YOUTH RESPITE POLICY IN OREGON

An Assessment of Current Respite Policy and Recommendations for the Future

System of Care Advisory Council

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SOCAC
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Acknowledgement

The System of Care Advisory Council (SOCAC) would like to thank the numerous contributors that helped make this research possible. Family members and youth have shared invaluable lived expertise, insight, and helped the SOCAC create a set of recommendations to improve access to youth respite across Oregon. The Oregon Family Support Network (OFSN) and Youth Era were vital partners in collecting youth and family voices through distributing surveys and hosting listening sessions. The SOCAC would also like to acknowledge state agency partners, specifically partners at the Oregon Health Authority (OHA), the Oregon Department of Human Services -Child Welfare Division, the Oregon Department of Human Services - Office of Developmental Disabilities Services, the Oregon Department of Education, the Oregon Department of Early Learning and Care, and the Oregon Youth Authority, whose prior work and expertise laid the foundation of this research and contributed to its content. Respite care providers, payers, and community-based organizations have also provided knowledge and expertise to this report's findings and recommendations. Lastly, the SOCAC would like to thank Local System of Care Coordinators from around the state for providing expertise and bringing the barrier about youth respite to the attention of the SOCAC.

Executive Summary

What is youth respite?

Oregon's System of Care uses the following working definition of respite:

Respite services provide a break for primary caregivers of children and youth with complex needs, as well as a break for youth themselves. Effective respite services are culturally and linguistically responsive, developmentally appropriate, flexible, and provide a range of options, from drop-in childcare to preplanned or overnight crisis services.

Why is respite a barrier in Oregon?

Respite is difficult to access for many reasons, including funding models, lack of appropriate workforce, lack of knowledge and information, stigma, and a lack of youth-initiated respite options. Barriers to respite persist in many communities and in the Behavioral Health system, the Child Welfare system, and the Intellectual & Developmental Disabilities (I/DD) system.

Youth and Family Experience with Respite

The System of Care Advisory Council (SOCAC), along with partner organizations OFSN and Youth Era, conducted surveys and hosted listening sessions with youth and family members/caregivers to better understand their experiences and needs related to respite. Overall, around half of youth and family members who provided feedback had used some type of respite service in the past three years and the majority found it to be beneficial. The biggest barrier for youth and families in accessing respite care was the lack of providers who could meet their needs in their geographic area.

Current respite in Oregon

Despite the numerous barriers identified, SOCAC's assessment identified the following types of informal and formal respite services are currently available in at least some areas of Oregon. Formal respite is generally defined as services based on specific program eligibility (such as I/DD or child welfare) or a diagnosis (e.g., behavioral health condition). Formal respite is often funded, in part, by Medicaid dollars, and therefore must follow more rigid regulations and laws. Informal respite is more universally offered and offers more flexibility in terms of providers and settings.

Informal respite services

Type of Respite	Where it's provided	Who's providing it	Who is eligible	Funding sources
Afterschool/out-of-school based supports	At schools, parks, & community centers	Trained staff, teachers, and volunteers	All students though exclusions may apply due to lack of training	State, federal, & local funding & grants
Childcare settings	Licensed childcare settings	Department of Early Learning and Care qualifications based on setting of care	All children with emphasis on those under 5 years	Federal, state, & local funding (profit and nonprofit organizations)
Community and faith-based programs	Community-based settings and centers usually	Volunteers and paid staff, training and certification may vary	All youth, age limits for some program types, exclusions may occur for youth with higher needs	CCO Health Related Services (HRS), SHARE, foundations, grants, etc.
Friends and family	At a youth's home or home of respite provider	Family, friends, babysitters who may or may not have formal training	All youth	None usually

Formal respite services

Behavioral Health Respite	In designated respite facilities and respite lodges	Licensed mental health providers	Youth with a behavioral health diagnosis served by a CCO	CCO Global Budgets and General Funds
Child Welfare Respite	In certified respite resource homes and Tribes in Oregon	Certified respite care providers and informal respite providers	Youth 18 and under who are in a resource home and biological families during trial reunification	State General Funds
I/DD	Often in youth's home or through a certified child foster home	Personal Support Workers, licensed & certified in-home agencies, and certified child	Any child determined eligible for I/DD services and has a need for the service	1915(k) Community First Choice State Plan Amendment (K plan – Medicaid)

		foster care providers		
Juvenile Justice Involved	In respite provider's home	OYA certified respite providers	Certified OYA foster parents and their youth	General Funds and Special Pay
Relief Nurseries	Designated and certified relief nurseries	Relief nursery staff and community partners	Children from birth through age 5 and families with at least 5 stressors	State General Funds, CCO Health Related Services, foundation or private funding, etc.

Prioritized Policy Recommendations

- Braid and blend funds across child-serving systems to develop continuum of respite infrastructure within local communities.
- Build on existing programs, organizations, and provider capacity.
- Develop guidance for Coordinated Care Organizations (CCOs) on how they can fund respite for the communities they serve.
- Increase the number of respite providers.
- Boost awareness of legislators and policymakers on what families and youth want when it comes to respite and supports.
- Connect respite services directly to existing programs and efforts such as afterschool programming.
- Have flexible options for respite programs and invest more in group or youth-initiated respite (hourly and overnight).

Introduction

According to Merriam-Webster, respite is defined as "a period of temporary delay" or "an interval of rest or relief". Per the ARCH National Respite Network, respite is "planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers." Informed by these definitions and discussion with system partners, Oregon's System of Care utilizes the following working definition of respite:

> *Respite services provide a break for primary caregivers of children and youth with complex needs, as well as a break for youth themselves. Effective respite services are culturally and linguistically responsive, developmentally appropriate, flexible, and provide a range of options, from drop-in childcare to preplanned or overnight crisis services.*

The SOCAC has identified two categories of respite, formal and informal respite. Formal respite is generally defined as services based on specific program eligibility (such as I/DD or child welfare system involvement) or a diagnosis (e.g., behavioral health condition). Formal respite is often funded, in part, by Medicaid dollars, and therefore must follow more rigid regulations and laws. Informal respite is more universally offered and offers more flexibility in terms of providers and settings. Informal respite isn't linked with insurance payments and is often funded through community organizations, schools, state agency funds, and grants.

Across the United States, it is estimated that there are 5.6 million family caregivers to children with special healthcare needs. Many of those caregivers are uncompensated while providing around the clock care to their children.[1] Research has shown that when provided respite, caregivers are able to better care for their children with reduced stress and greater family stability.[1] Respite services help caregivers meet a young person's specific needs and improve a caregivers' positive attitude toward the person for which they are caring. Respite prevents caregiver burnout, reduces escalation of behavior, and prevents placement disruptions for youth in child welfare custody.

Respite is foundational to a comprehensive service delivery model for youth with behavioral health needs and related conditions. Respite is one of several services within a functional system of care.[2] Aside from benefits to families and youth, respite is also cost savings as it prevents the need for more expensive, out of home services like residential treatment or

[1] Respite Facts and Talking Points, ARCH National Respite Network

[2] The Institute for Innovation & Implementation created a set of core components to a comprehensive service array in systems of care: Mobile Crisis Response and Stabilization Services (MRSS), Intensive Care Coordination using Wraparound, Intensive In-Home Mental Health Treatment Services, Parent and Youth Peer Support, Respite Care, Flex Funds, Trauma-Specific Treatments and Trauma-Informed Systems, Specific Evidence-Informed and Promising Practices, and Telehealth Services. Oregon is working on implementing all of the listed components statewide except for respite.

hospitalization.[3] Provision of respite to youth and their families builds family cohesion, reduces stress for youth and caregivers, lowers economic burdens for families and the system, and contributes to overall healthier communities.

Despite its importance, respite is difficult to find and access. As of March 2024, four Local Systems of Care[4] (L-SOCs) have elevated the lack of a respite as a barrier to the System of Care Advisory Council (SOCAC).[5] Respite is difficult to access for many reasons, including lack of funding, workforce, youth-initiated options, information about available respite, and stigma. While certain respite services are provided and reimbursed by both the Oregon Department of Human Services (ODHS) Child Welfare Division and Office of Developmental Disabilities Services (ODDS), even families eligible for these services face barriers.

Many entities in Oregon understand the importance of youth respite:

- The OHA Ombuds program recently issued a report that highlighted respite as a primary recommendation for improving the children's mental health system.
- For the 2023 – 2025 Agency Request Budget, the Oregon Health Authority (OHA) submitted a Policy Option Package to fund respite for Oregonians with Medicaid. This funding request was denied by the Legislature.
- The Health Evidence Review Commission (HERC) includes respite on its prioritized list of services for over 32 behavioral health diagnoses such as major depression, schizophrenic disorders, substance-induced mood, anxiety, delusional and obsessive-compulsive disorders, and others.
- The November, 2023 Report of the Special Master CASA for Children, et al. v. State of Oregon et al. United States District Court for the District of Oregon included respite for resource families and kin caregivers as a way to address temporary lodging for children in Oregon.

[3] Residential treatment and inpatient psychiatric hospitalization of youth are extremely costly to Medicaid and other insurance payers while respite costs are relatively low and can provide alternatives to high-cost, out-of-home settings and stays. A 2013 report from the Parent/Professional Advocacy League and the Massachusetts Department of Mental Health estimated the cost of three months of respite care as $3,000, while three months of care in a group home was estimated to cost $29,000.

[4] Lane County, Douglas County and Central Oregon and Linn, Lincoln and Benton Systems of Care.

[5] Oregon's System of Care Advisory Council (SOCAC) is a governor-appointed body that acts as a central, impartial forum for statewide policy development, funding strategy recommendations and planning. Established by Senate Bill 1 in 2019, the SOCAC's goal is to improve the effectiveness and efficacy of child-serving state agencies and the continuum of care that provides services to youth aged 0 – 25 years old.

Process and Methodology

SOCAC recruited a nine-month Portland State University Hatfield fellow in summer of 2023 to conduct an assessment of the policy landscape in Oregon, with aim of informing policy recommendations to be adopted by the SOCAC. The fellow conducted interviews with dozens of subject matter experts, including state agency staff, respite providers, System of Care coordinators, payers of respite services, and system leaders in other states. To center the experiences of youth and family, the SOCAC partnered with Youth Era and the Oregon Family Support Network (OFSN) to distribute online surveys across the state. The SOCAC also partnered with OFSN to host two parent/caregiver specific listening sessions virtually.

The Hatfield fellow convened a series of four respite policy workshops. Two of the workshops were focused on formal respite, for specific diagnoses or other eligibility criteria, and two of the workshops were focused on informal respite which is more universally offered. Participants included youth, family members, state agency partners, respite providers, and respite service payers. Participants reviewed themes from the youth and family focused engagement, and then identified primary barriers based on these themes. A series of recommendations to address the barriers was then generated. To further distill and prioritize the recommendations, a feedback loop session was held with workshop participants, interested family and youth, and state agency partners. This report is a culmination of the fellow's research and the policy recommendations co-created with system involved youth and family members.

*Disclaimer: Despite due diligence on the part of the fellow and the SOCAC, not all statements have been validated in this report. For instance, some information about services was gathered from websites, but we were unable confirm whether those services are still offered.

Definition and scope

This report has taken a broad approach to respite and encompasses services that may be ordinarily categorized as educational or childcare. This inclusion is intentional to illustrate the frequent exclusion of youth with complex needs from traditional services and supports. This report refers to youth with "special health care needs." Although this phrase is typically understood to include those with physical disabilities, this report is focused solely on the needs of young people with intellectual and developmental disability and/or behavioral challenges. Furthermore, although much of the respite literature refers to a lifespan approach that acknowledges that some people rely on caregiving throughout their life, this report focuses primarily on the needs of those 25 and under. Child(ren), youth and young people/person are used interchangeably to refer to the person receiving care during respite, regardless of age. Parent, family member, and caregiver are used interchangeably and refer to the adult with primary caregiving responsibility for a young person, regardless of legally defined relationship. Respite provider refers to the person providing respite services, regardless of setting, licensing, or certification. Quotes used throughout this report, indicated by italics or blue text in

textboxes, are from youth and family members who engaged with the SOCAC through surveys and listening sessions.

This report does not describe respite offered by Oregon's Tribes, nor does it include any information about respite provided by non-Medicaid insurance providers or respite available for hospice or physical medical conditions. Currently, insurance for United States Military families such as TRICARE or CHAMPVA has not approved respite services for youth under 18 or their caregivers and their current funding model (direct payments to providers for approved services) does not make it possible to braid funds for respite[6]. Many of the respite policy recommendations in this report are intended to be insurance neutral with aim of ensuring access to respite for any family or youth who needs it, regardless of insurance coverage.

Lastly, SOCAC's definition of respite does not fully encompass the daily realities that many families and youth face. Partners in this work have stressed the need for a clear definition and messaging about respite. For example, use of the word "break" to describe respite might feel stigmatizing to those who use respite. Alternate language such as *change in scenery* or *preventative support* are being explored by the SOCAC and partners. Language can carry stigma and shame, and further work is needed to rectify problematic or stigmatizing language around respite.

[6] Military insurance options only cover respite for caregivers of veterans and active service members. Currently there are no approved respite services for children on Military insurance plans as per the TRICARE and CHAMPVA covered services lists.

Youth and Family Experience

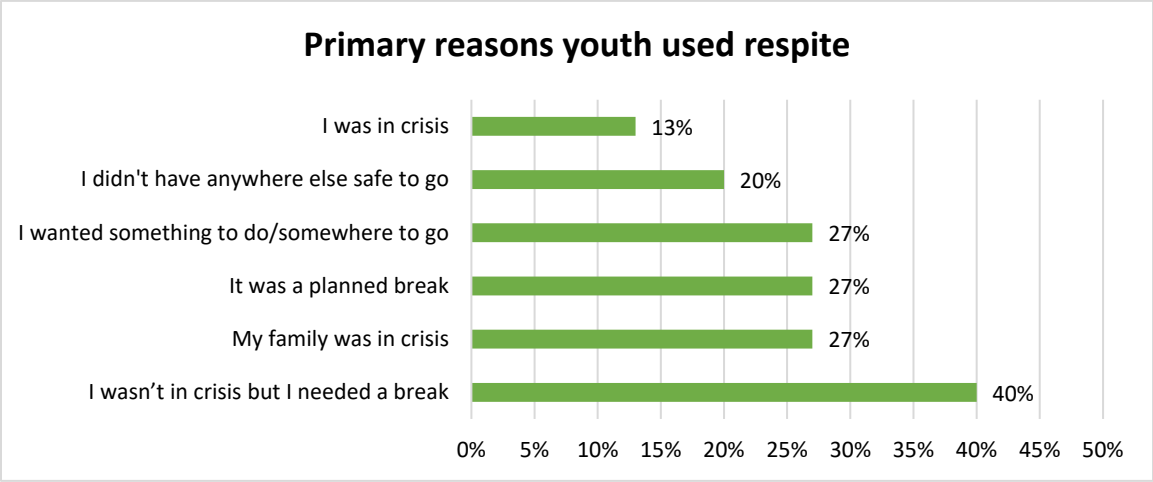
To understand the experiences of youth and family, the SOCAC distributed online surveys (in English and Spanish) via the Oregon Family Support Network (OFSN), Youth Era, and System of Care networks across the state. In partnership with OFSN, two online listening sessions were held with caregivers. The data presented below is in addition to the stories and experiences gathered via prior efforts conducted in development of the SOC Strategic plan and in related efforts hosted by regional SOC partners.

Youth

Surveys to youth were distributed across the state through local systems partners and Youth Era drop-in centers. All youth who participated in the survey were compensated for their time. Fifty-one people attempted to take the survey though only 29 respondents were under 25 years old and eligible to take the survey. Of those who completed the survey, 60% stated they were living with their biological family while others mostly lived with adoptive or foster parents. Most youth responses came from Washington, Clatsop, Marion, and Lane counties. 73% of youth respondents identified as White or White and some other race/ethnicity, 53% as Hispanic/Latino/a/x, and 13% as Black or African American. Seven youth were female, six were male, and two were transgender or non-binary.

Youth who had received respite

Fifty-seven percent of youth who took the survey had used a form of respite in the past three years which they all stated as generally positive experiences (wonderful or just okay). Youth expressed different reasons for needing respite and different experiences while receiving care.

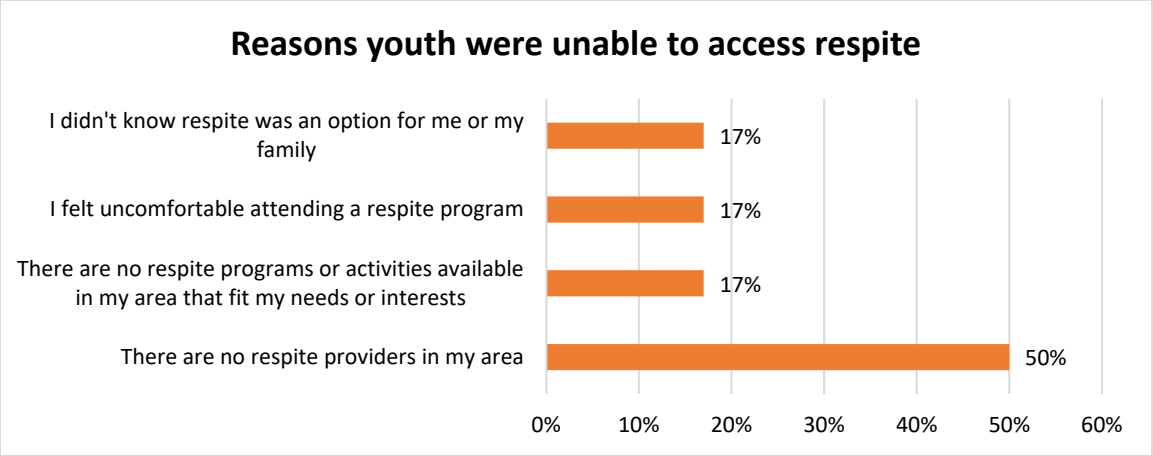


Five youth used respite for a full day but not overnight, six youth respite experiences lasted for one or more nights, and three youth had respite for only a few hours. Half of the youth received

respite at a friend or family member's home while others stated they received respite in their home, at a resource family's home, or a dedicated respite facility. Youth highlighted getting a break from stress and being able to socialize as the best part of respite and missing home/their family as the worst part. As a whole, youth found breaks from their home lives as beneficial.

Youth who had not received respite

Of youth who had not used respite, the themes of what they wanted to experience were similar to those who had received respite. Most of the youth said they wanted respite to get a break or because of a personal or family crisis, and that they had only wanted a few hours of respite. Half of respondents said they would have liked to receive respite in a friend or family member's home, a drop-in youth program, in their home, at a school-based program, or a faith-based program. The primary barrier was not knowing of any providers in their area who could address their needs.



All youth respondents

For all youth who took the survey and other sources of youth input in Oregon,[7] the most common elements desired are availability of recreation and activities, providers who understand what they're going through and are available to talk/socialize, and a sense of safety and peacefulness. Most youth cited that they didn't want overstimulating or crowded environments, a lack of choice/flexibility during their stay, and too many rules/strictness.

Overall, youth appear to want flexibility and choice in the type, location, and duration of respite. Staff should be trained, approachable, and understanding of what the youth are going through. Much of what youth desire aligns with what family members and caregivers want their youth to receive.

[7] The North Coast System of Care hosted two listening sessions about respite with their Youth Advisory Council on March 8, 2023, and April 12, 2023.

Family and Caregivers

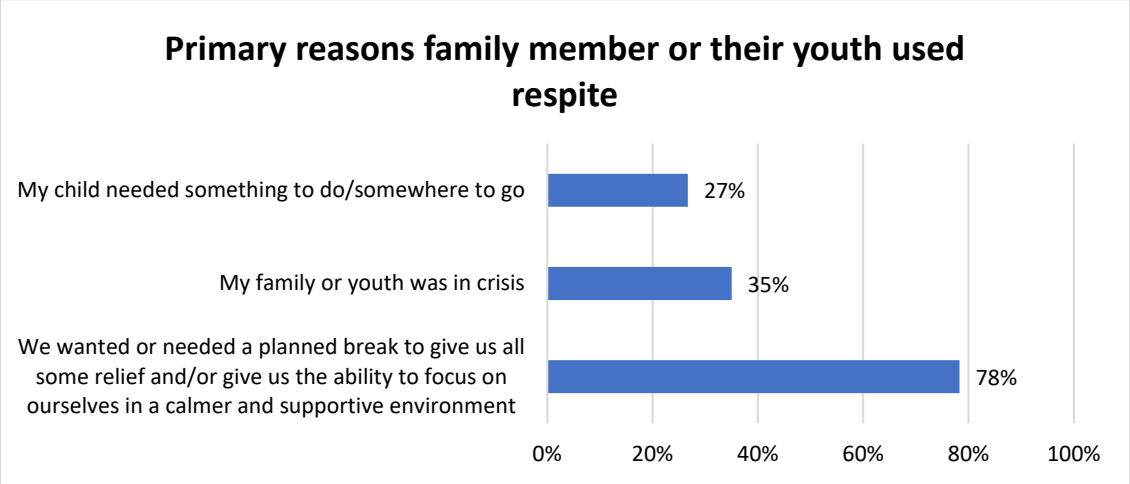
Family and caregivers of youth were reached through the distribution of surveys by OFSN and local systems partners, and through two listening sessions hosted by OFSN.

One hundred and seventy-three family members and caregivers took the survey (165 took the English version and eight took the Spanish version). Seventy-one percent of respondents were their youth's biological parent while 27% were adoptive, foster/resource parents, or legal guardians of youth. Based on the survey results, biological parents accessed respite care nearly 15% less than adoptive, foster/resource, or legal guardians did. At least one response was received from 20 (out of 36) counties in Oregon, with majority of responses from Lane and Multnomah counties. The vast majority (90%) identified as White or White and some other race/ethnicity, followed by 19% identifying as Hispanic/Latino/a/x, 11% identifying as American Indian/Alaska Native, 4% identifying as Black/African American and 3% identifying as Asian.[8] The majority of respondents identified as female (84%), followed by 9% who identified as male, and 8% who identified as transgender or gender non-confirming.

Family and Caregivers who had used respite

Forty-four percent of all survey respondents had utilized respite in the past three years. Of those who had used respite, all rated it favorably (wonderful or just okay). Of the survey respondents whose family or youth had received respite:

- The majority (78%) used respite as a planned break to get relief.



[8] 65% of respondents identified as White only. Race was measured using the Race, Ethnicity, Language, and Disability (READ) method in which survey participants were asked to select all of the racial and ethnic identities that applied to them.

- 38% used respite for a few hours, 24% used it for 1 overnight, and 22% used it for multiple days/nights.
- 29% of youth stayed in a friend or family member's home, 20% stayed in their home with a provider, and 15% of youth stayed with a resource parent. Other locations included dedicated respite homes, drop-in centers and shelters, residential treatment facilities and schools.

When asked about the best parts of the respite services they used, caregivers cited the ability to have alone time/a break from parenting and that respite providers were caring, safe and well-trained. The worst parts were lack of available respite in their community, and lack of training among providers.

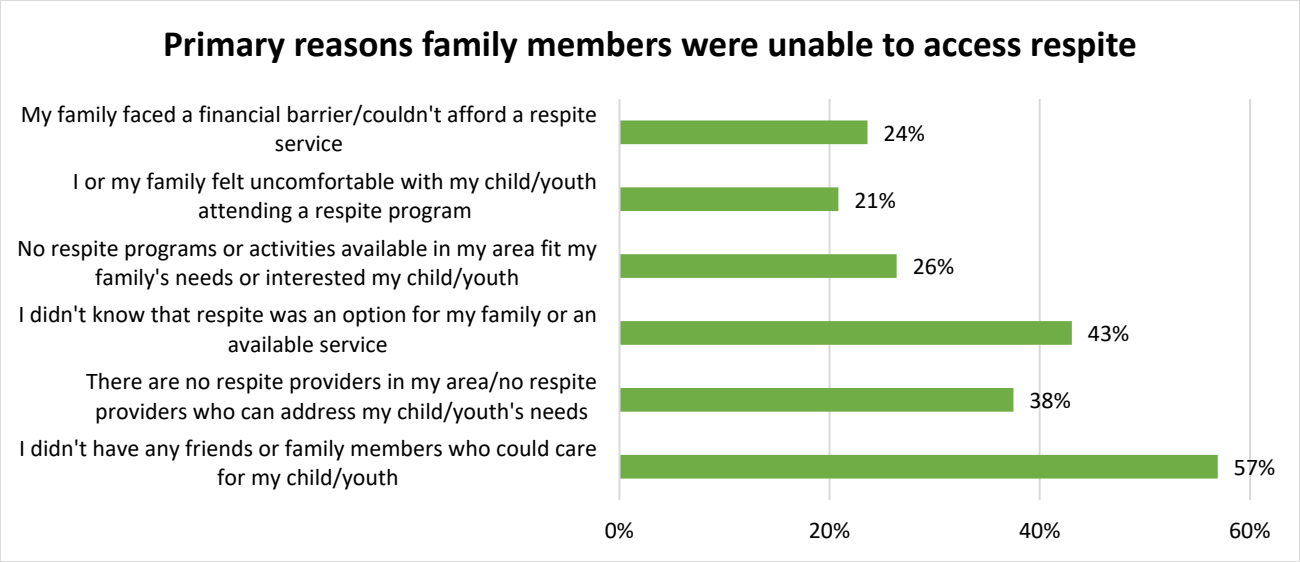
Similarly, family members who attended the listening sessions had primarily used respite for a few hours at a time instead of overnight care. Though many people had accessed some sort of respite, they agreed that the system is not very accessible nor a "regular" support. Caregivers would like more support from systems they are already engaged in, for example schools and Intellectual and Developmental Disability services, and for respite services to be more frequent. Respite takes many forms and families consider anything from appointments their children have with Direct Support Workers to their teenagers going to a drop-in center for a few hours as respite.

Family and Caregivers who had not used respite

The themes and desires expressed by family members who had not accessed respite were fairly consistent with those who said they had used respite.

- Nearly 80% said they had wanted respite for a planned break, 30% needed it during crisis, and 30% wanted to give their young person something to do.
- 60% needed respite for just a few hours, 55% wanted respite for a full day, and 43% wanted overnight care.
- 60% would have liked to receive respite in their home, followed by 46% who wanted it at a friend or family member's home and 31% who preferred school-based supports.

Caregivers faced a variety of barriers to accessing respite for themselves and their youth. The lack of available respite was the largest reason people were unable to receive respite.



Survey respondents and listening session participants also identified barriers related to existing systems and the lack of training among respite providers. Families served by the I/DD system desire greater flexibility in how and when respite is provided and for support workers to be able to provide respite. For example, many agencies only allow for overnight respite, while families would like respite services during the day. Existing respite/youth programming through schools and community programs are often inaccessible to youth with complex needs due to the lack of training/awareness on how to deal with "big behaviors" and disabilities. Families talked about being kicked out of afterschool/community programs or consistently having to miss activities due to their children's dysregulation. Family members and caregivers also brought up the fear of leaving their children with strangers or untrained providers.

> *"Imagine being given a recipe, but instead of all the ingredients, you get random things, and you still need to produce the finished product. That's what it feels like navigating the system and getting our needs met."*

All family members and caregivers

Overall, all families who engaged with the survey or listening sessions felt that respite was valuable to them and their children and would like to have more of it available. The most consistent theme when it came to respite was the ability for parents and caregivers to "*fill their cup before it's dry*" through respite services.

Current Respite Services and Supports

Respite services are categorized as either formal or informal. Formal respite is generally defined as services based on specific program eligibility (such as I/DD or child welfare) or a diagnosis (e.g., behavioral health condition). Formal respite is often funded, in part, by Medicaid dollars, and therefore must follow more rigid regulations and laws. Informal respite is more universally offered and offers more flexibility in terms of providers and settings. Regardless of where or how respite is provided, cultural and linguistic responsiveness is a best practice.

Informal respite

Informal respite availability varies by communities, family resources, geographic regions, and other factors. Access to informal respite resources is highly inconsistent across the state, and the level of care provided to each child varies from provider to provider.

Afterschool and out-of-school based supports

> *"My granddaughter needs more after school opportunities to separate her from media and provide other activities to keep her from decompensating."*

Although school is not respite, public schools do provide a free and consistent break for caregivers of school-aged children. While schools are required by law to provide accommodations for students with disabilities, numerous barriers exist in meeting the educational needs of all students. Abbreviated school days and inequities in the application of local discipline policies are particular challenges to meeting the needs of students with complex behavioral needs and related disabilities.

The majority of parents who participated in listening sessions reported that their student was kicked out of or unable to attend afterschool or summer programming.

While many families find afterschool programming extremely beneficial, afterschool activities (sports, clubs, etc.) hosted by schools and community programs struggle to provide inclusive programming for all kids. Breaks in the school calendar and the length of an average school day also pose challenges for caregivers, especially for those who work. Though private camps and out-of-school programs provide enriching extracurricular activities for students, youth with complex behavioral and physical health needs are often excluded from these opportunities due to lack of experienced staff.

Criteria	Description
Where its provided	At schools, parks, and community centers.
Who is providing it (training,	Staff consists of licensed teachers, educational assistants, volunteers, community-based organization staff, retired teachers,

licensure/certification requirements)	etc. Required trainings for staff and volunteers are determined by funding source and vary. [9]
Who's eligible for the service	All students, but discipline policies may be exclusionary. Staff may not be trained to provide care for children with complex needs.
Cost of service (rates, room and board, etc.)	Ranges from free to expensive for private programs.
Funding sources	Federal, state and local funding, including state and non-state funders.
Rules	581-017-0620, 581-017-0623, 581-017-0629, 581-017-0632, 581-071-0635
Resources	https://www.oregon.gov/ode/students-and-family/equity/culturallyspecificafterschoollearning/pages/culturally-specific-after-school-learning-(csasl)-grants.aspx https://www.oregon.gov/ode/schools-and-districts/grants/esea/21stcclc/pages/default.aspx[10] https://www.oregon.gov/ode/studentsuccess/pages/summer-programs.aspx https://oregoncf.org/grants-and-scholarships/grants/ https://www.oregonymcas.org/ https://www.bgca.org/

[9] For The Nita M. Lowey 21st Century Community Learning Centers (21st CCLC), 5% of their total budget must be dedicated towards professional development. There are also program requirements for professional development in the Oregon Department of Education's (ODE) Student Success Act Summer Programs grant. Oregon Community Foundation also has a large footprint in staffing and training of providers.

[10] The Nita M. Lowey 21st Century Community Learning Centers (21st CCLC) grant is the only federal funding source dedicated exclusively to the creation of before school, afterschool, and summer learning programs. The 21st CCLC grant is a competitive grant authorized under Title IV, Part B of the Elementary and Secondary Education Act, as amended by the Every Student Succeeds Act (ESSA) of 2015.

Childcare settings

Only 22% of children under age five have access to childcare.[11] While early learning and childcare settings are not respite, like K-12 education, they also provide important caregiving breaks for families. While some care is subsidized through programs like Head Start or the Employment Related Day Care program, most care is prohibitively expensive, especially for infants. Aside from the burden of finding affordable care, especially in rural areas, suspension and expulsion can be remarkably common for young children who present needs that exceed early learning and care professional resources and expertise. The Oregon Department of Early Learning and Care's Early Childhood Suspension and Expulsion Prevention Program is building capacity and professional development among the early childhood workforce to better equip them in meeting the needs of all children.

Criteria	Description
Where its provided	In licensed childcare settings – both facility and home based. Some providers are exempt from licensure.
Who is providing it (training, licensure/certification requirements)	Staff providing services have achieved qualifications identified in Certified Child Care or School Age Child Care Centers Rules; Certified or Registered Family Child Care Homes Rules; Head Start Performance Standards.
Who's eligible for the service	All, especially children under five years old
Cost of service	Varies, from free to very expensive. Average annual cost of full-time care per head is $13,000.
Funding sources	Federal, State and Local Funding (profit and nonprofit organizations)
Rules	414-500-0050, 414-061-0020
Resources	https://www.oregon.gov/delc/programs/Pages/sepp.aspx

Some communities and organizations across the state have implemented a "village" model to support families with young children and cultivate a sense of community through childcare. One such organization is Central Oregon's ReVillage which connects families to each other and works to cultivate affordable, accessible, and equitable childcare cooperatives centered on relationship.

[11] Based on data collected before the Covid-19 pandemic. Access to childcare is predicted to be higher in 2024.

Community and faith-based programs

Respite is sometimes offered by community-based organizations (CBO), including faith-based programs. This type of respite can look like a sponsored "parents' night out", a youth or adult drop-in space or a mentoring program. Some faith-based programs such as Safe Families for Children can provide long term care for children whose families are experiencing crisis. While faith-based partners provide important care resources, not all families may find these services appealing or culturally responsive. Oregon providers of community-based respite include Oregon Family Support Network, Safe Families for Children, Youth Era, North Star Clubhouse, Holla Mentors, and Rogue Valley Mentoring.

> *"As a different needs family, often we are excluded or forgotten in most regular events or programs due to behavioral and social factors that impede a connection in neurotypical settings. To find a place where it feels like the youth can be met where they are and who they are would be a great way to help build in gaining even a sliver of respite by simply finding a place that feels like "second home" for those with exceptional needs."*

Criteria	**Description**
Where its provided	Varies – but typically in community-based settings, religious spaces, and youth-focused centers.
Who is providing it (training, licensure/certification requirements)	Volunteers and paid staff– who may or may not have formal training or certification, peer support specialists.
Who's eligible for the service	All; drop-in centers usually only allow youth 14 and older.
Cost of service (rates, room and board, etc.)	Usually free, sliding scale or low cost.
Funding sources	CCO Health Related Services, SHARE, foundations, etc.
Resources	https://ofsn.org/ https://safe-families.org/ https://www.youthera.org/ https://www.northstarclubhouse.org/ https://www.hollamentors.org/ https://rvmentoring.org/

Youth drop-in centers run by non-profit organizations exist in many communities and are typically available during afterschool hours for youth ages 14 – 21. Many drop-in centers are staffed by peer mentors and provide a safe place for youth to relax, have fun, and work on goals. Youth indicated a strong preference for more drop-ins to exist.

Friends and family

> *"I'm so scared to leave my kiddo with a stranger even if they are qualified. Our family/friends are helpful sometimes, but our kiddo's behavior can be a lot. However, we need a break."*

Most respite is provided via informal networks like friends, family, babysitters, and family support groups. While common, this type of care can be difficult to acquire for children and youth with special needs. Informal respite providers may not have the skills to care for a child with a behavioral health diagnosis or developmental disability. Parents and caregivers may not have adequate social networks or may feel uncomfortable leaving their child with a friend or family member. Some organizations (such as the Autism Society's "Take a Break" or "Take a Breather" programs) allow families to get reimbursed for a respite provider of their choosing, but this service is limited to certain diagnoses and require the caregiver to find their own provider. Family support groups through organizations such as the Oregon Family Support Network, the Autism Society of Oregon, or the National Alliance on Mental Illness Oregon may provide respite to one another, but care is dependent on group membership and relationship-building.

Criteria	**Description**
Where its provided	At youth's home or home of respite provider.
Who is providing it	Family, friends, babysitters who may or may not have formal training or experience.
Who's eligible for the service	All youth
Cost of service	Varies – from free, trades to an hourly rate.
Funding sources	None – caregiver is responsible for full payment unless participating in specific programming through an organization.
Resources	https://autismsocietyoregon.org/support/take-a-break-on-aso/ https://ofsn.org/ https://namior.org/support-groups/

"It's really difficult to find both the level of care for my child with special needs and someone I trust to watch my child. The people from services are qualified, but it feels like you have to let strangers watch your child and hope it all goes well. At the same time, I trust my friends and family, but it feels like they don't have the adequate experience to watch my special needs child. Currently, I am trying to get a friend who also has special a special needs child to become his DSP. In return I am trying to become her child's DSP. It seems to be the only way to get both the experience and trust we are looking for."

Formal respite

The availability of formal respite for families and youth depends on many factors including insurance plans, geographic region, behavioral or medical acuity, and system involvement. Even when families and youth qualify for formal respite services, barriers exist and families report their needs are unmet. Youth who are involved in multiple systems may have access to respite from multiple sources.

Behavioral health respite

The Centers for Medicare and Medicaid Services (CMS) policy does not currently allow for behavioral health respite for youth to be included in the state plan, and there are no state general funds allocated for respite. However, CCOs are allowed to pay for behavioral health respite for youth through their global budget, and some CCOs do. According to the SOC Dashboard, 357 young people received a respite service in 2022 (190 of these were aged 17 and younger). Although there is no rule, policy or procedure that defines this service, based on key informant interviews, it is generally a crisis related respite service provided in a certified facility that provides residential behavioral health treatment. The Health Evidence Review Commission has identified 31 behavioral health conditions for which respite is on the prioritized list of services. Although the implementation of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit has expanded access to services on the prioritized list for those 21 and under, respite is not included in EPSDT because it is not allowed in the state plan. Most states provide behavioral health respite via the 1115 [12] or 1915 waivers[13], an opportunity Oregon has not yet explored. Youth respite is not known to be funded by any non-Medicaid insurance providers.

OHA reimburses for up to 30 days of "Crisis Respite Services" for Medicaid-eligible individuals who are currently residing in a Residential Treatment Facility (RTF), including secure facilities. Those living in Residential Treatment Homes and Adult Foster Homes are not eligible for this service. Although named respite, the definition of this service is not consistent with how respite is defined in this report. In addition, staring in 2024, Oregon will be piloting a peer delivered respite service for those 18 and over, using state general funds.

Certain respite services can also be funded by Coordinated Care Organizations (CCOs) through CCO Health Related Services (HRS) spending. CCOs may use their Medicaid global budgets to provide HRS at both the member and community level. HRS are not a covered benefit, but

[12] Under the 1115 demonstration waiver, respite services may include temporary placement of a beneficiary who otherwise lives at home into an institutional setting so that the beneficiary's at-home caretaker can have a break from caretaking.

[13] For 1915(c) and 1915(i) demonstration waivers, room and board may be claimed for temporary short-term respite services that are furnished in settings that are not the participant's own private residence, and a state may elect to pay the portion of the rent and food. There are no federal limitations on the frequency of respite services under these authorities.

rather are complementary to OHP covered benefits. In 2022, $2.1 million was spent on youth respite services by CCOs through two primary HRS spending categories - education for health improvement or education supports and other non-covered social community health services and supports.

Criteria	Description
Where its provided	In designated respite facilities & respite lodges[14]
Who is providing it	Licensed Mental Health providers (provider type 33)[15]– see footnotes for code related requirements.
Who's eligible for the service	Young people with a behavioral health diagnosis served by a CCO. Young adults 18 and over are eligible for peer respite.
Cost of service	The following codes are being used: H0045 – Respite care services, not in the home, per diem ($858.00)[16] T1005 – Respite care services, up to 15 minutes[17] S5150 – Unskilled respite care, not hospice; per 15 minutes
Funding sources	CCO Global Budgets, General funds
Rules	309-020-0105
Resources	https://www.oregon.gov/oha/HSD/BH-Child-Family/Pages/index.aspx

What happens in other states?

North Carolina uses a 1915(i) waiver to cover respite services for the primary caregivers of children and adolescents aged 3 to 20 with a serious emotional disturbance or substance use disorders (SUD) as well as for the family members of a beneficiary with an I/DD or traumatic brain injury diagnosis. Both in-home and out-of-home respite services can be used on an overnight basis, for a weekend, or on an emergency basis (excluding out-of-home crisis).[18]

Through OhioRISE, the state's single Medicaid managed care plan dedicated to serving children with complex behavioral health needs, Ohio uses a 1915(b)(3) waiver authority to fund respite services that are available on a planned or emergency basis. Behavioral health respite services are available for the primary caregivers of children and youth up to age 21 and "provide short-temporary relief in a home or community-based environment."

[14] Respite lodges are home-like settings that are run by community organizations with trained staff (house parent roles) such as Kairos or Catholic Community Services where youth can stay overnight for planned or crisis respite.
[15] Provider Type 33 includes : Community Mental Health Program, Community MH Center, Adolescent/Children Community Mental Health Center, CCBHC Certified Community Behavioral Health Clinic, Community/Behavioral Psychiatric Residential Treatment Facility, ABA Organization, Education Agency, and more.
[16] Rate provided is for Fee For Service, CCOs determine their own unique rates. H0045 requires modifiers HK and HE or TG. Covered for MH providers only, limited Dx Codes, not Medicaid covered.
[17] MMIS shows covered for Prov Type 33 (MH) only and with limited MH Dx codes.
[18] Until recently, North Carolina used 1915(b)(3) authority to fund respite services, but, recently, the state transitioned to use of a 1915(i) State Plan Amendment, effective July 1, 2023.

Child Welfare

> *"We begged DHS for respite care before we reached a point at which foster, and then residential care was the only option to save our family. Prior to that, we were consistently told there were no resources available. After we reinvolved DHS, they offered us a respite service."*

The Oregon Department of Human Services (ODHS) defines respite care as "an arrangement to relieve a family, with an open child welfare case or a certified resource family, of their responsibilities by a person temporarily assuming responsibility for the care and supervision of a child or young adult." Resource families have access to respite services and ODHS is developing a program that would expand respite to biological families during a trial reunification. Respite care can be pre-planned or provided as crisis-support for a resource family. Resource families are eligible for up to 3 respite stays per month with additional opportunities to increase beyond 3 stays depending on the family's needs. The ODHS Foster Care Program develops rules, processes, and training. ODHS staff certify respite providers and support resource families in accessing this service. A Certified Respite Provider is trained to provide temporary care and supervision of children and youth in foster care. Informal respite care is defined as "respite care provided by an individual known to the certified resource parent and/or the child or young adult in care when that individual is not a Certified Respite Provider or a certified resource family."[19]

Criteria	**Description**
Where its provided	In certified respite resource homes and Tribes in Oregon
Who is providing it	Certified respite care providers[20] and informal respite providers.
Who's eligible for the service	Children and youth 18 and under who are in a resource home, and biological families during trial reunification
Cost of service	$55 per day for informal respite and $80 per day for formal certified respite
Funding sources	State General Funds
Rules	419-440-0150, 413-200-0281
Resources	https://www.oregon.gov/odhs/providers-partners/foster-care/pages/default.aspx

[19] Informal respite providers through ODHS are often family and friends of the youth or the resource family.
[20] As defined by 413-205-0035, 413-205-0060, **413-205-0025**.

Intellectual and Developmental Disability services

Families caring for a youth with diagnosed intellectual or developmental disability have access to respite or alternative care. Although not officially respite, care provided by Personal Support Workers or Direct Service Providers also provides respite for many families. Within I/DD services respite care is called "relief care."

"Our son is nonverbal and uses ASL [American Sign Language] to communicate. We have yet to find a DSP that knows any ASL in our area. I would be worried about his ability to communicate his needs to the respite care worker."

Criteria	**Description**
Where its provided	Most often in the home of the child, though a certified child foster home is an eligible setting.
Who is providing it (training, licensure/certification requirements)	Most often, Personal Support Workers provide relief care, though licensed and certified in-home agencies are able to deliver relief care as are certified child foster care providers.
Who's eligible for the service	Any child who is determined eligible for I/DD services and who has a need for the service
Cost of service (rates, room and board included, etc.)	PSWs get $19.50 per hour. Other providers get $232.25/day, which is an inclusive rate.
Funding sources	1915(k) Community First Choice State Plan Amendment (K plan).
Rules	Chapter 411, Division 450
Resources	https://www.oregon.gov/odhs/providers-partners/idd/Documents/odds-expenditure-guidelines.pdf

Juvenile Justice involved

OYA foster parents who are caring for a youth may also access respite services. As defined by OYA, respite is a temporary arrangement of 12 hours or more that allows an OYA treatment foster parent(s) time away from an adjudicated youth.

Criteria	**Description**
Where its provided	In respite provider's home
Who is providing it (training, licensure/certification requirements)	OYA certified respite providers
Who's eligible for the service	Certified OYA foster parents
Cost of service (rates, room and board, etc.)	This depends on the rate the foster parent is being paid: Advanced-55$/day, Medically Enhanced-66$/day
Funding sources	General Funds and Special Pay
Rules	416-530-0060 and 416-530-0200
Resources	https://www.oregon.gov/oya/foster/pages/default.aspx

Relief Nurseries

Relief Nurseries offer therapeutic educational classroom programming, respite services, home visits, basic needs, and other parenting supports to families experiencing poverty, mental illness, addiction, and trauma.[21] Relief nurseries partner with families to provide the help, tools, and information they need to be the best parents they can be. Relief Nurseries provide early intervention that focuses on promoting strong parent-child attachment and the safety of the household by offering comprehensive and integrated family support services.

Criteria	**Description**
Where its provided	Designated facilities that are certified by the Oregon Association of Relief Nurseries
Who is providing it	Relief Nursery staff are trained in the Relief Nursery Model, which provides therapeutic classrooms and home visiting. Teachers are Step 7 or higher through ORO, and many are endorsed in Infant Mental Health. All Relief Nursery sites are certified through the Office of Childcare. Services vary across sites, but all include home visiting, therapeutic classrooms, parenting education, and respite for enrolled families.
Who's eligible for the service	Children from birth through five and their families.
Cost of service	Free
Funding sources	State General Funds, CCO HRS, foundations, etc. In 2022, CCOs invested $730,655 in Relief Nurseries.
Resources	https://www.oregonreliefnurseries.org/

[21] Services differ by site and region of the state. To participate in relief nursery programming, families must demonstrate at least five family stressors which are self-determined. Programming provided is tailored uniquely to each individual family and families/staff will work on anything identified as a stressor.

Respite Policy Recommendations

The SOCAC convened a series of workshops for family members, youth, state agency partners, respite payers, and respite providers. Participants identified barriers to respite based off of findings from surveys and listening sessions. For each barrier, participants then identified strategies through small group discussion and brainstorming on electronic whiteboards. These strategies were further informed by research and findings from state agency partners, best practices in other states, and recommendations from Local Systems of Care (L-SOCs). To further distill the policy recommendations, the SOCAC then hosted a feedback loop session with workshop participants, interested family and youth, and state agency partners to prioritize the recommendations identified in the policy workshops.

Top barriers to youth respite

- Funding models for respite which restrict eligibility or access
- Workforce
- Stigma and messaging around respite
- Lack of knowledge and information
- Lack of youth-initiated options

Prioritized Policy Recommendations

Policy recommendations are organized by barrier, with prioritized recommendations indicated by italicized text.

Funding models for respite which restrict eligibility or access

- ***Braid and blend funds across child-serving systems to develop a continuum of respite infrastructure within local communities.***
  Braiding and blending funds from Medicaid, private insurance, and other child-serving agencies and organizations can help to bridge the gap for program funding. An example of how this may occur is braiding funding for summer programming for youth with existing funding streams such as Medicaid and state education funds. Other funding streams such as funding through the Family First Prevention Services Act should be explored as possible methods of funding respite care in communities. Mobile Response and Stabilization Services (MRSS)[22] is another funding stream that could offer respite as a service following a crisis response or create more respite opportunities within Crisis Stabilization Centers. Braiding and blending funds will help to increase broad, community level access to respite services for all families, regardless insurance or medical diagnosis. Braided and blended funds should ensure access to varying levels of respite from prevention services to higher acuity crisis settings.

Example: New York's youth respite delivery model implements a two-tiered system that includes a State Plan Amendment (SPA) and the 1915(c) Children's Waiver. In 2011, New York combined six 1915 waivers into one waiver, the 1915(c) Children's Waiver. The SPA for respite require a diagnosis, while the waiver for respite is for high need, high risk youth with diagnoses. Respite through the SPA is based on need and must be used before the waiver for respite can be turned on. Respite provided through the 1915(c) Waiver is for youth with higher needs than the SPA can provide and is for planned and crisis respite. Respite services through the SPA and waiver are administered through Medicaid Managed Care Plans (similar to CCOs) which serve the majority of children in New York. Billing for respite services is handled by the Managed Care Plans and rates and billing types vary based on respite type and lengths of stay. New York also has many informal respite services in which counties received money from the state to provide respite programming.

[22] Mobile Response and Stabilization Services (MRSS) are developmentally appropriate crisis response services for youth and their families in Oregon. Every county in Oregon has MRSS services available which can provide in-person face-to-face crisis response to youth and their families, connect youth and families to behavioral health supports, deescalate situations, and prevent unnecessary trips to emergency departments and law enforcement interactions. MRSS is considered to be a beneficial service within a functional system of care.

- ***Leverage existing programs, organizations, and provider capacity.***
  There are numerous opportunities to expand on existing respite programs. By leveraging programs and models already in use, respite offerings can be scaled to meet the need. This could be accomplished through:
  - Tapping into programs such as relief nurseries or behavioral rehabilitation programs to coordinate volunteers and training requirements for incoming respite providers,
  - Establishing payment mechanisms for informal and natural supports to enable payments to family and friends who provide respite,
  - Expanding the availability of and funding to peer-led respite and drop-in centers and their umbrella organizations, and
  - Providing capacity-funded overnight respite care already provided in existing programs.

Example: The Arc of Lane County provides group respite events to youth who experience a disability, mental health or behavioral health concerns. The Arc of Lane County had previously provided respite programs for youth but had to stop due to a lack of funding streams. Revival of the respite program was made possible with grants from the Lane County System of Care and the prior experience the Arc of Lane County had with providing respite.

- ***Develop guidance for Coordinated Care Organizations (CCOs) on how they can fund respite for their members.***
  CCOs, per their contract with OHA, are responsible for convening Local Systems of Care (L-SOCs). CCOs can provide respite though available funding mechanisms such as Health Related Services (HRS)[23] and the Supporting Health for All through Reinvestment (SHARE) initiative.[24] OHA should provide guidance to CCOs on how these funds could be leveraged. Community Based Organizations (CBOs) do not often apply for the funds due to uncertainty around eligibility and parameters for programming. L-SOCs and CCOs should work to build relationships with CBOs and provide examples of how these funding streams can support youth respite. OHA can also provide additional guidance and communication to CCOs on the Medicaid codes already available to use for youth respite.[25]

[23] Health Related Services (HRS) are services beyond CCO members' covered benefits to improve care delivery, and support overall member and community health and well-being. HRS services include flexible services which help individual members to supplement covered benefits and community benefit initiatives which are community-level interventions to improve population health and health care quality.
[24] The Supporting Health for All through Reinvestment (SHARE) initiative requires that CCOs invest some of their net income or revenues back into communities to address health inequities and the social determinants of health.
[25] The following codes are being used: H0045 – Respite care services, not in the home, per diem; T1005 – Respite care services, up to 15 minutes; S5150 – Unskilled respite care, not hospice; per 15 minutes.

In a data search conducted by OHA Staff, it was found that $2.1 million was spent on youth respite services by CCOs through HRS spending on over 20 projects. Below are three relevant examples of CCOs who used HRS to support youth respite services in 2022:

- Columbia Pacific CCO helped fund the Wildflower Play Collective for free and sliding scale memberships. Wildflower Play Collective has a free play space, parenting classes, child enrichment programs, and other programming for families with young children.
- PacificSource - Marion Polk helped fund the Family Building Blocks relief nursery for therapeutic classrooms, outreach home visiting, wraparound services, and emergency respite care.
- Umpqua Health Alliance helped fund the Douglas Education Service District's PartnerSports Camp, which is a summer camp for children of all ability and skill levels. HRS covered the camp costs and tuition for all participants.

- **Research coverage offered by private and non-Medicaid insurance providers.** The Oregon Department of Consumer and Business Services (DCBS)[26] could work with private and non-Medicaid insurers to explore pathways for covering respite services. Multiple respite facilities such as Kairos' Interval House in Jackson County require youth to be on the Oregon Health Plan (OHP) and contract with specific CCOs which prevents youth without OHP from accessing respite services.

- **Consider alternate funding models through Medicaid used by other states to fund youth mental health respite.** The Centers for Medicare and Medicaid (CMS) allows for youth respite to be funded through a variety of mechanisms, including waivers, as part of Health-Related Social Needs (HRSN) services. Specifically, the Home and Community-Based Services authorities Sections 1915(b), 1915(c), 1915(i), 1915(j), 1915(j), and 1115, and In Lieu of Services (ILOS) provision can all be leveraged for respite. Within the HRSN services, CMS allows for respite to be received either in a facility or in the youth's home and cannot exceed 90 days duration.

[26] The Oregon Department of Consumer and Business Services is Oregon's consumer protection and business regulatory agency. They have authority in setting and enforcing standards in matters involving workplace safety and health, financial and insurance laws, building codes, and workers' compensation benefits.

Workforce

- ***Increase the number of respite providers.***
  Workforce issues are a barrier to providing respite care. Youth and their families face barriers to finding culturally and linguistically responsive respite providers. The number of new respite providers in Oregon can be increased by expanding educational opportunities and outreach efforts to recruit interested individuals to provide respite. Qualified individuals can come from a wide array of professions and backgrounds such as behavioral health providers, school staff, other youth, resource parents, future adoptive parents, family and youth support specialists, personal support workers, childcare providers, etc. Existing programs and organizations also provide an opportunity to increase the number of new respite providers as their existing volunteer networks or support groups hold many qualified individuals who may not been previously involved in respite service provision. Consistency in respite reimbursement rates and increases in worker pay will also encourage new respite providers and organizations.

Some examples of organizations and L-SOCs' efforts to increase the number of respite providers:

- Catholic Community Services' (CCS) Rainbow Lodge, a home-like respite facility in Yamhill County for youth ages 6 – 17, employs college students as group life workers to staff the lodge during the weekdays/nights (a formal "house parent" staffs the house on weekends and CCS staff is always on call). This model is mutually beneficial to the college students, who can receive training and develop skills to bring into the workforce post-graduation, and to the youth as the staff are able to fill peer mentor roles since they are closer in age to the youth.
- Eastern Oregon CCO and Greater Oregon Behavioral Health Inc. (GOBHI) attend community events to recruit respite resource families. Respite resource families are certified homes that provide respite to youth in the child welfare/foster care system.

- **Ease administrative burden and encourage people to stay or become respite providers.** Administrative burden is created by completion of required paperwork, redundant or unnecessary trainings, and certification processes. Often times the certification process for becoming a respite provider can be unclear and cause delays, this can be seen within Tribal communities and the Child Welfare Foster Care Program.[27]

[27] In a recent Legislative Commission on Indian Services report prepared by the Office of Tribal Affairs in December, 2023, updates on the Child Welfare Division highlighted how respite services for Tribal youth in foster care are being implemented with improved accessibility and support for families and providers.

The administrative costs of providing respite care often outweigh the payment received for the service. Organizations may see providing respite as too costly to justify. For example, Kairos is only able to maintain one respite home and can't serve youth in behavior rehabilitation services (BRS)[28] programs due to certification and payment barriers.

The Child Welfare Foster Care Program is working with Oregon Tribes to increase accessibility of respite care services for Tribal youth in care. Tribal certifications for placements of children in ODHS Child Welfare care and custody have long been accepted; there is not a written procedure on Tribal certification for the ODHS workforce and this lack of clarity can result in unnecessary processing burdens and placement delays. The Foster Care program is working on writing procedure to streamline the acceptance of Tribal certifications for child placements.

- **Increase provider training for existing providers who work with specialized needs such as complex and high-acuity behaviors.** Many family members mentioned that informal respite provides were often unable to care for their children due to lack of training and experience caring for children with complex needs. Family members requested the following types of courses be made available to respite providers:
    - Trauma-informed approaches
    - Medication distribution
    - Caring for physical disorders such as epilepsy or diabetes management
    - Autism-specific trainings
    - Linguistic responsiveness including American Sign Language (ASL) and working with non-verbal youth
    - CPR and first aid certification
    - Parent and caregiver support
    - Oregon Intervention System training
    - Cultural sensitivity

[28] Behavior rehabilitation services (BRS) provide services to youth with high acuity behavioral needs or trauma in Therapeutic Foster Care or residential facilities. Rules and certification around BRS provision have a high bar to entry for resource parents and any resource home or organization interested in providing respite to BRS-level youth must be fully BRS certified.

Stigma and messaging around respite

- ***Boost awareness of legislators and policymakers on what families and youth want when it comes to respite and supports.***
  Both youth and family members often feel unheard by policymakers. Youth and family members are unsure of how to effectively share their opinions and experiences with legislators and policymakers. When legislators and policymakers understand who the policy is serving and why it's important, it increases the likelihood of successful policy implementation. The SOCAC has recently brought on a youth and family engagement specialist who will work to ensure that lived expertise in navigating Oregon's systems is considered equally important to the Council's activities. This staff member will partner with other SOC staff and partners to increase supports and engagement for families and youth with lived expertise in the 2025 Oregon legislative session.

Example: REAP, a multicultural youth leadership program based in the Portland Metro area, is working to empower the voices of youth by creating opportunities for students to have a voice in decisions that affect them. REAP goes into schools and works with youth to engage them in current issues and develop leadership skills. One way REAP is empowering student voice is by engaging youth with elected officials and policymakers around education policy.

- **Reframe and communicate about respite differently**. Creating a shared language about "respite" has been challenging as different groups, individuals, and state agencies use different definitions. The SOCAC's working definition of respite uses the word "break" which can imply stigma and shame for families. Alternate language such as *change in scenery* or *preventative support* are being explored by the SOCAC and partners. Messaging and information about respite should be co-created with family, youth, and respite providers.

Example: Multiple states such as Montana and Nevada have worked to increase outreach about respite care to family members who may not know how to access respite or feel "guilty" about wanting a "break" from caregiving duties. Public awareness initiatives include resource guides, respite care toolkits, and videos to lessen stigma and connect families to providers and programs.

- **Build communities for families of youth with complex needs to minimize feelings of isolation.** Isolation is a common feeling among families and youth with complex needs. Parent groups convened by organizations like the Oregon Family Support Network, the Autism Society of Oregon, or the National Alliance on Mental Illness Oregon offer community and support to caregivers. Youth with system-involvement and/or complex needs can find community through drop-in centers, peer mentorship through organizations like Holla Mentors, or online through programs like Uplift by Youth Era which is focused on empowering and connecting youth.

Lack of knowledge about respite

- ***Tie youth respite to existing programs and efforts such as afterschool and out of school programs to increase funding, accessibility, and awareness.***
  Integrating youth respite services with existing programming can raise awareness of available respite and make existing programs more inclusive. By advertising respite services in schools and community centers, more people will use and advocate for it. Many youth with complex needs are unable to access informal respite programs like afterschool activities due to lack of trained and/or experienced staff. If traditional services, like afterschool programs are marketed as respite, awareness about and inclusivity in these programs can grow. By tapping into funding streams for traditional programming (such as State Education funds provided to school districts), more resources can be directed toward respite training and supports in those programs; exploring opportunities for Medicaid to fund afterschool programming and supports is also something that merits further investigation. One way that schools and communities can make programming more accessible is by increasing professional development opportunities for program staff about working with youth with complex needs.

Examples:

- The Oregon Department of Early Learning and Care (DELC) is working to make early child learning programs more inclusive through the Early Childhood Suspension & Expulsion Prevention Program which works to increase provider supports and training so that children with complex needs can participate fully in early childhood programs.
- The Oregon Expanding Afterschool and Summer Experiences (EASE) Collaborative is working to overcome historically inaccessible and inequitable afterschool and summer programming to ensure equitable access all Oregon students and families. To make the efforts and programs that come out of the EASE collaborative sustainable, the collaborative is looking for funding models that support long term investments which include things like summer learning grants and partnering schools with community organizations.

- **Activate knowledge about respite via parent groups that meet in person or via social media.** To normalize respite for families, more people need to be aware that it exists. Posting about or discussing respite in parent groups for youth who may or may not have system-involvement is a good way to increase knowledge about respite while also reducing stigma around needing relief.

- **Develop map and directory of available respite providers and services.** Many youth and family members who engaged with the youth respite surveys were unaware of the types of respite currently available. Multiple survey respondents highlighted not knowing about respite services available despite living in areas that had youth respite services available.[29] In order to increase the amount of youth respite in the state, there first must be an understanding what services are currently offered. SOCAC and other agency partners could conduct an inventory and mapping of available respite services and supports.

[29] Of the survey respondents, over 57% of youth and 61% of family members lived in the Portland, Salem, or Eugene/Springfield Metro areas which often have more services for youth than rural areas of the state.

Lack of youth-initiated respite options

- ***Provide flexibility in respite, including type, location, and duration.*** Youth and family members continuously stressed the need for flexibility in respite. Youth, in particular, would like to have more agency in choosing the respite program that is right for them and their circumstances. While some youth would like to be on their own, others would prefer to be in a group setting with others who are in similar circumstances. Family members would like less rigidity in how respite through ODHS or ODDS can be used. Increased programming for drop-in centers, peer supports, and mentorship can all be leveraged to expand youth-initiated respite.

> Respite Voucher Programs are one way that families can have more flexibility and control over respite. Respite Voucher Programs make funds available to families through self-directed respite care, whereby the care recipient and the family determine who provides the service and how it will be achieved. States implement voucher programs in a variety of ways, from Medicaid Waivers to county-funded respite.

- **Expand mentorship, peer support programs and drop-in centers for youth.** Creating youth-centered spaces in regions across the state, especially in rural areas, can support feel and facilitate interaction with peers who understand what they're going through. Community organizations can provide mentoring programs or create drop-in centers. For example, the Yamhill Community Action Partnership (YCAP) expanded their drop-in center locations to both Newberg and McMinnville. OHA, via contract with four providers, is piloting four peer respite centers for youth aged 18 and over dealing with mental illness or trauma response symptoms, an opportunity that could be leveraged in the future to serve those under 18 as well.[30]

[30] House Bill 2980 (2021) mandated that OHA provides funding to peer-run organizations, in the Portland metro area, southern Oregon region, Oregon coast, and the eastern and central Oregon region, to operate peer respite centers for adults over 18. At least one of the peer-respite centers must provide culturally responsive services to historically marginalized populations. Contract negotiation is ongoing as of February, 2024 with peer-run organizations to pilot respite programs.

Implementation Plan

A concerted effort must be made by the SOCAC, state agencies, the legislature, providers, and communities to overcome barriers to respite. The policy recommendations listed above require commitment from all parties. The SOCAC will work with partner agencies and L-SOCs to identify actionable items and next steps for each recommendation. The following table provides potential next steps for prioritized recommendations.

Recommendation	Potential Next Steps
Braid and blend funds across child-serving systems to develop continuum of respite infrastructure within local communities.	OHA is developing a 2025 Policy Option Package (POP) for respite and a respite ILOS proposal. OHA and ODHS could further explore opportunities within current Medicaid waivers such as the 1915 waivers and 1115 waiver.
Build on existing programs, organizations, and provider capacity.	L-SOCs can convene and connect organizations.
Develop guidance for Coordinated Care Organizations (CCOs) on how they can fund respite for their members.	OHA can provide guidance to CCOs on the benefits of respite and how to fund respite through existing Medicaid codes, HRS and SHARE initiatives.
Increase the number of respite providers.	Oregon can assess the current and potential workforce for respite, training needs, and licensing requirements. Outreach and recruitment campaigns can be developed. Expedited certification processes for formal respite providers should be explored.
Boost awareness of legislators and policymakers on what families and youth want when it comes to respite and supports.	SOCAC and other agency partners can advocate for respite with the legislature and Governor's office for the 2025 legislative session.
Tie respite to existing programs and efforts such as afterschool programming more explicitly.	Leverage efforts occurring in DELC and ODE to build inclusion within traditional and mainstream childcare settings.
Develop map and directory of available respite providers and services.	The SOCAC convened respite workgroup can work together on a resource guide/map to be distributed statewide.
Have flexible options for respite programs and invest more in group respite (hourly and overnight).	The SOCAC, agency partners, L-SOCs, and CBOs can begin to hear and act on the real needs of youth and families related to respite and take actionable steps to bring them to light. Funding must be a crucial element to implementing solutions to respite barriers.

Next Steps

SOCAC staff and partners will work to further prioritize and finalize the policy recommendations into actionable steps. In a Respite Workgroup[31] convened by the SOCAC, members expressed a strong desire to continue meeting and working to elevate solutions to respite barriers in communities across the state. The SOCAC will advocate for improvements across the continuum of youth respite services to legislators, policymakers, state agencies, and communities.

Respite Resources

- ARCH National Respite Network and Resource Center
    - Respite Facts and Talking Points
- Report from the Institute for Innovation & Implementation: The Evolution of the System of Care Approach for Children, Youth, and Young Adults with Mental Health Conditions and Their Families
- Substance Abuse and Mental Health Services Administration (SAMHSA): National Guidelines for Behavioral Health Crisis Care Best Practice Toolkit
- Oregon Children's System of Care Data Dashboard
- Adopt US Kids Report: Creating and Sustaining Effective Respite Services
- Support Caregiving: Respite Care: State Policy Resource Guide
- CMS guidance on allowable services: Coverage of Health-Related Social Needs (HRSN) Services in Medicaid and the Children's Health Insurance Program (CHIP)
- Respite Care: State Policy Resource Guide

[31] The Respite Barrier Workgroup meets monthly, and participants include local SOC coordinators, state agency partners, CCO partners, community partners, and SOCAC staff.