunity 1.3. Normalize TAY behavioral health through targeted marketing efforts.

What this solves for: Destignatizing behavioral health issues among TAY ultimately calls for a cultural shift in how we view behavioral and mental health. One step in that direction is to communicate publicly about behavioral health, targeted to TAY through marketing and social media, with the goal to normalize behavioral health challenges and guide TAY to initial resources (e.g., who to contact or where to find more information).

**Impact:** Medium considering the scale of reach of marketing and social media, and also the challenges in using marketing to promote awareness and successfully motivate action.

**Complexity:** Medium considering the resources required to conduct statewide or even regional communications.

Opportunity 1.4. Provide guidance for TAY family, caregivers, and support networks on navigating BH needs.

What this solves for: Family, caregivers, and support networks are often key players in helping TAY in their BH journey, but these individuals often do not know where to start or how to navigate a complex system. Guidance specifically directed at family, caregivers, and support networks could help these individuals recognize signs of challenges, talk with TAY, and find resources. This guidance could take the form of published content – or links to existing guidance produced by other organizations – on a state government or statewide-nonprofit website.

**Impact:** Medium considering the statewide scale of family, caregivers, and support networks that could benefit from this guidance.

**Complexity:** Low considering that the state, and/or nonprofit partners, could develop and publish this guidance, like starting with a small-scale pilot to test how helpful and usable the guidance is with real people.

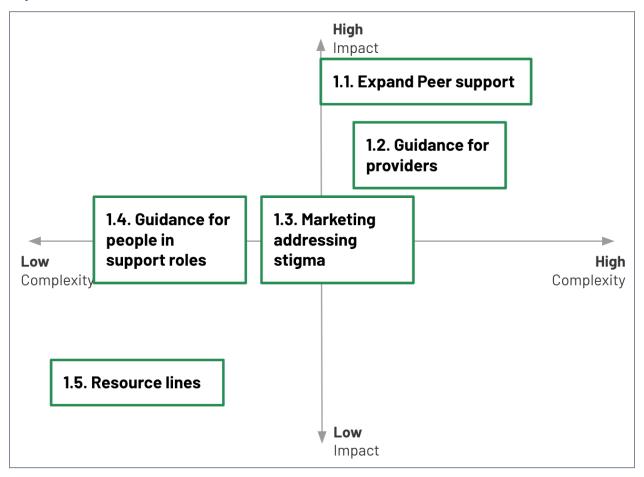
#### Opportunity 1.5. Evaluate the expansion of existing resource lines.

What this solves for: Resource lines, like Teen Link, already exist to help people navigate behavioral and mental health challenges. Exploring how people use these lines was outside our sprint's scope, but the state is in a good position to examine existing data in service of understanding what is working, what could be improved, and what would be needed to help these resource lines grow, since HCA and other state agencies are often supporters of these resource lines.

**Impact:** Low reconsidering that this will start with assessing how well existing resource lines are working and where the opportunities are to improve and expand them.

**Complexity:** Low considering this starts with an assessment that could be completed by a small team in a short period. Making improvements to the resource lines or expanding them into other regions or topics could be a little higher complexity, given the necessary involvement of other partners and resources.

#### **Impact matrix**



Recommendation 2. Provide TAY-centered services at the appropriate level, across the continuum of care.

Finding 2.A Due to high demand and limited resources, many services prioritize treatment over prevention, missing chances for early intervention and often causing harm.

"Knowing that I had been experiencing those symptoms for that long, I'm grieving what I might have been capable of, what I might have accomplished if I had had that information sooner. How my choices would have been different, like, throughout my life. Just, just understanding that... I probably would have made different choices."

Transition-age youth

The TAY we heard from, including this speaker, recognize that the lack of early treatment and preventative care is harmful, which is then worsened by the grief of knowing their challenges could have been easier or shorter lived if they had had the care they needed at the right time. This also connects to mid-intensity services, which mostly do not exist in our current care continuum when they play a vital role in prevention and right-sized support.

To better ensure appropriate and timely treatment, education and awareness are crucial. Experts in psychosis, along with programs like New Journeys, emphasize that many TAY show early signs of psychosis and schizophrenia which often go undetected. They advocate for making this knowledge more widely understood, so that early intervention can happen when it's most effective.

"What are the signs of someone who could be going down that slippery slope of dealing with the mental health crisis? We just had no idea. We were just kind of dealing with each thing as it came up and then we realized, 'Oh my gosh, we're in it.' Whereas maybe we could have prevented the crisis in the first place."

Parent/guardian

Understanding these signs could help prevent crises before they escalate.

For TAY with complex behavioral health needs in school, foster care, or any setting where adults in a youth's life come together to address issues, punitive measures often occur even *before* the first meeting with TAY and their families/caregivers. As the direct service provider below explains, this has cascading effects.

"Every single time we get one of these referrals and we have this meeting, the youth has already been suspended. And so you've got a kiddo who's going through a lot of stuff and then you take out their school support system, which may be the only break or respite that they get throughout the day and then we're sending them home and they've got all this free time... And getting them out of that school support structure is only further pushing them down that rabbit hole."

Direct service provider

This disconnect removes youth from vital support systems, which can lead to further struggles and contribute to the school-to-prison pipeline.

Punitive school policies often lead to suspensions or expulsions for behaviors related to mental health conditions, which prevents students from getting the support they need. Researchers like Michelle Alexander highlight that these policies disproportionately affect low-income Black and Brown youth. Alexander points out that Black students are expelled at three times the rate of their white peers, resulting in missed classes, failing grades, and higher dropout rates. Youth with little

education and no job have few options for earning a living apart from illicit activities, leading to encounters with law enforcement, incarceration, and a lifetime of being heavily surveilled by authorities.

Longitudinal studies across the country show very high rates of homelessness, incarceration, unemployment, and lack of access to health care among youth who aged out of foster care... These outcomes are disproportionately worse for Black, Native, and Brown youth, as well as gueer and trans youth.

Aged Out: How We're Failing Youth Transitioning Out of Foster Care

Similar to direct service providers describing the limitation of schools and workplaces for neurodivergent youth in Finding 1.A., without education and job prospects, the future of TAY with complex behavioral health is at risk for instability in all areas of life. Preventive support in schools when youth, especially Black and other youth of color have behavioral health needs, is vital to not only treat their symptoms but also in eschewing long term harmful effects.

Environments that prioritize treatment over punishment are critical measures for prevention. It's vital for middle and high schools to implement changes so that asking questions comes first, before disciplinary action, and that Black and Brown youth are afforded the same support and leniency as their white peers. This shift is essential not only for youth behavioral health but also for dismantling the broader systems of inequality that contribute to the school-to-prison pipeline.

# Finding 2.B. More care options exist for people with high-intensity needs than for those with middle- to lower-intensity needs, creating a counterproductive incentive for health conditions to worsen before getting treatment.

The benefits of mid intensity services are twofold: when they exist, they address concerns that require this level of care, they also prevent non-emergency scenarios from escalating into a crisis, potentially reducing the high rates of emergency department visits that could have been avoided.

"There were not a lot of people and not a lot of providers who really understand autism. Or at least at that time, which was four years ago. Especially in teenagers. I think a lot of people focused on younger kids and the supports that they could get, but not older kids. So we ended up finding a therapist for younger children and that was good for a little bit. But [my transition-age youth] was like, 'This person is talking down to me and using puppets to explain things. I'm 15.' So we were like OK, we'll find someone else. And just at the time it was so hard to find a therapist. I know it's still hard... Eventually we found someone for a bit but it just wasn't a good match."

Parent/guardian

The lack of mid-intensity services in the care continuum in part stems from a lack of recognition of TAY as a distinct population with its own needs, with specializations that deliberately focus on this stage of life. Many TAY are placed in pediatric settings that can feel infantilizing or in adult settings that may presume a level of maturity that is not appropriate. Both of these placements miss the mark, making conditions harder.

On the provider side of prevention, we heard how preventative care includes overhauling the ways many fee-for-service professionals get paid. As the provider below explains, rigid billing codes dictate what counts as care and what doesn't. The system devalues critical support activities like outreach and follow-up, making it harder for providers to meet TAY's needs and intervene before moments of crisis.

"They think more means 'better' and it does not. What actually means 'better' is the right intervention, the right set of services. The right thing is 'better,' not 'more.' They think 'Oh, therapy is not working; then let's do more therapy.' No, that is not the answer. So what's happened is that because all this outreach and engagement doesn't count toward your billing, if I make one attempt to see this transition-age youth, who then no-shows me, I don't have time to keep trying to reach out to this 17- or 18-year-old and go and find them. I need to move on."

Direct service provider

Which underscores the importance of unrestricted funds such as grant money that lets providers be nimble with their services:

"That's why it was so great when we just had that grant money, we could send [an outreach person] out. He can spend all day and we could pay for his position. It didn't even matter because I knew he was out there trying to find them [young adults] and his hours, whether he found them or not, it didn't matter because...no MCO is gonna be breathing down my neck about the fact that he wasn't billing for hours."

Direct service provider

Finding 2.C. Gaps in services create breaks in care for transition-age youth. At 18, many TAY lose benefits, age out of programs, or get dropped from Medicaid without knowing, disrupting their care and setting them back.

As one TAY shared with us, they had cycled through numerous foster homes while also serving as the primary caregiver for their sibling, who, due to an Intellectual Developmental Disability, functioned at the level of a young child. The need for their own housing was urgent, as it would allow

them to better manage both their own unstable social determinants of health and their sibling's. At 18, they were about to age out of foster care and Medicaid, forcing them to leave their current foster home. When they applied for Section 8 housing, they were unaware that accepting the voucher would mean losing critical extended foster care benefits. The burden of administrative tasks needed to fix this issue caused unnecessary hardship for both siblings.

"[I didn't know that] you have to choose between staying in extended foster care or taking a section eight voucher... When they gave me all my documentation, they could have given me like a sheet of all the resources and also tell me about the section eight voucher, because I wouldn't have made the mistake of losing six months of my life... Instead I had to learn the hard way and almost be homeless for me to learn that I had a place to go."

Transition-age youth

#### **Opportunities**

From these findings, we identified opportunities for action: to ensure that a variety of services are available to meet different levels of need, and that these services are accessible and tailored to the distinct needs of TAY.

Opportunity 2.1. Offer providers guidance on how to promote safe and trustworthy services to TAY.

What this solves for: Providers need a way to clearly communicate to TAYthat their environments and services are inclusive and welcoming of diverse needs and intersectional identities. From our research, TAY identified queer competence and familiarity with neurodivergence as key areas that they struggled to evaluate when first researching and choosing providers. To help bridge this gap, providers could use:

- Visual cues on their websites or in physical spaces (e.g., pride flags)
- Indications of certifications or specific expertise on websites and directories (e.g., a tag for "Neurodivergent-friendly")

The state could work with professional associations, MCOs, and advocacy groups to leverage existing guidance or create new guidance, and share it with providers.

Impact: Medium assuming that providers have these competencies and only need help communicating them to appeal to more TAY. Building competencies in these areas — including gaining new knowledge (e.g., becoming more familiar with neurodivergence) and shifting mindsets (e.g., becoming more welcoming to queer TAY) — could be significantly more impactful and more complex.

**Complexity:** Low/Medium • considering the multiple partnerships that would need to be involved to create and validate/endorse this guidance and promote it to providers.

Opportunity 2.2. Build out private insurance high-intensity wraparound services to have parity to Medicaid.

**What this solves for:** WISe is not available outside of Medicaid, and yet there are needs for high-intensity wraparound services within the private insurance market. This could be addressed by augmenting WISe to accept private insurance (in addition to Medicaid), or by creating separate high-intensity wraparound programs in the private insurance market.

**Impact:** Medium/High considering the high number of people on private insurance that could benefit from high-intensity wraparound services, who cannot access WISe.

**Complexity:** High considering that both augmenting WISe to accept private insurance and creating WISe-like services in the private insurance market would require significant contractual partnerships with private insurers and provider networks. Expanding WISe to accept private insurance may also require state policy changes.

- **Opportunity for a pilot:** Launching a new or significantly expanded program presents a great chance for a pilot phase to test the concept on a small scale and gather insights to guide larger-scale implementation. Given the state's experience with pilots, we will emphasize these points:
  - Focus on a clear question to answer or a hypothesis to test.
  - Document, communicate, and agree on this question or hypothesis with all partners involved.
  - Put a clear plan in place to assess whether the pilot answers the question or confirms or negates the hypothesis.
  - Aim to run the pilot in the simplest, least complex way possible to gather the necessary evidence.

#### Opportunity 2.3. Build out Medicaid-funded mid-intensity wraparound services.

What this solves for: As highlighted in the findings, individuals often end up in higher levels of care (e.g., WISe, crisis services) when they can't find resources and programs to address their needs at lower levels of care. While WISe provides high-intensity wraparound services, the research suggests a significant unmet need for mid-level intensity services — between low-intensity (e.g., seeing an outpatient therapist with no care coordinator, for needs that don't have a significant impact on daily life) and high-intensity (coordinated services across multiple providers for needs that have significant impact on daily life). Without clear mid-intensity services, there's a risk that WISe — designed for a small, high-acuity population — could be stretched to serve a broader group, weakening its effectiveness for those who need it most, while still leaving the needs of those outside this high-acuity group unmet.

("Mid-level intensity" is used here as a general concept and would need to be defined more specifically as part of the exploration of this idea.)

**Related note:** This team considered a related recommendation to extend WISe eligibility through age 25, to provide high-intensity wraparound services throughout the TAY age range. But data as of 2024 shows that young adults ages 18 to 20 make up less than 5% of youth who have received WISe,

despite efforts by the HCA to increase access for this group. So while there may be a need for high-intensity wraparound services beyond age 20, the data and past efforts raise questions about whether WISe is the most appropriate model for this age group. For this reason, we are not putting forward an opportunity to extend the WISe age range. What is clearer is the pressing need to address the gap in mid-intensity services, which are crucial for supporting the entire TAY age range.

**Impact:** High • considering the number of people with underserved needs that could benefit from more available and accessible services.

**Complexity:** High considering the need to build out new program standards, funding and data infrastructure, and provider networks, as well as the potential need for policy or legislative action

• **Opportunity for a pilot.** See related note under Opportunity 2.2.

Opportunity 2.4. Help Medicaid enrollees navigate the transition from household to individual Medicaid at age 19.

**What this solves for:** The transition from family Medicaid to individual coverage at age 19 can catch families by surprise and risk a loss of coverage if the family/TAY does not take proactive action. While the exact impact is unknown, it's clear that support is needed to prevent gaps in coverage during this shift.

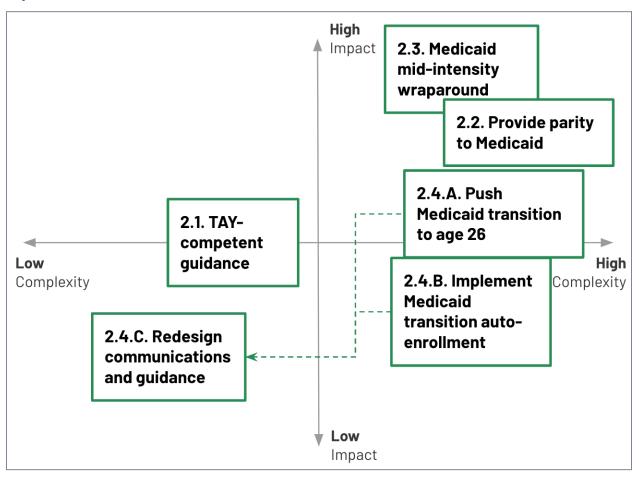
The state has multiple ways to address this challenge, including:

- **2.4.A. Extending the transition age to 26** to align with the maximum age for staying on private family insurance plans.
- **2.4.B. Implementing auto-enrollment** to shift a young person from family to individual coverage, or at least reduce the steps needed in this process.
- **2.4.C. Redesigning communications** to better inform Medicaid enrollees about the transition and how to enroll in individual coverage.

**Impact and complexity** vary depending on the approach:

- 2.4.A. Extending the transition age to 26: Medium/High impact considering the number of people that could benefit from longer coverage, while High complexity, assuming this would require state legislative, and potentially federal, action.
- **2.4.B. Implementing auto-enrollment:** Medium impact considering the number of enrollees who could avoid loss of coverage or disruptions in care, while High complexity, assuming this would require state policy, and potentially federal, action.
- 2.4.C. Redesigning communications: Low/Medium impact considering the benefit to people who may be losing coverage or navigating burdensome paperwork, while Low/Medium complexity, considering that this work would call for a dedicated team to generate, test, and share more effective, user-centered guidance to navigate the transition.

#### **Impact matrix**



Recommendation 3. Enable providers to work with TAY effectively and at the level that is needed.

Finding 3.A. Providers of TAY struggle with unstable funding and complicated insurance, leading to resource shortages that disrupt programs and stifle consistent service.

At a systemic level, we repeatedly heard about how preventative treatment is at odds with funding and reimbursement structures. Similar to what we heard from TAY and caregivers about the difficulties in finding and accessing meaningful preventive care (see <u>Finding 2.A.</u>), providers also shared the challenges they face in delivering it.

"Preventative care is not lucrative. You make more money in emergent care. So that kid in a gang who is in and out of the hospital is going to make the people who own those hospitals more money than in preventive services. Then they pay more for insurance, and then insurance

gets to keep that money because all insurances except for Ambetter/Coordinated Care are privately traded on Wall Street... So you get this weird insurance system that then profits from people suffering."

Direct service provider

At its core, for-profit health insurance models and decisions about which services are covered (including public and private insurance) make it hard for providers to offer meaningful preventive care and early interventions. When they do try, they often face a confusing and unstable mix of funding sources.

"[Closed enrollment periods for grants] are so discouraging as a provider... Because it's not your primary objective, you have all these other things going on that day because you're running a business and working with people with disabilities, plus everything else in life and then you have to squeeze in a contract, which is very complicated into like a window that's only three months and you gotta do it exactly perfect or you have to do it all over again. It's the same thing that parents struggle with. They're like, 'I spent all this time just to get denied. I'm not gonna do it again.""

Direct service provider

Many providers spend a lot of time trying to secure funding – often through grants – to keep their programs running. Available funding often comes with strict limitations, dictating what they can spend it on or enforcing a short period to spend without the option to renew. While grant funds can be helpful, they are often specifically scoped for new and innovative projects, in which the funding is not meant to be sustained over time. For example, one provider talked about hiring a new staff member for outreach to young people, using a grant received during the early days of the COVID-19 pandemic. This staff member was effective in reaching youth in their communities and building ongoing relationships. However, after the grant ended, the provider struggled to find ongoing funding for the position because it didn't fit well with existing reimbursement models. Providers could benefit greatly from flexible models that enable them to use the money in a way that best supports their operations.

"DDA [Developmental Disabilities Administration]...has done a really good job with making their contracts more flexible, like specialized habilitation is a cool contract. We like it a lot because it pays enough to do one on one [services], but it's also flexible that you can do it in a group. So you can actually run a group setting where you focus on similar things, and then fund it that way because you're bringing more people in and it's not just done in a one-on-one setting or you can do one on one, which I think is really great. I love that flexibility model."



#### Direct service provider

For providers that accept insurance, managing reimbursement processes can be complex and challenging due to low payment rates and inconsistencies in receiving funds. Providers often struggle to receive adequate compensation for important services like care coordination and preventive care. We also learned that insurance companies can alter contracts and demand repayment for services rendered years later, leading to instability and uncertainty for providers.

"I'm still owed thousands of dollars — not gonna get paid. We have these things called clawbacks. We have to pay money back [up to] three years later... We have no rights as providers...it is illegal for us to discuss our rates that we're getting [from insurance]."

Direct service provider

These financial uncertainties lead to resource shortages that hinder the effective operation of programs. This instability creates an environment where TAY cannot depend on consistent support, and also means that providers struggle to retain staff and resources.

# Finding 3.B. Workforce shortages are common in behavioral health, especially in Washington. Poor working conditions and low pay increase turnover, pushing providers into private practice and limiting access to services for TAY.

In a high-stress behavioral health environment, compounded by low wages, organizations often find it challenging to retain a stable and experienced workforce. Many providers opt to leave insurance-based practices, as they find that accepting private pay or pursuing specialties or research are more financially and mentally rewarding. This shift can lead to a two-tiered system, where those who can afford to pay out of pocket receive more consistent support while everyone else is left to navigate an already strained system.

However, we heard examples of workplaces with low turnover rates. One provider shared their experience working under a strong leader who fostered a culture of learning, mutual respect, transparency, and inclusivity in decision-making. This supportive atmosphere led to higher staff retention and lower incident rates.

"[What made my boss a good leader was] she took courses... We went into the best trauma informed care training as I've ever been in...we all did them including admin staff — every single person did those clinical trainings. So we all had intensive clinical skills..we had team meetings that were required every single day. We were required to know where people were at all times

because when you're doing wraparound care, you have to go different places. We used talking sticks for a while so that people would stop barking at each other and we created talking norms...she did one on ones with us every single week... So we were all included in the process of the program growing and...our turnover rate was ridiculously low. I mean, people just stayed."

Direct service provider

Addressing the poor working conditions and workforce shortages is crucial for improving the overall landscape of behavioral health care in Washington. When an organization has an unstable workforce, it not only affects the quality of care that TAY receive but also limits their access to essential services. With fewer providers available, many young people face long wait times or are unable to find the support they need, exacerbating their challenges during a critical developmental period.

By investing in better pay and improved working conditions, organizations can enhance retention and attract new providers to the field. Additionally, creating supportive environments that prioritize provider well-being can help mitigate burnout and turnover, ensuring that TAY receive the consistent, high-quality care they deserve. Without these changes, the cycle of workforce shortages and inadequate access to services is likely to persist, leaving vulnerable youth without the support they need to thrive.

#### **Opportunities**

From these findings, we identified opportunities for action: to ensure providers have the resources needed to perform critical non-billable work with TAY and can invest in their workforce to effectively deliver this essential support.

Opportunity 3.1. Increase funding for outreach, peer support, and care coordination.

What this solves for: These activities are often non-billable or non-reimbursable by insurance and Medicaid rules when they are not attached or provided to a specific reimbursable service. Given the limited scope of this sprint, we were not able to assess how well the current funding amounts and mechanisms for these activities meet the need. However, interviews with providers suggest that available funding falls short or is inconsistent and unsustainable (in the case of grants).

**Impact:** High considering the extent to which sustainable funding is needed to support outreach, navigation, and care coordination, and the number of TAY with behavioral health needs that could benefit.

**Complexity:** High considering that while funding and programs do exist, increasing the overall amount of available funding and/or restructuring how it would be allocated could require significant effort and potential policy action.

#### Immediate action opportunities:

- 3.1.A. Catalog the existing funding and programs that can resource TAY outreach, navigation, and care coordination work, including where the funding comes from, how providers access funds (e.g., grants, contracts, billable/reimbursable), what criteria apply, how many providers can access it, how much funding is available, and how the provider's accountability is evaluated. This is a quick Low impact and Low complexity way to get started.
- **3.1.B.** Assess existing data on current funding for TAY outreach, navigation, and care coordination (including how many providers have sought funding for this work) to understand how well the data can help estimate the supply and demand for funding for these activities and pinpoint where more funding might be needed. This is another quick Low impact and Low complexity way to start addressing the funding need.

Opportunity 3.2. Streamline the funding process and requirements to ease burden on providers.

What this solves for: When reimbursement or funding is available for outreach, peer support, or care coordination, providers often find those funding sources difficult to access. Applying for grants and contracts is particularly challenging for smaller providers, with high barriers to registering as a vendor and submitting complex, time-intensive applications. Some providers said overwhelming reporting requirements also discouraged them from seeking state funding for outreach, navigation, and coordination. While a thorough application process is essential for the state to allocate funds responsibly and collect data for provider accountability and outcome measurement, there's likely an opportunity to reevaluate which application and reporting requirements are truly necessary. Streamlining these processes could reduce the burden on providers and make participation more feasible — and thus increase the efficacy of state resources for this critical work.

**Impact:** High • considering the extent to which these processes are barriers to providers' ability to resource critical difficult-to-fund work.

**Complexity:** High considering that expanding funding and potentially creating new funding streams could require cross-departmental and/or budgetary or policy action.

Opportunity 3.3. Integrate funding opportunities across behavioral health agencies for a simplified provider experience.

What this solves for: Multiple agencies within Washington's behavioral health system have their own funding and application portals. Smaller providers often lack the resources to track and manage the various funding opportunities across these agencies. This creates barriers to providers' ability to find and use existing funding. Integrating these opportunities into a single portal for behavioral health providers would make it easier for organizations to stay informed about available funding and submit applications.

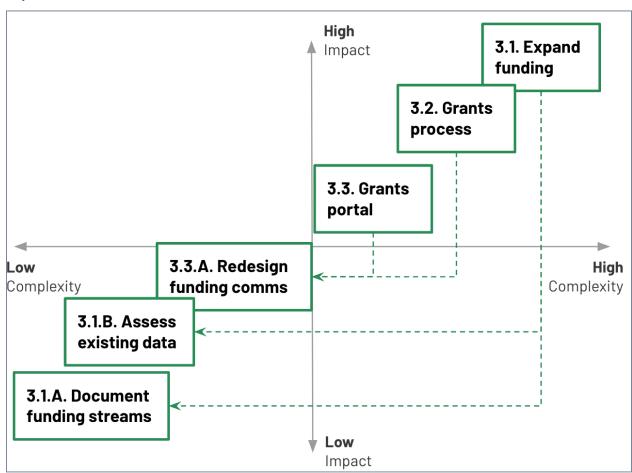
**Impact:** Medium/High considering the number of small providers and organizations that could benefit from lower barriers to state funding.

**Complexity:** Medium/High considering that multiple agencies would need to be involved, requiring data and systems integration that could be technically complex.

#### Immediate action opportunity:

• **3.3A. Redesign communications about provider funding** to better promote funding opportunities across agencies, and more effectively guide organizations in understanding requirements in applying for funding. This could be done in the existing environment of multiple funding portals and differing application processes, as a Low impact, Low complexity incremental improvement.

#### Impact matrix



Opportunity 3.4. Align with the CYBHWG Workforce and Rates subgroup on opportunities to support the workforce (not placed on the matrix).

**What this solves for:** Providers reported workforce challenges like poor working conditions, staff wellness, and high turnover that affect how they deliver services to TAY. Providers and SMEs also expressed a need to help build skills in how providers work with TAY, especially in building trust,

communicating, and doing outreach. Some of this work is already happening, like DCYF transition planning, and should be built on.

Attracting, retaining, and equipping the behavioral health workforce are significant, system-wide challenges that the CYBHWG Workforce and Rates subgroup is working on — and Washington Thriving can help move the needle. We acknowledge these larger-scale needs, but defer to the expertise of this ongoing work to set specific actions for improvement (and so, this opportunity is not on the impact matrix). As an immediate next step, Washington Thriving should share these findings with the CYBHWG Workforce and Rates subgroup and align with their current efforts to support the behavioral health workforce.

#### Conclusion

Washington's behavioral health system urgently needs to better address the specific needs of TAY. While TAY face a variety of experiences, they share key life milestones and developmental stages that make it essential to recognize them as a distinct group within the system. Current services are often geared toward either children or adults, leaving thousands of TAY without the appropriate care and support they need. To address this gap, it's essential to adopt a more TAY-centered approach.

This sprint explored the challenges that TAY face, with recommendations for an array of opportunities to improve the TAY experience, the structure and delivery of services, and the support for providers. Given the systemic nature of these challenges, the state should focus on practical steps that result in both quick and long-term gains and foster more collaboration among agencies. With these opportunities, the State of Washington can better support TAY with complex behavioral health needs, leading to more positive and healthier outcomes.

## Appendix: Charlie's story

View the high-resolution journey map here

