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Maryland kids in distress are being kept in emergency departments for weeks, months

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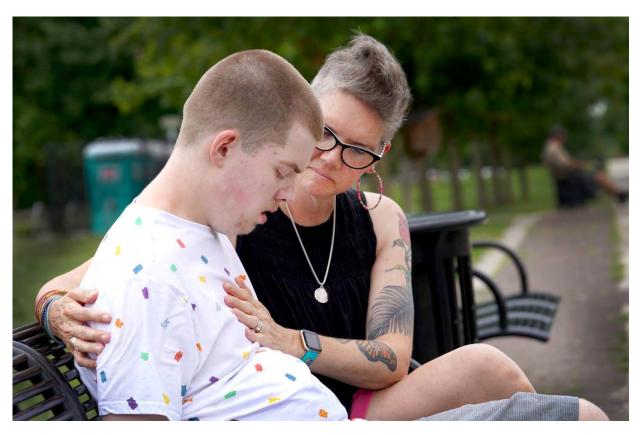












Maryland children are spending weeks and months living in emergency departments and other areas of hospitals because of a failure by the state to provide the right places for them. Noah Godfrey, who constantly keeps on the move, takes a moment's rest on a bench with his mother Sunday Stilwell at Glasgow Regional Park in Delaware. (Kirk McKoy/The Baltimore Banner)

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Hundreds of Maryland children have spent weeks or months living in emergency departments and other areas of hospitals over the last few years — confined to bare rooms and barred from going outside, seeing friends or having access to an education.

The longer these children with behavioral issues stay, hospital physicians and administrators say, the more their mental health deteriorates, and the more that limited and costly emergency room resources are shifted away from other patients.

There are few alternatives. Their release is dependent on an open spot somewhere that can help treat their challenging behavior problems, and keep them safe. Those places are so scarce that hospitals have often become the default dumping ground.



LGBTQ community awaits new federal policy relaxing blood donation rules for gays

Maryland kids in distress are being kept in emergency departments for weeks, months - The Baltimore Banner Case 1:84-cv-04409-ELH Document 677-9 Filed 05/09/23 Page 3 of 24

As the number of facilities that could treat these children decreased over the last five years, Maryland state agencies failed to take significant action, fueling what is now a crisis, according to medical professionals, social workers and children's advocates.

State officials acknowledge they've given little attention to the dilemma amid the coronavirus pandemic, during which the problem has only become more fraught.

Earlier this summer, after a three-month stay in a Western Maryland hospital emergency room, Jeremiah Boyd, a 14-year-old who has autism, returned home 100 pounds heavier and on 13 medications, said his mother, Jessica Boyd. Once a smiling teddy bear of a boy, he now never smiles, she said. After only 10 days at home and no services such as aides, therapy or school to help his family cope with his escalating agitation and aggression, Boyd said that he became uncontrollable and landed at Northwest Hospital's emergency room on July 28.



Maryland children are spending weeks and months living in emergency departments and other areas of hospitals because of a failure by the state to provide the right places for them.

Jessica Boyd is photographed outside of Northwest Hospital, where her son, Jeremiah Boyd, is currently being held. (Kirk McKoy/The Baltimore Banner)

He remains at that hospital's emergency department wing while different agencies argue over where to send him next. His mother despairs that there is little chance he will be released soon.

"He is not an animal. He deserves to be human, to be out and living life, not just sitting in a hospital becoming bedridden," Boyd said.

For Noah Godfrey, 17, and his family, the wait dragged on for 369 excruciating days. Everyone — his mother, and those helping to manage his case — wanted to see him moved from the hospital, but every facility was at capacity or said they couldn't handle his sometimes aggressive behavior. Finally, he ended up at Shorehaven in Elkton, where he lives in a group home and goes to school.

"Kids are spending so much time in emergency rooms, it's borderline illegal," said Kevin Keegan, a former official at the state Department of Human Resources. "It's bad for kids, it's bad for families, it's bad for institutions. No one wants a hospital room tied up."

Who they are

Maryland kids in distress are being kept in emergency departments for weeks, months - The Baltimore Banner Case 1:84-cv-04409-ELH Document 677-9 Filed 05/09/23 Page 5 of 24 While advocates say children as young as 5 years old have ended up in the emergency room for long periods of time, they most often see teenagers there, who fall into two categories. The first are foster children who have been neglected or abused, and have cycled through multiple homes. Their trauma causes them to act out, the advocates said, sometimes with aggression, but they haven't necessarily been diagnosed with a specific mental illness.

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The second group includes children with developmental disabilities such as autism who grew into teenagers with difficult behavior, like Noah and Jeremiah.

In both cases, the intensity of their needs has overwhelmed families who feel they aren't equipped to deal with the unpredictable, and sometimes violent, behavior.

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Maryland children are spending weeks and months living in emergency departments and other areas of hospitals because of a failure by the state to provide the right places for them. Sunday Stilwell pushes her son Noah Godfrey in a swing in Glasgow Regional Park in Delaware. (Kirk McKoy/The Baltimore Banner)

Noah was a perfectly normal, chatty 2-year-old boy who crawled, walked and talked on time, said his mother, Sunday Stilwell. Then, overnight, he changed.

"I was walking down the stairs and he was in the kitchen and I was like, 'Hey, buddy, how you doing?' And he didn't turn around. And I thought maybe he just didn't hear me. 'Noah. Noah,' I said it four times ... And when finally I touched his shoulder, he turned around, but he didn't look at me," Stilwell said. "And literally that day, he stopped speaking. He stopped responding to his name."

Noah was her second child with autism and she knew how to leverage the system to get help. Noah was in his own world, she said, but he was a happy child.

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And then when he was 11, Noah began showing signs of obsessivecompulsive disorder — he had to make sure everything was securely closed.

"He would go through the entire house, and he would make sure that, like, the caps are down on the Dawn dish liquid, that cabinets are completely closed, the toilet seat is down," she said. "Everything had to be in its place. It had to be perfect. And he could never calm down and stop the process."

They gave away their dog, Ernie, because Noah's OCD made him frantic if the dog was out of its crate.

He went to the Kennedy Krieger Institute for behavioral therapy, but his behavior continued to deteriorate as he got older. Stilwell was constantly being called to pick him up at school when his behavior worsened. He was repeatedly suspended. In December 2019, police took Noah away when he threw a candle at his mother, shattering the glass container, which cut her. He spent 23 days in a locked pediatric psychiatric pod at the Johns Hopkins Children's Center.

Then, in March 2020, the pandemic shut all schools. Since he was 3 years old, Noah had an established routine: He woke up, went to school, came home, did things he liked doing at home, and then he would run errands with his mother before eating dinner and going to bed.

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Maryland children are spending weeks and months living in emergency departments and other areas of hospitals because of a failure by the state to provide the right places for them. Noah Godfrey sits on a bench while his mother, Sunday Stilwell, stands at Glasgow Regional Park in Delaware. His brother, Sam Godfrey, is seated left. (Kirk McKoy/The Baltimore Banner)

"So you've got a child who was already in crisis, already exhibiting selfinjurious behaviors, aggression. And now we've taken his entire schedule away. And everything just blew up and blew up. So we were whiteknuckling it through every day," said Stilwell.

Noah's older brother Sam began sleeping in his parents' walk-in closet because he was afraid of his brother. "We were all walking on eggshells. One moment, he would be smiling and laughing. And the next moment, he's throwing stuff, screaming, yelling and trying to throw himself off the balcony," Stilwell said.

There were holes in the walls where he had thrown whatever he could find. Family members barricaded the living room balcony and boarded Case 1:84-cv-04409-ELH Document 677-9 Filed 05/09/23 Page 9 of 24 over Noah's bedroom window so he couldn't jump out. Kennedy Krieger gave Stilwell a shield to protect herself if Noah became aggressive. Her husband would walk out the door each morning and wish her luck. For six weeks that spring, Noah was in an inpatient unit at Kennedy Krieger and Stilwell hoped for a solution: a new medication or a behavior management plan. Kennedy Krieger's wide spaces felt less confining to Noah, and when his aggressive behavior eased, the staff there sent him home.

But Kennedy Krieger's specialists observed that his behavior began worsening again — even with an aide visiting daily — and they recommended he be sent to a residential setting. He would have to wait for a place to open up.

One day in August 2020, Noah woke up angry, and when an aide arrived to help his mother, he lost control. First he bit her, then he shoved the aide against the wall. As his mother desperately tried to lock him in his room, he yanked her hand, severely injuring her wrist. They called 911.



Maryland children are spending weeks and months living in emergency departments and other areas of hospitals because of a failure by the state to provide the right places for them. In a calming gesture, Sunday Stilwell places her hand on her son Noah Godfrey. (Kirk McKoy/The Baltimore Banner)

When the police arrived, it took several officers to handcuff and shackle Noah. It was their third visit to the house and they told Stilwell they feared that next time, someone would be dead or badly injured. They took him to Northwest Hospital and he was transferred into a neuropsychiatric unit for children with autism at Sheppard Pratt, where the usual stay is one or two weeks. After two weeks, Sheppard Pratt called to tell Stilwell they were discharging Noah.

She refused to pick him up, as she had been advised by several of those who had treated Noah over the years. Sheppard Pratt called Child Protective Services, the agency that investigates parents who have abandoned their children, and they investigated Stilwell. But the agency agreed that Noah could not be returned to his home and she hadn't abandoned him, Stilwell said. So he stayed at Sheppard Pratt for an entire year waiting for a placement.

Citing patient confidentiality, Sheppard Pratt and other hospitals involved in Noah's and Jeremiah's care would not discuss their specific situations. But Disability Rights Maryland attorneys representing the two children confirmed some of the details.

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Maryland children are spending weeks and months living in emergency departments and other areas of hospitals because of a failure by the state to provide the right places for them. Sunday Stilwell races her son Noah Godfrey, who constantly keeps on the move, in Glasgow Regional Park in Delaware. (Kirk McKoy/The Baltimore Banner)

'Not what's needed'

Just how many children are stuck in hospitals — either in emergency departments or in-patient beds — is unclear. Data from the Maryland Department of Human Services show that 80 to 100 children a year are overstaying their time in a hospital for weeks, and sometimes months. However, those numbers only include children in the custody of the state. Neither Noah or Jeremiah would have been counted in those numbers because they legally remain in the custody of their parents.

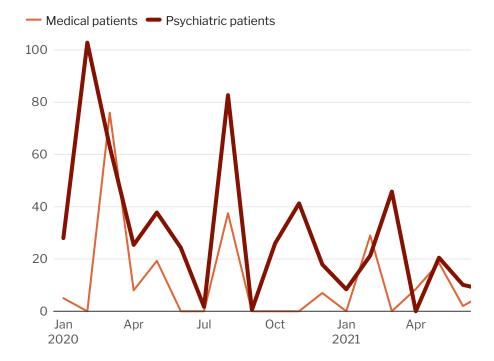
A Baltimore Banner analysis of MDHS data found that hospital stays past the point of medical necessity increased as out-of-state placements, especially of psychiatric patients, dropped. They were far more likely to Case 1:84-cv-04409-ELH Document 677-9 Filed 05/09/23 Page 12 of 24 experience an overstay than medical patients, with stays for psychiatric patients lasting a week longer on average, according to the data compiled in state reports first mandated in 2019.

Between January 2020 and September 2021, two out of every three children admitted to a psychiatric bed in a hospital stayed longer than necessary compared to only 1 in 10 children admitted for medical care.

Overall, 147 children spent an average of 28 days more than medically necessary in psychiatric wards, though some patients were stuck longer than three months.

Some Maryland children in state custody were held in psychiatric hospital beds for months longer than medically necessary

Though average stays peaked in early 2020, two youths spent more than 100 days each in March 2021. Both were eventually placed in out-out-state residential centers.



Note: Average days calculation only includes patients who had overstays. Chart: Ryan Little • Source: Maryland Department of Human Services

The number of children who experienced overstays has increased as fewer children have been placed in out-of-state residential treatment

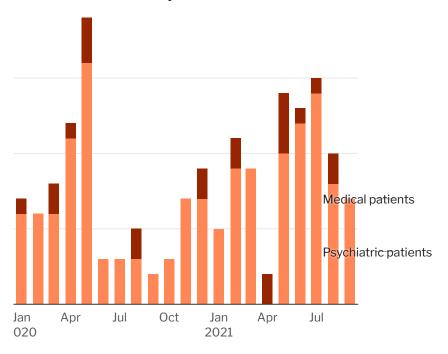
centers. In January 2021, only 55 children were placed in such centers.

That's 168 fewer children than in January 2015.

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The number of children staying in hospitals past medical necessity increased in 2021

Though average stays were half of 2020, the state was on track to exceed 100 overstays in 2021.



Note: Sentember 2021 is the last month state officials have nublished data for

The Maryland Hospital Association, which advocates for the state's hospitals, physicians and patients, began investigating pediatric hospital overstays about three years ago, after members flagged the problem.

They are still collecting data, but in June and July of this year, they found that about 51 children every week were being boarded in a hospital. A placement could not be found for about a third of those children; another third were waiting for a bed to open. The hospital association said their data is likely incomplete because not all hospitals in the state are participating. MDHS said 11 of those children were in their custody last month.

With its concentration of research hospitals and its relatively wealthy tax base, Maryland may be at a competitive advantage compared to other states to meet its children's needs, said Erin Dorrien of the Maryland Hospital Association. Still, the state struggles to place children. The association found that from April to May 2019, 2,009 patients experienced a discharge or transfer delay. The delay for patients under age 18 tended to be twice as long as for adults.

When Dr. Anthony A. Chico started at Greater Baltimore Medical Center 18 years ago, the medical director of emergency psychiatry said he could often connect patients with a referral in a few hours. Today, Chico said, that timeline has stretched to days — or even months.

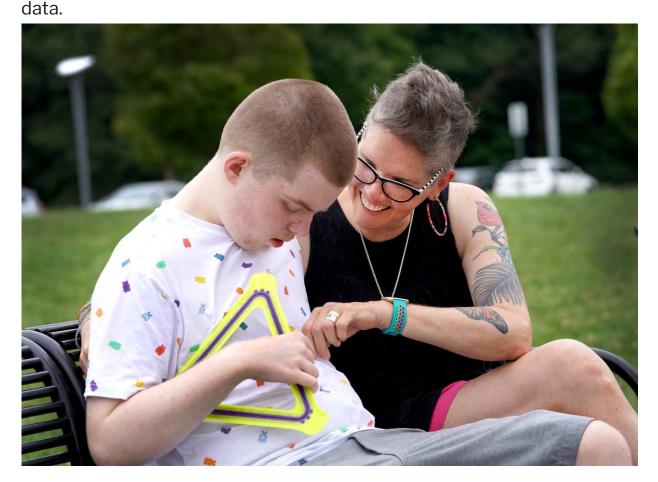
GBMC, which doesn't have a psychiatric inpatient program, must refer patients with behavioral or mental health challenges to other providers. Chico said he is often the first person whom families meet when trying to find the right placement.

"I want to put the best foot forward in terms of doing the right thing, but it doesn't always look that way. In the moment, I don't always have the tools," Chico said. "My job is to stabilize and refer, not to treat someone for weeks on end."

State health officials say more tools are on the way. They are transitioning to a model that includes more crisis response services they hope will prevent the need for higher-level services later and can help keep more families together.

Additionally, the agency has dedicated \$5 million in funding to providers specifically for programming for people experiencing long hospital stays. It has also created a bed registry for hospitals, and a provider directory for physicians and families. Health officials also have upped the daily rate residential treatment providers can charge for services; increased the

Case 1:84-cv-04409-ELH Document 677-9 Filed 05/09/23 Page 15 of 24 number of beds at residential treatment facilities; are directing the build-out of more psychiatric treatment facilities; are petitioning for more community-based respite care beds; and are working to amass more



Maryland children are spending weeks and months living in emergency departments and other areas of hospitals because of a failure by the state to provide the right places for them. Noah Godfrey, who constantly keeps on the move, takes a moment's rest on a bench with his mother, Sunday Stilwell, in Glasgow Regional Park in Delaware. (Kirk McKoy/The Baltimore Banner)

There is a shortage

Hospital emergency wings should be a last resort for children with behavior issues, but they are now being used more frequently because other options aren't available yet at the scope or scale as needed.

Physicians said many of the children are housed in rooms for psychiatric patients that are part of the emergency departments. In some cases,

Case 1:84-cv-04409-ELH Document 677-9 Filed 05/09/23 Page 16 of 24 they may be just across a hall from the regular emergency room. The rooms are designed for people who could harm themselves, so they are often stripped down to the bare essentials.

If the system worked properly, there would be a wide range of supports for families to keep children at home, including day schools, outpatient mental health care and aides who help parents at home. When that support system wasn't enough, children in crisis situations could go to short-term respite care facilities. And finally, there should be enough longer-term residential options, including group homes, where they can get therapy and go to school.

But all of those resources in Maryland have diminished over time. Chico, of GBMC, described the hospital emergency rooms as a choke point where children are getting caught.

"Our neurodivergent or autistic children are by far our most vulnerable patients and the irony is those are the ones who wait the longest," he said.

In Gov. Martin O'Malley's first term in office, which started in 2007, the state committed to a broad range of services for children and families, with an emphasis on home support and treatment, Keegan said. The system, in his view, was a blueprint for how youth issues should be addressed and funded.

"I'd argue that in Maryland we were leading the conversation and leading the pack when we were pushing ourselves to fund community-based services and prevention," said Michelle Zabel, director of the University of Maryland School of Social Work's Institute for Innovation and Implementation, which supports children and family programs across the country.

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After a Maryland teen, Janaia Barnhart, died in a group home in Delaware
in 2016 and facilities in Massachusetts and Pennsylvania came under
scrutiny or were closed, Maryland reversed its practice of sending more
children out of state. The arrangement often allowed the state to pay
providers more, because they were located outside of Maryland
regulations. In return, the state needed fewer places for children with
highly specialized needs.

Three in-state programs also closed.

"So there was this influx of a relatively large number of kids with developmental disabilities who also had behavior issues," said Leslie Margolis, a managing attorney at Disability Rights Maryland, which is representing some of the children. "But what we didn't do was create new programs or new community based programs."

Out-of-state placements in hospitals and residential treatment centers dropped

168 fewer children were placed in out-of-state residential treatment centers in 2021, more than the number of children who experienced hospital overstays between January 2020 and September 2021.

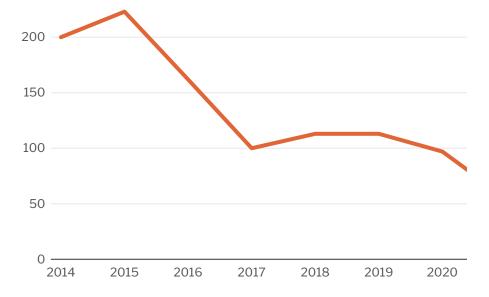


Chart: Ryan Little · Source: Maryland Department 🐧

Case 1:84-cv-04409-ELH Document 677-9 Filed 05/09/23 Page 18 of 24 Johns Hopkins immediately began noticing more children turning to the institution for emergency services and an "alarming" increase in the length of stay for young patients, said Annie Coble, assistant director for state affairs for Johns Hopkins University & Medicine.

Some children held in Hopkins' child and adolescent psychiatry units have stayed as long as 115 days at a time — well beyond what is medically necessary, Coble said in written testimony for the Maryland General Assembly. Children's overstays drain hospital resources and limit Hopkins' ability to treat other kids: the child and adolescent psychiatry unit receives more than 2,000 referrals a year and can only accept 20% because the unit is at capacity, Coble said.

Despite budget surpluses that could have covered the cost of programs needed to minimize stays, the state did little to invest in the problem.

State agencies under Gov. Larry Hogan have also not collaborated to the fullest extent possible, Keegan said, creating silos in government and leaving officials from the state's Department of Human Services and Behavioral Health Administration at odds in determining a path forward.

"There are challenges across the system ... and then you have added intensity for patients with higher acuities," said Marshall Henson, director of operations at the state health department's Behavioral Health Administration.

Dr. Drew Pate, chairman of psychiatry and behavioral health at LifeBridge Health, which oversees Northwest Hospital, said: "In general those are the kids who really get stuck because we have decided as a society that we won't provide the services. The solutions are there. We have decided as a society not to embrace them."

Part of the problem is that the agencies are "not talking to each other in the way that they need to," Margolis said. "These are systemic issues and they can't be solved child by child by child."



Maryland children are spending weeks and months living in emergency departments and other areas of hospitals because of a failure by the state to provide the right places for them. Jessica Boyd is photographed outside of Northwest Hospital, where her son, Jeremiah Boyd, is currently being held. (Kirk McKoy/The Baltimore Banner)

Jeremiah is one of those children stuck

Jeremiah is one of those children stuck because of a lack of options.

When the Western Maryland hospital sent him home in July after three months, Jessica Boyd barely recognized him. "He was a big boy, but he was never to the point of this big," she said.

Not yet 15, but already 6 feet tall, he weighed more than 300 pounds after he was released and got winded just from walking. The nurses told her they had fed him a lot of pizza, his favorite food, to keep him calm. In addition, some of the medications had increased his appetite and made him so groggy that he slept a lot.

Case 1:84-cV-04409-ELH Document 677-9 Filed 05/09/23 Page 20 of 24 Jessica Boyd had finally agreed to let the state find a residential place for Jeremiah to live, but she didn't want to send him as far away as Kansas or Florida when those options were mentioned. She would never see her son, she said, and she wouldn't know what was happening to him.

State and local agencies applied to 20 out-of-state facilities, including group homes and residential facilities, and 25 places in Maryland. Every one turned Jeremiah down because there were no available spaces or they couldn't meet his needs, said Payton Aldridge, a staff attorney at Disabilities Rights Maryland.

Jeremiah's many hospital stays and unsuccessful school placements have only hurt him, his mother believes. He picked up new behaviors, including touching other people inappropriately and smearing his feces on the walls of one hospital room. As his behavior has worsened, facilities have become more reluctant to take Jeremiah.

Jessica Boyd was assured when he left the hospital that she would be given help, but no aides came and the county public schools hadn't yet put in place home teaching. As the days passed, he grew more agitated.

One day in July, Jeremiah picked up his black tennis shoes and walked to the front door.

"School. School," he repeated.

She had to tell him no. He stood for a moment, then began to rage. He tore the shades down, and grabbed the kitchen trash can and threw it against the wall. He went for anything that was perched on top of the refrigerator or hanging from the walls and threw it around the house.

His grandmother called the number for a crisis management team, but she was peppered with basic questions about Jeremiah. She hung up, Case 1:84-cv-04409-ELH Document 677-9 Filed 05/09/23 Page 21 of 24 eventually reaching someone who sent the crisis team, but precious minutes had been lost as Jeremiah tore up the house.

They took him to the hospital emergency room, the latest in an odyssey of failed attempts to keep Jeremiah at home.

"The longer he sits in an emergency room, the more intense his needs become," Margolis said.

One of the problems in finding a place for children like Jeremiah is that places are becoming increasingly selective about who they take, said Dr. Ted Delbridge, executive director of the Maryland Institute for Emergency Medical Services System.

"They're looking for specific patients who they think their expertise can match," Delbridge said. "Any particular place on one day could take a patient like [Jeremiah], and the next day, can't, because they already have one like him. It would overwhelm them to have two patients with very similar needs."

Jeremiah is lucky to have a family fighting for him.

Foster children are less likely to have the same fierce advocates. In some cases, they bounce from hospital ER to hospital ER, according to Carroll McCabe, chief of the mental health division of the Maryland Public Defender's office, which represents foster children.

McCabe got reports that DSS refused to pick up foster children ready for hospital discharge because they had no place to take them. When forced to pick them up, social workers would take them to another hospital emergency room.

"The kids keep getting bounced around to different hospitals," McCabe said. "I am sure the social workers feel terrible about this. It is not their fault. They haven't created the situation. The state is responsible for

Case 1:84-cv-04409-ELH Document 677-9 Filed 05/09/23 Page 22 of 24 caring for these children. We are failing to provide for these kids and they are being harmed again."

Boarding children also can be exorbitantly expensive. Hopkins' Coble estimated inpatient psychiatric services cost as much as \$2,109 per day; that's over \$242,000 for a child who stays 115 days at a time, which Hopkins said is no longer uncommon. Medicaid and other private insurance often will cover a few hundred dollars per day, pushing the costs onto hospitals.

At another hospital, the Medicaid reimbursement rate for a medically unnecessary stay is \$475 for a child or teenager, but that is only a portion of the \$1,300 a day it would cost the hospital, the Maryland Hospital Association's Dorrien said.

If children spend too long in a short-term psychiatric bed, they use up a scarce resource. All told, Maryland has just 39 psychiatric beds for children and 153 for adolescents, according to the state.

Hospitals are uniformly concerned about caring for these children. Psychiatrists and administrators at GBMC, Sheppard Pratt and MedStar all said long-term stays in their hospitals are harmful for the children.

It is like going to the hospital for knee pain and ending up in a cardiac care unit, said Jeff Richardson, vice president and chief operating officer for community services at Sheppard Pratt. "It is applying expensive resources in a way that doesn't really solve the problem," he said.

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Maryland children are spending weeks and months living in emergency departments and other areas of hospitals because of a failure by the state to provide the right places for them. Sunday Stilwell gives her son, Noah Godfrey, an encouraging hug as they take a walk in Glasgow Regional Park in Delaware. (Kirk McKoy/The Baltimore Banner)

A better way

While these children have complex problems, the treatments are usually well-agreed upon. Physicians and attorneys said state agencies will have to lead a coordinated approach to solving the problem, and legislation could help force change as well.

There is agreement that a continuum of services needs to be created that will allow children to stay at home if possible, coupled with short term care when they is a crisis, and residential group homes and facilities.

"Maryland has not had the focus to invest in services other than acute episodic treatment," said Richardson, of Sheppard Pratt. The question is: "How do we create a continuum of services that allows kids to get care in the least restrictive environment."

Free to roam in a large backyard in a group home at Shorehaven with four or five other kids, Noah is now calmer and happier, his mother said. Most days, he goes to a Shorehaven school nearby.

On a recent Saturday, Stilwell picked up Noah and spent the day in a park where he can run in a fenced playground for children with disabilities and take a three mile walk. Their mother-son relationship still strong, Stilwell laughs and runs with Noah while they recite the lines from his favorite books as they go.

She is grateful he is healthier and she knows Noah is, at the moment, one of the lucky ones.

As of last month, there were about 50 children stuck in hospitals with no place to go.

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