Behavioral Healthcare Through the Consumer Lens
Adolescent Behavioral Health Service Provision in Arizona & West Virginia

May 9, 2022
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Executive Summary

Objectives

The Medicaid Innovation Collaborative (MIC) aims to advance health equity in Medicaid by enabling Medicaid programs to adopt innovations that can address deep-rooted health disparities. To that end, MIC brings together the voices of clinical providers, community-based organizations, health plans, state Medicaid agencies, and beneficiaries to develop and deploy digital health and care delivery innovations that reflect the diverse range of real-time priorities and needs of the full Medicaid ecosystem. In this inaugural cohort, made possible through the generous support of The MolinaCares Accord, CommonSpirit Health, and Hopelab, Arizona and West Virginia’s state Medicaid programs elected to focus their efforts on adolescent behavioral health access and utilization.

Key to the success of this work is effectively and sustainably integrating the voice of the entire Medicaid ecosystem into both defining the problem as well as developing and implementing solutions that will work best for those they are intended to serve: beneficiaries. To that end, the Center to Advance Consumer Partnership (CACP) conducted 49 interviews in Arizona and 33 interviews in West Virginia with beneficiaries, clinical providers, community-based organizations, health plans, and state Medicaid agencies to learn about stakeholder end-to-end experiences both accessing and delivering behavioral health care and services. Interviews were designed to assess challenges, barriers, and successes stakeholders experience and what elements are needed to close access, quality, and equity gaps. This report provides contextual background for this work and summarizes key findings from stakeholder interviews.
Summary of Findings

For families enrolled in Medicaid, the behavioral health experience in both Arizona and West Virginia is characterized by challenges related to:

- Financial struggles, emotional burden on caregivers as a result of financial struggles
- Rural infrastructure particularly as it relates to transportation, distance to care, access and/or ability to use technology
- Cultural practices and beliefs
- Mistrust and fear of stakeholders in the ecosystem, both from concerns about immediate penalties and from generational/ancestral experiences

Each state experiences an acute shortage of both inpatient and outpatient providers. Once teenagers and/or their families\(^1\) begin to seek outpatient care, they experience extremely long wait times (3-8 months), as well as limited availability of 1:1 counseling services.

However, Arizona Medicaid beneficiaries report some access to group therapy, as well as other social support services, which was supported by interviews with community-based organizations (CBO). There is a strong crisis support network that is committed to de-escalation and has established relationships with schools and law enforcement, and expertise with adolescents. Arizona providers and CBOs report being committed to trauma-informed care practices, which recognize the need to meet and treat the family holistically, where they are. This is important because, as reported by families and providers in both states, childhood trauma is a root cause of behavioral illness, and challenges families experience are often passed from one generation to the next.

In West Virginia, the School Based Health Center (SBHC) model is an option for many families, which provides medical and dental care, and counseling services in local communities. Community-based organizations report that resource allocation and on-site therapeutic options at SBHCs vary by community. However, in many cases this is the only medical care that Medicaid beneficiaries in West Virginia receive.

Both states experience significant challenges when it comes to providing care and services to families living in rural areas. Lack of internet, cellular signals, and other basic infrastructure impede provision of telehealth. Rural families live hours from the nearest provider, and lack of public transportation prevents them from receiving in-person care.

Finally, culture plays a significant role in care-seeking behavior among families. In both states, fear or mistrust of the medical system coupled with families relying on each other for support (rather than outsiders) prevents many from initiating care in the first place.

\(^1\) We define “families” as the primary caregiver of an adolescent. This may include biological parents, grandparents, other legal guardians, or the foster system.
Background & Introduction: Adolescent Behavioral Health

Arizona

Arizona experiences high rates of adolescent behavioral illness, ranking 49th in the US in overall prevalence and acuity of serious youth behavioral illness (Reinert, 2021). Approximately 20.5% of the state’s population is insured by Medicaid, and another 10.8% is uninsured—ranking Arizona 12th and 10th highest Medicaid insurance and uninsurance in the nation, respectively (Kaiser Family Foundation, 2022). Statewide, 70.1% of Arizonan youth with any behavioral illness report that they are not able to receive needed treatment. This number is higher than the national average of 60.3% (Reinert, 2021). Prevalence of past-year major depressive episodes (17.41%) and substance abuse (4.83%) among adolescents are both higher than the national average (Reinert, 2021).

There are significant gaps in access to adolescent in- and outpatient care, treatment availability, and behavioral health and substance use screening across the state, particularly in rural settings and among Latinx and American Indian communities. According to 2020 data from HRSA, 13 of 15 total counties in Arizona are classified as Health Professional Shortage Areas (HPSAs) (Health Resources & Services Administration, 2022). According to early qualitative beneficiary research, Arizona’s crisis system is failing to meet the needs of many, as it “was built for serious BH, and really isn’t working otherwise — for families and children specifically.” - Medicaid beneficiary or Local CBO representative (??)
West Virginia

According to Mental Health America, West Virginia experiences high rates of behavioral illness, ranking 44th in the US in overall prevalence and acuity of serious adolescent behavioral illness (Reinert, 2021). Approximately 21.5% of the state’s population is insured by Medicaid, and another 5.1% is uninsured (Kaiser Family Foundation, 2022). Statewide, 63.9% of West Virginian youth report that they are not able to receive needed behavioral health treatment. This number is higher than the national average of 60.3% (Reinert, 2021). Among youth, prevalence of past-year major depressive episodes (13.3%) and substance abuse (4.44%) are both higher than the national average (Reinert, 2021).

According to 2018 data, an estimated 4.44% of West Virginia adolescents (age 12-17) experience substance use disorder, and 4.24% of adolescents need but do not receive substance use treatment (Substance Abuse and Mental Health Services Administration, 2021). Both prevalence estimates are higher than the national average (Substance Abuse and Mental Health Services Administration, 2021).

The entire state experiences significant gaps in access to adolescent in- and outpatient care, treatment availability, and behavioral health and substance use screening and treatment. This shortage is felt acutely in Appalachia and other rural parts of the state. According to 2020 HRSA data, 54 of 55 counties in West Virginia are classified as HPSAs (Health Resources & Services Administration, 2022).
Entry Points to Adolescent Behavioral Health

When asked to describe how families generally enter their journey to seeking behavioral health care, Medicaid beneficiaries in Arizona and West Virginia shared similar entry points, summarized below.

### Self/Family Choice
When a family makes the decision to seek care, they typically begin looking for 1:1 counseling, and encounter long wait lists. Without that appointment, some end up in one of the other entry points noted below.

<table>
<thead>
<tr>
<th>Example of What’s Happening</th>
<th>How I’m Feeling</th>
<th>What I Need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of Providers, lack of 1:1 support.</td>
<td>Unheard. My counselor doesn’t believe me (e.g., that I’m clean), overwhelmed.</td>
<td>1:1 counseling.</td>
</tr>
</tbody>
</table>

### Crisis-Hospital Emergency Room
When teens begin in a hospital emergency room, it’s the result of an escalated event at home, at school, or in the community. They often wait here from days to weeks for next-level care.

<table>
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<tbody>
<tr>
<td>My parents brought me here because they didn’t know where else to bring me.</td>
<td>Unheard, scared, isolated. I don’t understand why I have to wait here for so long.</td>
<td>De-escalation, stabilization, regulation. To know what’s happening to me now, to be away from my family for a while. Not to be with people.</td>
</tr>
</tbody>
</table>

### Crisis-Interaction with Law Enforcement
Encounters with police are scary for teens, but sometimes family or school contact the police for help deescalating. This incident may end up with legal consequences or a visit to the ER.

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<tr>
<td>Someone called the police.</td>
<td>Unheard. I don’t want to go to jail, I want help. I don’t want to be in trouble, and I don’t want to cause legal trouble for my family.</td>
<td>Treatment. Avoid legal consequences of unmanaged behavioral health.</td>
</tr>
</tbody>
</table>
Child Protective Services (CPS)

Interactions with Child Protective Services (CPS) may be the result of an escalated incident with a teenager that resulted in a report to CPS. It can also be the result of a report and investigation of a parent. Or, as reported in West Virginia, it may be a desperate attempt for an organization/family to receive coverage for residential or intensive outpatient (IOP) coverage. We heard of a school recommending “incorrigibility” paperwork to parents, which was described as turning parental rights over to CPS, because children in CPS custody are covered by Medicaid for residential or IOP services. In West Virginia, this school shared that 100 of their students had open CPS cases that had not yet been assigned to a social worker, 90 of which were the result of opioid use by parents.

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<tr>
<td>Domestic violence, abuse, neglect, or SUD. School has suggested foster care to me for IOP/Residential treatment.</td>
<td>Unheard, distrustful, shameful, embarrassed, angry, inconvenienced, intruded on.</td>
<td>I want CPS to close their case, I don’t want to be the reason there are problems.</td>
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</table>

Court Requirement for Behavioral Health Counseling

A court requirement for counseling is often a consequence of an earlier escalated incident that has resulted in probation with mandatory counseling.

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</tr>
</thead>
<tbody>
<tr>
<td>Court ordered counseling/treatment as a result of probation or legal issues.</td>
<td>Angry, weighed down.</td>
<td>I want to complete the court ordered therapy so that I can be done with the case/probation.</td>
</tr>
</tbody>
</table>

School Referral for Behavioral Health Counseling

In schools, teens might visit a school nurse or counselor, while in West Virginia, they might visit a School Based Health Center (SBHC). An SBHC will often recommend counseling based on some of those interactions. During an escalated event, schools are aware of history or previous events. They are familiar with families, and they have a relationship with law enforcement. If an issue with law enforcement happens outside of school, there is typically a communication to the school to handle a child with care. In Arizona, we learned about after-school programming by CBOs, who tailor programming and services to teens. This includes group counseling and meals during times that accommodate parent work schedules.
<table>
<thead>
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</tr>
</thead>
<tbody>
<tr>
<td>School contacted my parents and suggested counseling. I’m having a hard time self-</td>
<td>Nervous, anxious, bullied, frustrated, not heard, scared.</td>
<td>I want my teachers and school counselors to listen to me and not just run tests and recommend medicine.</td>
</tr>
<tr>
<td>regulating.</td>
<td></td>
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Inevitably, most teenagers report having their first crisis event while waiting for an appointment or treatment. Some report accepting an offer for group therapy with other teens because of the wait for 1:1 services.

Areas of Cross-State Innovation Opportunity

In both Arizona and West Virginia clear themes related to the adolescent and family experience emerged across seven domains. Each domain includes a description of the barrier or obstacle, insights in the voice of the consumer, and supporting quotes from interviews with teenage Medicaid beneficiaries, teen caregivers, community-based organizations, and providers. MIC vendor partner solutions should address one or more of these barriers or obstacles related to seeking and receiving adolescent behavioral health care and services.

1. **Navigating Care in a Fragmented Ecosystem**
   - There’s no unified way to find out what is available to me and my family

2. **Accessing Higher-Skilled Providers**
   - Finding or getting to providers who have a specialty or deep knowledge and experience with teenagers is hard

3. **Avoiding Teen Crisis**
   - When there’s a crisis, we’re in the hospital ER for days waiting for help, the police are sometimes involved, the path is unclear

4. **Holistic Family Support**
   - Our whole family needs help, support, and resources

5. **Cultural Responsiveness**
   - We don’t trust people who don’t understand our culture, beliefs and values as they relate to family and health care

6. **Voice and Choice**
   - We don’t feel heard and we don’t feel part of discussions and decision about what happens to us

7. **Care Avoidance**
   - We often don’t seek help because we fear what could happen if we do
Navigating Care

When and where Medicaid beneficiaries begin their journey matters. Parents, teenagers, providers, and CBOs all report different entry points into the behavioral health system, many of which occur prior to families engaging in their first true ask for help. The early experiences families have are an indicator of how engaged they’ll remain in care and ongoing treatment. This journey is depicted below.

Teenagers and their families, or caregivers, need simple, trusted, and easy to understand information, resources and/or tools. This information needs to be available in the language they speak, know, or read, recognizing that not all caregivers can read.
Synthesis in the Voice of Consumers:

- Our first interaction in the ecosystem either builds trust, making us feel helped and supported, or reinforces biases we may already have against the system.
- We are trying to figure all these systems out while we are overwhelmed and in crisis.
- If our experience is negative and/or incomplete, we will likely not return or follow up.
- The processes and policies are complicated, and we don’t understand them.
- The rules around who can be seen, where, when, and how aren’t clear, particularly for Intensive Outpatient (IOP) and Residential treatment.
- It feels like the right hand isn’t talking to the left. One person says one thing about my case and what I am eligible for, and another person at another agency gives me a completely different story.

Direct Quotes from Research

“What services can I get? How do I get them? How do I find help? Where can I go?” — Clinical Provider

“People don’t know what is available, how to get it or where to go.” — CBO

“If tribal leaders don’t understand the delivery systems, families certainly won’t.” — CBO

“Families need more exposure into how to enter the behavioral health system and what that requires... There’s this a lack of knowing where to go, what to do once you start having mental health issues with your child.” — CBO

Challenges Accessing Providers

Accessing Higher-Skilled Providers
Finding or getting to providers who have a specialty or deep knowledge and experience with teenagers is hard

The Arizona and West Virginia behavioral health ecosystems are characterized by an acute shortage of in- and outpatient providers in both urban and rural settings. Provider organizations report a lack of funding for state-sponsored service provision. This lack of funding has driven qualified providers into private practice where they can work fewer hours for higher pay serving clients with fewer clinical complexities. This has resulted in long appointment wait times; low availability of 1:1 counseling; and poor quality of wraparound service provision, care coordination, and trauma-informed care for families covered by Medicaid.

Simply knowing where to begin accessing care and services is complex and prevents teens and families from seeking and receiving care. Families struggle to understand how to get the right help. Referrals are given and recommendations are sought, but families don’t know what they can ask for, or how to find the type of provider that is right for their situation. Parents and children report wanting to
find someone they have a connection with, which, in the voice of teenagers, is as simple as “someone who understands us.”

The choices and options are limited, wait times are long for the choices that do exist, and families often try several providers before finding the right fit. Sometimes they give up during the search or wait so long for an appointment without care that they end up in crisis.

**Synthesis in the Voice of Consumers:**

- We have a hard time finding appointments with providers who take our insurance – many of them do not. This makes it hard to get any kind of care, albeit short or long term care, or just to be seen and get a diagnosis.

- Some teenagers and their caregivers are managing both mental health and developmental differences; Testing/screening is not happening early enough.

- We wait months for first appointments and even then, we often compromise on the way we’d prefer to receive treatment.

- We don’t have broadband access, cellular signals, and/or public transportation, so we can’t make or keep appointments (in-person or telehealth).

**Direct Quotes from Research**

“*What we see is families taking children to children’s hospitals, which is not the right thing for our system.*”

— CBO

“*Even in metro areas we struggle to maintain workforce. Many of my colleagues are going into private practice – more pay and less paperwork.*”

— Clinical Provider

“I wanted to do the 1-on-1 [therapy]… but it was more of a longer wait. Once I said I wanted to get into group [therapy], that started right away.”

— Teen Beneficiary

“There are limited resources in rural areas. Families may have to travel to [the closest city] to get what they need. We have tried to promote telehealth but that is challenging as not everyone has internet or phones.”

— Clinical Provider

“There is no true trauma training for staff [at children’s facilities]. They say the training they have will prepare the staff to work with these kids and it doesn’t. Traumatized children just continue to get traumatized by the system.” — CBO

“There’s this big stigma around the ‘M words’, Medicaid and Medicare, clinicians don’t want to accept Medicaid and Medicare. The pay isn’t as good as private insurances.” — CBO

“There are lots of regulations from the federal level that are different for different populations… Folks can’t just pick up the phone and make a call if there is no written auth for treatment.” — CBO
Avoiding Teen Crisis

Avoiding Teen Crisis
When there’s a crisis, we’re in the hospital ER for days waiting for help, the police are sometimes involved, the path is unclear

Given the aforementioned challenges with navigating the system and accessing providers, adolescents often arrive in care at a point of acute crisis. These crisis events can be the result of:

- Long wait time to initial appointment
- Lack of providers/facilities
- Lack of early identification/diagnosis of a behavioral health condition and/or a developmental disability – parents and caregivers are also not equipped to troubleshoot and diagnose
- Long wait times for prior authorizations

These crisis events are emotional, stressful, and unfamiliar for families, and there is accompanying shame for some. Teens feel unheard and scared, and almost all caregivers and family members are tired, confused, and frustrated.

It is important to consider that the formal entry into the behavioral health ecosystem can be the result of a traumatic event that results in a visit to the emergency room (ER), inpatient hospitalization with assessment, interaction with law enforcement, or a telephonic or mobile behavioral health crisis team, which is a well-known resource in parts of Arizona.

Synthesis in the Voice of Consumers:

- We most often begin our journey when we are in crisis. We don’t know what kind of help we need, who to ask, or where to get it.
- If my teen has a crisis and needs a bed at a psychiatric hospital, it is almost impossible to find one.
- The best we can do to keep my teen safe is go to the ER and wait for a bed at a specialty hospital to open-up.

Direct Quotes from Research

“A child may wait weeks for a bed to open up in one of the psychiatric facilities.”

“Children wait 6-9 months for both therapy and for a psychiatrist” — CBO

“Schools are at least 80% of our business... There should be more of a system... when we’re seeing the volume of calls that are generating from schools day after day. It feels like something should be captured in those schools and we’re just seeing the crumbs.” — CBO

“I believe [we need to] get teens into a facility and to find out the reason why they’re having these issues, and work on that before sending them to jail. These kids, once they go to jail, they become hardened.” — Parent
Holistic Family Support Needs

Our insights indicate that generational trauma and cycles of oppression exist for many families receiving care and services. Solutions should understand and consider the holistic support needs for a family, from finances and childcare to emotional and wellbeing support for caregivers. Rarely does a teenager experience a behavioral health issue or crisis without it affecting the entire family.

All family and caregiver types and structures should be considered, including family of origin, kinship care, foster care, and families with a child in residential treatment. Solutions should consider that some families are managed by one or two parents, and some homes include other siblings, and/or multiple generations. Some families, particularly in Arizona, have tribal status and relationships that dictate where they go for care.

Since COVID, many teens and families are experiencing multiple losses including caregivers, like grandparents; employment; income; and connections to people and places they received support from including afterschool programs, teams, and organized community events.

Developmental or intellectual disabilities require different approaches, modalities, and solutions than behavioral health conditions, particularly during crisis events. However, some teenagers and their caregivers are managing both.

Synthesis in the Voice of Consumers:

- For some of us, generational trauma plays a role in when and how we get help.
- Our family members are often in different stages of their own awareness, help, and healing (if any).
- There are so many “systems” at work in our lives. The school system, the court system, the medical system, the behavioral health system, the insurance system. Everything feels like it needs to be managed, or completely avoided, so that bad things don’t happen.
- We don’t want Child Protective Services (CPS) getting involved and separating our family or taking our children.
- We’re afraid of our legal status being found out and causing problems.
- We worry about substance use issues being found out and police, court, or probation consequences.
- When we have a bad experience with law enforcement, a judge, or a probation officer, it makes us need behavioral health services even more.

Direct Quotes from Research

“I’m actually working with a family now where like, you know, the mom knows that she needs help...But she’s just repeating the same cycle...Her kids will always end up in DCF custody if she can’t get the proper questions answered.” — Clinical Provider

“It happened to their parents, to their parents’ parents. Culturally speaking you learn your business is your business and if you tell someone who is not in your culture, they will call DCS.” — CBO

“Appalachian families don’t see services as helpful, [but] more punitive. [There is] a stay-out-of-my-business mindset” — CBO
In West Virginia, we heard about “the bootstrap mentality”. When it comes to caring for families, there is great pride in being able to survive and thrive without relying on others for help, particularly in rural Appalachia. Systems that intervene (school, medical, behavioral health, law enforcement) are often perceived as intrusive, and families go to great lengths to self-solve. It is reported that there is a general sense of fear of engagement with Child Protective Services (CPS) for fear of losing parental rights. In other instances, families are referred to Child Protective Services to access treatment, as it is perceived as a solution to getting coverage.

In Arizona, there is a significant amount of mistrust, particularly among Native Americans and immigrant families, who have a long history of mistreatment by government agencies. Many Native American healthcare and social services are grant funded and rely on the federal government for continued implementation. However, with changing administrations or shifting federal priorities, these programs are often not sustainable. Providers leave and communities are forced to make do without until more funding becomes available.

Furthermore, Native American and immigrant families in Arizona are multi-generational, with cultures that value family solutions. Some regions, particularly in rural areas, experience more confusion because of the option to use Tribal Regional Behavioral Health Authorities (TRBHA), which isn’t well understood. Community-based organizations report the importance of acknowledging and understanding cultural healing practices, particularly among people with tribal affiliations and for those who live on reservations.

Synthesis in the Voice of Consumers:

- We want to see providers that look and talk like us, but it is really hard to find them.
- We want our doctors and therapists to understand our cultural values.
- We can solve our problems within our family.
- We are proud to not use our health insurance card (West Virginia).
- Regular care and treatment options don’t consider or honor our traditional practices.
- These “systems” (health, school, CPS, legal...etc.) are intrusive.

Direct Quotes from Research

“Appalachian people are a proud people. They don’t like asking for help. They don’t like people to know their business. So, if they have a kid that is acting out, a lot of times they hide it within the family.” — CBO

“With providers I feel like there is not enough representation of people of color. It comes back to the pay. People don’t come to get rich, but therapists still need to pay their bills. It takes a toll on your spirit [to be a provider of color and hear these stories].”
— Clinical Provider

“A lot of native programs are grant-funded. When grants are finished providers leave, it’s been like that forever. It’s hard to trust a provider, because they’ll leave once they finish their grant or education or pay off their loans.”
— CBO

“When you’re meeting with tribal leader nations and people, you must establish trust. I can remember meeting with a tribal leader and she said your language and how you all speak so fast is not how we do things here.” — CBO
Families report feeling like the process is happening to them, as opposed to with them. They don’t know where to begin and are constantly reacting to processes and policies outlined by community stakeholders.

Teenagers need opportunities to share how they are doing, to ask questions about the continuum of care when applicable, and to get help throughout the process of seeking and getting care. Most importantly, teenagers (and engaged caregivers) report wanting to feel like they are understood and heard.

**Synthesis in the Voice of Consumers:**

- We don’t feel heard or part of discussions and decisions about what happens to us.
- We want to feel a sense of control when it comes to our care and treatment options, medications, and decisions.
- When I don’t feel heard, I don’t feel like I’m getting good care, and will not come back.
- People rush to judgment and don’t take time to listen and understand our experience.
- When there is a crisis at school, if the police or Child Protective Services are called, or if we are at the hospital ER, the process is just happening to us.

**Direct Quotes from Research**

“Just because the kid has a bad day doesn’t mean that that kid needs to be put on three different psych meds, because now they have a mood disorder, or they’re ADD or ADHD. I think sometimes... it’s just easier to be like... ‘here’s a pill and hopefully it’s gonna work for you.’” — Parent

“Most teens feel like we’re never being heard, and... you guys consider us young adults, but you don’t treat us like that. If we’re young adults, then we wanna be treated like that. We, we don’t wanna be, keep being treated like a little kid.” — Teen Beneficiary

“Listen to the child’s side more than listen to the parents’ side because a lot of parents do lie.” — Teen Beneficiary

“They were going to send me to an all-girls home in Ohio. I didn’t think it was fair and right that they were trying to do that to me so I moved to another county hoping I could get a fresh start there. But I didn’t they basically forced me to drop out of school. I guess it was a lesson for me. It was a lesson and not a mistake.” — Teen Beneficiary
Fears & Care Avoidance

Care Avoidance
We often don’t seek help because we fear what could happen if we do

Families avoid care for a variety of reasons, including fear, culture and beliefs, financial burdens, language barriers, access issues, employment, transportation, shame, stress, and previous bad experiences.

In Arizona, teens and families living in border communities may be hesitant to seek behavioral care and services if they are undocumented or have an undocumented family member in the home. The fear of deportation is ever-present. Further complicating the matter in Arizona is the presence of high numbers of migrant workers living in these communities. These individuals frequently move from one community to the next, and are unable to follow up on care and services due to the nature of their work.

In West Virginia, Appalachian culture traditionally “does not recognize behavioral health” as an illness and views services as punitive and invasive for reasons already discussed. As such, many families avoid care until their child experiences a crisis.

In both states, teenagers and engaged caregivers face significant challenges initiating care and maintaining ongoing treatment.

Synthesis in the Voice of Consumers:

- For some of us, generational trauma plays a role in when and how we get help.
- Our family members are often in different stages of their own awareness, help, and healing (if any).
- There are so many “systems” at work in our lives and around us. The school system, the court system, the medical system, the behavioral health system, the insurance system. Everything feels like it needs to be managed, or completely avoided, so that bad things don’t happen.
- We don’t want Child Protective Services (CPS) involved and separating our family or taking our children.
- We’re afraid of our legal status being found out and causing problems.
- We worry about substance use issues being found out and police, court, or probation consequences.
- When we have a bad experience with law enforcement, a judge or a probation officer, it makes us need behavioral health services even more.

Direct Quotes from Research

“I’m actually working with a family now where like, you know, the mom knows that she needs help... But she’s just repeating the same cycle...Her kids will always end up in DCF custody if she can’t get the proper questions answered.”
—Clinical Provider

“It happened to their parents, to their parents’ parents. Culturally speaking you learn your business is your business and if you tell someone who is not in your culture, they will call DCS.” —CBO

“Appalachian families don’t see services as helpful, [but] more punitive. [There is] a stay-out-of-my-business mindset.” —CBO
Beyond Innovation: Addressing Gaps in the Ecosystem

Throughout the course of this work, it became clear that gaps exist in the behavioral health ecosystem in both Arizona and West Virginia. These systemic gaps impact the quality and continuity of care that adolescents and their families receive.

Gap 1: Cross-Agency Communication

Our interviews show that community stakeholders are critical to early identification, diagnosis, treatment, and ongoing support. However, many stakeholders operate in silos with poor communication and, ultimately, poor continuity of care for adolescents and families as they move throughout the ecosystem.

“If you try to design a project that will address a population like this, you realize there are so many different agencies and services that need to be coordinated.” — CBO

Gap 2: Identification of At-Risk Youth

There is consensus that having strong provider partnerships, data sharing, and continuous support improves the Medicaid beneficiary experience when receiving care and services. Facilitating wraparound care and enabling collaboration across all areas of the ecosystem benefits all stakeholders—most importantly, Medicaid beneficiaries. However, simply identifying adolescents and families for services is challenging, as many families go without care due to lack of providers. This is particularly true in West Virginia.

“It would be nice if we had a process that allowed us to risk stratify [and see adolescents with the highest need quickly]. But in order to do that, and identify those with high risk of conditions, you have to have the data. And if families don’t go to providers, you don’t know they’ve got risks.” — CBO
Gap 3: School Engagement

Given the lack of clinical resources, many providers and community advocates recognize that schools play a critical role in identifying early signs of behavioral illness in children, and that they could assist in gathering valuable information to help identify adolescents and families in need of care. However, most agree that schools are not staffed for these types of activities. They simply do not receive enough funding.

“When you look at kids and where they may look for help – like schools, the people in those places typically aren’t mental health focused. There’s a huge gap in the areas where kids are most frequent. If anyone can get a message out for investment, they need behavioral health support in the school itself.” — Provider

While addressing gaps in cross-agency communication, identifying at-risk youth, and school funding may be outside the scope of MIC’s innovation goals, these items are worth highlighting, as they arose so frequently during this work.

Appendices

Methodology

To understand the full range of barriers and challenges specific to access, quality, and experience that adolescents and their caregivers face in relation to receiving behavioral health services, CACP conducted interviews with key stakeholders from across the Medicaid behavioral health ecosystems in Arizona and West Virginia.

Defining Key Stakeholders

The Adolescent Behavioral Health Ecosystem demonstrates the interplay between systemic and individual-level factors affecting adolescents’ ability to access and receive ongoing behavioral health services in both Arizona and West Virginia. Key stakeholders for interviews were drawn from each identified layer of the ecosystem, and in this work are defined as: beneficiaries and their families, clinical providers, managed care organizations, community-based organizations, and state Medicaid agencies.
Federal & State Policy: Reimbursement Rates & Structure, Social Services, Tax Credits, Justice System, DHHS, Families Initiative, Bureaus of Indian Affairs, Immigration Enforcement

Community: Schools, Local Law Enforcement, Provider Availability, Advocacy, Organizations, Faith Based Organizations, Family & Juvenile Court, Urban vs Rural Residence, Public Transportation

Payer: Community & Coordination with Other Ecosystem Stakeholder, Contractual Requirements

Clinical Care: Cultural Competence, Trauma Informed Care, Translation, Appointment Availability, Care Coordination, Wraparound Services, Family Residential Treatment, Communication & Coordination with Other Ecosystem Stakeholders

Adolescent: Age, Race/ethnicity, Gender, Sexual Orientation, Coping Skills, Diagnosis, SDoH, Social & Emotional Support, Employment, Family Structure, Childhood Adversity, Trauma History
Domains of Exploration
Interviews with key stakeholders were designed to better understand adolescent and family end-to-end experiences across the following domains:

- Learning about and understanding behavioral health benefits
- Accessing behavioral health care and services
- Defining high quality
- Needs for and experiences with ongoing support, including long term services and supports (LTSS), transportation, social determinants of health (SDoH) support
- Identifying best practices and unmet opportunities for enhanced service delivery and innovation

Recruitment & Engagement Process
To understand the full range of barriers and challenges specific to access, quality, and experience that adolescents and their caregivers face in receiving behavioral health services, CACP conducted interviews with 49 key stakeholders in the Medicaid behavioral health ecosystem in Arizona and 33 in West Virginia, as shown below.

<table>
<thead>
<tr>
<th>Stakeholder Type</th>
<th>AZ Interviews (N)</th>
<th>WV Interviews (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beneficiary</td>
<td>11</td>
<td>5</td>
</tr>
<tr>
<td>Clinical Provider</td>
<td>19</td>
<td>9</td>
</tr>
<tr>
<td>Community-based Organization</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>State Medicaid / Other State Govt.</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td><strong>TOTAL INTERVIEWS</strong></td>
<td><strong>49</strong></td>
<td><strong>33</strong></td>
</tr>
</tbody>
</table>

To be considered eligible for an interview, beneficiaries were required to meet the following requirements:

1) Be an adolescent (age 12-18), or the legal guardian of an adolescent, and receive insurance through Arizona Medicaid/ACCCHS,

2) Have experience with behavioral health and/or crisis services,

3) Currently reside in a community setting.

Adolescents currently receiving stabilization, crisis, or inpatient services were not eligible to participate due to the sensitive nature of these conversations.
In Arizona, Arizona Health Care Cost Containment System (AHCCCS) provided an initial round of introductions to 20 local clinical providers and community-based organizations for interviews. Of those organizations, 14 agreed to have staff participate in informational interviews. Of those 14 organizations, three agreed to distribute materials to adolescents and their families.

### Arizona Stakeholder Outreach, Engagement, & Outcomes

<table>
<thead>
<tr>
<th>Participating Stakeholder Organizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Arizona Health Care Cost Containment System (AHCCCS)</td>
</tr>
<tr>
<td>2. AHCCCS - Tribal Liaisons</td>
</tr>
<tr>
<td>3. AZ Advisory Council of Indian Health Care</td>
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<tr>
<td>4. El Rio Community Health Center</td>
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<tr>
<td>5. Family Involvement Center</td>
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<tr>
<td>6. Family Involvement Center</td>
</tr>
<tr>
<td>7. Jewish Family &amp; Children’s Service (JFCS)</td>
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<tr>
<td>8. La Frontera - Tucson</td>
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<tr>
<td>9. La Frontera Impact Suicide Prevention Center</td>
</tr>
<tr>
<td>10. Mariposa Community Health Center</td>
</tr>
<tr>
<td>11. Raising Special Kids</td>
</tr>
<tr>
<td>12. Solari Crisis and Human Services</td>
</tr>
<tr>
<td>13. Terros Health</td>
</tr>
<tr>
<td>14. The Centered Spirit Program - Pascua Yaqui</td>
</tr>
</tbody>
</table>

West Virginia state Medicaid provided an initial round of introductions to 20 local clinical providers and community-based organizations for interviews. Of those organizations, 12 agreed to have staff participate in informational interviews. Of those 12 organizations, three agreed to distribute materials to adolescents and their families. To increase beneficiary participation in West Virginia, CACP placed a call for interview participants on Craigslist. A total of five individuals responded to the posting. Of those, three were eligible to participate and two were successfully interviewed.
West Virginia Stakeholder Outreach, Engagement, & Outcomes

<table>
<thead>
<tr>
<th>OUTREACH VIA COMMUNITY-BASED ORGANIZATION (CBO)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outreach to 20 CBOs</td>
</tr>
<tr>
<td>12 CBOs Respond (right) &amp; 28 Interviews Complete</td>
</tr>
<tr>
<td>3 CBOs Outreach to Members</td>
</tr>
<tr>
<td>5 Members Sign Up</td>
</tr>
<tr>
<td>3 Member Interviews Complete</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>OUTREACH VIA CRAIGSLIST</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 Individuals Respond to Posting</td>
</tr>
<tr>
<td>3 Individuals Eligible for Interview</td>
</tr>
<tr>
<td>2 Interviews Complete</td>
</tr>
</tbody>
</table>

Participating Stakeholder Organizations
1. Berkeley County Schools
2. Genesis Counseling Center
3. Marshall Health
4. Cabell County Schools
5. Morgan County Schools
6. WV Office of Children, Youth, and Families
7. Project AWARE
8. The Village Network
9. Thomas Health
10. Valley Healthcare System
11. WV Medicaid
12. WV Primary Care Association

Participating individuals in each state received a $25 Visa gift card as compensation for their time and effort. “Arizona Stakeholder Outreach, Engagement, & Outcomes” and “West Virginia Stakeholder Outreach, Engagement & Outcomes” chart depict outreach efforts and outcomes in Arizona and West Virginia. “Community-based Organization Geographic Coverage Area” charts show the geographic coverage areas of participating CBOs.
Community-based Organization Geographic Coverage Area

Participating Stakeholder Organizations
Arizona Health Care Cost Containment System (AHCCCS)
AHCCCS - Tribal Liaisons
AZ Advisory Council of Indian Health Care
El Rio Community Health Center
Family Involvement Center
Family Involvement Center
Jewish Family & Children’s Service (JFCS)
La Frontera - Tucson
La Frontera Empact Suicide Prevention Center
Mariposa Community Health Center
Raising Special Kids
Solari Crisis and Human Services
Terros Health
The Centered Spirit Program - Pascua Yaqui
West Virginia Geographic Coverage Area

Participating Stakeholder Organizations
- Berkeley County Schools
- Genesis Counseling Center
- Marshall Health
- Cabell County Schools
- Morgan County Schools
- WV Office of Children, Youth, and Families
- Project AWARE
- The Village Network
- Thomas Health
- Valley Healthcare System
- WV Medicaid
- WV Primary Care Association
Project Partners

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Bureau for Medical Services

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Bibliography


