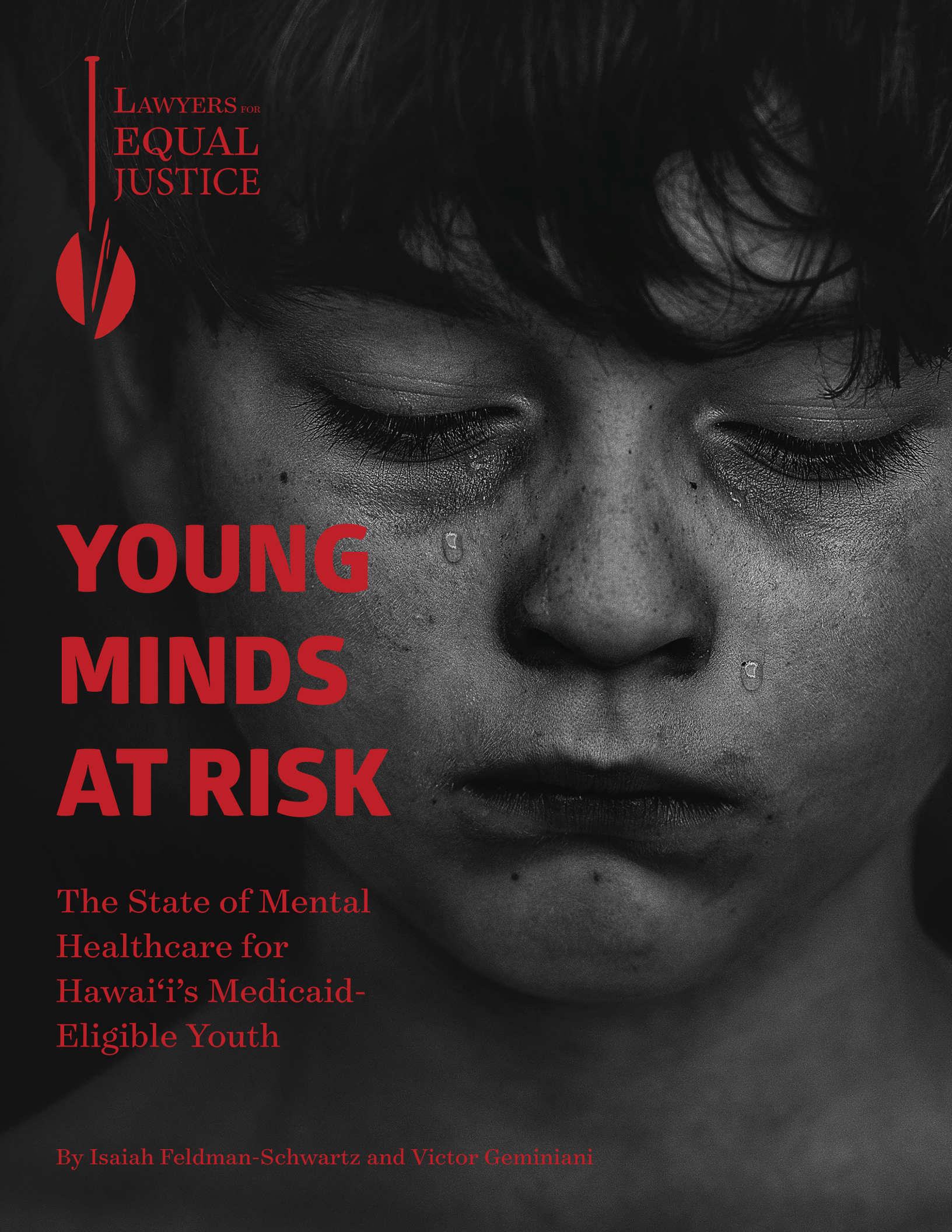

LAWYERS FOR EQUAL JUSTICE

YOUNG MINDS AT RISK

The State of Mental Healthcare for Hawai‘i’s Medicaid-Eligible Youth

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Young Minds at Risk

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All photos contained in this report are stock photos.

“The State shall ... provide for the treatment and rehabilitation of handicapped persons.” — The Constitution of the State of Hawai‘i, Article IX, Section 2.

EXECUTIVE SUMMARY

Every person has the right to live a dignified life. Essential to this dignity is the fulfillment of basic needs. Adequate medical care is one such need, but as a result of the high cost of healthcare in this country, it often goes unfulfilled.

In an effort to ensure that low- and moderate-income people have access to care, our federal government created the Medicaid program. Medicaid is the only source of health insurance for millions of low-income families. More than 100,000 keiki in Hawai'i get their health care through Medicaid.[1]

However, the mental health care system for these children is broken. Patients, providers, and administrators alike agree that quality care is hard to come by—there is a catastrophic dearth of services for low-income youth. Thousands of the most vulnerable children among us live with untreated, severe mental illness, and the number only continues to grow.

This is not a new problem. In 2013, a Juvenile Justice Working Group created by the state of Hawai'i issued a report highlighting deficiencies of the mental health system in the context of the juvenile justice system. The report included the following findings:

- There is an "urgent need for enhanced access to mental health and substance abuse treatments," especially at the early stages of a youth's contact with the court.
- Wait times and administrative criteria inhibit or "severely delay" access to treatment and services.
- Even after a youth's needs are identified, those needs may be left untreated, leaving the youth to "languish in the system."
- There is a "significant deficiency in treatment resources across the state."[2]

In August 2016, Lawyers for Equal Justice (LEJ) met with the then-leaders of the Hawai'i Department of Health (DOH) and Department of Human Services (DHS) to raise concerns regarding the mental health system surfaced by an extensive investigation involving the review of reams worth of public documents and interviews with service providers and others with knowledge of mental health services in Hawai'i. While the state provided assurances that it was working to address the issues, nearly three years later, the problems persist.

Meanwhile, Hawai'i's children and youth who are struggling with mental health issues suffer the consequences. And all of Hawai'i's is left to deal with the lifetimes of adverse impacts that result from each child who doesn't receive adequate mental health treatment when it matters most.

In this report, LEJ summarizes its findings with respect to the accessibility and quality of mental health care for Hawai'i's Medicaid-eligible youth. Many of the State's practices violate the law. As detailed below, LEJ has filed suit in an effort to correct one of the clearest illegalities: the DOH's failure to provide necessary mental health services to youth after they turn 18.

LEJ hopes that the State will take seriously the constructive criticisms set forth in this report; that the governor will direct the attorney general and the heads of DOH and DHS to take immediate action to address the problems identified; that the Hawai'i State Legislature will provide appropriate funding; and that DOH and the Department of Education (DOE) will take advantage of opportunities to renew their dedication to helping boys and girls struggling with mental illness.

These issues will be best resolved through a proactive, cooperative approach rather than protracted and expensive litigation that will almost certainly end in court orders directing the state to provide the vital services required by federal law. But something must be done.

METHODOLOGY

The conclusions set forth below emerged from multiple rounds of interviews with approximately a dozen state-contracted service providers; in some cases, as many as five recurring interviews were conducted with a single provider over the course of several years.

More than a dozen clients—youth and their families—offered first-hand accounts of their experiences navigating the system.

These perspectives were supplemented and reinforced by comments from a number of former and current state officials regarding official policy and standard practice. Overall, the assessments provided by these various actors remained remarkably stable throughout the period of investigation.

In addition, LEJ reviewed thousands of pages of state policy documents and procedural manuals spanning well over a decade, as well as relevant national publications and academic literature. These documents provided important context and evidence to support the observations made in the field.

LACK OF ACCESS

On the most basic level, the systems in place fail to serve those for whom they are designed. Estimates suggest that thousands of Medicaid-enrolled Hawai'i youth live with untreated serious emotional disturbances (SEDs).[3] In theory, DOH administers mental health care to these individuals through its Child and Adolescent Mental Health Division (CAMHD). However, available data paints a bleak portrait of this arrangement.

A comprehensive nationwide survey found that 5–9 percent of all American children suffer from SEDs,[4] which means that of the 115,000 Medicaid-enrolled children in Hawai'i, between 5,750 and 10,350 likely have a qualifying diagnosis.[5] Yet only 2,000 individuals are registered with CAMHD to receive services.[6]

Advocates and service providers familiar with the system uniformly indicate that this discrepancy is largely the result of a failure by DOE to identify and refer for treatment at-risk and needy students, responsibilities that the DOE took on in the 1990s.

In 1994, the State settled a class action lawsuit, *Felix v. Waihe'e*, which alleged that Hawai'i failed to provide mental health services to children for whom such services were essential in order for them to benefit from their education. This settlement—known as the Felix Consent Decree—divided mental health responsibilities between the DOE and DOH such that the DOE would identify children in need of "low-end" services (defined as children who need non-intensive behavioral health supports) and provide appropriate treatment through its School-Based Behavior Health (SBBH) program. Crucially, DOE was also taked with identifying children in need of "high-end" services (defined as children who need intensive mental health treatment), would would then be refered to CAMHD for treatment.

There is a certain logic to this arrangement. Schools are the primary points of contact between children and the state, making them a natural place to identify those who need help. However, in the years since Felix oversight ended in 2005, the DOE appears to have effectively walked away from its responsibility to identify and treat, leaving thousands of vulnerable youth in its wake.

The DOE's systematic failure to identify students with mental health care needs seems to be the primary reason that the number of youth registered with CAMHD is lower than it should be.[7]

Multiple policies and practices interact to produce this failure. Children with "internalizing" behaviors, such as those suffering from anxiety or depressive disorders, are systematically ignored because they do not act up in class. On the other hand, many children with "externalizing" behaviors, who do act up in class, are removed from school for disciplinary reasons when they have specific learning disabilities, emotional disturbances, and other health impairments that should be treated as such.[8] Youth caught in the throes of substance abuse meet a similar fate: students who come to school with illegal substances are suspended or expelled, and nothing is done to address the underlying drug problem.[9]

These incidents take place at critical junctures in childhood development, and children are not receiving the constructive interventions they so desperately need.

Those who are lucky enough to have their mental health needs recognized face numerous barriers to receiving care. Disagreements persist—both between and within the relevant departments—with respect to eligibility criteria. As Dr. William Dikel, an independent psychiatrist contracted by the DOE, explained in a scathing 2006 audit of the DOE's SBBH program:

> [A] student at one site with behavioral manifestations of clinical depression may be referred for a psychiatric evaluation, whereas a student with the same symptom cluster at another site may receive behavioral interventions only and not be referred for diagnosis or clinical treatment. If the second student were to commit suicide (the SBBH staff reported a number of recent near-suicides on their caseloads, so this is not a theoretical issue), DOE would have significant legal and financial liabilities. This issue is of special concern, given the frequency of suicidal behaviors noted in students served by SBBH staff, and given the fact that approximately one quarter of the students served by SBBH had documented evidence ... of clinically significant depression.[10]

Many students whose symptoms are flagged are thus never referred for treatment. And those who ultimately find their way to CAMHD continue to face obstacles.

By law, CAMHD has 30 days to perform any and all necessary mental health evaluations after receiving a referral.[11] For individuals who are deemed eligible for services, CAMHD guidelines make clear that Coordinated Service Plan (CSP) meetings with the youth and their families must then take place no more than 30 days later.[12] The Care Coordinator (CC) assigned to each individual is responsible for making appropriate referrals to service providers within three days of the CSP meeting.[13]

In reality, these timelines are often disregarded. Parents report months-long delays in every step of the process, often in spite of their repeated efforts to contact school administrators and DOH officials. In one case, a client's mother reported leaving over 30 messages for intake workers at DOH. She never received a call back.

Subpar inter-agency collaboration appears at least partially responsible for the backlogs. Because CAMHD services are often provided in conjunction with the DOE through Individual Education Plans (IEPs), children are regularly subjected to evaluations by both departments, which may reach different conclusions regarding the services they should receive. Unsurprisingly, the resulting redundancy, ambiguity and disorganization lead to ineffective delivery of services.

The case of "KMC" is illustrative. KMC is a 12-year-old boy with serious developmental disabilities. After his school refused to address his mental health needs, KMC's mother sought out CAMHD on her own. KMC's initial CAMHD appointment was delayed by a month when CAMHD failed to inform his mother of the date of the appointment. When KMC finally received his initial CAMHD evaluation, he was diagnosed with Bipolar Disorder, Generalized Anxiety Disorder, and Autism Spectrum Disorder.

Despite these diagnoses, when KMC attempted to return to school, his school determined that he did not need specially designed instruction. KMC's mother fought hard for another evaluation, and the school eventually conceded that KMC was eligible for special education. At that point, the services recommended in KMC's initial CAMHD evaluation—intensive in-home therapy, medication, and an alternative educational setting—had already been delayed for several months.

Finally, DOE produced an IEP laying out KMC's mental health treatment plan. The IEP stated that CAMHD would provide case management, referral services, medication management, and intensive in-home therapy. Apparently, CAMHD disagreed. The in-home therapy never materialized. KMC's condition continued to deteriorate as his mother struggled to enforce his rights. At the time of the family's last interview with LEJ, KMC still had not received some of the services he was prescribed.

This bureaucratic breakdown can have life-threatening consequences. The law mandates the creation of crisis plans for at-risk youth. Crisis plans constitute an essential safety measure for those whose mental illness may lead them to harm themselves or others.[14] As a mental health crisis starts to spiral out of control, it is critical that de-escalation measures are in place in order to prevent irreparable harm. Nonetheless, many children never receive a crisis plan.

The implications of this failure are frightening, and in some instances, the worst has occurred. "E," an 18-year-old girl suffering from severe psychosis, was repeatedly hospitalized and then released with no crisis plan in place. Despite her mother's tireless efforts to engage CAMHD and ensure her daughter's safety, E was left to fend for herself, and fell victim to sex trafficking and other physical and psychological abuse during her most intense psychotic episodes.

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E's plight points to the deep-rooted lack of accountability that plagues the system as a whole. There is no way for families to accelerate the process of registering children who are eligible for services. There is sometimes no notice or opportunity for a hearing when eligibility or services are changed or denied.[15] Predictably, youth who lack a strong team of advocates have difficulty accessing services.

Even those parents who are able to dedicate time and resources to obtaining services on behalf of their children do so at substantial cost to themselves and their families.[16] For example, KMC's mother—a tireless advocate on her son's behalf—is a single mother who works multiple jobs to provide for her family while also attending school. She has unilaterally pressured DOE into correcting mistakes and providing services for her son. Her advocacy has been indispensable to KMC's well-being, but her efforts have taken an enormous financial, emotional and physical toll. KMC's mother, like many parents, would do anything for her son, regardless of the cost. Nonetheless, the sorts of sacrifices she has made should not be necessary.

INADEQUATE SERVICES

Compounding the system's ineffectiveness is an acute shortage of services and providers, as well as the state's inability to adequately fund service delivery. Far too few qualified clinicians are available to serve Medicaid-enrolled children.

For example, on Maui, there is not a single child psychiatrist who accepts Medicaid insurance.[17] In an effort to compensate for this deficiency, the departments have taken to assigning paraprofessionals to administer services. However, despite their best efforts, these paraprofessionals are simply not qualified to provide many of the treatments prescribed. The quality of care suffers as a result.

Furthermore, even when qualified providers are available, the delivery of services is severely restricted by budgetary constraints, resulting in lower levels of services than are medically necessary (or fewer service "units," in bureaucratic parlance). This reality is frankly acknowledged by state administrators.[18]

One symptom of the current systemic breakdowns is the lack of "step-up" and "step-down" care. "Step-up" care entails providing youth with more intensive and more comprehensive services as their mental health deteriorates in order to prevent full-blow crises. "Step-down" care involves gradually decreasing services as youth are discharged from high-level treatment, rather than terminating intensive care without sufficient supports in place. The state lacks the infrastructure to appropriately address either scenario.

Traditional step-up options include therapeutic foster care homes, whose number are currently limited due to budget cuts and unsustainably low compensation for foster families; intensive care facilities, which currently serve few patients and can be found only on O'ahu; and therapeutic group homes (an alternative to single-child foster placements aimed at youth who have a greater need to interact with their peers), which have been eliminated entirely.[19]

This lack of capacity has produced an uptick in Emergency Room (ER) visits, especially for the most critically ill. Hospitalization represents an absolute last resort on the spectrum of care: traditional hospitals are ill-equipped to assess the mental health needs of young patients, and cannot provide long-term support. Nevertheless, a trip to the ER has increasingly become the standard operating procedure for low-income children experiencing mental health crises.

Providers and families agree that step-down care is rarely in place when these children are discharged.[20] As previously noted, this lack of foresight can have dire consequences. Without continuity of care, mentally ill youth are far more likely to slip into patterns of self-destructive behavior; the absence of nuanced and consistent care greatly increases the risk that the most vulnerable among them will come into contact with the juvenile justice system.[21]

Perhaps most indicative of the fundamental inadequacy of the State's mental health care infrastructure is the necessity of placing children in off-island treatment centers. Long-term residential treatment programs are generally unavailable in Hawai'i, forcing children to leave for the mainland to obtain services.[22] This state of affairs should raise alarm bells. Healthcare should not come at the cost of a disconnect with families and communities.

"THIS STATE OF AFFAIRS SHOULD RAISE ALARM BELLS. HEALTHCARE SHOULD NOT COME AT THE COST OF A DISCONNECT WITH FAMILIES AND COMMUNITIES."

In one case, the state placed a youth in a residential treatment facility located in Utah against her parents' wishes. Despite fighting the placement "tooth and nail," the youth's parents were unable to override the state's decision.[23] While in Utah, the youth was cut off from her support systems at home. She developed Stevens-Johnson syndrome, a potentially lethal condition, in reaction to a drug the facility prescribed. Even after she ended up in the ER, the facility never notified her parents of the incident. They only learned about it later in a Facebook message from their daughter.[24]

IN FOCUS: "AGING OUT"

With this overview in mind, LEJ has decided to focus its current litigation efforts on one of the system's most straightforward failures: the state's practice of terminating mental health services to youths on Medicaid after they turn 18, instead of continuing to provide services up to age 21 as required by law.

Mental health care providers in Hawai'i refer to this as the "aging out" policy. These providers agree that youths aged 18 are expected to leave CAMHD and either transition to the Adult Mental Health Division (AMHD) or exit the Medicaid-funded mental health care system altogether.[25] This practice violates the law.

Medicaid's Early and Period Screening, Diagnosis, and Treatment (EPSDT) provision clearly demands that children have access to youth-oriented mental health services until they turn 21. Any state accepting federal Medicaid funds must provide the full gamut of services to all eligible youth; courts have made clear that a state's obligation under EPSDT is "extremely broad."[26]

The State of Hawai'i's consistent failure to facilitate the provision of mental health services to Medicaid-eligible youth between the ages of 18 and 21 (the "aging out" population) thus constitutes a breach of its legal obligations.

Various dynamics conspire against the aging out population. There are few programs available to youth over 18, making it extremely difficult for them to obtain services.[27] Even those with a long history in CAMHD often find themselves denied certain services once they turn 18.[28]

As previously discussed, youth often receive mental health services through IEPs. This means that for many of those who graduate, services effectively evaporate: the IEP is the trigger for mental health care, so when it expires, care can expire with it.[29] Providers report multiple instances in which youths' mental health services were abruptly terminated because they graduated from high school.[30]

In this way, youth served by CAMHD are prematurely forced out of treatment programs and, in some cases, into the streets: providers report learning that some of their former clients became homeless after they were removed from care.[31]

Aging out youths are sometimes transferred from CAMHD to AMHD.[32] However, adult mental health services are distinct in both kind and degree from their youth-oriented counterparts. Only CAMHD is charged with providing the full array of EPSDT services.

Eligibility requirements also vary significantly between the two divisions. This incongruity produces situations in which teenagers whose mental health has improved under the watch of CAMHD see their mental health care terminated once they turn 18 because they are not eligible for services under AMHD guidelines.

"LEJ HAS FILED SUIT ON BEHALF OF A YOUTH WHOSE STRUGGLES FOR ADEQUATE CARE EXEMPLIFY MANY OF THESE ISSUES, AS WELL AS OTHERS RAISED IN THIS REPORT ... IN PURSUING HER CASE, LEJ HOPES TO ACHIEVE JUSTICE FOR KF AND HER FAMILY AND NEW LIGHT ON THE STATE'S POLICIES AND PRACTICES."

THE SUIT

LEJ has filed suit on behalf of a young woman whose struggles for adequate care exemplify many of these issues, as well as others raised in this report.

"KF," who is now 20, has suffered from severe mental illness since she was 14, and qualified for CAMHD services. Her parents are informed and vigorous advocates on her behalf. Just before KF's 18th birthday, CAMHD approved her placement in a residential treatment program on the mainland. While KF's parents would have preferred she receive treatment closer to home, due to the deficiencies in Hawai'i's mental health care system, the mainland program was their best option.

A year later, the mainland program

terminated her treatment with a recommendation that CAMHD place her in an adult residential program in Hawai'i, or, at minimum, an "all day intensive outpatient services and medication management [program]."

When she returned to Hawai'i in June, 2017, CAMDH unilaterally transferred KF to AMHD over the protests of her parents. AMHD not only failed to place KF in a residential or intensive outpatient program, but cut back her treatment so drastically that the only services she received were a few hours a week of in-home therapy.

In written communications with KF's parents just before the transfer to AMHD, representatives of CAMHD stated that "behavioral health services such as residential treatment are no longer available to her through CAMHD, due to her age." CAMHD also confirmed that KF would probably receive a lower level of services from AMHD: "I do not know if adult mental health services [(AMHD)] would cover [residential treatment]. I doubt it."

In a heated meeting recorded by KF's parents, a CAMHD representative declared that KF would be transferred to AMHD no matter what her parents thought. CAMHD officially terminated KF's services on July 13, 2017.

Although CAMHD provided KF's parents with an opportunity to appeal the decision to withdraw KF from the mainland residential program, it did not provide them with any due process regarding the decision to terminate her enrollment with CAMHD and transfer her to AMHD. The family unsuccessfully appealed the former decision.

Before denying the appeal, a CAMHD official said in an email to KF's parents that unlike most cases, which involve clinical decisions, KF's case involves "primarily a policy issue related to what services CAMHD is allowed by Medicaid to provide to young adults with serious mental issues who are MedQUEST recipients." This statement suggests that the CAMHD official somehow believed that Medicaid *bars* the state from providing mental health services to individuals between the ages of 18 and 21, when in fact Medicaid *requires* the provision of such services.

After her transfer to AMHD, KF cycled in and out of the Molokini psychiatric ward on Maui for over a year, receiving no long-term treatment. Her parents continued to advocate for increased services on her behalf, and at one point brokered an agreement between AMHD, Med-QUEST, and DOE to pay for a mainland residential program. By the time this agreement was reached, however, KF's condition had deteriorated to the point that no program would take her.

In the fall of 2018, she twice assaulted Molokini staff members as a result of her psychosis, leading to her commitment in December 2018 to the Hawai'i State Hospital, where she remains.

This tragic situation might have been avoided—or at the very least, mitigated significantly—if KF had simply continued to receive the services to which she was legally entitled. In pursuing her case, LEJ hopes to achieve justice for KF and her family and new light on the State's policies and practices.

It bears repeating that the state is obliged to provide *all* Medicaid-eligible youth with *any and all* medically necessary mental health services. If youth don't receive these services from the State, any mental illness they suffer from will go untreated. There is no safety net when the State fails to do its job—the State is the safety net. The publication of this report is a call to action for the State to re-imagine a system that works on behalf of those children most in need of our protection.

ENDNOTES

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A serious emotional disturbance is defined as "a mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified in the DSM-III-R that results in functional impairment that substantially interferes with or limits one or more major life activities in an individual up to 18 years of age."

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7 Interviews with service providers on August 7, 2015 and August 14, 2015.

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12 *Id.*, p. 7.

13 *Id.*, p. 11.

14 *Id.*, p. 10.

15 Interview with service provider on March 10, 2017.

16 *Ibid.*

17 Interview with service provider, July 2019.

18 Audio recording of CAMHD termination meeting in the case of KF, July 10, 2017.

19 Interviews with service providers on August 5, 2015.

20 Interview with service provider on August 14, 2015.

21 Interview with service providers on August 6, 2015. Numerous studies corroborate this conclusion. See, e.g., Development Services Group, Office of Juvenile Justice and Delinquency Prevention, "Intersection between Mental Health and the Juvenile Justice System: Literature Review," https://www.ojjdp.gov/mpg/litreviews/Intersection-Mental-Health-Juvenile-Justice.pdf.

22 Interview with service provider on August 14, 2015.

23 Sophie Cocke, "State lacks resources for troubled kids," *Honolulu Star-Advertiser*, December 13, 2015.

24 *Ibid.*

25 Interviews with service providers, summer 2018.

26 *Parents League for Effective Autism Services v. Jones-Kelly*, 339 Federal Appendix, p. 542, 565 (6th Circuit 2009).

27 Interviews with service providers, summer 2018.

28 Interview with service provider, summer 2018.

29 Interview with service provider, summer 2018.

30 Interview with service provider, summer 2018.

31 *Ibid.*

32 *Ibid.*

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