Medicaid Innovation Collaborative

Adolescent Behavioral Health in Arizona and West Virginia: Foundational Insights from Medicaid Beneficiaries and the Community

Results of Primary Research by The Center to Advance Consumer Partnership

the center to advance consumer partnership

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Background and Context for Potential Vendor Partners

Background: 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 mental illness (Reinert, 2021). Approximately 20.5% of the state's population is insured by Medicaid, and another 10.8% is uninsured – 12th and 10th highest in the nation, respectively (Kaiser Family Foundation, 2022). Statewide, 70.1% of Arizona's youth with any mental 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 mental health and substance use screening across state, particularly in rural settings and among Latinx and American Indian communities. According to 2020 data from HRSA, 13 of the 15 counties in Arizona are classified as Health Professional Shortage Areas (HPSAs) (Health Resources & Services Administration, 2022). According to early qualitative research, Arizona's crisis system is failing to meet the needs of many, as it "was built for serious behavioral health and really isn't working otherwise, for families and children specifically."

West Virginia:

According to Mental Health America, West Virginia experiences high rates of mental illness, ranking 44th in the US in overall prevalence and acuity of serious adolescent mental 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 Virginia's youth report that they are not able to receive needed mental 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 data from 2018, 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 a significant gap in access to adolescent in- and outpatient care, treatment availability, and mental 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 the 55 counties in West Virginia are classified as Health Professional Shortage Areas (HPSAs) (Health Resources & Services Administration, 2022).

Cross-State Themes: For families[1] enrolled in Medicaid, the behavioral health experience in both Arizona and West Virginia is characterized by challenges related to:

- Financial struggles and the emotional burden on caregivers because of financial struggles
- Rural infrastructure, particularly as it relates to transportation, distance to care, access and/or ability to use technology; distances needed to travel to access care and services are significant, particularly for families with limited resources
- 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 caregivers reach the point where they seek outpatient care, they experience extremely long wait times for that first connection (3-8 months), as well as limited availability of one-on-one counseling services.

Arizona beneficiaries report some access to group therapy, as well as other social support services, which was supported by interviews with community-based organizations. There is a strong crisis support network with a commitment to de-escalate, which has established relationships with school and law enforcement as well as expertise with adolescents. In addition, Arizona providers and community-based organizations report being aware of and 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 many behavioral health concerns and the challenges families face are often generational.

In West Virginia, the School Based Health Center (SBHC) model is an option for many families, which not only provides medical and dental care in many communities, but also offers mental health counselling services. Community-based organizations report that resource allocation and on-site therapeutic options at SBHCs vary from community to community. However, in many cases, this is the only medical care that some 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. Many families live hours from the nearest provider, and lack of public transportation prevents families from receiving in-person care.

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

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[1] *For the purposes of this report "Families" are defined as the primary caregiver of an adolescent. This may include biological parents, grandparents, other legal guardians, or the foster system.*

Entry Point to Adolescent Behavioral Health

When asked to describe how families generally begin their journey to address mental health, we hear similar entry points in both Arizona and West Virginia, summarized in Figures 1-6.

Self/Family Choice

- When family makes the decision to seek care, they typically begin looking for one-on-one counseling and encounter long wait lists. Without that appointment, some end up in one of the other entry points noted below.

Example of what's happening	How I'm feeling	What I need
Lack of providers, lack of 1:1 support	Unheard, overwhelmed. My counselor doesn't believe me (e.g. that I'm clean).	1:1 counselling

Figure 1: Self/Family Choice

Crisis - ER

- When teens begin care in a hospital emergency room, it is the result of an escalated event at home, at school, or in the community. They often wait in the ER for days to weeks for next-level care.

Example of what's happening	How I'm feeling	What I need
My parents brought me here because they didn't know where else to bring me	Unheard, scared, isolated. I don't understand why I have to wait here for so long.	De-escalation. Stabilization, regulation. To know what's happening to me now and next. To be away from my family for a little. Not to be with people.

Figure 2: Crisis-Hospital Emergency Room

Crisis - Police

- Encounters with police are scary for teens, but sometimes family or school contacts the police for help de-escalating. This incident may end up with law enforcement consequences or a visit to the ER.

Example of what's happening	How I'm feeling	What I need
Someone called the police	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.	Treatment. Avoid law enforcement consequences of unmanaged mental health.

Figure 3: Crisis-Interaction with Law Enforcement

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 be the result of a report to and investigation of parents or, as reported in West Virginia, it could be a desperate attempt to receive coverage for residential or intensive outpatient (IOP) treatment. 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 who had not yet been assigned to a social worker, 90 of which were the result of opioid use by parents.

Example of what's happening	How I'm feeling	What I need
Domestic violence, abuse, neglect, or SUD. School has suggested foster care to me to get IOP or residential treatment	Unheard, distrustful, shameful, embarrassed, angry, inconvenienced, intruded on	I want CPS to close their case. I don't want to be the reason there are problems.

Figure 4" Child Protective Services (CPS)

Court Requirement

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

Example of what's happening	How I'm feeling	What I need
Court ordered counselling/treatment as a result of probation or legal issues	Angry, weighed down	I want to complete the court ordered therapy so that I can be done with the case/probation.

Figure 5: Court Requirement for Mental Health Counseling

School

- In schools, teens might visit a school nurse or counselor. In West Virginia, they might visit a School Based Health Center (SBHC). A school will often recommend counseling based on some of those interactions. During an escalated event, schools are aware of the history or previous events, they're familiar with family, 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 community-based organizations, who tailor programming and services to teens. This includes group counseling and meals during times that accommodate parent work schedules.

Example of what's happening	How I'm feeling	What I need
School contacted my parents and suggested counselling. I'm having a hard time self-regulating.	Nervous, anxious, bullied, frustrated, not heard, scared	I want my teachers and school counselors to listen to me and not just run tests and recommend medicine.

Figure 6: School Referral for Mental Health Counseling

Inevitably, most teenagers report having their first experience in a 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 one-on-one services.

Cross-State Areas of Opportunity

In both Arizona and West Virginia, clear themes related to the adolescent and family experience emerged across seven domains, as depicted in Figure 7. Each domain includes a description of the barrier or obstacle, insights in the voice of the consumer, and suppoting quotes from interviews with teenage Medicaid beneficiaries, caregivers of teens, and community-based organizaitons or providers. Medicaid Innovation Collaborative vendor solutions should address one or more of these barriers to seeking and receiving behavioral health resources and services.

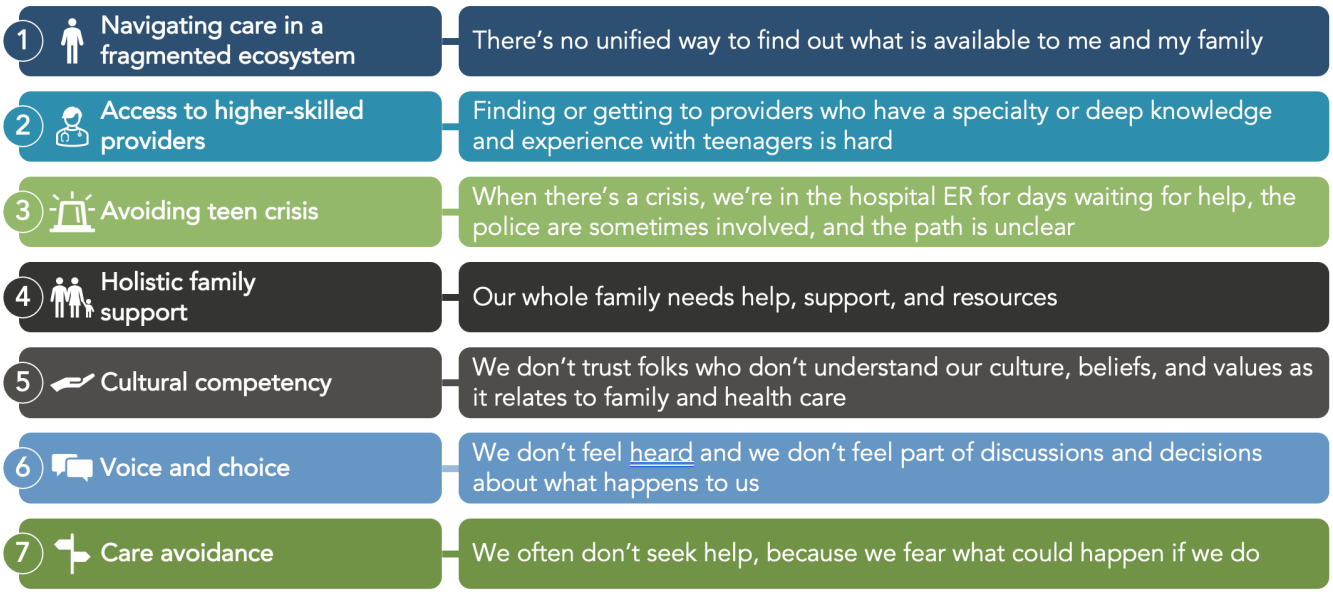


Figure 7: Seven (7) Cross-State Areas of Opportunity

1 Navigating care in a fragmented ecosystem — There's no unified way to find out what is available to me and my family

Navigating Care

When and where Medicaid beneficiaries begin their journey matters. Parents, teenagers, providers, and community-based organizations all report different entry points into the mental health system, many of which occur prior to families engaging in their first true ask for help. The early experiences families have been an indicator of how engaged they will remain in care and ongoing treatment. This journey is depicted below in Figure 8.

Teenagers and their families or caregivers need simple, trusted, and easy to understand information, resources, and tools. This information needs to be available in the language they speak, know, or read, recognizing that not all caregivers are literate or English proficient.

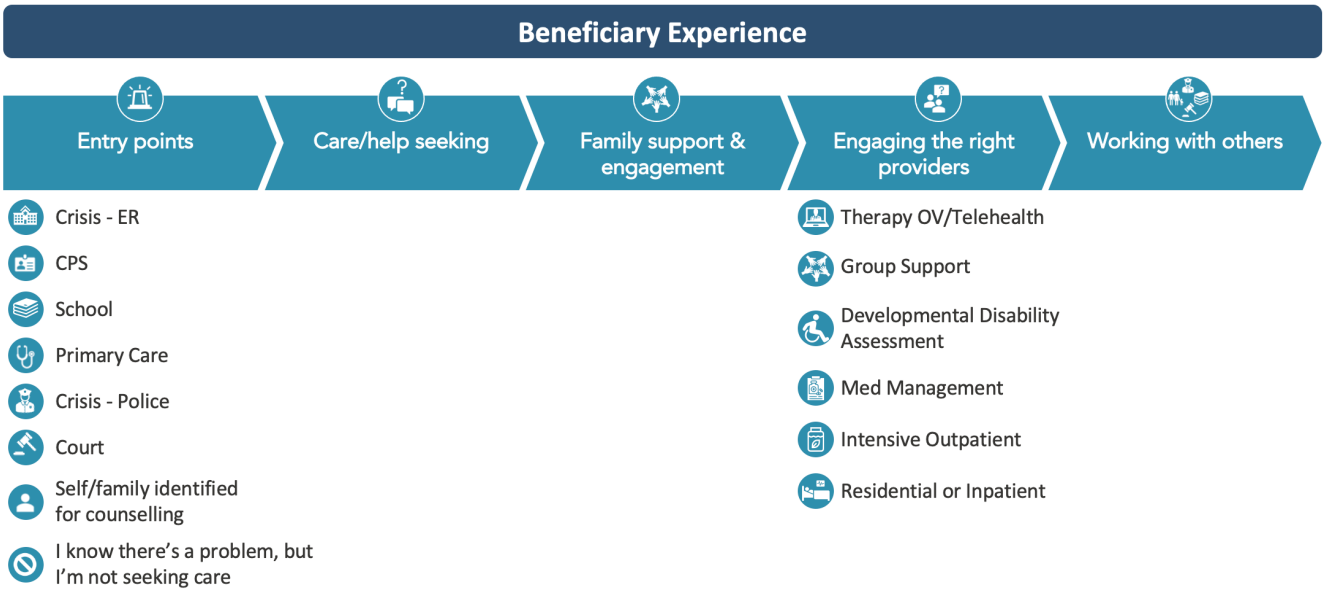


Figure 8: The Consumer Journey - A Conceptual Framework

Synthesis in the Voice of Consumers:

- Our first interaction in the ecosystem either builds trust, making us feel helped and supported, or reinforces bias we may already have against the system
- We're trying to figure all these systems out while we're overwhelmed and in crisis
- If our experience is negative or incomplete, we will likely not return or follow up
- The processes and policies are complicated, and we don't understand
- 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

2 Access to higher-skilled providers

Finding or getting to providers who have a specialty or deep knowledge and experience with teenagers is hard

Challenges Accessing Providers

Families struggle to understand how to get the right help. Referrals are given, recommendations are sought, but these 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 exist, and families often try several providers before finding the right fit. Sometimes they give up during the search and end up in crisis. Sometimes, they wait so long for that appointment, without care, that they end up in a crisis.

Synthesis in the Voice of Consumers:

- We have a hard time finding appointments with providers who will take our insurance, because many of them do not. This makes it really hard to get any kind of care, either over a long period of time or just to be seen and get a diagnosis
- We wait months for first appointments and, even then, we often must compromise on the way we receive treatment
- We don't have broadband, cellular signals, or public transportation so we can't make or keep appointments (in person or telehealth)

"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." - Teenage 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

Avoiding Teen Crisis

Given the challenges already noted in navigating the system and accessing providers, many adolescents arrive in care at a point of acute crisis. These crisis events are the result of:

- Wait time to initial appointment
- Lack of providers/facilities
- Lack of early identification and diagnosis of a mental health condition and/or a developmental disability; parents and caregivers are not equipped to troubleshoot and diagnose either
- Wait times for prior authorizations

These crisis events are emotionally charged, stressful, and unfamiliar for families. There is accompanying shame for some, teens feel unheard and scared, and almost all caregivers and family members are tired, confused, and frustrated.

While our insights indicate that developmental and generational trauma exists for many families, it is important to consider that formal entry into the mental health ecosystem can be the result of a traumatic event that results in a hospital emergency room visit, a hospitalization with assessment, interaction with law enforcement, or in the case of Arizona, a mobile mental health crisis unit.

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

"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 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

Families need holistic services, from financial support and childcare, to mental health care and wellbeing support for caregivers. Rarely is a teenager experiencing a mental health issue or crisis without it affecting the entire family.

Family and caregiver structures vary, including family of origin, kinship care, foster care, and families with a child in residential treatment. Some families are managed by one or two parents, have siblings, and/or multiple generations in the home. 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 loss of caregivers, employment, income, and connections to people and places where they previously received support, like afterschool programs, teams, and organized community events.

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

Synthesis in the Voice of Consumers:

- The issues we're dealing with are often family problems
- I'm emotionally exhausted trying to coordinate everything
- We struggle to balance appointments and evaluations with family and financial needs
- Appointment frequency and location matters. Missing work time isn't an option
- It is challenging finding childcare or pulling other children out of school to get to appointments
- I don’t have a car or public transportation, therapists are hours away, and transportation is expensive
- When I'm looking for help, I need it now; I can't wait months
- If my child does get admitted, when they're discharged, we're [the whole family] not prepared, informed, or helped to make sure the transition is good
- We don't all have families that are able or know how to support us

"I feel like I am inadequate because I'm the go-between for all of these different individuals, and I'm trying to just figure out what is going on with my kid and why she's having the difficulties that she is." - Parent

"I can't leave work, pull all my kids out of school, and drive two hours to an appointment every week." - Parent

"Families aren't prepared to manage their returning child from treatment. They got help, but the holistic care wasn't there, the family wasn't included in the care. Families are absolutely lost when their children come home." - Clinical Provider

"We're dealing with a system that's built for behavioral health, but developmental disability needs aren't addressed by those tools." - Clinical Provider

"We have a real problem with folks with adolescents with developmental disabilities. They try to leverage solutions on [the psychiatric] side, but there isn't a bridge between the two systems." - CBO

5 Cultural competency

We don't trust folks who don't understand our culture, beliefs, and values as it relates to family and health care

Cultural Competency: Understanding Cultural Norms and Practices

In West Virginia, we heard about the "bootstrap mentality." When it comes to caring for families, there is great pride in being able to do this without relying on others for help, particularly in rural Appalachia. All types of systems that intervene (school, medical, mental health, law enforcement) are often perceived as intrusive, and families go to great lengths to self-solve. It is also reported that there is a general sense of fear of engagement with Child Protective Services, for fear of losing parental rights. In some instances, families are referred to Child Protective Services as a way 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. Often, these families are multi-generational with cultures that value family solutions. There is an added layer of confusion for some regions, particularly in rural areas, because of the option to use Tribal Regional Behavioral Health Authorities (TRBHAs), 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 reservation.

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

"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

Voice and Choice

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 won't 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 CPS are called, or if we are at the hospital ER, the process is just happening to us
- We feel like they [providers] rush to judgment and don't take time to fully understand our experience

"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." - Teenage Beneficiary

"Listen to the child's side more than listen to the parents' side, because a lot of parents do lie." - Teenage Beneficiary

7 Care avoidance | We often don't seek help, because we fear what could happen if we do

Fears and Care Avoidance

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

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 mental 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 mental health services even more

"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

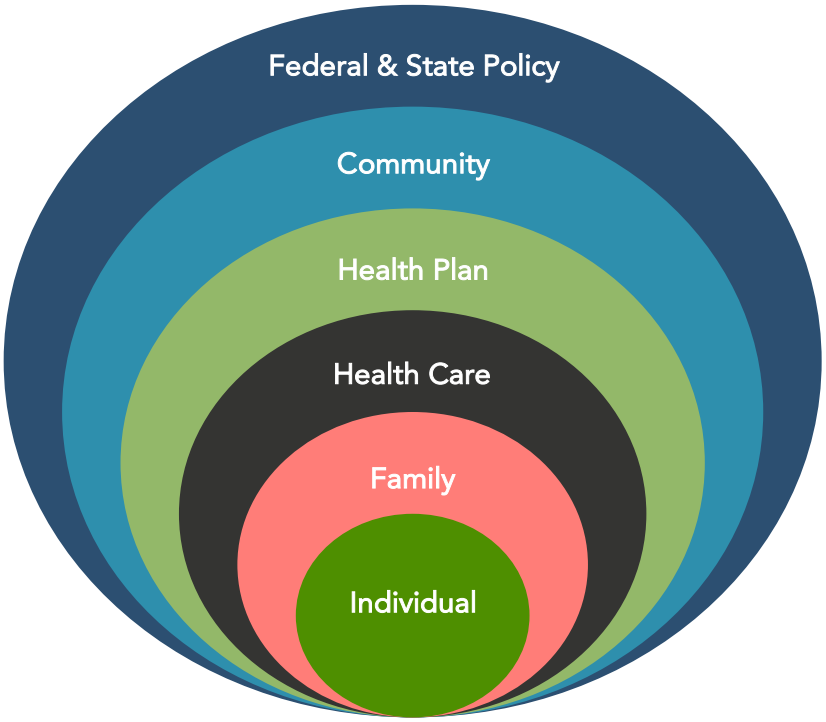
"It happened to their parents, to their parents' parents. Culturally speaking, you learn your business is your business and if you tell someone who is not in your culture, they will call DCS." - CBO

"At the end of the day, you're talking about cycles of poverty and you're talking about cycles of ongoing oppression and colonization." - Clinical Provider

Other Considerations: Involvement and Awareness of Community Stakeholders

Community stakeholders are critical to early identification, diagnosis, treatment, and ongoing support. However, many stakeholders operate in silos. Having strong partner relationships, data sharing, and familiar supports improves the experience that Medicaid beneficiaries have within the behavioral health ecosystem. Facilitating or enabling collaboration across all areas of the ecosystem would benefit all stakeholders and, most importantly, Medicaid beneficiaries.

Spheres of Influence in the Behavioral Health Ecosystem



Federal and State Policy

CMS, AHCCCS, DHHS, Reimbursement Rates, Immigration Enforcement, Social Services, Tax Credits, Justice System, Bureau of Indian Affairs, Families First Initiative

Community

Social Determinants of Health, Schools, Local Law Enforcement, Provider Availability, Advocacy Organizations, Faith-Based Organizations, Family and Juvenile Court

Health Plan

Communication and coordination with other ecosystem stakeholders, Contractual Requirements, Provider Network, Programs, Behavior Incentives

Health Care

Cultural Competence, Trauma-Informed Care, Translation and Interpretation Services, Appointment Availability, Care Coordination, Wraparound Services, Communication and coordination with other ecosystem stakeholders

Family

Social Determinants of Health, Social and Emotional Support, Employment, Family Structure, Childhood Adversity of Caregiver, Trauma History of Caregiver

Individual

Age, Race/Ethnicity, Gender, Sexual Orientation, Coping Skills, Diagnosis, Social Determinants of Health, Social and Emotional Support, Employment, Family Structure, Childhood Adversity, Trauma History

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