

HATFIELD RESIDENT FELLOWSHIP PROJECT BRIEF

Youth Respite in Oregon

Project Dates: July 2023 – March 2024

PROJECT GOAL

The overall goal of this fellowship project was to assess the state of youth respite care in Oregon and make recommendations for overcoming barriers to respite service access for youth. The System of Care Advisory Council (SOCAC) oversaw the research and recommendation development while also heavily relying on input from youth and family partners. Ultimately, this project will help the SOCAC to advocate for youth respite services to legislators and state agencies.

TAKE-AWAYS

The biggest take away from this project is that the current system for providing care to youth in Oregon is deeply flawed, especially when it comes to respite care. Respite means “a break” for youth and their families/caregivers. While many families are struggling to get a break, youth with system involvement, particularly youth with behavioral health struggles, are often left behind or not given adequate care to alleviate current or future crises.

- Behavioral health respite for youth under 25 is very inaccessible due to a lack of facilities, a lack of trained providers, discrepancies in rural versus urban resources, and issues with insurance payers.
- DHS Child Welfare and Intellectual and Developmental Disability Services provide some respite care to youth who meet their population guidelines though it is often hard to find providers and provider payments are low.
- The Centers for Medicare and Medicaid Services (CMS) currently do not allow for mental health respite for youth under 18 to be covered under Oregon’s State Plan and mental health respite can only be paid for through Coordinated Care Organizations’ (CCOs) global budgets.
- Youth, their families, and communities have been advocating for increased respite opportunities for many years and are passionate about getting it increased/existing in their areas.
- Respite can occur in formal or informal settings. Youth and families often prefer informal settings.

CHALLENGES

One of the core tenants to the SOCAC’s mission is to build meaningful partnerships with families and youth while also utilizing cross-system collaboration to support families and youth with complex needs. A challenge in this project was around engaging youth and family members to be meaningful partners in this work while staying on a tight timeline with set goals. To overcome and work through this challenge, this project relied heavily on pre-existing relationships that SOCAC colleagues and partner organizations had with youth and family, the fellow and colleagues practiced authenticity and openness in all interactions with family and youth, cast a wide net in recruitment for events, and continuously looked for lessons in how the SOCAC and systems can improve in the future.

Another challenge arose from the lack of information about respite usage and Medicaid payment for respite care. Many state and federal systems are equipped to provide and pay for respite services for elderly adults while system-involved respite care for youth and their families is a relatively new concept. Much of the information about respite service coverage for youth is hard to find and inconsistent from source to source, and even when concrete answers are available, they are often vague or confusing. It was difficult to gather correct information about respite service availability/payments and aggregate all of the widespread information into a digestible format. While there may be some pieces of the Medicaid/payment puzzle missing, much of this challenge was overcome by meeting with many state agency experts to confirm that the information gathered was correct, looking for insight on best practices from other states with youth respite, and working with youth and family to assure that the project covered all of the aspects and policies they cared about.

STRATEGY

Many different strategies were employed to accurately assess the current state of youth respite care in Oregon and to create policy recommendations for legislators and state agencies regarding youth respite.

- Conducted many interviews with local System of Care coordinators, youth respite providers, and state agency partners to map out current respite services and gaps in care for youth in Oregon.
- Distributed surveys to youth and family members across Oregon to gather their lived experiences and input on respite care. Additionally the SOCAC held two listening sessions with family members of youth with complex needs to further gather input.
- The SOCAC held a set of four youth policy recommendations workshops (two on formal respite services and two on informal respite services) with family members, youth, state agency partners, and respite care providers to identify top barriers to receiving care and create a set of policy recommendations to be pursued by the SOCAC. To further involve partners in this work, a feedback loop session was held for the public and partners to give input to the policy recommendations they felt the SOCAC should prioritize most strongly.
- Worked closely with colleagues and state agency partners to further develop policy recommendations and action steps to achieve them.

RESULTS

At the completion of the project, the fellow achieved the following results:

- Created a comprehensive Youth Respite Policy Assessment that outlined what is current existing and known about youth respite care in Oregon.
- Developed and prioritized a package of policy recommendations for the System of Care Advisory Council to advocate for to legislators and state agencies.
- Presented findings and recommendations to the System of Care Advisory Council on March 5, 2024.

POLICY RECOMMENDATIONS

The fellow developed the following youth respite policy recommendations through youth and family member engagement, workshops, best practice research, and expert input:

- Funding model for respite:
 - Develop guidance for Coordinated Care Organizations (CCOs) on how they can fund respite for their members.
 - Braid and blend funds across child-serving systems to develop continuum of respite infrastructure within local communities.
 - Consider alternate funding models through Medicaid used by other states to fund youth mental health respite.
 - Build on existing programs, organizations, and provider capacity.
- Workforce issues and lack of known and trusted providers:
 - Increase the number of respite providers overall.
 - Ease administrative burden and encourage people to stay or become respite providers.
 - Increase provider training for existing providers who work with specialized needs such as complex and high-acuity behaviors.
- Stigma, messaging, and knowledge around respite:
 - Boost awareness of legislators and policymakers on what families and youth want when it comes to respite and supports.
 - Develop map and directory of available respite providers and services.
 - Tie respite to existing programs and efforts such as afterschool programming or Mobile Response and Stabilization Services (MRSS) more explicitly.
- Lack of youth-initiated respite options:
 - Have flexible options for respite programs and invest more in group respite (hourly and overnight).
 - Expand mentorship, peer support programs and drop-in centers for youth.