



Children’s Mental Health Services: The Right to Community-Based Care

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In 2016, there were approximately 3.8 to 4.6 million children between the ages of nine and seventeen with mental health needs resulting in a significant functional impairment.² A growing base of evidence and experiences demonstrates that, with the right approach, youth with significant mental health needs can and do thrive in family settings.³ Accordingly, states,

¹ Substantial research contributions for this issue brief were provided by [Rachel Holtzman](#) and [Alexis Robles](#), Health Policy Fellows.

² Children with significant mental health needs are sometimes referred to as having a “serious emotional disturbance” (SED). SED is not a diagnostic category in the Diagnostic and Statistical Manual of Mental Disorders. Instead, the Substance Abuse and Mental Health Services Administration (SAMHSA) created the classification in 1993 to inform the distribution of block grants, and are defined as children up to age 18 who “currently or at any time during the past year . . . [h]ave had a diagnosable mental, behavioral, or emotional disorder . . . [t]hat resulted in functional impairment which substantially interferes with or limits the child’s role or functioning in family, school, or community activities.” 58 Fed. Reg. 29422, 29425 (May 20, 1993). While SED does not describe an actual diagnosis, it is a useful term insofar as it has allowed SAMHSA to estimate the number of children and adolescents that have mental health needs that result in a significant functional impairment. SAMHSA estimates that in 2016, there were approximately 3.8 to 4.6 million children with SED between the ages of 9 and 17. SAMHSA, Drug and Alcohol Information System, *SMI/SED Prevalence Estimates, 2016*, <https://www.dasis.samhsa.gov/dasis2/urs.htm>.

³ “Family setting” is used here to refer to non-group home-based settings. A family could be biological parent(s), a foster parent, a grandparent or other relative, or adoptive family. See *generally* Annie E. Casey Found., *Every Kid Needs a Family* (2015), <http://www.aecf.org/m/resourcedoc/aecf-EveryKidNeedsAFamily-2015.pdf>.

In 1999, the Surgeon General released a seminal report finding that there is convincing evidence to support the use of in-home services for this population. See SAMHSA and Nat’l Inst. of Mental Health,

municipalities, and communities are engaging in efforts to reform mental health care delivery and financing to support and expand effective community-based services.⁴

Despite extensive system reform efforts in many states, it is still all too common for state actors, school officials, and mental health providers to rationalize placing children in congregate settings, claiming that the child has exhausted community-based resources.⁵ Advocates must look behind such statements and assess not only whether the services necessary to meet the needs of children exist, but also determine if the services are actually available in sufficient quality and quantity to meet the state's legal obligations to young Medicaid enrollees with disabilities. With basic information about states' legal obligations and experiences implementing home-based services, advocates will have a greater ability to judge the adequacy of current services, and tools to imagine a better functioning system.

Mental Health: A Report of the Surgeon General 168 (1999), <https://www.surgeongeneral.gov/library/reports/index.html>. Additionally, the report notes that there is only weak or anecdotal evidence to support the use of residential treatments centers (RTC) or psychiatric residential treatment facilities (PRTFs) for children with significant mental health needs. RTCs are a broad category referring to all non-acute, long-term mental health facilities for youth. PRTFs refer to the subset of RTCs that are Medicaid funded. Additional information on evidence supporting the use of home-based services for this population is included in the appendix to this report.

⁴ See SAMHSA, *The Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances Program, Report to Congress* (2015), https://www.samhsa.gov/sites/default/files/programs_campaigns/nitt-ta/2015-report-to-congress.pdf. See also Joint CMS and SAMHSA Informational Bulletin, *Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions* 5 (May 7, 2013), <https://www.medicaid.gov/federal-policy-guidance/downloads/cib-05-07-2013.pdf>. See Oswaldo Urdapilleta et al., *National Evaluation of the Medicaid Demonstration Waiver Home- and Community-Based Alternatives to Psychiatric Residential Treatment Facilities, Final Evaluation Report* (May 30, 2012, Amended April 2, 2013), <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/downloads/cba-evaluation-final.pdf>

⁵ There are no accurate national estimates of the number of children with SED who are confined to congregate settings. This is due to a lack of federal oversight of many of these facilities. See U.S. Gov't Accountability Office, GAO-08-345, *Residential Facilities: Improved Data and Enhanced Oversight Would Help Safeguard the Well-Being of Youth with Behavioral and Emotional Challenges* (2008), <http://www.gao.gov/products/GAO-08-346>. However, there are over 500 residential treatment centers for children across the country. SAMHSA, *Behavioral Health Servs. Info. Sys. Series: National Directory of Mental Health Treatment Facilities* (2017), <https://www.samhsa.gov/data/sites/default/files/2017%20MH%20Directory.pdf>.

I. The Right to Community-Based Services

Two separate but complementary legal requirements undergird children's right to intensive mental health services in the community. First, Medicaid's broad Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit entitles beneficiaries under age twenty-one to medically necessary mental health services that are targeted to effectively ameliorate identified conditions.⁶ Second, a state's systemic failure to develop an adequate array of community-based services may violate the Americans with Disabilities Act (ADA), which requires states to provide services to individuals with disabilities in the most integrated setting appropriate to their needs (the "integration mandate"). The integration mandate is implicated if a lack of community-based services causes unnecessary segregation or puts children at risk of such segregation.⁷ Moreover, the ADA prohibits the use of "criteria or methods of administration" that subjects individuals to discrimination on the basis of disability or has "the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the public entity's program with respect to individuals with disabilities."⁸

States must ensure that services are actually delivered in a manner that meets the corresponding goals of the EPSDT benefit and the ADA.⁹ The services must be targeted to

⁶ 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B); 1396d(r); *see also S.D. ex rel. Dickson v. Hood*, 391 F.3d 581, 590 (5th Cir. 2004) (services that are appropriately defined as "medical assistance" under the Medicaid regulations and are medically necessary to correct or ameliorate a condition" must be provided to children under 21.).

⁷ Americans with Disabilities Act, 42 U.S.C. §§ 12101-12213; 28 C.F.R. § 35.130(d); *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999); U.S. Dep't. of Justice, *Statement of the Dep't. of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.* (June 22, 2011), https://www.ada.gov/olmstead/q&a_olmstead.htm (hereinafter "DOJ Olmstead Q&A").

⁸ 28 C.F.R. § 35.130(b)(3) (Americans with Disabilities Act); 28 C.F.R. § 41.51(b)(3) (Rehabilitation Act). *See, e.g. Cota v. Maxwell-Jolly*, 688 F.Supp.2d 980, 995 (N.D. Cal. 2011) (internal citations and quotation marks omitted) ("This provision applies to written policies as well as actual practices, and is intended to prohibit both blatantly exclusionary policies or practices as well as policies and practices that are neutral on their face, but deny individuals with disabilities an effective opportunity to participate.")

⁹ State Medicaid programs must also comply with Section 1557 of the Affordable Care Act. 42 U.S.C. § 18116. Section 1557 prohibits health programs and activities receiving federal financial assistance from discriminating on the basis of a number of protected classes, and specifically incorporates the Section 504 of the Rehabilitation Act's prohibition on discrimination on the basis of disability. Advocates may wish to explore using Section 1557 as an additional cause of action. *See generally* Elizabeth Edwards et al., Nat'l Health Law Prog., *Highlights of Section 1557 Final Rule* (May 2016).

effectively ameliorate or treat youths' identified mental health needs, and be provided in the most integrated setting appropriate to their needs.

A. Medicaid's Early and Periodic Screening, Diagnostic and Treatment Benefit

EPSDT Medicaid services are a comprehensive benefit for children under age twenty-one that includes screening, diagnostic, and treatment services. EPSDT's statutory provisions require states to provide and arrange for a broad range of services necessary to meet children's medical needs, including behavioral health needs.¹⁰ Specifically, if a service is listed under 42 U.S.C. § 1396d(a) (the section of Medicaid statute that defines "Medical Assistance"), and the service is medically necessary, then the state *must* provide the service.¹¹ This mandate applies to all categories of Medical Assistance, even if the service is generally classified as an "optional" service.¹² In other words, "while a state may choose which medical services beyond the mandated seven it may offer to eligible adults, states are bound, when it is medically necessary, to make available to Medicaid-eligible children all of the twenty-eight types of care and services included as part of the definition of medical assistance in the Act."¹³

The Medicaid Act includes broad categories of services that must be covered, but does not list every specific medical or mental health service that falls under each broad category, nor would it be practicable to do so. Therefore, like many individual services, many of the services children with significant mental health needs require to live in the community are not specifically identified in the listed categories of "Medical Assistance" in 42 U.S.C. § 1396d(a). However, a series of cases and ensuing settlements have fleshed out the contours of the right to these intensive services, when medically necessary, pursuant to the broad EPSDT mandate.¹⁴

¹⁰ 42 U.S.C. § 1396a(a)(43); see also 42 U.S.C. §§ 1396a(a)(10)(A); 1396d(a)(4)(B); 1396d(r).

¹¹ The EDPST benefit, while broad, is not boundless. For example, states do not have to cover services that are experimental. CMS, STATE MEDICAID MANUAL § 5112. States may also choose the most cost effective treatment, as long as that treatment is equally effective and actually available. CMS, *EPSDT – A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents* 24 (2014).

¹² *S.D. ex rel. Dickson v. Hood*, 391 F.3d 581, 590 (5th Cir. 2004) (states must offer children "such other necessary health care, diagnostic services, treatment, and other measures described in § 1396d(a)," whether or not such services are covered in the state's Medicaid plan).

¹³ *Rosie D. v. Romney*, 410 F. Supp. 2d 18, 25 (D. Mass. 2006).

¹⁴ While litigation helped define the extent of the right to many of the services discussed in this paper, EPSDT is a statutory mandate. Advocates can always look to see what services CMS has approved in other state plans to determine if a service is "coverable," and therefore required for youth when medically necessary.

Advocates have filed several actions challenging states' failure to ensure that children receive intensive community-based mental health services. One of the most significant was *Rosie D.*, a class action filed in 2001 on behalf of all children in Massachusetts diagnosed with significant mental health needs that would benefit from home-based services.¹⁵ After a six week trial in 2005, Judge Ponsor issued a 98-page decision holding that states must arrange for intensive care coordination and intensive home-based services for children with significant needs.

The *Rosie D.* court first “look[ed] to the array of actual clinical interventions that constitute, in the terms of the Medicaid statute, ‘medically necessary’ services for class members,” and determined that the components of the services sought were mandated under the EPSDT benefit.¹⁶ Second, the court found the state’s obligation went beyond simple “coverage.” Identifying applicable billing codes through which a provider could theoretically provide these services is not enough. As the court in *Rosie D.* recognized, “even if the state offers the service or treatment on paper, courts will examine whether children can, in practice, actually access these services.”¹⁷ After reciting Plaintiffs’ extensive evidence, the court held that Massachusetts “failed to meet the substance of the EPSDT mandate.”¹⁸ The question of remedy was not addressed in *Rosie D.*; the court bifurcated the case, and the remedy was ultimately negotiated.

At approximately the same time *Rosie D.* was filed, across the country in California a case called *Katie A. v. Bonta* was filed on behalf of a class of plaintiffs in foster care or at risk of foster care. The named plaintiffs were five Medicaid-eligible children in the foster care system who needed more intensive mental health services due to their serious mental and emotional disabilities. The lead plaintiff, Katie A. herself, was removed from home at age four and experienced thirty-seven different moves or placements in foster care, including nineteen psychiatric hospitalizations, by the time she was fourteen years old.¹⁹

The district court granted a preliminary injunction ordering the state to provide wraparound services and therapeutic foster care, but the Ninth Circuit remanded, holding that the district court conflated what should have been a two-part inquiry. First, the district court should ask

¹⁵ Complaint, *Rosie D. v. Romney*, 410 F. Supp. 2d 18 (D. Mass. 2006) (01-CV-30199), <http://rosied.org/page-526903>

¹⁶ *Rosie D.*, 410 F. Supp. 2d at 30 (D. Mass. 2006).

¹⁷ *Id.* at 29.

¹⁸ *Id.* at 53.

¹⁹ See Kimberly Lewis, Nat'l Health Law Prog., *Fact Sheet: EPSDT Home and Community Based Services Mental Health Services: Settlement Agreement in Katie A. v. Douglas* (Feb. 2012).

whether the services under the Medicaid Act were being provided effectively. If not, the court should then determine if the services needs to be financed as a single, bundled service via wraparound.²⁰ On remand, the district court ordered the parties back into negotiations. Nearly ten years after *Katie A.* was filed, and after extensive litigation and a lengthy settlement negotiation, a landmark settlement was reached to provide tens of thousands of children in California with intensive home-based mental health services.

While advocates should be mindful that courts may give states some flexibility in designing a how services are packaged, courts have nevertheless been clear that Medicaid requires states to ensure that medically necessary services for children with significant mental health needs are available, accessible, and actually delivered in a manner that is reasonably calculated to meet their needs.²¹ In fact, the Ninth Circuit, in *Katie A.*, reinforces in its decision that states have an obligation to cover every type of health care or service necessary for EPSDT corrective or ameliorative purposes that is allowable under § 1396d(a) and also have an obligation to see that the services are provided when screening reveals that they are medically necessary for a child.²²

²⁰ *Katie A. ex rel. Ludin v. Los Angeles County*, 481 F.3d 1150, 1158 (9th Cir. 2007).

²¹ CMS, STATE MEDICAID MANUAL § 5110 (“Services provided under EPSDT must be sufficient in amount, duration, or scope to reasonably achieve their purpose.”); *id.* at § 5122 (while “42 C.F.R. 440.230 allows ... [states] to establish the amount, duration and scope of services provided under the EPSDT benefit ... services must be sufficient to achieve their purpose (within the context of serving the needs of individuals under age 21)”); *Katie A. ex rel. Ludin v. Los Angeles County*, 481 F.3d 1150, 1159 (9th Cir. 2007) (“States also must ensure that the EPSDT services provided are reasonably effective. ... While the states must live up to their obligations to provide all EPSDT services, the statute and regulations afford them discretion as to how to do so.”); *Rosie D.*, 410 F. Supp. 2d at 43 (declining to order specific programs, but holding that the state must find programs to offer that provide children with SED programs that provide adequate care coordination and in-home services: “Defendants may choose to comply in other ways or by other means; they cannot, as they are currently doing, choose to deprive the vast majority of children with SED of adequate ESPDT services.”). *But see* Nov. 7, 2016 Order, *Troupe v. Barbour*, 2013 WL 12303126 (S.D. Miss. 2013) (3:10-cv-00153), ECF No. 120 (granting Defendants’ Motion to Dismiss EPSDT claims, finding Plaintiffs did not state a claim because Plaintiffs failed to request an EPSDT screening prior to requesting behavioral health services.). The holding in *Troupe* is contrary to guidance from CMS. CMS has “long considered any encounter with a health care professional practicing within the scope of his/her practice inter-periodic screening.” CMS, Dear State Medicaid Director (January 10, 2001), <https://downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/smd011001a.pdf>; see also U.S. Dep’t of Justice Statement of Interest to Clarify Meaning of EPSDT Statue, *Troupe v. Barbour*, 2013 WL 12303126 (S.D. Miss. 2013) (3:10-cv-00153) ECF No. 57, https://www.ada.gov/olmstead/olmstead_cases_list2.htm

²² *Katie A. ex rel. Ludin*, 481 F.3d at 1158.

B. The Americans with Disabilities Act Integration Mandate

In addition to Medicaid's broad EPSDT mandate, the ADA places additional requirements on states to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."²³ This is what is commonly referred to as the ADA's "integration mandate." As the Supreme Court explained in *Olmstead v. L.C. ex rel. Zimring*, in passing the ADA "Congress explicitly identified unjustified segregation of persons with disabilities as a form of discrimination."²⁴ Section 504 of the Rehabilitation Act contains a similar antidiscrimination mandate, but applies only to state programs and activities receiving federal monies.²⁵ Because of the similarities between the two laws, courts apply them in a consistent manner.²⁶

Systemic failures to develop an adequate array of community-based services, resulting in unnecessary and unwanted residential and institutional placements and segregated settings, violate the ADA's integration mandate.²⁷ States have an obligation to design and implement the EPSDT benefit to provide services in the most integrated environment appropriate for enrollees' needs. Simply locating a facility in a residential neighborhood does not fulfil the integration mandate. The "most integrated setting" is "a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible."²⁸ The state's

²³ 28 C.F.R. § 35.130(d).

²⁴ *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 600 (1999)(internal citations omitted). States must provide community-based treatment for individuals with disabilities when: a) "the State's treatment professionals determine that such a placement is appropriate"; b) "the affected persons do not oppose such treatment," and c) "the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." *Id.* at 607

²⁵ 29 U.S.C. § 794(a); 28 C.F.R. § 41.51(d).

²⁶ 28 C.F.R. § 35.103; *Olmstead*, 527 U.S. at n.16.

²⁷ *Olmstead*, 527 U.S. at 605-06. A fundamental alteration defense to a specific claim does not excuse a state from its overall obligation not to operate its Medicaid system in a way that tends to segregate individuals with disabilities. See *Frederick L. v. Dep't of Pub. Welfare of Pa.*, 422 F.3d 151, 157 (3d Cir. 2005).

²⁸ 28 C.F.R. pt. 35, App. B; see also *Steimel v. Wernert*, 823 F.3d 902, 911 (7th Cir. 2016) (deferring to DOJ's interpretation that integration means opportunities to interact with nondisabled persons and holding that *Olmstead's* integration mandate applies to "all settings, not just to institutional settings. It bars unjustified segregation of persons with disabilities, wherever it takes place.").

obligation is not only triggered when its policies actually cause institutionalization, but also when a state's actions leads to a serious risk of institutionalization and segregation.²⁹

Furthermore, the ADA prohibits state from using methods of administration that “have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability ... [or] have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the public entity's program with respect to individuals with disabilities,” and a state must make “reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability.”³⁰ This “methods of administration” requirement prohibits states from utilizing criteria or a method of administering a program that has the effect of discriminating against individuals with disabilities, including subjecting individuals to unnecessary segregation.³¹

²⁹ See *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1181 (10th Cir. 2003) ([T]here is nothing in the plain language of the regulations that limits protection to persons who are currently institutionalized. ... Those protections would be meaningless if plaintiffs were required to segregate themselves by entering an institution before they could challenge an allegedly discriminatory law or policy that threatens to force them into segregated isolation. Second, while it is true that the plaintiffs in *Olmstead* were institutionalized at the time they brought their claim, nothing in the *Olmstead* decision supports a conclusion that institutionalization is a prerequisite to enforcement of the ADA's integration requirements”); *M.R. v. Dreyfus*, 663 F.3d 1100, 1116 (9th Cir. 2011), *opinion amended and superseded on other grounds on denial of reh'g*, 697 F.3d 706 (9th Cir. 2012) (“An ADA plaintiff need not show that institutionalization is “inevitable” or that she has “no choice” but to submit to institutional care in order to state a violation of the integration mandate. Rather, a plaintiff need only show that the challenged state action creates a serious risk of institutionalization.”); *Pashby v. Delia*, 709 F.3d 321-22 (4th Cir. 2013) (citing DOJ *Olmstead* Q&A guidance holding that *Olmstead* applies to persons at serious risk of institutionalization); *Davis v. Shah*, 821 F.3d 231, 263-64 (2nd Cir. 2016) (same). See also DOJ *Olmstead* Q&A, *supra* note 7, at question 6.

³⁰ 28 C.F.R. 41.51(b)(3), (7) (Rehabilitation Act); 28 C.F.R. § 35.130(b)(3) (Americans with Disabilities Act);

³¹ See *Day v. D.C.*, 894 F. Supp. 2d 1, 22–23 (D.D.C. 2012) (internal citations omitted) (“to state a claim under either the ADA or the Rehabilitation Act ... it is sufficient to allege, as plaintiffs do, that the District provides, administers and/or funds the existing service system through which plaintiffs receive long-term care services and/or that the District, in so doing, has utilized criteria or methods of administration that have ‘caused [plaintiffs] ... to be confined unnecessarily in nursing facilities in order to obtain long-term care services, rather than facilitate their transition to the community with appropriate services and supports.”); DOJ *Olmstead* Q&A, *supra* note 7, at question 2 (“[A] public entity may violate the ADA's integration mandate when ... through its planning, service system design, funding choices, or service implementation practices, promotes or relies upon the segregation of individuals with disabilities in private facilities or program.”).

Olmstead does not require states to establish entirely new Medicaid services, but a state may be required to reasonably modify the array of services available. States cannot offer services in an institutional environment but refuse to offer similar appropriate treatment in the community by claiming the community-based service is a “new service.” As the Ninth Circuit has explained: “where the issue is the location of services, not whether services will be provided, *Olmstead* controls.”³² For example, a state could not offer psychosocial rehabilitation services such as group therapies, care coordination, and intensive individual therapy within an institution while refusing to cover similar services in the community. As the Northern District of Illinois noted when denying the state’s motion to dismiss an *Olmstead* claim on behalf of children in psychiatric hospitals that were seeking services in less restrictive settings: “The plaintiffs’ desire for appropriate treatment in a non-hospital setting is not inherently a request for a new program; rather, it speaks to how and where services are available.”³³

Earlier decisions establishing children’s rights to services in the community, such as *Rosie D.* and *Katie A.*, relied entirely on the EPSDT mandate. (The *Katie A.* complaint raised an ADA claim, but the court did not reach this issue).³⁴ However, since then, numerous cases on behalf of youth with significant mental health needs have been filed relying both on the EPSDT mandate and the Americans with Disabilities Act.³⁵ While none of these cases have been litigated to judgment, a West Virginia investigation resulted in a DOJ findings letter, litigation in Washington resulted in a court-approved settlement agreement, and additional settlement agreements have been reached in North Carolina and Alabama.³⁶

³² *Townsend v. Quasim*, 328 F.3d 511, 517 (9th Cir. 2003); see also DOJ *Olmstead* Q&A, *supra* note 7, at question 8 (“Public entities cannot avoid their obligations under the ADA and *Olmstead* by characterizing as a ‘new service’ services that they currently offer only in institutional settings. The ADA regulations make clear that where a public entity operates a program or provides a service, it cannot discriminate against individuals with disabilities in the provision of those services. ... Once public entities choose to provide certain services, they must do so in a nondiscriminatory fashion.”).

³³ *N.B. v. Hamos*, 2013 WL 6354152, at *8 (N.D. Ill. Dec. 5, 2013)

³⁴ First Amended Complaint, *Katie A. v. Bonta*, 433 F. Supp. 2d 1065 (C.D. Cal. 2006),

<https://www.clearinghouse.net/chDocs/public/CW-CA-0005-0012.pdf>

³⁵ See generally Dep’t of Justice Statement of Interest, *Troupe v. Barbour*, 2013 WL 12303126 (S.D. Miss 2013) (3:10-cv-00153) ECF No. 41, https://www.ada.gov/briefs/troupe_interest_br.pdf; Complaint, *T.R. v. Dreyfus*, C09-1677-TSZ (W.D. Wash. Nov. 24, 2009), https://youthlaw.org/wp-content/uploads/2014/11/WA_MentalHealthComplaint.pdf; Motion to Amend Complaint, *N.B. v. Hamos*, 2013 WL 6354152 (1:11-cv-06866) (N.D. Ill. Oct. 8, 2011), https://docs.wixstatic.com/ugd/e4f729_b3ff3bb390264c168ce8a21f854007f4.pdf.

³⁶ Settlement Agreement, *T.R. v. Dreyfus*, C09-1677-TSZ (W.D. Wash. Dec. 19, 2013), https://www.disabilityrightswa.org/wp-content/uploads/2017/12/Settlement-Agreement-and-Order-signed-8.30.2013_0.pdf; Dep’t of Justice, *Findings Letter, Investigation of West Virginia Children’s*

II. Specific Services to Meet States' ESPDT and ADA Obligations

The twin guideposts of Medicaid's ESPDT benefit and the ADA's integration mandate can be relied on to compel states to ensure that Medicaid funded mental health services are provided in a manner that is reasonably designed to treat children with significant mental health needs in the most integrated setting appropriate to their needs. While children's needs are individualized, the following services are basic building blocks states such as Washington, California, and Massachusetts have provided to meet this mandate: 1) Intensive Care Coordination; 2) Crisis Services, 3) Intensive Home Based Services; and 4) Therapeutic Foster Care.³⁷ These services must be available to children when "necessary ... to correct or

Mental Health System Pursuant to the Americans with Disabilities Act (June 1, 2015), https://www.ada.gov/olmstead/documents/west_va_findings_ltr.pdf; *Disability Rights North Carolina v. Brajer*, 5:16-cv-854 (E.D.N.C. 2016) <http://www.disabilityrightsncc.org/sites/default/files/L28-3-1%20Settlement%20Agreement.pdf>; Alabama Joint Settlement Agreement, https://centerforpublicrep.org/wp-content/uploads/2018/01/Alabama_Joint-Settlement-Agreement_executed.pdf. *Accord O.B. v. Norwood*, 838 F.3d 837 (7th Cir. 2016), *aff'g* 170 F. Supp. 3d 1186 (N.D. Ill. 2016) (affirming the district court's injunction requiring the state to arrange for the provision of in-home nursing services, directly or through referral. On remand, the district court also upheld the Plaintiffs' ADA claims, finding the State's policies were inconsistent with the integration mandate.); *A.H.R. v. Wash. State Health Care Auth.*, 2016 WL 98513, at *14-15 (W.D. Wash. Jan. 7, 2016) (granting preliminary injunction for plaintiffs on claim that state's failure to arrange for the provision of in-home nurses violated the ADA's integration mandate).

³⁷ As DOJ explained in its findings letter regarding its investigation of West Virginia Children's Mental Health System,

A sufficient array of in-home and community-based services incorporates several discrete clinical interventions, including, at a minimum:

- Intensive care coordination, e.g., Wraparound with fidelity to the National Wraparound Initiative standards;
- In-home and community-based direct services of sufficient frequency, intensity, comprehensiveness, and duration to address the youth and family's needs . . .
- Responsive and individualized crisis response and stabilization services available 24 hours a day, 7 days a week, including immediate access to back-up crisis stabilization when actually needed so a youth can spend the majority of his/her time living in a more integrated community setting; and
- Therapeutic Foster Care, which . . . is an intensive, individualized mental health service provided in a family setting, using specially trained and intensively supervised foster parents.

ameliorate defects and physical and mental illnesses and conditions ...” and the services should be provided in the most integrated setting appropriate to the needs of the child.³⁸

A. **Intensive Care Coordination**

Children with significant mental health needs and their families often require intensive engagement, planning, and support services that includes assistance accessing services and monitoring the implementation of services. As the court in *Rosie D.* noted: “The danger, for these children, given their complex problems, is that they will not only receive insufficient services, but that a lack of coordination among the service providers will undermine the effectiveness of the treatment that they do receive.”³⁹ One way to provide necessary engagement, planning, and support services is through a service called “Intensive Care Coordination” (ICC).⁴⁰

Dep’t of Justice, *Findings Letter, Investigation of West Virginia Children’s Mental Health System Pursuant to the Americans with Disabilities Act 22* (June 1, 2015),

https://www.ada.gov/olmstead/documents/west_va_findings_ltr.pdf

³⁸ 42 U.S.C. § 1396d(r)(5) (ESPDT); 28 C.F.R. § 35.130(d) (ADA integration mandate). In non-legal terms, the framework for delivering necessary treatment and support that allows children with SED to live successfully in their homes is often referred to as a “system of care.” See generally SAMHSA, *Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances Program, Report to Congress* (2015),

https://www.samhsa.gov/sites/default/files/programs_campaigns/nitt-ta/2015-report-to-congress.pdf.

See also Children’s Bureau, HHS, *Systems of Care 1* (Feb. 2008),

<https://www.childwelfare.gov/pubPDFs/soc.pdf>

(A “system of care” is: “[A] service delivery approach that builds partnerships to create a broad, integrated process for meeting families’ multiple needs. This approach is based on the principles of interagency collaboration; individualized, strengths-based care practices; cultural competence; community-based services; accountability; and full participation of families and youth at all levels of the system.”).

³⁹ *Rosie D. v. Romney*, 410 F. Supp. 2d 18, 32 (D. Mass. 2006).

⁴⁰ Kirsten Painter, *Outcomes for Youth with Severe Emotional Disturbance: A Repeated Measures Longitudinal Study of a Wraparound Approach of Service Delivery in Systems of Care*. 41(4) CHILD & YOUTH CARE FORUM 407 (2012); Washington State Inst. for Pub. Policy, *Full Fidelity Wraparound for Children with Serious Emotional Disturbance (SED)* (Jan. 2012),

<http://www.wsipp.wa.gov/BenefitCost/ProgramPdf/267/Full-fidelity-wraparound-for-children-with-serious-emotional-disturbance-SED> (meta-analysis of four prominent research studies on Full Fidelity

Wraparound found that youth in Full Fidelity Wraparound services experienced a decrease in all three outcomes of interest: disruptive behavior disorder symptoms, externalizing behavior symptoms, and internalizing symptoms.).

ICC is a robust, comprehensive form of case management services, designed specifically for children and youth with significant mental health needs. ICC should include: “assessment and service planning; [assistance with] accessing and arranging for services, coordinating multiple services, including access to crisis services. ... [assistance with meeting] basic needs, advocating for the child and family, and monitoring progress....”⁴¹ ICC is often provided via “wraparound,” which is a structured method of service planning that incorporates the following core values: the process is “family- and youth-driven, team-based, collaborative, individualized, and outcomes-based; and adheres to specified procedures: engagement, individualized care planning, identifying strengths, leveraging natural supports, and monitoring progress.”⁴²

Although ICC is a service involving a number of different actions or interventions, the components of ICC are well-grounded in the Medicaid statute, particularly the case management benefit and the rehabilitation services benefit. Case management includes: “[g]athering information from other sources, such as family members ... to form a complete assessment.”⁴³ Rehabilitative services are defined under the Medicaid Act as “any medical or remedial services (provided in a facility, a home, or other setting) recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under State law, for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level.”⁴⁴

⁴¹ Joint CMS and SAMHSA Informational Bulletin, *Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions* (May 7, 2013), <https://www.medicaid.gov/federal-policy-guidance/downloads/cib-05-07-2013.pdf>; see also Cal. Mental Health Servs. Div., Dep’t of Health Care Servs. & Cal. Dep’t of Social Servs., *Medi-Cal Manual for Intensive Care Coordination (ICC), Intensive Home Based Services (IHBS) & Therapeutic Foster Care (TFC) for Medi-Cal Beneficiaries*, 25-28 (3rd ed. Jan. 2018), http://www.dhcs.ca.gov/services/MH/Documents/PPQA%20Pages/Katie%20A/Medi-Cal_Manual_Third_Edition.pdf (ICC service components/activities include: planning and assessment of strengths and needs; reassessment of strengths and needs; referral, monitoring and follow-up activities; and transition.)

⁴² Ctr. for Health Care Strategies, *Intensive Care Coordination Using High-Quality Wraparound for Children with Serious Behavioral Health Needs: State and Community Profiles 5* (July 2014), <https://www.chcs.org/media/ICC-Wraparound-State-and-Community-Profiles1.pdf>; see generally Jennifer Schurer Coldiron et al., *A Comprehensive Review of Wraparound Care Coordination Research, 1986-2014*, 26(5) J. CHILD & FAM. STUDIES 1245 (2017).

⁴³ 42 U.S.C. §§ 1396d(a)(19); 1396n(g)(2); 42 C.F.R. § 440.169(d).

⁴⁴ 42 U.S.C. § 1396d(a)(13); 42 C.F.R. § 440.130(d).

“Strength and Needs Assessments,” which are component of ICC, are covered by the case management benefit.⁴⁵ Team formation, and specifically child and family engagement activities, are also covered by the case management benefit.⁴⁶ Other ICC components, such as ongoing crisis prevention and management, are covered as rehabilitative services.⁴⁷

In *Katie A.*, the court explained that while

Wraparound has nine component services ... Plaintiffs’ supplemental interrogatory responses ... link, in chart form, each component of wraparound services to ... the corresponding category or categories of 1396d. ... The Court finds likely that virtually all of the corresponding categories of 1396d(a) identified by Plaintiffs do, in fact, encompass the linked-to service.⁴⁸

Courts and state agencies have recognized that ICC should be covered when medically necessary. For example, the court in *Rosie D.* concluded that the services included in ICC, such as “comprehensive assessments and scrupulous service coordination are essential parts of the Commonwealth’s EPSDT responsibility to children with SED.”⁴⁹ The court went on to explain the importance of ICC:

“[T]o address the complex needs of this particularly vulnerable population, clinical oversight—that is, ongoing case management and monitoring—will almost always constitute an essential component of any treatment regimen. The solid weight of the evidence establishes that a great number of Medicaid-eligible children with SED badly need, but are not being provided, adequate case management services in the Commonwealth ... [because] no trained individual meets regularly with the child and

⁴⁵ 42 C.F.R. § 440.169(d)(1).

⁴⁶ 42 C.F.R. § 440.169(e) (“Case management may include contacts with non-eligible individuals that are directly related to the identification of the eligible individual’s needs and care, for the purposes of helping the eligible individual access services, identifying needs and supports to assist the eligible individual in obtaining services, providing case managers with useful feedback, and alerting case managers to changes in the eligible individuals’ needs.”) See also 42 U.S.C. §§ 1396d(a)(19), 1396n(g)(2)(A)(i).

⁴⁷ 42 U.S.C. § 1396d(a)(13); 42 C.F.R. § 440.130(d).

⁴⁸ *Katie A. v. Bonta*, 433 F. Supp. 2d 1065, 1074-75 (C.D. Cal. 2006), *rev’d on other grounds Katie A. ex rel. Ludin v. Los Angeles County*, 481 F.3d 1150 (9th Cir. 2007).

⁴⁹ *Rosie D. v. Romney*, 410 F. Supp. 2d 18, 32 (D. Mass. 2006).

family, oversees formulation of a treatment plan, and takes responsibility to ensure that the plan is carried out and modified as the child's needs evolve.”⁵⁰

California, Washington, and Massachusetts have established a Medicaid billing rates and codes for ICC, to make it easier for providers to be reimbursed.⁵¹ Advocates in states where the state Medicaid agency has not established a billing rate or articulated a clear obligation for Managed Care Organizations (MCOs) to provide ICC can point to these authorities to argue that the state (and MCOs) are obligated to provide ICC and that the components of ICC clearly are covered in the case management and rehabilitative benefit categories.

Moreover, the ADA provides additional justification for ICC. The ADA requires states to administer Medicaid services to individuals with disabilities in the most integrated setting appropriate to their needs.⁵² ICC allows youth with significant needs to receive mental health treatment in integrated settings—ideally in their own homes, with their own families, and in neighborhood schools.⁵³ If a failure to provide ICC contributes to a mental health system that

⁵⁰ *Id.* at 52-53. See also Settlement Agreement, *T.R. v. Dreyfus*, C09-1677-TSZ (W.D. Wash. Dec. 19, 2013) (court-approved settlement delineating the contours of ICC that can and should be covered, including a “Strength and Needs Assessment” that is “strength-based, needs driven, [and] comprehensive” to form the basis for the child’s plan; “Planning” that is “person and family-centered ... specifies the goals and actions to address medical, social, educational and other services needed” and “Referral, monitoring and related activities” including “a care coordinator to work directly with the child and family to implement elements of the ISP [care plan]; [who] prepares, monitors, and modifies the ISP in concert with the care planning team; ... [and] will identify , actively assist the youth and family to obtain and monitor the delivery of available services. ...”

<https://www.dshs.wa.gov/sites/default/files/BHSIA/dbh/documents/cbhtfullagreement.pdf>

⁵¹ Dep’t of Health Care Servs., Cal. Health & Human Servs. Agency, *Information Notice 16-004* (Feb. 5, 2016) (on file with author); MassHealth, *Targeted Case Management Services, Intensive Care Coordination Performance Specifications*, <http://www.mass.gov/eohhs/docs/masshealth/cbhi/ps-tcm-icc-ps.pdf>; Div. of Behavioral Health and Recovery, Wash. Dep’t of Soc. & Health Servs., *Service Encounter Reporting Instructions for BHOs* (Jan. 12, 2018),

https://www.dshs.wa.gov/sites/default/files/BHSIA/dbh/Mental%20Health/SERI_v201705-3EffectiveApril1_2018.pdf. The practice of “wraparound” varies widely, with many states claiming to have implemented the practice model. However, traditionally many states have failed to conduct independent analysis of their program. See e.g., April Sather & Eric J. Bruns, *National Trends in Implementing Wraparound: Results of the State Wraparound Survey, 2013*, 25(10) *J Child Fam. Stud.* 3160 (2016) (finding that 100% of states report that they provide “wraparound” services, but only 60% have written standards for implementation and 56% of states’ programs measured fidelity.).

⁵² 28 C.F.R. § 35.130(d).

⁵³ Susan Mears et al., *Evaluation of Wraparound Services for Severely Emotionally Disturbed Youths*, 19(6) *RES. ON SOC. WORK PRAC.* 678 (2009) (youth receiving wraparound services showed significantly

engenders unjustified isolation and segregation of youth with mental health needs (e.g., reliance on juvenile justice facilities, group homes, and residential treatment to deliver mental health services), such a policy or practice may constitute a violation of the ADA.⁵⁴

B. Mobile Crisis Response and Stabilization Services

Mobile Crisis Response and Stabilization (“mobile crisis”) services help children and youth experiencing an acute behavioral health issue receive immediate assistance, and prevent unnecessary hospitalization. Mobile crisis services are mental health services that entail rapid deployment of a team of individuals trained in crisis intervention, who “are instrumental in defusing and de-escalating difficult mental health situations and preventing unnecessary out-of-home placements, particularly hospitalizations.”⁵⁵ These services are available 24/7 and can be provided in the home or anywhere that a crisis occurs. There is often also a planning component—these services often involve working with families to create a “crisis plan,” e.g., a way to identify and reduce future crises, and a strategy to address the crisis if it arises again.

Mobile crisis services are “widely recognized as clinically appropriate and, indeed, essential for children with serious emotional disturbances.”⁵⁶ Mobile crisis services should be differentiated from stabilization services within in facility, as outcomes are better when crisis intervention is provided in community-based settings, such as a child’s home or school.⁵⁷ Mobile crisis services are an effective mental health intervention.⁵⁸ These services are be appropriately

lower levels of impairment and improved levels of functioning at post-treatment, as measured by CAFAS scores, compared to youth receiving traditional child welfare services).

⁵⁴ Dep’t of Justice, *Findings Letter, Investigation of West Virginia Children’s Mental Health System Pursuant to the Americans with Disabilities Act* (June 1, 2015), https://www.ada.gov/olmstead/documents/west_va_findings_ltr.pdf

⁵⁵ Joint CMS and SAMHSA Informational Bulletin, *Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions* at 5 (May 7, 2013), <https://www.medicaid.gov/federal-policy-guidance/downloads/cib-05-07-2013.pdf>

⁵⁶ *Rosie D. v. Romney*, 410 F. Supp. 2d 18, 31 (D. Mass. 2006).

⁵⁷ See Jeffery Vanderploeg et al., *Mobile Crisis Services for Children and Families: Advancing a Community-based Model in Connecticut*, 71 CHILD. & YOUTH SERVS. REV. 103 (2016) (Rapid mobile response with face-to-face crisis stabilization in the home, school, and community can improve functioning and reduce utilization of emergency departments and juvenile justice facilities).

⁵⁸ Ryan Shannahan & Suzanne Fields, Nat’l Technical Assistance Network for Children’s Mental Health, *Services in Support of Community Living for Youth with Serious Behavioral Health Challenges: Mobile Crisis Response and Stabilization Services* 3 (2016) (“MRSS are considered a viable alternative to EDs and inpatient treatment because they consistently demonstrate potential for cost-savings while helping to improve or maintain the level of

categorized as a Medicaid rehabilitation service, and therefore must be provided when medically necessary.⁵⁹

To the extent that a lack of mobile crisis services contributes to a serious risk of or actual unnecessary institutionalization, mobile crisis services may also be required pursuant to the ADA.⁶⁰ For example, if a Medicaid program only pays for crisis stabilization in the context of an inpatient hospital, but will not fund the same crisis intervention services in the community, even though children could successfully receive crisis intervention in the community, the program design would very likely run afoul of Medicaid's EPSDT mandate as well as the ADA's Title II integration mandate.⁶¹ The same would be true if the state fails to provide mobile crisis services necessary to help a child stay in the most integrated setting appropriate to their needs, and avoid repeated hospitalizations or other segregated settings.⁶²

C. Intensive Home-Based Services

Intensive home-based services (IHBS) are services and interventions, identified through the plan developed using ICC, to support a child with engaging in treatment, developing skills, and

functioning for children and youth. When compared to ED and inpatient admissions, MRSS tend to achieve better outcomes at lower cost, and with higher family satisfaction.”)

⁵⁹ 42 U.S.C. § 1396d(r)(5); see also 42 U.S.C.A. § 1396d(a)(13); 42 C.F.R. § 440.130 (“‘Rehabilitative services,’ except as otherwise provided under this subpart, includes any medical or remedial services recommended by a physician or other licensed practitioner of the healing arts, within the scope of his practice under State law, for maximum reduction of physical or mental disability and restoration of a beneficiary to his best possible functional level.”) SAMHSA, Crisis Services: Effectiveness, Cost Effectiveness, and Funding Strategies (2014), <https://store.samhsa.gov/shin/content//SMA14-4848/SMA14-4848.pdf> (according to an environmental scan conducted by SAMHSA, all 50 states and the District of Columbia indicate that they provide some kind of crisis services, but the services vary widely in type and availability state -- there is no consistent federal definition); see also Massachusetts Medicaid State Plan Amendment providing for Mobile Crisis Intervention and Crisis Stabilization for children pursuant to the 42 U.S.C. § 1396d(a)(13), http://rosied.org/resources/Documents/SPA_EPSDT.pdf.

⁶⁰ *Kenneth R. v. Hassan*, 293 F.R.D. 254, 267 (D.N.H. 2013) (allowing class action to proceed that raised the common questions of “whether there is a systemic deficiency in the availability of community-based services, and whether that deficiency follows from the State's policies and practices. ...”).

⁶¹ Dep’t of Justice Findings Letter, Investigation of West Virginia Children’s Mental Health System Pursuant to the Americans with Disabilities Act, https://www.ada.gov/olmstead/documents/west_va_findings_ltr.pdf;

⁶² DOJ Olmstead Q&A, *supra* note 7.

achieving the goals and objectives of her individualized plan.⁶³ IHBS often consists of a clinician or a trained para-professional working “in the home on a regular basis—forming a relationship with a child, modifying problematic behaviors....”⁶⁴ IHBS may also include family and youth peer support, which is a service provided by an individual who has received mental health services or who is the parent of a child who received mental health services and supports, to help the family build self-advocacy skills to address the needs of the child.⁶⁵ Generally, families who receive such peer support experience higher levels of satisfaction with mental health services when compared with families not receiving the additional support.⁶⁶ Other direct services that may be provided as an IHBS could include family training, in-home functional behavioral assessments, the development of behavioral intervention plans, and assistance in implementation of such plans.⁶⁷

⁶³ Cal. Mental Health Servs. Div., Dep’t of Health Care Servs. & Cal. Dep’t of Social Servs., *Medi-Cal Manual for Intensive Care Coordination (ICC), Intensive Home Bases Services (IHBS) & Therapeutic Foster Care (TFC) for Medi-Cal Beneficiaries* 25 (3rd ed. Jan. 2018), http://www.dhcs.ca.gov/services/MH/Documents/PPQA%20Pages/Katie%20A/Medi-Cal_Manual_Third_Edition.pdf (ICC service components/activities include: planning and assessment of strengths and needs; reassessment of strengths and needs; referral, monitoring and follow-up activities; and transition.)

⁶⁴ *Rosie D. v. Romney*, 410 F. Supp. 2d 18, 36 (D. Mass. 2006).

⁶⁵ Ctr. for Health Care Strategies, *Medicaid Financing for Family and Youth Peer Support: A Scan of State Programs* (2012), <https://www.chcs.org/media/Family-Youth-Peer-Support-Matrix-reformatted-070714.pdf> (noting the numerous states cover family and youth peer supports, via state plan amendments and waivers);

⁶⁶ Marlene Radigan et al., *Youth and Caregiver Access to Peer Advocates and Satisfaction with Mental Health Services*, 50(8) COMMUNITY MENTAL HEALTH J. 915 (Nov. 2014) (having access to a youth or a family advocate had a significant effect on increasing caregivers' and youths' satisfaction with the mental health services, youths' comprehension of their medication plan, and caregivers' sense of social connectedness.).

⁶⁷ See Mass. Child. Behavioral Health Initiative, *In-Home Behavioral Services Practice Guidelines* 7 (2015), <http://www.mass.gov/eohhs/docs/masshealth/cbhi/practice-guidelines-ihbs.pdf>; see also *Medi-Cal Manual for Intensive Care Coordination (ICC), Intensive Home Bases Services (IHBS) & Therapeutic Foster Care (TFC) for Medi-Cal Beneficiaries* 31 (non-exhaustive list of interventions included in IHBS), http://www.dhcs.ca.gov/services/MH/Documents/PPQA%20Pages/Katie%20A/Medi-Cal_Manual_Third_Edition.pdf. In-home functional assessments and implementation of behavioral plans has been mandated as medically necessary EPSDT service for Autistic youth. See *Chisholm ex rel. CC, MC v. Kliebert*, 2013 WL 3807990 (E.D. La. July 18, 2013) (granting Plaintiffs’ motion to modify a contempt order to enforce Medicaid reimbursement for Board Certified Behavior Analysts for children with autism, who conduct a functional assessment, recommend an intervention plan, a oversee “every aspect of intervention.”).

States take a variety of approaches to financing these services under Medicaid. In-home therapies, peer support, and functional behavioral analysis may be covered as a rehabilitative service, or under the category of “other licensed practitioner.”⁶⁸ If IHBS is not specifically listed as a covered service under the state plan or a waiver, the state will still need to provide it as an EPSDT benefit because states must provide all medically necessary optional and mandatory services to children, whether or not the service is included in the state plan. Furthermore, since IHBS is necessary to avoid unnecessary institutionalization or segregation, states may also have an obligation under the ADA to provide such services.⁶⁹ In the aggregate, IHBS are significantly more cost-effective when compared to institutional services.⁷⁰ Therefore, under the ADA, states should include IHBS in the array of services offered, even when “taking into account the resources available to the State and the needs of others with mental disabilities.”⁷¹

D. Therapeutic Foster Care

Therapeutic Foster Care (TFC) is a set of clinical interventions used to support children who have significant mental health needs and cannot live in their own homes. The clinical interventions provided via TFC are of the intensity that would normally be available in a

⁶⁸ 42 C.F.R. § 440.130(d) (rehabilitative services); 42 C.F.R. § 440.60. (“Other Licensed Practitioner” means “any medical or remedial care or services, other than physicians’ services, provided by licensed practitioners within the scope of practice as defined under State law.”).

⁶⁹ See, e.g., Dep’t of Justice Findings Letter, *Investigation of West Virginia Children’s Mental Health System Pursuant to the Americans with Disabilities Act* at 18, https://www.ada.gov/olmstead/documents/west_va_findings_ltr.pdf (concluding that the state violated Title II of the ADA when the state documented the shortage of intensive community-based mental health needs but “failed to use these reports to develop a comprehensive, cross-system plan to address high levels of unnecessary institutionalization of West Virginia’s children in segregated residential treatment facilities.”).

⁷⁰ In 2008, CMS funded a five year demonstration program to examine whether children who met the level of care for a PRTF could be served in the community (PRTF Demonstration). Participating states provided an array of intensive home based services and care coordination. CMS found that the alternative services were both cost-effective and effective. CMS’ report to Congress stated: “For all nine states over the first three Demonstration years for which cost data was available to be collected, there was an average savings of 68 percent. In other words, the waiver services cost only 32 percent of comparable services provided in PRTFs. The Demonstration proved cost effective and consistently maintained or improved functional status on average for all enrolled children and youth.”). HHS, *Report to the President and Congress, Medicaid Home and Community-Based Alternatives to Psychiatric Residential Treatment Facilities Demonstration 3* (July 2013), <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/institutional-care/downloads/prtf-demo-report.pdf>

⁷¹ *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 607 (1999).

congregate facility, but instead are provided by specialty trained foster parents who can help the child learn skills to live in a family-like environment. The TFC parents are considered to be “professional participants of the clinical treatment team,” and provide a model for healthy communications and behaviors, and help teach social and life skills.⁷²

TFC is particularly useful when it is not possible to provide services directly in a child’s own home with the child’s permanent caregivers, either because the child’s behaviors make him or her unsafe in that environment, or because the child’s home is not an appropriate placement for other reasons.⁷³ TFC allows a child to learn skills necessary to live in the community without the negative effects of congregate care.⁷⁴ TFC’s philosophy is that “long-term outcomes for troubled youth may be most successfully promoted when treatment occurs in the context of family and community.”⁷⁵ When delivered with fidelity, TFC is an effective community-based intervention.⁷⁶

⁷² Laura W. Boyd, *Therapeutic Foster Care: Exceptional Care for Complex, Trauma-Impact Youth in Foster Care* 3 (July 2013), <https://childwelfaresparc.files.wordpress.com/2013/07/therapeutic-foster-care-exceptional-care-for-complex-trauma-impacted-youth-in-foster-care.pdf>

⁷³ Phillip A. Fisher & Kathryn S. Gilliam, *Multidimensional Treatment Foster Care: An Alternative to Residential Treatment for High Risk Children and Adolescents*, 21(2) PSYCHOSOCIAL INTERVENTION 195, 196 (Aug. 2012) (summarizing “extensive research” demonstrating that housing extremely-high risk youth in congregate settings with peers is “a questionable intervention theory,” both because there is generally lower levels of supervision available in congregate settings, and because of what is sometimes called the “iatrogenic effect,” where youth with behavioral challenges may reinforce each other’s behavior.).

⁷⁴ *Id.*

⁷⁵ There are several different programs or approaches fall under the general category of TFC, but one of the most well-known is “Treatment Foster Care Oregon” (TFCO) (formerly called “Multidimensional Treatment Foster Care”). TFCO is an evidence-based program that originally targeted youth involved in the juvenile justice system, but has been adapted to serve children serious behavioral issues and histories of trauma, from age 3-18. Fisher & Gilliam, *supra* note 73 at 197. See generally Sheila M. Eyberg et al., *Evidence-Based Psychosocial Treatments for Children and Adolescents with Disruptive Behavior*, 37(1) J. CLINICAL CHILD & ADOLESCENT PSYCHOL. 215, 228 (2008) (literature review of psychosocial treatments for child and adolescent disruptive behavior, determining that “Two well conducted studies have found MTFC superior to usual group home care for adolescents with histories of chronic delinquency ... meeting criteria for probably efficacious treatment.”).

⁷⁶ Eyberg, *supra* note 75; cf. Thomas Pavkov et al., *Service Process and Quality in Therapeutic Foster Care: An Exploratory Study of One County System*, 36(3) J. SOC. SERVICE RES. 174 (2010) (county’s failure to adhere to evidence-based model of TFC resulted in poor outcomes and outcomes similar to those in traditional foster care. The researchers criticize the use of the term TFC without standardizing the programs).

Much like ICC or IHBS, the term “therapeutic foster care” is not found in federal statute, but the Centers for Medicare & Medicaid Services has approved federal financial participation for TFC.⁷⁷ Even in states where TFC is not recognized by the state as a distinct service, advocates can argue that TFC (even by another name) is a service that states must cover when medically necessary, pursuant to the EPSDT mandate.⁷⁸

Further, given that TFC is an effective service intervention that is necessary to allow children to live in the most integrated setting, advocates should also argue that states are required under the ADA to provide TFC in order to avoid institutionalizing children.⁷⁹

III. Strategies and Next Steps

ICC, mobile crisis services, IHBS, and TFC are services for children that must be covered by state Medicaid programs when medically necessary for a covered child.⁸⁰ Furthermore, pursuant to *Olmstead*, states may be required to provide these services to the extent that 1) such services are already provided in institutional settings but not in the community, or 2) the

⁷⁷ See, e.g., Cal. State Plan Amendment 4.19-B, approving payment for specialty mental health services provided in treatment foster homes, http://www.dhcs.ca.gov/formsandpubs/laws/Documents/09-004_ApvPkg.pdf; Okla. State Plan Amendment 4.19-B, approving payment for mental health services in Therapeutic Foster Family Homes, <https://www.medicaid.gov/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/OK/OK-13-12.pdf>. Unlike many states, Oklahoma foster parents are considered Medicaid providers. Okla. Admin. Code § 317:30-5-740.1 (defining a “treatment parent specialists” and explaining that they “serve as integral members of the team of professionals providing services for the child. The TPS receives special training in mental health issues, behavior management and parenting techniques; and implements the in-home portion of the treatment plan with close supervision and support. They provide services for the child, get the child to therapy and other treatment appointments, write daily notes about interventions and attend treatment team meetings.”)

⁷⁸ In *Katie A.*, the court recognized that, like wraparound services, TFC has numerous components, and found it was likely that all of the components were covered by categories of services included in 42 U.S.C. § 1396d(a) (rehabilitative services, case management services, and personal care services.). *Katie A. v. Bonta*, 433 F. Supp. 2d 1065 (C.D. Cal. 2006), *rev'd on other grounds*, *Katie A. ex rel. Ludin v. Los Angeles County*, 481 F.3d 1150, (9th Cir. 2007). It should be noted, however, that although the EPSDT benefit is broad, Medicaid is not without limits. Room and board and some costs specific to the administration of foster care are not eligible for federal financial participation. 42 C.F.R. § 441.18(c).

⁷⁹ Dep’t of Justice, *Findings Letter, Investigation of West Virginia Children’s Mental Health System Pursuant to the Americans with Disabilities Act* (June 1, 2015), https://www.ada.gov/olmstead/documents/west_va_findings_ltr.pdf;

⁸⁰ 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43); 1396(a)(4)(B), 1396d(r)(5).

services are necessary to remedy or prevent unnecessary institutionalization or segregation. States that offer these services only on a pilot basis, in a limited geographic area, to a limited population of Medicaid eligible children, or on a time-limited basis regardless of the child's individual needs, are very likely violating ESPDT and Olmstead requirements.

States should clearly communicate to Medicaid providers and enrollees that these services are covered. As the court in *Rosie D.* recognized, “It is well understood by anyone familiar with the provision of Medicaid services—and confirmed by testimony at trial—that clinicians hesitate to prescribe treatments and services for Medicaid patients that are not specifically listed in billing codes.”⁸¹

However, merely “covering” these services is not enough. As the general requirement to cover these services is recognized by more and more states, often the major challenge advocates face is how to differentiate between services that are available in theory and services that are available in adequate quality and quantity to meet federal requirements.⁸² States that implement systems in a manner that fails to adhere to established and effective practice models, with insufficient provider capacity, or insufficient scope and intensity, may be implementing the services so poorly that the services are neither meaningfully available nor do they effectively prevent unnecessary institutionalization.

Advocates should first determine if the state's Medicaid plan and/or state law, policy, and practice complies with the federal requirement to cover intensive care coordination, home-based services and supports, therapeutic foster care and mobile crisis. If such services are clearly covered in Medicaid by the state, advocates should then determine if these services are being provided to all Medicaid eligible children, when medically necessary to maintain the child at home or in a home-like setting, or to return the child to their home and community from an institution or congregate care setting. If services are not available when medically necessary and with adequate quality and quantity, advocates should consider whether action should be taken to enforce both the EPSDT mandate and the ADA.

The National Health Law Program is serving as co-counsel in a number of cases involving children's mental health services throughout the country. Contact NHeLP to assist you or other advocates in learning about opportunities to address the needs of Medicaid eligible children

⁸¹ *Rosie D. v. Romney*, 410 F. Supp. 2d 18, 45 (D. Mass. 2006).

⁸² See, e.g., April Sather & Eric J. Bruns, *National Trends in Implementing Wraparound: Results of the State Wraparound Survey, 2013*, 25(10) J. CHILD FAM STUD. 3160 (2016) (finding that 100% of states report that they provide “wraparound” services, but only 60% have written standards for implementation and 56% of states monitored fidelity).

and youth in your state to obtain mental health services, through either technical assistance or co-counsel arrangements.

Appendix:
**Selected Studies of Home-Based Services for
Children with Significant Mental Health Needs**

Intensive Care Coordination

- Kirsten Painter, *Outcomes for Youth with Severe Emotional Disturbance: A Repeated Measures Longitudinal Study of a Wraparound Approach of Service Delivery in Systems of Care*, 41(4) CHILD & YOUTH CARE FORUM 407 (2012).
 - Longitudinal study on Wraparound for children with Serious Emotional Disturbances (SED) found that caregivers reported children in Wraparound services experienced significant improvements in behavioral and emotional outcomes, including depression, anxiety and overall functioning, as well as decreases in caregivers' strain. All three outcomes were sustained through 24 months after intake.
- Wash. State Inst. for Pub. Policy, *Full Fidelity Wraparound for Children with Serious Emotional Disturbance (SED)* (Jan. 2012), <http://www.wsipp.wa.gov/BenefitCost/ProgramPdf/267/Full-fidelity-wraparound-for-children-with-serious-emotional-disturbance-SED>.
 - Meta-analysis of four prominent research studies on Full Fidelity Wraparound for youth with Serious Emotional Disturbance (SED) found that youth in Full Fidelity Wraparound services experienced a decrease in all three outcomes of interest: disruptive behavior disorder symptoms, externalizing behavior symptoms, and internalizing symptoms.
- Ctr. for Health Care Strategies, *Intensive Care Coordination Using High-Quality Wraparound for Children with Serious Behavioral Health Needs: State and Community Profiles* (July 2014), <https://www.chcs.org/media/ICC-Wraparound-State-and-Community-Profiles1.pdf>.
 - Nationwide research on Intensive Care Coordination using Wraparound (ICC/wraparound) for children with serious behavioral health needs found that there are fully established ICC/wraparound programs in Louisiana, Massachusetts, Michigan, Nebraska, New Jersey, Cuyahoga County in Ohio, and Dane and Milwaukee Counties in Wisconsin, and evolving ICC/wraparound programs in Georgia, Maryland, Oklahoma, Pennsylvania, and Clermont County in Ohio. High-quality ICC/wraparound programs have been found to be generally effective, with variations by state. ICC/wraparound reduced the number of

children in psychiatric hospitalization in Milwaukee, reduced the total net Medicaid spending for youth in ICC/wraparound in Maine, and contributed to money saved in inpatient psychiatric expenditures in New Jersey.

- Jennifer Schurer Coldiron et al., *A Comprehensive Review of Wraparound Care Coordination Research, 1986-2014*, 26(5) J. CHILD & FAM. STUDIES 1245 (2017).
 - Systematic literature review of peer-reviewed publications on Wraparound for youth with Serious Emotional and Behavioral Disorders (SEBD) found that youth in controlled studies of Wraparound services generally performed better in both functional outcomes (such as fewer suspensions, fewer criminal recidivism instances, and higher utilization of community services) and residential outcomes (such as fewer instances of running away, fewer hospitalizations, and higher chances of “achieving permanency”). Findings from non-experimental studies also support the notion that Wraparound is effective in improving some of the outcomes of interest for youth and their families.
- Susan Mears et al., *Evaluation of Wraparound Services for Severely Emotionally Disturbed Youths*, 19(6) Res. on Soc. Work Prac. 678 (2009).
 - Quasi-experimental study on Wraparound for youth with Serious Emotional Disturbance (SED) found that youth receiving Wraparound services showed significantly lower levels of impairment and improved levels of functioning at post-treatment, compared to youth receiving traditional child welfare services.

Mobile Crisis Intervention

- Jeffery Vanderploeg et al., *Mobile Crisis Services for Children and Families: Advancing a Community-based Model in Connecticut*, 71 CHILD. & YOUTH SERVS. REV. 103 (2016).
 - Rapid mobile response with face-to-face crisis stabilization in the home, school, and community can improve functioning and reduce utilization of emergency departments and juvenile justice facilities.
- Substance Abuse and Mental Health Servs. Admin. (SAMHSA), *Crisis Services: Effectiveness, Cost Effectiveness, and Funding Strategies* (2014), <https://store.samhsa.gov/shin/content//SMA14-4848/SMA14-4848.pdf>.
 - According to an environmental scan conducted by SAMHSA, all 50 states and the District of Columbia indicate that they provide some kind of crisis services, but the services vary widely in type, availability, and payment mechanisms by state -- there is no consistent federal definition.

- Seokjoo Kim & Hyunsoo Kim, *Determinants of the Use of Community-based Mental Health Services After Mobile Crisis Team Services: An Empirical Approach Using the Cox Proportional Hazard Model*, 45(7) J. COMMUNITY PSYCHOL. 877 (Sept. 2017).
 - 44.2% of individuals used community-based mental health services within 30 days of mobile crisis team contact. Mobile crisis intervention as a program model and mobile crisis teams play an important role in linking individuals with services, referrals, and resources.

Intensive Home-Based Services

- Nicola Curtis et al., *Multisystemic Treatment: A Meta-Analysis of Outcome Studies*, 18(3) J. FAM. PSYCHOL. 411 (2004).
 - Meta-analysis of 11 publications on MST for youth found that youth in MST experienced a positive effect on their individual outcomes (such as youth symptoms and hospitalization), and family outcomes (such as family stress), and reduced criminal justice system involvement.
- Marlene Radigan et al., *Youth and Caregiver Access to Peer Advocates and Satisfaction with Mental Health Services*, 50(8) COMMUNITY MENTAL HEALTH J. 915 (Nov. 2014).
 - Survey of youth and caregivers of youth with emotional or behavioral issues found that having access to a youth or a family advocate had a significant effect on increasing caregivers' and youths' satisfaction with the mental health services, youths' comprehension of their medication plan, and caregivers' sense of social connectedness.
- Samantha Moffett et al., *Intensive Home-based Programs for Youth with Serious Emotional Disturbances: A Comprehensive Review of Experimental Findings*, 85 CHILD. & YOUTH SERVICES REV. 319 (2018).
 - Comprehensive review of experimental and quasi-experimental studies on Intensive Home Based Treatments (IHBTs) for youth with Serious Emotional Disturbances (SED), finding that overall the studies suggest that these interventions improve children's emotional and behavioral functioning, but noting the need for additional evaluation.

Therapeutic Foster Care

- Phillip A. Fisher & Kathryn S. Gilliam, *Multidimensional Treatment Foster Care: An Alternative to Residential Treatment for High Risk Children and Adolescents*, 21(2) PSYCHOSOCIAL INTERVENTION 195 (Aug. 2012).

- Literature review of Multidimensional Treatment Foster Care (MTFC) as a program for providing treatment to children and adolescents. This method is compared with residential care programs. This article provides information on the structure and components of MTFC programs, as well as information on this program as a positive and viable alternative to residential treatment programs.
- Sheila M. Eyberg et al., *Evidence-Based Psychosocial Treatments for Children and Adolescents with Disruptive Behavior*, 37(1) J. CLINICAL CHILD & ADOLESCENT PSYCHOL. 215 (2008).
 - Literature review that explores the use of Multidimensional Treatment Foster Care (MTFC) for children and adolescents with disruptive behavior. Youth in this program are given intensive support and treatment in the foster home, as well as meetings at least weekly with behavioral support specialists and therapists, and regular meetings with psychiatrists. Meanwhile, the youth's parents receive intensive parent management training. The studies referenced found that this form of foster care was superior to traditional group care for youth and adolescents with a history of chronic delinquency.
- Thomas W. Pavkov et al., *Service Process and Quality in Therapeutic Foster Care: An Exploratory Study of One County System*, 36(3) J. SOC. SERVICE RES. 174 (2010).
 - This study follows the implementation of a therapeutic foster care (TFC) program in one county in the Midwest, finding that when the TFC model is not implemented according to the evidenced-model, it is not as effective. The researchers criticize the use of the term "Therapeutic Foster Care" without standardization of the term.