



Oregon
Family Support
Network



SB1557 Family & Youth Engagement

Phase I: Input on Experiences and Priorities

Introduction

Caring for a child with serious emotional disturbances or mental illness touches every aspect of a family's life. The emotional toll is profound. Parents contend with feelings of guilt, helplessness, and exhaustion as they navigate the complex and sometimes punitive child-serving systems. Siblings feel overlooked as family routines, shared meals, and moments of connection are put on hold in favor of crisis management. When a child's level of acuity results in hospitalization or placement in a subacute care setting or psychiatric residential treatment facility (PRTF), the family is further and more deeply impacted.

The individual and logistical challenges of out-of-home placements can strain relationships, heighten stress, and obliterate anything that resembles the essence of ordinary. Overwhelming uncertainty and the relentless demands of navigating a sense of family from a distance become an excruciatingly twisted norm. The opportunity for home- and community-based services and support, as outlined under the provisions of Senate Bill (SB) 1557, could alter the experience for children and families. It holds the potential not only to minimize disruption, but also to create the capacity within which to nurture relationships and leverage each family's unique strengths to promote resilience and wellbeing.

Recognizing that:

Children, youth and their families are the experts on their lives and needs and must be meaningfully included in all decisions about their individual services and supports and be meaningfully included in policy making and service design the importance of family and youth voice in informing service design and delivery, (p. 1)

SB 1557 calls for family and youth to collaborate in its investigation and eventual implementation. For this phase of engagement, the specific objective was to learn from families about their experiences leading to the need for PRTF or hospital-level care: the behaviors that prompted their concerns, the kinds of help they sought, and the services that were offered. It also aimed to understand what they found helpful in the process and what additional resources could have supported them.

Method

To gain insight into the experiences of families caring for children with serious emotional disturbances, Oregon Family Support Network (OFSN) conducted semi-structured interviews with 21 parents¹ (19 of

¹ **Parent's Race/Ethnicity** – American Native: 2, Asian: 1, Black/African: 3, Hispanic: 4, White: 12. **Children's Race/Ethnicity** – American Native: 1, Black/African: 7, Hispanic: 5, White: 9. **Location** – Clackamas County: 2, Douglas County: 1, Lane County: 2, Marion County: 4, Multnomah County: 4, Polk County: 1, Umatilla County: 1, Washington County: 5. **Insurance** – OHP: 17, Commercial: 2, Both: 3. **Children identified with I/DD diagnoses:** 9

whom were mothers) between October 18 and December 6, 2024. Participants were recruited through an email invitation sent to parents involved with networks and organizations which serve and support families. The email outlined the purpose of the interviews and emphasized the importance of the family and youth voice in informing ongoing work under SB 1557. Parents who were interested in sharing their experiences responded directly to the invitation and volunteered to participate in a conversation.

Following each interview, key points were noted and systematically grouped into themes that captured recurring patterns in the conversations. To provide additional perspective and contextualization, the summarized themes were 1) shared with participants for feedback and validation, and 2) presented to 20 attendees at a regular convening of the *Families Leading Children's Behavioral Health* group. Feedback was incorporated into the final summary to ensure the themes accurately reflected the lived experiences and insights of parents and caregivers.

Outreach to youth followed a similar process. Connections were established with five organizations that provide culturally responsive support, advocacy, and resources tailored to the unique needs of young people from diverse racial, ethnic, and social backgrounds. To begin characterizing the experience, on December 10, 2024, OFSN attended a convening of 12 adjudicated youth at the Levi Anderson Learning Center in Beaverton, Oregon. The conversation was summarized, and key points were noted.

Findings

Parents and Caregivers

To be willing to speak about the challenges of accessing care and the experience of raising a child with serious emotional disturbances or mental illness is an act of profound vulnerability and extraordinary courage. For every family who shared their story, there remains the indelible question of "what if." *What if we had access to the right services sooner? What if we had been heard and supported when we first asked for help?* These stories reveal not only the pain of navigating an under-resourced, sometimes reproaching, system but also an unyielding hope for change. We extend our deepest gratitude to the parents who opened their hearts and shared their journeys with trust that their voices will make a difference for those who come next. May their honesty and resilience light the way forward.

Conversations with families were insightful and deeply meaningful. The discussions centered on their experiences leading to residential treatment and the potential benefits of home- and community-based services. The challenges they described were neither new nor unfamiliar but remain unresolved.

From these conversations, five overarching themes emerged.

Escalation of behavioral symptoms and family isolation: All parents described behavioral symptoms which escalated over time, manifesting as aggression, self-harm, extreme emotional outbursts, and withdrawal. These behaviors drastically altered the family dynamic, disrupted routines, and created an environment of fear, frustration, and helplessness. The emotional and physical demands of managing their child's escalating needs often made social connections difficult to maintain. As natural supports receded, overwhelming isolation deepened the emotional and logistical challenges of caregiving.

Our families and some friends couldn't understand what was happening. First, they gave us advice – lots of advice. Then they just avoided us. We weren't even invited for holiday dinners. It

wasn't intended to be hurtful; they just didn't have space for what they were witnessing. We were on our own. (October 18, 2024)

After a while we were not a family, we were a care center. We had locks on the doors and cameras throughout the house to protect our other children. We were always on alert. (November 7, 2024)

All families recalled the gradual and often predictable road to crisis. As their child's needs became more acute, crisis services and emergency departments became the default response for managing extreme behaviors. This often served as a stopgap in lieu of more directed care and as a gateway to hospitalization, subacute care, or residential treatment.

[...] the police came every time. Sometimes that scared him into freezing, so it stopped what was happening right then. Sometimes, if he calmed down too fast, they thought I was doing something – that I was hurting him. Nobody can believe that a 9-year-old can brutalize his mom or wreck an entire house. [...] When we got to the emergency room, he was held down by four adults [...] they gave him more meds and finally he passed out. They acted like they were trying to subdue a wild animal. He was a little boy. He still remembers that. They kept him in the emergency room overnight and then a psychiatrist told us to give him Benadryl when it happened again. That was the help that was available. (October 18, 2024)

My life was on the line. He was hospitalized a couple of times on a parental hold. [...] He was 10 then. (November 4, 2024)

Parents voices dismissed – the consequences of ignored concerns: In most cases, parents noted behavioral symptoms beginning in early childhood and, in nearly every instance, their initial concerns were met with delays, blame, relative indifference, or punitive action – particularly in school. The lack of acknowledgment and meaningful action left parents feeling dismissed and alone as they continued to navigate an ever more volatile landscape.

We knew that something was wrong when he was 2. No one listened. They attributed our observations to typical development. This went on for years. He had therapy all along. When he was 6, the therapist knew he needed more – something more intensive. She did everything she could. She tried her best to help, but there was nothing available. [...] He was repeatedly punished in school – isolated at lunch, sent home. [...] When he went into residential treatment at 8, they asked us why we hadn't gotten help earlier. We had f___ing begged for help! (October 25, 2024)

I kept telling them what she needed. This went on for years until she was finally diagnosed. [Providers] need to trust moms; we are the experts in our children. (November 4, 2024)

They could do holds at school, so they held him down and he would fight back. That's how they helped. He was sent home from school almost every day in kindergarten, first, and second grade. [...] We were involved with [CBO] to get help like counseling and medication. It was okay, just not enough. They were nice to us. (November 4, 2024)

I can't even count how many times I asked for help. No one listened. I'm telling you; they just wouldn't listen. [...] He ended up in subacute and then they sent him to [PRTF] and then after

that he was at [PRTF]. When he came out of these places, he wasn't the same. [...] And now he's in jail. (November 19, 2024)

Challenges in accessing effective services: Parents described their struggle to find adequate support for their children as overwhelming. They described the difficulties of needing help within a one-size-fits-all system.

The therapist would tell us how something works – that it's been proven. But when it didn't work for us, somehow it was my child's fault. Or we didn't do something right. They couldn't see that it wasn't right for him. (October 25, 2024)

While most had access to outpatient therapy, parents reported that it often fell short of addressing the severity and complexity of their child's needs. One family noted that Parent-Child Interaction Therapy (PCIT) was helpful initially, but over time, the child's behavioral symptoms continued to escalate. Collaborative Problem Solving was generally viewed favorably, but it similarly failed to be an effective strategy as behavioral issues became more acute.

Twelve families had access to Wraparound with a range of perspectives on its utility. While many appreciated certain aspects of the program, some found it insufficient given the complexity of their child's needs.

What good is a team that makes plans and coordinates care when there is no care to be had. [...] After a while it felt like we were going through the motions but for what? I was running around like a madwoman just to complete a to-do list, but none of it was to help her. (October 18, 2024)

Relationships with Wraparound team members and providers were a key factor in how parents perceived the program's helpfulness. Some parents felt controlled or judged by team members, others questioned their relative skill level or proficiency, still others spoke of the disruption of frequent staff turnover. In contrast, one parent described Wraparound as the “community” she relied on and trusted for support

Wraparound makes me feel seen. (November 8, 2024)

Importance of the right services at the right time: Fourteen families had access to peer support, most cited it as a significant strength, highlighting the importance of connection with others who understood their experiences. Three families had access to Intensive In-Home Behavioral Health Treatment (IIBHT) following residential treatment and found it immensely helpful in supporting their child's transition to home.

And then we went into this great program called IIBHT [...] There was a lot of in and out with providers at first. Some he didn't click with. That makes a difference. Now he can't wait to see them. He waits at the door when he knows they're coming. He has a counselor and we both have skills trainers. [...] This seems so backward. If this had been available sooner, when we needed help early on – I can't even imagine. (November 4, 2024)

Three families who received home-based services provided through Child Protective Services (CPS) experienced it as largely unhelpful. Families described CPS providers as manipulative, disengaged, and more focused on fulfilling systemic requirements than addressing the specific needs of the family.

There was no transparency. We never knew what was going on. The worker would make things up. It looked like we had services, but it wasn't what we needed. (November 6, 2024)

I didn't have a car – no reliable transportation. We needed help with transportation. How was I supposed to get my kids to all these places? [...] If I couldn't make it somewhere on time, she found all kinds of things to pin on me. It was all about blame. (November 7, 2024)

When asked to imagine what services or support they believed might have allowed them to prevent out of home care, almost all parents mentioned the need for even brief periods of respite.

Self-care doesn't exist. You're always watching out or running around. [...] I don't know if I can ever be the same again. I needed a break. I was doing this all myself. There was no break and now I feel broken. (November 5, 2024)

One parent, who had access to IIBHT, felt that the time her child spent with in-home service providers was a form of respite.

I can do other things when she's with them. I can take a shower! (November 5, 2024)

For most, it was difficult to characterize what help would look like. Notably, however, almost all parents discussed the timing of services, highlighting the devastating effects of serial crises.

We know the police by name. [...] She needed intensive help from the start. I couldn't have predicted that. I can see it now. (October 18, 2024)

If we have to wait for a crisis, or many, a facility would be better – unless someone is going to be in our home 24/7. It's too much. We need help before the crisis. (October 25, 2024)

There has to be something between outpatient therapy and hospitalization. Some kind of treatment – even a little compassion. He obviously needed help. His behavior was getting worse. He was punished at school all the time. It changed him. It changed me. [...] I guess it got us to disaster and the disaster got us help. (October 25, 2024)

If home based services require that level of crisis – if we had to be at the level of crisis to be eligible for services, it wouldn't have helped. It would have been too late. (November 7, 2024)

Yes, I think support at home could have made a difference. We needed it before I had to send my other kid away. (November 11, 2024)

We needed help before it got so bad. It's kind of a joke. Yeah, we'll send help, but you have to be destroyed before you can qualify. (November 19, 2024)

Systemic failures that compound family crisis: This theme reflects three interconnected subthemes² that emerged from interviews with parents, some of which were underscored by the *Families Leading Children's Behavioral Health* group: unmet basic needs, cultural neglect, and lack of transparency in adoption. These subthemes highlight how structural deficiencies and inequities which have become normalized create pervasive challenges for families navigating the child-serving systems. They reflect

² While each of these issues represents a major systemic flaw deserving of comprehensive attention, they are considered subthemes here as this report presents a thematic synthesis of key points discussed by families within a limited context and for a prescribed purpose.

longstanding and ongoing conversations and emphasize some of the most profound, deeply entrenched, and difficult-to-change systemic norms.

While these issues are described here solely from the family perspective, it is important to recognize that they represent a multidimensional problem requiring the inclusion of many perspectives, including those of agencies, providers, policymakers, service users, and advocates. Addressing these challenges effectively will demand systemwide collaboration, cross-sector partnerships, power sharing, and focused legislative attention in service of real, sustainable change.

Unmet basic needs: Among the parents who shared their experiences for this report, there was a range of socioeconomic backgrounds, family composition, and household sizes, reflecting the diverse realities of families navigating the child-serving systems. The subtheme of unmet basic needs – also clearly and poignantly discussed by youth – highlights not only the daily challenges families face, but also the far-reaching impact to families when basic necessities such as stable housing, food security, transportation, and reliable childcare are unavailable or insufficient. Several families spoke of the impact of scarcity.

I know I made mistakes. I didn't know what else to do. I was trying my best [...] and sometimes it was food. I had to be able to feed them. (November 8, 2024)

They see what I'm not doing. But does anyone see how hard I'm working? (November 8, 2024)

Parents described the rush to judgement they felt and the punitive approach to problem-solving which pushed them deeper into crisis.

[...] and now we're involved with CPS because I'm poor. (November 4, 2024)

The school saw that his clothes were dirty – he wore dirty clothes. They assumed he was neglected. No one asked [...] That does things to a family. (November 18, 2024)

Cultural neglect: Forty-seven percent of parents who participated in interviews identified as belonging to racially or ethnically diverse groups. Many shared experiences reflecting long-recognized yet insufficiently addressed challenges commonly faced by historically marginalized communities. Parents described feeling unheard and frankly overlooked, expressing a lack of trust that services, readily available to others, would also be accessible to them.

If you have an accent, they don't hear, so of course it gets worse [...] Who would hear me say I need services to come to my home? (November 5, 2024)

School prepares them for prison. (November 19, 2024)

Discussing the impact of having a medically fragile child, one parent noted disparity in the level of support provided through the Children's Intensive In-home Services (CIIS) Program.

I have an American friend whose daughter qualifies as a fragile child, gets 250 hours, and she can walk, talk, and eat. [My daughter requires 24/7 care. They want to cut my hours.] It feels unfair that I'm being offered fewer hours. Even my friend thinks it's unjust. I'm unsure if it's discrimination, but I feel there will never be equality between Latinos and Americans. Sadly, that's the reality. (December 6, 2024)

One parent, referring to the potential benefit of home-based services, described being prohibited from sacred indigenous practice in a congregate care setting.

[...] they wouldn't let me smudge him – they wouldn't let us pray. I could do that at home.
(November 19, 2024)

Another aspect of cultural neglect concerns less visible communities, such as recent immigrant populations, who are often overlooked in mainstream service delivery and policymaking. This gap in visibility was evident during a gathering on November 30, when OFSN met with approximately 25 families who had immigrated from West African countries.

The event provided an extraordinary opportunity to connect with the community and experience its natural warmth and strong sense of interconnectedness. Although it is not known whether these families have faced mental health crises, PRTF placements, or hospital-level care, their comments revealed experiences of marginalization and learned mistrust of systems.

They need to know what is going to happen to their children if they talk to you. They don't want to lose their children. (October 30, 2024)

We haven't gotten help [...] We didn't know – if we should...or how. (October 30, 2024)

We are together, supporting one another [...]The promise of this place – it's not what we thought it would be. (October 30, 2024)

The experience reinforced the need for relationship-building and for engaging communities in ways that respect their traditions and lived experiences – to leverage Interpersonal dynamics that do not always align with colonialist frameworks or rigid reporting timelines. This was emphatically emphasized by a participant in the *Families Leading Children's Behavioral Health* group.

The focus of this work is always on the mainstream...standards focus on the [dominant population] anyone who falls out of this – Africans, African Americans, Asians – is seen as an outlier and we are trying to bring them to [so-called] normalized behavior [...] That causes a lot of people to step back and not even want help from systems [...] They have found ways to thrive and survive in their own communities. (December 10, 2024)

Lack of transparency in adoption: Four adoptive families strongly emphasized that in-home services provided only at the point of crisis would not have been enough to address the profound emotional, behavioral, and relational challenges stemming from early adverse experiences, such as abuse, neglect, or attachment trauma. They highlighted how the lack of transparency in the adoption process, particularly regarding the child's history and needs, compounded these difficulties and left them unprepared for the challenges they faced.

There was so much going on with her. I was not aware of what happened to her in foster care. It wasn't shared. After a while, I honestly don't think any amount of support could make a difference. We needed support on day one. They send you home with all the fantasies about what it will be like. That's crap. They know these kids will have all kinds of issues. Reactive attachment disorder – it's different for all of them but for her [...] I don't know, we seriously needed in-home support from the start. (October 18, 2024)

We had a lot of services in place. We had Wraparound, a therapist [...] By the time the crisis happened we had about 20 people supporting us and none of them could help. [...] Adoptive parents are not prepared and there is not help out there. We are navigating a minefield, and we don't even know where to start. Agencies are aware of that. They know what we're walking into, and they let us go into it with no support. It's impossible to recover. (November 7, 2024)

She came to us just before she turned 5. We hadn't been told about a very severe psych evaluation or that she had tried to [hurt a previous caregiver.] We were only told she needed a 'very strong mother' and then they kept telling me I was a strong mother. [...] It is one of the most debilitating things when you start to lose trust in even with the medical professionals and social workers [...] (December 10, 2024)

While these do not reflect the experiences of all adoptive families, they highlight a level of intensity that, in the shadow of early neglect and abuse, might be anticipated and supported assertively and proactively to avert eventual crisis.

Youth

Voices from the margins: On December 10, 2024, OFSN attended a convening of 12 adjudicated youth at Levi Anderson Learning Center to discuss their lived experiences and reflect on what might have helped them avoid crisis and out-of-home placement. In a deeply impactful conversation lasting just under an hour, these young people shared their perspectives with candor and courage, offering invaluable insights into the challenges they faced and the unmet needs that shaped their journeys.

Their honest and heartfelt expressions highlighted how unmet basic needs, social connection, and empowerment are deeply interconnected in fostering stability, agency, and well-being. Like many adults, the youth emphasized the importance of having stable housing, access to food, and sufficient financial resources to meet their basic needs.

While some participants believed that in-home services such as skills training, therapy, and peer support could be helpful, it is difficult to conceive of these services without the basic knowing of a home. Approximately two-thirds of the group had experienced houselessness or housing insecurity, underscoring the enduring effect of these challenges on their lives.

Most remarkable, however, was the profound impact of unmet social needs – particularly the absence of meaningful relationships and a sense of belongingness – as central to the crises they experienced. Their voices revealed the critical importance of relationships with caring, non-judgmental adults who notice their struggles and genuinely invest in their well-being. In turn, each participant spoke of longing for connection and understanding.

People aren't really interested until it's too late.

It felt good when someone asked what was wrong.

I wish someone had asked...

They shared how they sometimes felt invisible to the adults and systems around them. Many described how their behavioral expressions of distress were misunderstood, leaving them feeling judged or punished rather than supported.

I let myself get into trouble so people wouldn't notice my parents. Some kids' behavior might not be because they're acting out, but because they want to protect the people behind them.

They highlighted how important school can be, especially when their homes lack safety or stability. For many, school is not just a place for academic learning but also a potential refuge where they can begin to understand what safety looks like.

Kids should learn in school that it's okay to talk.

I didn't know I was being abused, it's just what happened.

It's a bad thing and it's good to talk about it.

On balance, these thoughtful reflections underscored the critical need for systems that support not just individuals, but entire families. Many participants highlighted the importance of addressing their parents' needs and providing holistic support for the family unit. Their stories illuminated how unmet basic needs ripple through and impact the entire family. They revealed how a lack of timely support invites crisis.

We are deeply grateful to the youth who shared their stories, insights, and vulnerabilities. Their willingness to speak openly about their experiences offered invaluable wisdom and a clearer understanding of the challenges they face. Their contributions are a powerful call to action.

Summary & Considerations

In spite of the systemic challenges which form the balance of this report, families highlighted the positive impact of compassionate individuals working within the system, including Family Support Specialists, Wraparound team members, clinicians, and other providers who demonstrated empathy and understanding. These personal connections served as an important source of support and hopefulness within an often-overwhelming sequence of experiences.

These stories reveal how gaps in resources and a lack of timely support can leave families struggling to navigate crises on their own. One parent described the various supports she had painstakingly accessed through volunteer services, scholarships, donations, and borrowing:

Mentorship, IEP attorneys, equine therapy, naturopathy, acupuncture for PTSD, Chinese medicine, neurofeedback, adoption and trauma expert for intensive parent coaching, specialized FASD parent coaching, hired 'mother's helper', various sports programs, martial arts, genomic testing, privately arranged respite, temporary placement with friends, private residential treatment, specialized programs and multiple specialized summer camps, special needs program within a private Catholic high school. (October 18, 2024)

Her efforts vividly highlighted the profound and pervasive needs of the entire family, emphasizing how these challenges deeply affect every aspect of their lives.

All families feel the pressing urgency of immediate needs contrasted with the lag time of systems to effect change. Participants in the *Families Leading Children's Behavioral Health* group, several of whom were involved in the development of SB 1557, voiced significant frustration with the slow pace of its implementation. They also raised concerns about what they perceive as unnecessary redundancy in the process. Their frustrations reflect not only a specific point of view but also the indomitable persistence, resourcefulness, and exhaustion that typify nearly every parent's experience:

What was happening in our household was more than we could manage, but we managed. Somehow, we managed. (November 7, 2024)

Reference

Oregon State Legislature. (2024). *Senate Bill 1557: Relating to services to individuals who are under 21 years of age; declaring an emergency*. Salem, OR: Oregon State Legislature. Retrieved from <https://olis.oregonlegislature.gov/liz/2024R1/Measures/Overview/SB1557>