INVESTIGATION OF THE STATE OF ALASKA'S BEHAVIORAL HEALTH SYSTEM FOR CHILDREN



United States Department of Justice Civil Rights Division

December 15, 2022

SUMMARY OF FINDINGS

After an extensive investigation, the United States Department of Justice (DOJ) concludes there is reasonable cause to believe that the State of Alaska violates Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. § 12132, by failing to provide services to children with behavioral health disabilities¹ in the most integrated setting appropriate to their needs. Consistent with Title II regulations, 28 C.F.R. § 35.172, we provide this Report to notify Alaska of DOJ's conclusions, the facts supporting those conclusions, and the minimum remedial measures necessary to address the deficiencies identified.

In Alaska, children with behavioral health disabilities are institutionalized at high rates and for long periods because the State does not ensure that community-based services are available and accessible. Hundreds of children, including Alaska Native children in significant numbers, receive treatment in institutional settings within Alaska each year, often far from their homes and communities. Hundreds more are sent to segregated facilities in states as distant as Texas and Missouri.

Many of these children are eligible and appropriate for community-based services and supports that Alaska offers through its Medicaid program. Indeed, Alaska has made commendable efforts in recent years to bolster its community-based behavioral health service array, most notably through implementation of a Section 1115 Medicaid demonstration waiver.² Still, Alaska's system of care is heavily biased toward institutions, and key services and supports are often unavailable to children in their communities. As a result, many children with behavioral health disabilities who are appropriate for community-based services are forced to endure unnecessary and unnecessarily long admissions to psychiatric hospitals and psychiatric residential treatment facilities. This unnecessary segregation violates the ADA.

Alaska can fulfill its obligation to serve children in the most integrated setting appropriate to their needs by making reasonable modifications to its service system that are aligned with the State's own policies and objectives.

¹ Children with behavioral health disabilities are individuals up to the age of 21 who have a diagnosable serious emotional disturbance, mental illness, and/or substance use disorder. This population includes children with co-occurring intellectual or developmental disabilities.

² Under Section 1115 of the Social Security Act, the Secretary of the U.S. Department of Health and Human Services has authority to approve demonstration projects to promote the objective of the Medicaid program. The purpose of these waivers, which give states additional flexibility to design and improve their programs, is to "demonstrate and evaluate state-specific policy approaches to better serving Medicaid populations." Centers for Medicare and Medicaid Services, *About Section 1115 Demonstrations*, available at

https://www.medicaid.gov/medicaid/section-1115-demonstrations/about-section-1115-demonstrations/index.html [https://perma.cc/GDM5-H7AE].

I. INVESTIGATION

On December 17, 2020, DOJ notified Alaska of DOJ's intent to investigate whether the State unnecessarily institutionalizes children with behavioral health disabilities, in violation of Title II of the ADA.

Our investigation included extensive outreach to facility-based and community-based service providers and administrators, both across Alaska and at out-of-state facilities where Alaskan children receive services. We conducted numerous interviews of State officials and met with representatives of more than a dozen tribal organizations, spanning almost every region of the state. Along with a clinical expert, we spoke directly with children receiving State-funded behavioral health services in segregated facilities at or around the time of the investigation, both within and outside Alaska. In some instances, we had the opportunity to interview the parents or guardians of children receiving such services.

We conducted two in-person visits to Alaska, in April and May 2022. During those visits, we toured segregated facilities that serve children with behavioral health disabilities, including two facilities operated by Alaska's Division of Juvenile Justice. We also met with key State officials, service providers and administrators in multiple regions of Alaska, and other stakeholders.

In addition, DOJ attorneys and retained experts³ reviewed thousands of documents and extensive data produced by the State, including medical records for a random sample of children who received State-funded behavioral health services in psychiatric hospitals or residential treatment facilities between 2019 and 2022.

We would like to thank the State for the assistance and cooperation extended to us throughout our investigation, and to acknowledge the courtesy and professionalism of all the State officials and counsel involved in this matter. We also thank the advocates, service providers, and other stakeholders across Alaska who spoke with us. We are particularly grateful to the children and families who trusted us with their stories.

II. LEGAL FRAMEWORK

Congress enacted the ADA in 1990 "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities."⁴ Congress found that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with

⁴ 42 U.S.C. § 12101(b)(1).

³ We retained three experts to consult us on this investigation: a clinical psychologist with over 20 years of professional experience and formal training in the fields of education and child and adolescent psychology; a medical anthropologist with extensive research and clinical experience in the areas of American Indian and Alaska Native behavioral health; and a clinical psychologist with more than 25 years of experience working with states and tribal entities to develop and implement community-based behavioral health services for children and families.

disabilities continue to be a serious and pervasive social problem."⁵ Accordingly, the "ADA is intended to insure that qualified individuals receive services in a manner consistent with basic human dignity rather than a manner which shunts them aside, hides, and ignores them."⁶

Under Title II of the ADA, public entities must "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."⁷ The most integrated setting appropriate is one that "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible."⁸ The regulations also require public entities to make reasonable modifications in policies, practices, or procedures when necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that such modifications would fundamentally alter the nature of the service, program, or activity.⁹

In *Olmstead v. L.C.*, the Supreme Court applied these authorities and held that public entities are required to provide community-based services to people with disabilities when (a) such services are appropriate; (b) the affected people do not oppose community-based services; and (c) community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of other people with disabilities.¹⁰ The Court explained that unnecessary institutionalization "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life."¹¹ The Court also recognized the harm caused by unnecessary institutionalization when it found that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."¹² The ADA's integration mandate applies both to people who are currently institutionalized and to people who are at serious risk of unnecessary

- ⁷ 28 C.F.R. § 35.130(d). *See also* 42 U.S.C. § 12101(b).
- ⁸ 28 C.F.R. Pt. 35, App. B.
- ⁹ 28 C.F.R. § 35.130(b)(7).
- ¹⁰ 527 U.S. 581, 607 (1999).

¹¹ *Id.* at 600.

 12 Id. at 601.

⁵ 42 U.S.C. § 12101(a)(2).

⁶ Helen L. v. DiDario, 46 F.3d 325, 335 (3d Cir. 1995).

institutionalization.¹³ A State's failure to provide community-based services may create a risk of institutionalization.¹⁴

Courts have found proposed modifications that expand existing services to be reasonable, particularly when the modifications align with the jurisdiction's own stated plans and obligations.¹⁵ States may also be required to implement reasonable modifications—such as expanding community-based services—even if that requires increased financial resources in the short term.¹⁶ If a state fails to reasonably modify its service system to provide alternatives to institutional care, it violates Title II of the ADA.¹⁷

Under the Early, Periodic Screening, Diagnostic, and Treatment Services (EPSDT) provisions of the Medicaid Act, the State has a separate legal obligation to provide children under the age of 21 with mental health screening tests to detect potential problems and identify any coverable services necessary to correct or ameliorate a mental illness or condition, regardless of whether that service is included in its State Plan or Medicaid waiver programs.¹⁸ This obligation requires Alaska to provide comprehensive health care services, including in-home and community-based behavioral health treatment, to children in the Medicaid program.¹⁹

¹⁴ Pashby, 709 F.3d at 322. See also Mississippi, 400 F. Supp. 3d at 579.

¹⁵ See, e.g., Henrietta D. v. Bloomberg, 331 F.3d 261, 280-81 (2d Cir. 2003) (upholding as a reasonable modification an order requiring agency to follow existing law and procedures); *Guggenberger v. Minn.*, 198 F. Supp. 3d 973, 1030 (D. Minn. 2016) (providing Medicaid waiver services to eligible people, particularly from existing waiver funds, is a reasonable modification); *Hiltibran*, 793 F. Supp. 2d at 1116 (a state providing a specific Medicaid service for people in institutions must provide it for Medicaid enrollees who need it in the community); *Haddad v. Arnold*, 784 F. Supp. 2d 1284, 1304-05 (M.D. Fla. 2010) (providing a service already in state's service system to additional people is not inherently a fundamental alteration); *Messier v. Southbury Training School*, 562 F. Supp. 2d at294, 344-45 (D. Conn. 2008) (plaintiffs' requested service expansion, which was consistent with defendants' publicly stated plans, was reasonable).

¹⁶ Frederick L., v. Dep't of Pub. Welfare, 364 F.3d at487, 494-96 (3d. Cir. 2004) (collecting cases); Mississippi, 400 F. Supp. 3d at 577 (collecting cases).

¹⁷ Olmstead, 527 U.S. at 607; 28 C.F.R. § 35.130(b)(7).

¹⁸ 42 U.S.C. § 1396d(r)(5).

¹⁹ Rosie D. v. Romney, 410 F. Supp. 2d 18, 52-53 (D. Mass. 2006) ("[T]he EPSDT provisions of the Medicaid statute require, by their very language, comprehensive assessments of children with SED [serious emotional disturbance] . . . the EPSDT provisions of the Medicaid statute require provision of adequate in-home behavioral support services for SED children"). See also Katie A. v. L.A. Cnty., 481 F.3d 1150, 1159-60 (9th Cir. 2007) (agreeing that states have an obligation under the EPSDT mandate to provide effective in-home behavioral support services to children with mental illness, but overturning the lower court's requirement that the services be

¹³ M.R. v. Dreyfus, 663 F.3d 1100, 1115–18 (9th Cir. 2011), opinion amended and superseded on denial of reh'g, 697 F.3d 706 (9th Cir. 2012); Steimel v. Wernert, 823 F.3d 902, 911-12 (7th Cir. 2016); Davis v. Shah, 821 F.3d 231, 262-64 (2d Cir. 2016); Pashby v. Delia, 709 F.3d 307, 321-22 (4th Cir. 2013); Fisher v. Okla. Health Care Auth., 335 F.3d 1175, 1180-82 (10th Cir. 2003); United States v. Mississippi, 400 F. Supp. 3d 546, 553-55 (S.D. Miss. 2019).

III. ALASKA'S SERVICE SYSTEM FOR CHILDREN WITH BEHAVIORAL HEALTH DISABILITIES

Alaska's Division of Behavioral Health (DBH)²⁰ is primarily responsible for overseeing and administering the State's publicly funded programs and services—including Medicaid-funded services—for children with qualifying behavioral health disabilities. Through DBH, Alaska funds and administers those services in home- and community-based settings as well as in facility-based settings.

A. The State of Alaska Relies on Psychiatric Hospitals and Psychiatric Residential Treatment Facilities to Serve Children with Behavioral Health Disabilities.

Children receive State-funded behavioral health services alongside other children with disabilities in facilities both within and outside Alaska. Those facilities include two psychiatric hospitals in Anchorage – North Star Hospital, operated by North Star Behavioral Health, and the Alaska Psychiatric Institute, operated by the State. In addition, either directly or through its contractors, the State approves placements of Medicaid-enrolled children in private psychiatric residential treatment facilities (PRTFs).²¹

In Fiscal Year 2020, more than 800 children received State-funded behavioral health services in a psychiatric hospital or PRTF. At least one third of those children are Alaska

²⁰ In March 2022, pursuant to an Executive Order by the Governor of Alaska, the State restructured the Department of Health and Social Services (DHSS) into two departments—the Department of Health (DOH) and the Department of Family and Community Services (DFCS). The State's Division of Behavioral Health is housed in DOH, and its Office of Children's Services is under DFCS. State of Alaska Department of Health and Social Services, *DHSS Reorganization*, <u>https://dhss.alaska.gov/Commissioner/Pages/reorganization/overview.aspx</u> [https://perma.cc/BUW8-K7EF].

²¹ Psychiatric residential treatment facilities (PRTFs)—also known in Alaska as residential psychiatric treatment centers—provide "highly structured, campus-based, long-term programs for children" who may have more intensive behavioral health needs. State of Alaska Division of Behavioral Health and Alaska Mental Health Trust Authority, *Caring for Alaska's Children and Youth in Out-of-Home Behavioral Health Care*, at 19 (March 19, 2019), <u>https://alaskamentalhealthtrust.org/wp-content/uploads/2019/03/DBH-Conference-Presentation_FINAL-2019-03-19.pdf</u> [https://perma.cc/FH39-JACH]. To be eligible to receive payment from the State for PRTF services, providers must meet the requirements—including licensing and certification requirements and capacity restrictions—set under 7 Alaska Admin. Code § 140.400. The federal Medicaid agency also sets requirements for such facilities, outlined at 42 C.F.R. Subpart D. Many, but not all, of the residential treatment facilities that serve children with behavioral health needs are PRTFs.

bundled); U.S. Department of Health and Human Services, *Center for Medicaid and CHIP Services Informational Bulletin: Leveraging Medicaid, CHIP, and Other Federal Programs in the Delivery of Behavioral Health Services for Children and Youth*, at 3, 7 (Aug. 18, 2022), <u>https://www.medicaid.gov/federal-policy-guidance/downloads/bhccib08182022.pdf</u>[https://perma.cc/B49P-GF6Q] (noting that "the obligation to provide all medically necessary care under EPSDT extends to prevention, screening, assessment and treatment for mental health" and that states can further the goal of the EPSDT benefit "by designing a robust benefit package . . . that includes coverage of intensive community-based services, crisis stabilization, and intensive care coordination to meet the needs of high-risk children and youth").

Native. Even as admissions to these congregate facilities have declined during the COVID-19 pandemic, children are staying at the facilities longer. All told, the State's Medicaid system paid over \$83 million to serve children with behavioral health disabilities at a psychiatric hospital or PRTF in 2020.

To receive treatment in a psychiatric hospital or PRTF, children in Alaska frequently move hundreds or thousands of miles from their communities. For months and even years, they live apart from their families, friends, schools, and culture. Some children are discharged home without adequate community supports, leading to further admissions to these congregate facilities.

1. <u>Psychiatric Hospitals</u>

Every year, hundreds of children receive State-funded behavioral health services at psychiatric hospitals, where they live in close quarters with other children with behavioral health disabilities on locked units. Based on the State's reporting, 425 children were treated in psychiatric hospitals through Alaska's Medicaid program in Fiscal Year (FY) 2020. Many of those children were treated in general hospitals²² in Alaska before entering psychiatric hospitals. Of the 654 children whom the State reports received acute psychiatric services at a general hospital or psychiatric hospital through Alaska's Medicaid program in FY2020, at least 300 children are Alaska Native.

At the State-run Alaska Psychiatric Institute (API), the Chilkat Unit provides in-patient treatment for adolescents with intensive behavioral health needs. After closing it in 2019, the State re-opened the Chilkat Unit in May 2021. It currently has capacity to serve up to 10 youth at one time. In FY2021, 55 Medicaid-enrolled youth were treated at the Chilkat Unit. Average lengths of stay at the facility have increased, from 17 days in FY2021 to over 42 days in the first half of FY2022.

North Star Hospital, in Anchorage, is the largest psychiatric hospital for children in Alaska, serving youth ages 5-18. It admits children from across the state, including directly from emergency rooms. North Star Hospital has two units, each with capacity to serve 20 children at any given time. At North Star Hospital, all aspects of daily life—including sleeping, eating, roommate selection, clothing, learning, recreation, and treatment—are controlled by the facility. Children are rarely permitted to leave. "Once you're in North Star, you don't go anywhere," we heard from a youth treated at the hospital in 2018. Another child interviewed at North Star Hospital in May 2022 reported that "we don't leave" the facility. Twelve years old at the time of the interview, that child had been at North Star Hospital for four months.

Children admitted to North Star Hospital between 2021 and 2022 have stayed, on average, for 40 days or longer. Inpatient service providers and administrators in Alaska report

²² General hospital settings in Alaska where children receive acute psychiatric services include emergency rooms and dedicated psychiatric units.

that lengths of stay at North Star Hospital have increased because of the lack of appropriate community-based services and supports for children in the state. When they stay for weeks and months in settings like North Star Hospital, children who are able to return to the community, but nevertheless remain, can get discouraged and regress in their behaviors, further prolonging their hospital stays according to inpatient clinical staff in Alaska.

For some children in Alaska, like one Alaska Native child from Bethel, the weeks and months have turned into years. That child had been in congregate settings, almost continuously, for over four years when we reviewed her records. Her first admission to North Star Hospital occurred when she was 12 years old. At the time, she was feeling sad and irritable, and exhibiting some aggression toward her younger siblings. Our clinical expert found that she very likely could have been served in her own home, despite these symptoms, if she had received appropriate community-based services, such as Intensive Case Management, available in theory through the State's Medicaid program. *See infra* at 9-12. Instead, she remained at North Star for three weeks, only to return to the facility later that year for a five-week stay. After the second stay, rather than going home to her grandmother, she was transferred to the Alpine Academy, North Star's PRTF for adolescent girls, where she stayed for 18 months. She returned to North Star Hospital in 2019 and again in 2020, culminating in another placement to the Alpine Academy PRTF that was ongoing at the time of our review. Now approaching 18 years old, she appears to be more accustomed to life in an institution than at home.

In 2020, through its Medicaid program, the State paid over \$56 million to treat children in psychiatric hospitals and an additional \$14.5 million for acute psychiatric care for children in general hospitals. By comparison, Alaska's paid Medicaid claims for *all* community-based behavioral health services for children in 2020—excluding services provided in residential settings²³—totaled under \$32 million. While the number of children in psychiatric hospitals in Alaska declined during the COVID-19 pandemic, lengths of stay are increasing and the State is spending more on these institution-based services.

For many children in Alaska, hospitalization at North Star or API is a gateway to longerterm placement at psychiatric residential treatment centers, including out of state. Between July 2018 and February 2021, North Star alone referred at least 150 youth—including children as young as 8 years old—for out-of-state placement at PRTFs thousands of miles from their communities.

2. Psychiatric Residential Treatment Facilities

Through its Medicaid program, Alaska certifies more than 20 PRTFs where, collectively, hundreds of children receive State-funded behavioral health services each year. In addition to

²³ Our analysis shows that in 2020 the State funded, through its Medicaid program, more than \$17 million in services at non-PRTF-level residential facilities in Alaska. We draw no conclusions with respect to those facilities in this Report.

four PRTFs located within Alaska, the State relies on 17 out-of-state PRTFs, including facilities in Texas, Utah, and Missouri, to serve Medicaid-enrolled children.

Each year from 2017 to 2021, at least 330 children received behavioral health services in a PRTF through the State's Medicaid program. Again, the burden falls substantially on Alaska Native children. Reflecting deep gaps in the State's community service system, see infra at 18-22, children dually diagnosed with behavioral health disabilities and intellectual and developmental disabilities are particularly vulnerable to placement in PRTFs and psychiatric hospitals.

While the total number of children in Alaska entering PRTFs has declined during the COVID-19 pandemic, as with psychiatric hospitalizations, lengths of stay at PRTFs have increased. Placements of between six months and one year are common. Some children remain in a PRTF for years.

Life in a PRTF, as described by youth in Alaska who have experienced it and by their parents and advocates, can be isolating, frightening, and chaotic. Children stay in locked buildings exclusively with other youth with behavioral health disabilities, often thousands of miles from their families and communities. Some children experience repeated residential placements, at times in quick succession, leading to sustained periods of institutionalization that have long-term effects on them and their families.

The experience of PRTF placement can be devastating for children—and uniquely so for Alaska Native children, compounding the trauma of past generations when Alaska Native youth were routinely taken from their communities and sent to boarding schools, including some run by the State or the federal Bureau of Indian Affairs.²⁴ Alaska Native children confined to PRTFs and other institutional settings are disconnected from their culture, losing opportunities to learn from elders, learn Native languages, learn how to live off the land, and participate in cultural traditions that affirm their identity. They frequently progress more slowly in treatment, stay at facilities longer, and sometimes run away because they do not want to be there. These children lose their sense of identity while in institutions, we heard from community leaders when visiting Alaska Native communities in western Alaska. After months or years in a highly regimented environment, they often struggle to adjust when returning to their communities.

Some children, like one 14-year-old Alaska Native child reviewed by our clinical expert, get caught in a cycle of restrictive placements. At the time of our review, that child had already experienced two placements to out-of-state PRTFs, totaling more than 13 months, in addition to at least three admissions to North Star Hospital. He was 10 years old the first time that he was removed from his Alaska Native community, a small village in the Northwest Arctic Borough, and sent to North Star. After nearly a month at the facility, he returned home to live with foster parents, but never received the services and supports he needed to manage his behavioral health symptoms effectively. Indeed, those services-including Home-Based Family Treatment,

²⁴ See Diane Hirshberg & Suzanne Sharp, Thirty Years Later: The Long-Term Effects of Boarding Schools on Alaska Natives and Their Communities (2005), available at

Intensive Case Management, and Crisis Services—are not available in his community. During his first out-of-state placement at a PRTF in Utah, and while he was in the custody of the State's Office of Children's Services (OCS), the child was put in seclusion or restraints at least eight times. Staff at the PRTF reported that his discharge was delayed because OCS was slow in coordinating aftercare. The following year, during his second admission to North Star Hospital, the child reportedly stabbed himself in the leg with a pencil when he learned that he was being sent to another out-of-state PRTF, in Missouri. The more time he spent in congregate facilities, the more he seemed to struggle with transitioning back to community settings and managing his behavioral health symptoms. In 2021, he was held for three months at McLaughlin Youth Center, the State's juvenile justice facility in Anchorage, before he was adjudicated delinquent and placed in foster care.

As required by Alaska law, the State reviews all referrals for out-of-state placement of Medicaid-enrolled children, including from private facilities like North Star Hospital. Alaska Stat. § 47.07.032. Typically, within 48 hours of receiving a referral for out-of-state placement, staff at DBH and OCS meet to determine whether, based on the information provided by the referring entity, "services that are consistent with [the child's] clinical diagnoses and appropriately address their needs are unavailable in the state." In cases involving children in the State's custody, OCS convenes and leads the meeting. Staff document their determination for each child referred, checking a box to indicate whether "[a]pproval [is] given for out of state placement."

Records produced by OCS for approximately 160 of these meetings between 2016 and 2020 involving children in the State's custody did not contain a single instance where the committee denied approval for out-of-state placement. The majority of the referrals were from North Star, and a significant number concerned Alaska Native children. The average age of the children referred was just 13. Treatment summaries included in these records often reflect a long history of congregate facility placement. One child, 11 years old at the time and being considered for placement at a PRTF in Texas, had already been placed at the same facility twice before. In determining that no appropriate in-state alternatives were available, the committee noted that the child's earlier discharge to his family was unsuccessful because he did not receive "necessary supports."

In 2021, Alaska's Medicaid program paid nearly \$37 million for PRTF services, up from just under \$30 million in 2018. Most of that money goes to out-of-state PRTFs, which collectively served 172 Medicaid-enrolled children from Alaska in 2021.

B. The State Funds and Administers Community-Based Services and Supports That Can Divert Children from Unnecessary Institutionalization.

The kinds of community-based behavioral health services and supports needed to help children avoid unnecessary institutional placement are part of the State's existing Medicaid program. Some interventions, such as Therapeutic Treatment Home Services, have long been available in some form to Medicaid-enrolled children in Alaska. With the implementation of its Section 1115 Medicaid behavioral health waiver in 2019, Alaska added a number of community-based services for children, including Home-Based Family Treatment, Intensive Case

Management, and Crisis Services. Medicaid-enrolled service providers in Alaska have the flexibility to offer culturally appropriate activities and interventions for Alaska Native youth—such as traditional counseling—under the State's existing service menu.²⁵

Research has shown that services and supports like those included in Alaska's Medicaid program, when provided consistently and with sufficient intensity, can effectively address the needs of children with behavioral health disabilities while maintaining their connection to their families and communities.²⁶ Community-centered behavioral health programs have had success in preventing institutionalization and producing better outcomes for children and families. With access to timely and appropriate services, even children with intensive behavioral health needs and a history of congregate facility placement are able to return to or remain in family homes where they are more likely to have improved clinical and functional outcomes, better school attendance and performance, and increased behavioral and emotional strengths compared to children receiving care in institutions.

Alaska acknowledges that community-based behavioral health services and supports are effective in maintaining children in a home environment and preventing unnecessary hospitalizations and residential facility placements—indeed, that was a central premise for its Section 1115 waiver. Through the waiver, Alaska seeks to implement a series of "strategies and evidence-based interventions aimed at more effectively addressing the needs of each of the target populations," including youth with behavioral health disabilities and their families. It chose to offer the following services²⁷—among others introduced under the Section 1115 waiver or established years prior through its Medicaid State Plan—to "reduce Alaska's over-reliance on . . . institutional care."²⁸

1. Home-Based Family Treatment

Home-Based Family Treatment is "a community-based early intervention service" that offers "wrap-around services" in the home to reduce the need for hospitalization and residential services for children and adolescents with behavioral health disabilities. There are three levels of Home-Based Family Treatment under the State's Section 1115 waiver, depending on the needs

²⁵ Tribal Health Organizations strive to incorporate aspects of Alaska Native culture. Restoring lost connections to tribal culture and addressing historical trauma are seen as important parts of treatment.

²⁶ See, e.g., Carrie W. Rishel, et al., *Preventing the Residential Placement of Young Children: A Multidisciplinary Investigation of Challenges and Opportunities in a Rural State*, 37 W. Va. Univ. Children & Youth Servs. Rev. 9 (2014), available at <u>http://dx.doi.org/10.1016/j.childyouth.2013.11.027</u>.

²⁷ Service descriptions are based on the State's publicly available standards and administrative procedures for behavioral health service providers. State of Alaska Department of Health and Social Services, *Alaska Behavioral Health Providers Services Standards & Administrative Procedures for Behavioral Health Provider* Services (June 30, 2021), available at <u>https://health.alaska.gov/dbh/Documents/1115/Standards-and-Administrative-Procedures-for-Behavioral-Health-Provider-Services.pdf [https://perma.cc/WMZ5-4P5M].</u>

²⁸ State of Alaska Department of Health and Social Services, *Medicaid Section 1115 Behavioral Health Demonstration Application*, at 32 (Jan. 31, 2018), available at <u>https://perma.cc/R5JW-N65G</u>.

of the child; Level III targets children at "imminent risk of out of home placement" or who have been discharged from a psychiatric hospital, residential treatment facility, or juvenile detention facility. Across all three levels, service components for Home-Based Family Treatment include case coordination and referrals; crisis diversion and intervention planning; comprehensive family assessment, group and individual therapy, and other clinical services; peer support services and navigation;²⁹ and ongoing monitoring for safety and stability in the home. Staff eligible to provide Home-Based Family Treatment, either individually or as part of an inter-disciplinary team, include physicians and physician assistants, registered nurses, Community Health Aides and Behavioral Health Aides, substance use disorder counselors, and peer support specialists.

2. Crisis Services

Seeking to fill a widely acknowledged gap in its behavioral health service continuum, Alaska rolled out three Crisis Services for children—as well as adults—through its Section 1115 waiver in 2019.³⁰

Mobile Outreach and Crisis Response Services are provided to children to (1) prevent a behavioral health crisis from escalating; (2) stabilize the youth during or after a behavioral health crisis; or (3) refer and connect the youth to other appropriate services needed to resolve the crisis. These services also include skills training, medication services, and assisting with creating a safety plan and other crisis planning. Mobile Outreach and Crisis Response Services programs must be available 24/7, coordinate with law enforcement and crisis stabilization center staff, and have capacity to provide a face-to-face response within an hour in urban areas or a "rapid" response in rural areas of the state. Programs must also document their attempts to follow up with a client within 48 hours of a response, to "ensure support, safety, and confirm linkage with any referrals."

23-Hour Crisis Observation and Stabilization Services provide a secure environment where youth experiencing acute behavioral health symptoms can receive individual assessment, psychiatric evaluation, medication, and other clinical services in addition to crisis intervention and stabilization services for up to 23 hours and 59 minutes. The State requires that providers of 23-Hour Crisis Observation and Stabilization Services coordinate with local law enforcement and with a crisis stabilization center, where available.

²⁹ Peer Support is available in Alaska as a component of other services, including Home-Based Family Treatment and Community Recovery Support Services, and on a standalone basis through the State's Peer-Based Crisis Service. Services are provided by peer support specialists – often individuals with lived experience with mental illness. In Alaska, key components of Peer Support can include crisis diversion and support services, resiliency services, and facilitating transition to other community-based resources or natural supports.

³⁰ Coinciding with the roll-out of its Section 1115 behavioral health waiver, the State partnered with the Alaska Mental Health Trust Authority to support improvements to Alaska's behavioral health crisis response system by implementing the nationally recognized Crisis Now framework. *See* Alaska Mental Health Trust Authority, *Behavioral Health Crisis Response*, <u>https://alaskamentalhealthtrust.org/alaska-mental-health-trust-authority/what-we-do/crisis-continuum-of-care/</u> [https://perma.cc/SQU9-C4D8].

Crisis Residential and Stabilization Services offer 24/7 psychiatric stabilization services, medication services, and referrals to appropriate ongoing services and supports. Lengths of stay beyond seven days at Crisis Residential and Stabilization programs require a service authorization. Stabilization services are also available in home settings under the State's Medicaid program, most notably through Home-Based Family Treatment. *See supra* at 10-11.

3. Therapeutic Treatment Home Services

Therapeutic Treatment Home Services for children include individual assessment and other trauma-informed clinical services, crisis intervention services, and case coordination. Provided by licensed foster parents in their homes and under the direction of a mental health clinician, Therapeutic Treatment Home Services are designed for youth who have severe mental, emotional, or behavioral health needs and who cannot be stabilized in a less intensive home setting. Foster parents are licensed and trained by the State or through community service provider organizations certified by the State.

4. Community Recovery Support Services

Community Recovery Support Services help to improve self-sufficiency and promote recovery for children and adolescents with behavioral health disabilities. Components of Community Recovery Support Services include coaching and referrals to build daily living skills; linking children and families to community resources; family psychoeducation and training; peer support for children and families; and assistance with level-of-care transitions. As with other community-based services offered through Alaska's Medicaid program, Community Recovery Support Services are designed to be culturally and linguistically appropriate and to assist youth and families in sustaining recovery and promoting stability.

5. Intensive Case Management

Intensive Case Management is designed for children at risk out-of-home placement who would benefit from more assertive care coordination and regular monitoring of their safety, stability, and behavioral health services. Intensive Case Management services include evaluation, outreach, support services, patient advocacy with community agencies, arranging services and supports, teaching community living and problem-solving skills, modeling productive behaviors, and teaching youth to become self-sufficient. Alaska requires that Intensive Case Management services be available and provided in the community as often as needed, and that providers be in contact with clients as frequently as "2-to-3 times a day."

C. Alaska Has Not Addressed Long-Standing Gaps in Available Community-Based Services and Supports.

As the State recognized in its 2018 application for the Section 1115 waiver, "[h]istorically, Alaska has not provided a comprehensive continuum of behavioral health care"³¹ The State wrote that the community prevention and early intervention services available to children at risk of out-of-home placement are "very limited."³² For children already receiving residential services, the State recognized that there are very few options "for sub-acute services designed to (a) provide services within the child's home or in the child's community and (b) prevent repeated placement in residential and inpatient services far from the child's community and home."³³ The State also acknowledged that limited services in Alaska contribute to facilitybased placements, stating that each month, an average of 130 children and youth reside in foster care or inpatient psychiatric treatment outside of Alaska due to a shortage of available therapeutic foster care placements and insufficient capacity of other community-based services.³⁴

This is not a new problem. The State has long recognized that its community-based behavioral health service system does not meet the needs of children at serious risk of institutionalization. A 2009 report commissioned by the State captured the dire state of affairs:

Alaska's current system of care does not include the appropriate continuum and array of services for individuals with . . . complex behaviors. Because of this, many of these individuals are served by the Alaska Psychiatric Institute (API), where they languish in an unnecessarily restrictive environment for extended periods of time, or they are inappropriately held in places such as . . . emergency rooms. Many are ultimately sent out of state for care, where in many cases they remain indefinitely. [] The result of the lack of appropriate services in Alaska is significant financial cost to the State and personal cost to the individuals and their families.³⁵

More than 10 years later, the State acknowledges that it still has limited capacity to provide timely, appropriate services and supports to prevent institutional placement of children

³² Id.

³³ Id.

³⁴ *Id.* at 18.

³¹ State of Alaska Department of Health and Social Services, *Medicaid Section 1115 Behavioral Health Demonstration Application*, at 11 (Jan. 31, 2018), available at <u>https://perma.cc/R5JW-N65G</u>.

³⁵ Western Interstate Commission for Higher Education, *Alaska Complex Behavior Collaborative*, at 3-4, available at <u>https://health.alaska.gov/dbh/Documents/TreatmentRecovery/CBC-Executive-Summary.pdf</u> [https://perma.cc/H7M5-BXDV].

with behavioral health disabilities.³⁶ Statewide gaps in community-based services, according to the State, contribute to a "tendency for individuals to move into residential settings."³⁷ Children with behavioral health disabilities "remain in crisis longer, wait for long periods in a setting not designed to help them, do not receive adequate care, and are discharged with no effective plan for long-term improvement" because of the State's fragmented system of care.³⁸

Against this backdrop, the State has sought to use its 1115 Medicaid waiver to "reduce Alaska's over-reliance on . . . institutional care" by creating "a more robust continuum of behavioral health care services," emphasizing early interventions, crisis services, and other community-based services.³⁹ But with the initial demonstration period set to expire in 2022, the State's waiver program has not meaningfully improved access to community-based services for children at serious risk of institutionalization in Alaska. Key services needed to help children remain in their communities remain in short supply. *See infra* at 18-22. In some communities, youth cannot access these services regardless of need because there are no enrolled providers.

Access to community-based services in Alaska is particularly limited in rural areas, where approximately a sixth of the state's population and a significant number of children with behavioral health disabilities live.⁴⁰ Tribal Health Organizations⁴¹ are often the only providers

³⁷Alaska FY2022-2023 Combined MHBG/SABG Application, *Step 2: Identify the unmet service needs and critical gaps within the current system*, 6 (August 16, 2021) available at https://health.alaska.gov/dbh/pages/default.aspx [https://health.alaska.gov/dbh/pages/default.aspx [https://perma.cc/FV68-FVS5].

³⁸ Alaska State Hospital and Nursing Home Association, *Acute Behavioral Health Improvement Project: Report and Recommendations for Positive Change in Alaska's Communities and Hospitals*, 16 (April 2019), available at <u>https://www.alaskahha.org/_files/ugd/ab2522_26376a6bb0b54a85bcf0381aff984a75.pdf</u> [https://perma.cc/9RD6-5QPY].

³⁹ State of Alaska Department of Health and Social Services, *Medicaid Section 1115 Behavioral Health Demonstration Application*, at 16, 32 (Jan. 31, 2018), available at https://perma.cc/R5JW-N65G.

⁴⁰ A 2016 study commissioned by the State estimated that 5,550, or 6 percent of, children aged 9 to 17 had a severe emotional disturbance (SED) the year before, and that rates of SED were highest in the rural northern and Yukon-Kuskokwim Delta regions. Also, by this estimate, more children with SED lived in a rural area like the Yukon-Kuskokwim Delta than in the city and borough of Juneau. Agnew::Beck Consulting, LLC and Hornby Zeller Associates, Inc., *Alaska Behavioral Health Systems Assessment Final Repo*rt, at 85 (Jan. 22, 2016), available at https://perma.cc/WB8L-F7N4.

⁴¹ Altogether, there are about 30 Tribal Health Organizations (THOs) in Alaska that collectively serve about 228 federally recognized tribes. THOs operate tribally managed facilities, including hospitals, health centers, community health aide clinics, and residential treatment centers. Each THO functions independently. Behavioral health providers are located in about 15 of 17 regions comprising Alaska's tribal health system, and about 10 of them operate community health centers that provide an opportunity for integration of physical and health services. When Medicaid services are provided to American Indian and Alaska Native beneficiaries, the Federal Medical Assistance Percentage (FMAP) rate is 100 percent, meaning that the federal government reimburses the

³⁶ Alaska Department of Health and Social Services and Alaska Mental Health Trust Authority, *Strengthening the System: Alaska's Comprehensive Integrated Mental Health Plan (2020-2024)*, at 41 (July 2019), available at <u>https://health.alaska.gov/Commissioner/Documents/MentalHealth/StrengtheningSystem-</u> <u>CompPlan 2020-24.pdf</u> [https://perma.cc/9TXJ-XUHY].

of behavioral health services in rural areas of Alaska—some as large as the State of Oregon and with places accessible only by air or water. Alaska faces unique challenges in ensuring access to community-based services in such vast rural areas.⁴² But there are opportunities for the State to build on existing programs and approaches to service delivery that offer viable, effective alternatives to institutional care, even for children and families living in remote parts of Alaska. *See infra* at 21-24.

IV. DISCUSSION

There is reasonable cause to believe that the State fails to provide services to children with behavioral health disabilities in the most integrated setting appropriate to their needs as required by the ADA.⁴³ Alaska plans, administers, and funds its public healthcare service system in a manner that unnecessarily segregates children in psychiatric hospitals and PRTFs, both within and outside the state, rather than providing these services in the communities where children and their families live.⁴⁴

A. Alaska's Administration of Its Behavioral Health Service System Results in Many Children Experiencing Needless Institutionalization

1. <u>Alaska Relies on Institutions to Serve Children Who Are Appropriate for Services</u> <u>in Their Own Homes and Communities and Whose Families Do Not Oppose</u> <u>Community-Based Services</u>

Many children in Alaska who are confined to psychiatric hospitals or PRTFs could be served appropriately in their own homes and communities. After reviewing extensive medical records for a random sample of children institutionalized between 2019 and 2022, interviewing children in institutions at the time of the investigation, and in some instances interviewing their facility-based treating professionals, our clinical expert concluded that the needs of children with behavioral health disabilities in Alaska who receive services in institutions are not materially different from those of other children who are thriving in community-based settings in other states. She further concluded that the types of services established through the State's Medicaid program, if provided and staffed consistently with the State's standards, would meet the needs of many children in Alaska who are placed in psychiatric hospitals or PRTFs.

State for 100 percent of the cost of Medicaid direct care services. The 100 percent FMAP rate applies to services that are directly provided by tribal providers as well as, under certain circumstances, services that are provided by non-tribal providers after a referral from a tribal provider. *See* Alaska Department of Health, *Tribal Refinancing*, https://health.alaska.gov/dhcs/Pages/Tribal-Health/Tribal-Refinancing.aspx [https://perma.cc/5JEQ-T8BF].

⁴² See, e.g., State of Alaska Department of Health and Social Services, *Alaska Substance Use Disorder and Behavioral Health Program 1115 Evaluation Design for FY2019-FY2024*, at 5 (2019).

⁴³ See 42 U.S.C. § 12132; 28 C.F.R. § 35.130(d); Olmstead v. L.C., 527 U.S. 581, 607 (1999).

⁴⁴ See 28 C.F.R. § 35.130(b), (d).

One child, just 12 years old at the time of our review, very likely could live in his home community of Kenai, Alaska if he received Therapeutic Treatment Home Services, Home-Based Family Therapy, Crisis Services, and other services that he is eligible for through the State's Medicaid program. Instead, the child had been living at out-of-state PRTFs for more than two years—the latest in a string of institutional placements that started with his admission to North Star Hospital in 2018, when he was eight years old. During the intake for that 2018 admission, he asked staff: "Do you know when I am leaving?" He was discharged from North Star after more than a month, only to return to the facility on three separate occasions between October 2018 and January 2020, typically staying for at least a month. When preparing to discharge from North Star after one of those stays in 2019, he told staff that he was happy to be leaving. Despite being in the custody of OCS, he never received the appropriate behavioral health services and supports he needed to remain at his community-based foster care placements. Ultimately, with the State's approval, he moved from North Star Hospital to a PRTF in Oregon, nearly 3,000 miles from his mother and home community.

Another child—15 years old and living at a PRTF in Utah when we interviewed her in 2022—could very likely return to her home near Bethel, Alaska with appropriate communitybased services, specifically including Community Recovery Support Services and Crisis Services. But the services she needs and is eligible for through the State's Medicaid program are not available in or near her village. Like many other children in Alaska, her first experience receiving behavioral health services was at an institution, North Star Hospital. She was 12 years old. After another multi-month admission to North Star, and despite receiving only limited individual therapy services in the community, she was placed at the PRTF in Utah. At the time of our interview, she had been there for nearly eight months. The child, who is Alaska Native, told us that she wants "to go back home," that she misses "being free," and that the most important people to her are her father and siblings. At the PRTF, she is allowed to call them three times a week, for no more than 10 minutes per call.

Stories like these are far too common in Alaska. Among the children we reviewed during our investigation, few received the community-based services for which they are eligible and appropriate. These services-including Intensive Case Management, Crisis Services, Therapeutic Treatment Home Services, Community Recovery Support Services, and Home-Based Family Treatment—are offered through the State's Medicaid program, but are not available to the children who need them to avoid institutionalization, particularly in rural communities. See infra at 18-22. As the director of a community-based provider organization in Alaska commented, "service need does not wait for services to be available." With nowhere to turn, children who could otherwise stay in their homes and communities are subjected to unnecessary and unnecessarily long institutional placements, often repeatedly. This is apparent not only from our review of medical records and interviews with youth, parents, advocates, and community service providers, but also from our conversations with facility-based treatment staff, some of whom acknowledged that youth from Alaska stay in institutions longer than necessary because the services and supports they need are scarce or nonexistent in their home communities. Prolonged institutional stays often cause children to regress in their behaviors because they become frustrated about being unable to leave, delaying their discharge even further.

Children with behavioral health disabilities in Alaska can and do achieve stability in the community when they receive timely and appropriate services, including after discharge from an institution. One provider from a small island community in southeastern Alaska told us that she "rarely" needs to refer children for treatment out of town, let alone outside the state. Another provider, based in Anchorage, has been successful in keeping children out of residential facilities—including children with a long history of institutional placement—by providing trauma-informed, family-based care. However, few children in our review population received these services when appropriate. What services they did receive often did not match their evolving needs, ultimately leading to institutional placements.

Almost without exception, the children whom we reviewed—and their parents—do not oppose receiving effective community-based services and supports—indeed, they strongly prefer them as an alternative to prolonged or repeated institutional placement. Their statements to facility staff and during our interviews reveal the emotional toll of institutionalization on youth and families. Children as young as six years old who were confined to psychiatric hospitals or PRTFs said that they want to go home, that they miss their parents, grandparents, and siblings, and that they miss going outside. One Alaska Native child told us that he wanted to learn his Native language and build a cabin with his grandfather, and that he missed celebrating holidays with family. Another child who had been living in a PRTF in Texas for nearly a year when we interviewed him asked us, "When will I get my visit from my mom?" He said it had been so long since they had seen each other that his mother did not know how much he had grown.

A child who was living at a PRTF in Utah during the investigation told us that he wants to return to his Alaska Native village and that his mother wants that, too. He loves taking care of his brothers and injured animals. With appropriate services and supports, our clinical expert found, this child very likely could be served in his community. Instead, he spent a month in North Star Hospital before being sent out-of-state for treatment in December 2021. He said that he felt scared when he learned that he would be leaving Alaska, and that he misses being home – in particular, hunting birds, fishing, spending time with his siblings, and seeing whales in the ocean. At the time of our interview, he expected to remain at the PRTF for six more months before finally returning to Alaska.

Being separated from their children for months or years is heart-wrenching for the families of Alaskan youth placed in institutional settings. Parents of children whom we reviewed said that they missed their children and wanted to be closer. Parents expressed concern about their children losing touch with their culture while in an institution. And parents worried that their children may be vulnerable to abuse in facilities too distant to visit more than once a year, if at all. Some parents resisted efforts, including by staff at North Star Hospital, to send their children to out-of-state PRTFs or to keep them there for months on end. Those parents ultimately took their children home against medical advice, without the benefit of appropriate discharge planning, rather than leave them in an institution.

One mother, whose ten-year-old daughter was living at a PRTF in Texas during the investigation, told us through tears: "I feel sad. I miss my baby so much. It has been really hard." She expressed frustration that "there are not services [in Alaska] for her."

2. <u>Alaska Has Failed to Provide Community-Based Services and Supports for</u> <u>Children with Behavioral Health Disabilities at Serious Risk of</u> <u>Institutionalization</u>

Community-based services that would enable children with behavioral health disabilities to live in their homes and communities are largely unavailable in Alaska. Shortages in community-based services are particularly acute in rural areas and for critical services like Home-Based Family Treatment, Crisis Services, and Therapeutic Treatment Home Services. The State's recent steps to reform its behavioral health service system have fallen short of addressing these deficiencies, which are widespread and ongoing.

a. Home-Based Family Treatment, Intensive Case Management, and Community Recovery Support Services

Home-Based Family Treatment, Intensive Case Management, and Community Recovery Support Services—designed by the State "to reduce use of inpatient hospitalization and residential services" by children with behavioral health disabilities—are not adequately available or provided across Alaska. In many rural communities, including places like Bethel, Nome, and Utqiagvik that serve as hubs for surrounding villages, there are no enrolled providers of one or more of these key services. Where the services are available, relatively few children receive them. In 2021, only 35 children in all of Alaska received Home-Based Family Treatment.

The dearth of community-based services in Alaska is so pronounced and widespread that institutional placement has become, for many behavioral health service providers in the state, the default option to which they refer children with long-term behavioral health needs. Multiple providers explained that, when recommending post-discharge services for children exiting institutions, they commonly find that children lack access to outpatient therapy, let alone to more intensive services like Home-Based Family Treatment. As a result, youth who may be appropriate for services in their own communities go to and remain in psychiatric hospitals longer than necessary, only to then be referred to PRTFs, often out of state. Some children, especially children in the State's custody, experience unnecessarily long PRTF stays because the post-discharge services they are able to receive in Alaska are limited. One provider observed that, once institutionalized, Alaskan children are forced to reach a higher-than-usual degree of stability before returning to the community because of the lack of community-based services available in the state.

Even children who are referred for appropriate community-based services in Alaska face significant barriers to actually receiving the care they need to remain in their homes. Children wait as long as three months for services from Medicaid-enrolled therapists and psychiatrists, and up to a year for a neuropsychological evaluation. Some children go into crisis while waiting for services, or experience more severe symptoms over time that contribute to longer stays in hospitals and residential treatment centers.

Deficiencies in community-based services are so longstanding in Alaska that, for some families, the experience of institutionalization is shared across generations. Parents admitted to a

psychiatric hospital or PRTF as a child have come to see their own children placed at an institution.

b. Crisis Services

Crisis Services for children are scarce in Alaska. Although there is a statewide crisis hotline, access to in-person services—including Mobile Outreach and Crisis Response Services, 23-Hour Crisis Observation and Stabilization Services, and Crisis Residential and Stabilization Services—remains limited more than two years after the State began implementing its Section 1115 behavioral health waiver. As of March 2022, there were only a handful of Medicaidenrolled providers of each of the Crisis Services. In Fairbanks, the second most populous metropolitan area in Alaska, there were no enrolled providers of 23-Hour Crisis Observation and Stabilization Services or Crisis Residential and Stabilization Services, and the sole provider of Mobile Outreach and Crisis Response Services typically does not serve children younger than 13 years old.

Where Crisis Services are available, few children receive them. In 2021, only five children received Mobile Outreach and Crisis Services, and only 110 children received Crisis Services of any kind through the State's Medicaid program. Alaska's paid Medicaid claims for all Crisis Services for children in 2021 totaled around \$750,000. By comparison, in 2020, the State's Medicaid program paid \$14.5 million for acute psychiatric services for children in general hospitals alone.

In both urban and rural areas of the state, emergency rooms function as de facto crisis stabilization units and gateways to long-term institutionalization. Providers at general hospitals in Alaska recognize that emergency rooms are not designed to treat children with behavioral health disabilities, and yet across the state children are regularly admitted to these settings during a behavioral health crisis.

After days or weeks in the emergency room, many of these children go on to be placed in a psychiatric hospital or PRTF. The experience of staying in an emergency room itself can be traumatizing for children. As one hospital-based provider told us, "Imagine being in a dark room with nothing to do, no access to TV, without even windows to see the outside world."

c. Therapeutic Treatment Home Services

Long-standing gaps in the availability of Therapeutic Treatment Home Services—a critical intervention for children at risk of institutional placement, particularly children in the State's custody—persist in Alaska. The State has capacity to serve about 150 children in therapeutic foster homes, although many more children are appropriate for this service and unable to access it. Therapeutic foster homes are concentrated in the southcentral region, around Anchorage, and are rare or nonexistent in many rural communities. Therapeutic Treatment Home Services provided by Alaska Native foster parents, especially, are in short supply, even as Alaska Native children account for over 60 percent of children with behavioral health disabilities in OCS custody.

Due to insufficient therapeutic foster homes and other community-based service options, children who are in the custody of OCS are more likely than other children to move from one institution to the next and often experience unnecessarily long institutional placements, sometimes months past the point of therapeutic value. Lengths of stay in psychiatric hospitals for OCS-involved children exceed 80 days on average. In out-of-state PRTFs, according to facility staff, there are children in OCS custody who, though ready for discharge, remain at the PRTF because there are no community placements available for them in Alaska. We interviewed one child who was living at an out-of-state PRTF and had been waiting a year for OCS to secure a placement.

Children in OCS custody are also at heightened risk of experiencing inappropriate placements outside institutions when they cannot access Therapeutic Treatment Home Services. Some children end up sleeping on the floor of an OCS office or at a shelter. Others stay in a traditional foster home without appropriate services and supports until they experience a behavioral health crisis and are hospitalized. "Kids get lost" in the system, lamented a hospital-based provider who has struggled to keep children in OCS custody out of the emergency room.⁴⁵

Therapeutic Treatment Home Services are often not available for children when they are most vulnerable to long-term or repeated institutional placement. Many therapeutic foster homes do not accept children discharging from a psychiatric hospital, even though they are appropriate for the service and have similar needs as children who are currently living in therapeutic foster homes, highlighting the need for changes in how the state manages its service system, including improved education, training, and recruitment of service providers.

d. Rural Alaska

The core services needed to support children with behavioral health disabilities in their own communities are especially scarce in rural areas of Alaska, even though the State could provide these services in many communities by leveraging existing community providers and infrastructure. At Tribal Health Organizations (THOs), often the sole source of behavioral services in rural Alaska, staff commented that community-based services are so limited in their regions that virtually *any* additional services would be helpful. The burden of these service gaps falls heavily on Alaska Native children and families, many of them living in remote villages off the road network. To see a behavioral health clinician, they sometimes must travel hundreds of miles to a regional hospital or clinic. Others wait weeks for an itinerant clinician to visit them in their village. In some rural communities, there are few alternatives to institutional placement for children who need intensive behavioral health services. "We have North Star [Hospital] and that's about it," according to staff at a THO serving a network of over 10 villages in northwest Alaska. Though THO providers widely acknowledge that culturally appropriate services are vital to promoting engagement by and better outcomes for Alaska Native children with

⁴⁵ Multiple providers in Alaska report that OCS keeps children in general hospitals because there are no safe places to maintain them, such as crisis or respite foster homes.

behavioral health disabilities, those services are rarely available in rural communities where many Alaska Native families live.

The State has recognized the need to support providers in the development of Mobile Outreach and Crisis Response Services, including through the expansion of telehealth services, but those services remain unavailable in some parts of Alaska.⁴⁶ For example, in the Yukon-Kuskowim Delta—an expansive region covering tens of thousands of square miles and home to around 25,000 people—there were no providers of Mobile Outreach and Crisis Response Services as of March 2022, including in the hub community of Bethel. While it may not be possible to ensure access to Mobile Outreach and Crisis Response Services in every village, the THO in that region has staff, including Behavioral Health Aides located in or near remote villages,⁴⁷ that are eligible to provide these services under the State's Section 1115 Medicaid waiver. Due to the lack of mobile crisis responders in rural areas, calls to a crisis hotline at times result in referrals to local law enforcement. In some cases, law enforcement responds to children in crisis by taking them to a general hospital or a jail. Children have stayed for days in local jails waiting for a flight to a hospital.

Services for children dually diagnosed with IDD and behavioral health disabilities, lacking across the State, are also practically nonexistent in rural areas outside congregate facilities. These children are frequently placed in out-of-state PRTFs where lengths of stay typically range between six and nine months, only to be discharged to the same lack of service access in their communities.

One mother from a rural community in southeastern Alaska told us that the closest provider of the integrated dual-disorder treatment her son needs is over 800 miles away. The mother said that she felt she had no choice but to send her son away from home, starting with an admission to North Star Hospital when he was just six years old. Her son has since experienced numerous hospitalizations and residential facility placements, including at a PRTF in Texas. After living for years in institutions, he has begun to feel like a stranger around his own family, according to his mother. She said that had appropriate community-based services been available to her son from the start, "it would have made all the difference."

⁴⁶ State of Alaska Department of Health and Social Services, *Request for Proposals Mobile Outreach for FY 2023*. <u>https://gems.dhss.alaska.gov/Solicitations/ShowSolicitation?entityId=789931b9-17bc-ec11-a99a-005056ae3c14</u> [https://perma.cc/3M8W-Y7JA].

⁴⁷ Behavioral Health Aides (BHAs) are certified paraprofessional staff trained to provide therapeutic services, respond to behavioral health crises, and "support the general mental health and wellbeing of individuals in rural and tribal areas." Kristin A. Neylon, *Strategies for the Delivery of Behavioral Health Crisis Services in Rural and Frontier Areas of the U.S.*, National Association of State Mental Health Program Directors, <u>https://nriinc.org/media/1679/2020paper10.pdf</u> [https://perma.cc/BL4U-CYVP]. BHAs live in the communities where they work and are often identified by other community members to serve in the role. Rebekah Falkner, *How Alaska Supports Rural and Frontier Behavioral Health Services*, National Academy for State Health Policy, <u>https://www.nashp.org/how-alaska-supports-rural-and-frontier-behavioral-health-services/ [https://perma.cc/Y89X-X94W]. *See also* Alaska Native Tribal Health Consortium, *Behavioral Health Aide Program*, <u>https://www.anthc.org/behavioral-health-aide-program/ [https://perma.cc/RR9M-KAX6]</u>.</u>

Even in rural areas of Alaska, there are opportunities for the State to implement and sustain the key community-based services that children and families need to avoid unnecessary institutionalization. Schools—for many children, the entry point for receiving behavioral services in their communities⁴⁸—are an underutilized resource in rural Alaska. In some remote villages, school counselors in Alaska provide prevention-based services and connect students, as needed, to ongoing therapeutic services and supports, including through Behavioral Health Aides and itinerant clinicians operating out of regional hubs. But even then, for students with more significant behavioral health needs, services are not available or provided with the intensity necessary to maintain them in their homes and communities. The State has recognized the importance of building its capacity to provide school-based behavioral health services statewide, including by embedding behavioral health professional in schools and improving access to telehealth services.⁴⁹ There are substantial federal resources available to the State to support these initiatives.⁵⁰

B. Alaska Can Reasonably Modify Its Service System to Serve Children with Behavioral Health Disabilities in Integrated Settings

The types of home- and community-based services and supports needed to sustain children with behavioral health disabilities in integrated settings already exist in Alaska, albeit often in scarce supply and only in parts of the state. The State has been funding and administering some of those services in one form or another for years. Under its Section 1115 waiver, the State added key behavioral health interventions to its service menu, most notably Home-Based Family Treatment and Crisis Services. *See supra* at 9-12. Since at least 2004, the State has acknowledged that "kids belong in their homes" and committed itself to building "an integrated, seamless system that will serve children in the most culturally competent, least

⁴⁹ State of Alaska Department of Education and Early Development, *Press Release: DEED Awarded \$9.1M Grant to Promote Student Mental Health* (September 29, 2020), <u>https://education.alaska.gov/news/releases/092920%20DEED%20Awarded%20\$9.1M%20Grant%20to%20Promote%20Student%20Mental%20Health.pdf</u> [https://perma.cc/67QT-D9QU]; Alaska Mental Health Trust Authority, *Case Study: Telehealth School Counseling*, <u>https://alaskamentalhealthtrust.org/wp-content/uploads/2022/09/01-Telehealth-BHinSchools-Phase2_REPORT.pdf</u> [https://perma.cc/MPG5-BYN6].

⁵⁰ U.S. Department of Education, U.S. Department of Education Approves Alaska's Plan for Use of American Rescue Plan Funds to Support K-12 Schools and Students, Distributes Remaining \$119 Million to State (August 27, 2021), <u>https://www.ed.gov/news/press-releases/us-department-education-approves-alaskas-plan-use-american-rescue-plan-funds-support-k-12-schools-and-students-distributes-remaining-119-million-state [https://perma.cc/D76N-CVMW]; State of Alaska Department of Education and Early Development, Press Release: DEED Awarded \$9.1M Grant to Promote Student Mental Health (September 29, 2020), https://education.alaska.gov/news/releases/092920%20DEED%20Awarded%20\$9.1M%20Grant%20to%20Promote %20Student%20Mental%20Health.pdf [https://perma.cc/67QT-D9QU].</u>

⁴⁸ Susan Wilger, *Issue Brief: Special Considerations for Mental Health Services in Rural Schools*, Now is the Time Technical Assistance Center,

https://rems.ed.gov/docs/resources/SAMHSA_Mental_Health_Services_Rural_Schools.pdf [https://perma.cc/ZD6V-UJPP].

restrictive setting."⁵¹ The State also acknowledges that treating children in psychiatric hospitals and PRTFs costs more than serving them in their homes and communities.⁵² Expanding existing community-based services and supports to children and families who need them to avoid unnecessary, costly institutional placements is a reasonable modification of the State's service system.⁵³

Additionally, as noted above, the State has a separate legal obligation under the Early and Periodic Screening, Diagnostic and Treatment Services (EPSDT) provisions of the Medicaid Act to provide children under the age of 21 with any coverable services, including community-based behavioral health treatment, to the extent they are medically necessary.⁵⁴ Because the State already must offer medically necessary behavioral health services to children across Alaska who are enrolled in its Medicaid program, meeting this obligation is inherently reasonable.

To support the necessary service expansion, the State has at its disposal substantial Medicaid funds, in addition to state and federal grant funds and annual allocations by the Alaska Mental Health Trust Authority, a quasi-public corporation that administers a perpetual trust for the benefit of Alaskans with mental illness and developmental disabilities, among other individuals with disabilities.⁵⁵ Alaska directs tens of millions of dollars each year—overwhelming federally sourced⁵⁶—toward serving children with behavioral health disabilities in institutions. *See supra* at 5-9. By boosting provider capacity and making the necessary

⁵³ See, e.g., Henrietta D. v. Bloomberg, 331 F.3d 261, 280-81 (2d Cir. 2003) (upholding as a reasonable modification an order requiring agency to follow existing law and procedures); *Guggenberger v. Minn.*, 198 F. Supp. 3d 973, 1030 (D. Minn. 2016) (providing Medicaid waiver services to eligible people, particularly from existing waiver funds, is a reasonable modification); *Hiltibran*, 793 F. Supp. 2d at 1116 (a state providing a specific Medicaid service for people in institutions must provide it for Medicaid enrollees who need it in the community); *Haddad v. Arnold*, 784 F. Supp. 2d 1284, 1304-05 (M.D. Fla. 2010) (providing a service already in state's service system to additional people is not inherently a fundamental alteration); *Messier*, 562 F. Supp. 2d at 344-45 (plaintiffs' requested service expansion, which was consistent with defendants' publicly stated plans, was reasonable).

⁵⁴ See 42 U.S.C. § 1396d(r)(5).

⁵⁵ The Alaska Mental Health Trust Authority authorizes approximately \$20 million in grants each year, divided among State agencies and beneficiary-serving organizations. *See* Alaska Mental Health Trust Authority, *Our Mission*, <u>https://alaskamentalhealthtrust.org/alaska-mental-health-trust-authority/ [https://perma.cc/KQ95-NDSR]</u>.

⁵⁶ Federal funds accounted for 72 percent of total Medicaid spending on behavioral health services in Alaska in FY18. *FY2020 Operating Budget Overview*, State of Alaska Office of Management and Budget, 18 (2020).

⁵¹ State of Alaska Department of Health and Social Services, Office of the Commissioner, *Bring the Kids Home*, available at <u>http://dhss.alaska.gov/Commissioner/Pages/btkh/default.aspx [https://perma.cc/3SBX-SNJ4]</u>.

⁵² State of Alaska Department of Health and Social Services, *Medicaid Section 1115 Behavioral Health Demonstration Application*, 3, 11-12, 21 (January 21, 2018), available at http://dhss.alaska.gov/dbh/Documents/1115/AK 1115 WaiverApplication.pdf [https://perma.cc/R5JW-N65G].

infrastructure investments to support statewide implementation of its Section 1115 waiver, the State could leverage existing resources to fulfill its obligation under Title II of the ADA to serve children in the most integrated setting appropriate to their needs.

Specifically, Alaska should take the following remedial measures, all aligned with its stated plans and obligations:

- Ensuring that community-based services are accessible and available with sufficient intensity to prevent unnecessary institutionalization. Services the State should ensure are available and accessible include Home-Based Family Treatment, Crisis Services, Therapeutic Treatment Home Services, Community Recovery Support Services, and Intensive Case Management.
- Coordinate with community-based service providers, tribal stakeholders, and local governments in Alaska to ensure that service planning and implementation is culturally appropriate and responsive to the needs of Alaska Native children and families.
- Support implementation of community-based behavioral health services in school settings. As the Centers for Medicare and Medicaid recently stated, schools are "uniquely positioned"⁵⁷ to help ensure that Medicaid-enrolled children can access the services they need.
- Develop adequate system-wide protocols for identifying children at serious risk of institutional placement and connecting them to appropriate, timely community-based services as needed to avoid unnecessary institutionalization.
- Develop adequate system-wide protocols to ensure that children transitioning from institutions to the community receive appropriate, timely community-based services as needed to remain in their homes and communities to the maximum extent possible.
- Ensure adequate oversight of Administrative Service Organizations, State grantees, and Medicaid-enrolled service providers and effective coordination among those entities, hospitals, and law enforcement to avoid unnecessary institutionalization.

V. CONCLUSION

For the foregoing reasons, we conclude that there is reasonable cause to believe the State fails to provide services to children with behavioral health disabilities in the most integrated

⁵⁷ U.S. Department of Health and Human Services, Center for Medicare and Medicaid Services, *CMCS Informational Bulletin: Information on School-Based Services in Medicaid: Funding, Documentation, and Expanding Services*, at 1 (Aug. 18, 2022), <u>https://www.medicaid.gov/federal-policy-guidance/downloads/sbscib081820222.pdf</u> [https://perma.cc/SSJ3-B9FB].

setting appropriate to their needs, in violation of the ADA. 42 U.S.C. § 12132; 28 C.F.R. § 35.130(d). The State plans, administers, and funds its behavioral health service system in a manner that unnecessarily segregates children in psychiatric hospitals and PRTFs within and outside Alaska, rather than providing these services where people live, in their community. *See* 28 C.F.R. § 35.130(b), (d).

We look forward to working cooperatively with the State to reach a consensual resolution of our findings. We are obligated to advise you that if we are unable to reach a resolution, the United States may take appropriate action, including initiating a lawsuit, to ensure the State's compliance with the ADA. Please also note that this Report is a public document. It will be posted on the Civil Rights Division's website.