The Challenge of Youth in Psychiatric Hospitals

How we got here and what we are doing.

by B.J. Walker, Acting Director

Young people with long and multiple stays in psychiatric hospitals, as a result of mental illness accompanied by extreme and sometimes threatening behaviors, are a growing concern in Illinois and nationwide.

When private insurance and Medicaid determine that these children and youth are stable and ready for release, the result is often an impasse – the child is determined to be "beyond medical necessity" (BMN) for hospitalization, but the challenges of effectively and safely managing the illness remain.

What this means is that child welfare systems such as DCFS are, by default, serving as the emergency room for these children and youth. We therefore often find ourselves at the deepest end of the mental health continuum of care, looking for ways to serve some of our state's most troubled youth and their families. That work is time-consuming and makes it difficult for us to simultaneously create and build the kind of systems and programs that are likely to prevent them from coming to our attention in the first place.

How did we get here? Desperate and loving parents come to the end of their road and are unable to manage their child, keep them safe, and pay for sustained treatment. DCFS is called to take custody of them. In other cases, young people have been subjected to horrific abuse and neglect, and the resulting trauma and behavior makes it more difficult to find them "forever" homes.

For a couple of months now, we have been providing ProPublica – an independent nonprofit newsroom – with data and interviews as they prepare an article that puts a needed spotlight on these children who become – as they say – "trapped" in mental health hospitals because there are not enough placements for them so they can leave the hospital. At DCFS, we know who these kids are

continued on next page

HOW LOCKOUTS HAPPEN:

- A youth with severe behavioral challenges is hospitalized by parents.
- Parents are exhausted, sometimes fearful for themselves or other children and run out of patience and strength and possibly financial resources.
- When insurance/Medicaid deems that further hospitalization for a child is going to be "beyond medical necessity" and no longer paid for, parents may refuse to take the youth home, often because they cannot find or afford alternative placement.
- This "lockout" of the youth by parents leads the hospital to make a hotline call to DCFS, forcing DCFS to investigate and determine if a "lockout" has in fact occurred or if there are indeed issues of abuse and neglect associated with the situation. Although DCFS investigates the report of a "lockout" as an allegation of abuse and neglect – in the vast majority of situations, the case is determined to be what is called a "no fault dependency."
- Once that decision is made, cases can be referred to the *Specialized Family Support Program* administered by

continued on next page

ABOUT THIS BACKGROUND REPORT

DCFS has received numerous requests in recent months for information regarding youth in psychiatric hospitals. That includes youth already in care who are hospitalized as well as those who come into foster care after what is called a "lockout" or "custody relinquishment" by their caregivers. This update provides background on the issue and addresses the most common questions we are asked.

Original Publication June 5, 2018
Updated August 14, 2018

because we are the agency charged with getting them out. The narratives surrounding the lives of these children and youth are many and tragic. The reality is that, as a society, we have missed multiple opportunities to intervene before these children reach the DCFS "emergency room" and then become BMN at a hospital.

The good news is that there is something that can be done. We are doing some of those things, but they will not and cannot happen overnight; this is a problem long in the making.

First, we must fully understand the scale of the problem. Out of nearly 17,000 children in DCFS custody, we are talking about less than 10% of our youth, or approximately 1,200 youth who enter psychiatric hospitals. Of those, about 240 become BMN in the course of a year out of approximately 2,000 psychiatric hospitalizations for children and youth across the state. That means four out of five of our youth with intense psychiatric needs are able to leave the hospital and receive treatment in more appropriate settings.

Second, at DCFS, we are building the treatment programs we project are needed. That is not work that can be completed hastily. It takes time to find a physical facility, identify and hire and train staff, set up the right programming. Over the last five years in Illinois, private agencies closed more than 500 beds for youth with serious and on-going mental health needs. We are working to open up new beds and we are matching those programs with the children and youth we actually see every day. Many of our facilities do have open beds – 60 to 80 on a given day – but they are often not the beds we need. Either they do not match the needs of the children and youth who are BMN in hospitals, or they do not have locked facilities that are often ordered by juvenile court judges.

In addition to new programs, we desperately need adults who are willing and trained to work with children and youth with serious mental illness – people who can remain calm, caring and committed in the face of behaviors that are unpredictable and sometimes frightening and threatening.

Third, on May 7, Governor Rauner announced that Illinois has gained approval for a waiver of some federal rules governing Medicaid so that we can be innovative and create a system that treats physical and behavioral needs of a person in an integrated and coordinated way. This 1115 waiver will provide about $1.3 billion in additional Medicaid funds in the next couple of years to

continued on next page

HFS, where parents are offered assistance in identifying resources to help. That program was created in 2015 by the General Assembly to divert potential "lockout" youth, and avoid having those youth come into DCFS care. Parents are offered additional clinical and support programs if they are willing to take the youth home. If the diversion is unsuccessful, DCFS then goes to Juvenile Court and requests temporary custody. If granted, DCFS then becomes responsible for the medical care and placement of the youth.

- It is important to know that DCFS began using the "no-fault dependency" label for a child who could not remain in the home for reasons beyond the fault of the parents. Parents who indicated that they were not picking up their child from the hospital because they were afraid the child would harm them or the family after returning home generally qualified for this alternative finding. Unfortunately, more and more parents, desperate for help, began expressing this concern, so BMN cases have been growing steadily since 2015.

What is "BMN"?

"Beyond medical necessity" is a payer determination about the authorized length of hospitalization. It is not a medical determination that the patient is cured or no longer in need of intensive services. Typically, the determination is made that the youth is "stabilized" enough so he or she can be cared for elsewhere. Therefore, stays beyond the approval of medical insurance are labeled "beyond medical necessity."

The BMN challenge for DCFS is not principally a matter of funding but availability of services. The needs of these youth are very specific. They cannot simply go anyplace that has a bed available. On any given day, we have some 60 available beds in various locations around the state, but the matching process deems them unsuited for the particular youth being placed.

A number of youth in care have an emergency need for psychiatric hospitalization, but three-fourths of them return to their placement. Some of them, particularly those from foster homes, are not able to return to those homes. They endure extended hospitalization while new placements and therapeutic services are identified and arranged. Similarly, a number of youth come into foster care on the day they become BMN, because their parents feel unable to take them home. (See table on page 4.)

Ensuring a proper subsequent placement with the treatment to stabilize and strengthen these youth is critical. If

continued on next page

build more community-based care and to help facilities broaden their services to be "integrated health homes" that can serve both mental and physical care. We will have Medicaid-funded relief time for caregivers of kids like these in our care, so that these parents and other caregivers can get a break, which often is what loving parents really need when their children so often exhibit these very "unlovable" behaviors.

Changes Illinois is making as part of the waiver innovations will also expand mobile crisis services and intensive placement stabilization to reduce reliance on hospital emergency rooms and psychiatric units. This kind of intervention not only saves money; it actually provides better care for acute behavioral episodes that are typical of severe mental illness. We know that if kids are going to live successfully at home and with foster families, their illness demands that we have this type of service.

Fourth, Governor Rauner and the Department of Healthcare and Family Services, our Medicaid agency, have entered into a consent decree to address the needs of Medicaid-eligible children, including DCFS youth, who are in need of intensive community behavioral health services. More services will reduce the need for youth to go to psychiatric hospitals. The estimated cost to the state is more than $300 million, a substantial new investment in mental health services in Illinois.

We need to understand that any crisis intervention, whether in community programs or hospitals, does not produce a "cure." It stabilizes the patient's condition, but continuation of care and a good living environment will be necessary to support the families as they support their youth. There is no such thing as "beyond medical necessity" when you have a severe and chronic mental illness, especially when combined with developmental disabilities; the need for intervention persists in good times and bad.

This problem, therefore, needs and deserves a comprehensive approach and demands the attention of multiple stakeholders – not to simply continue a dialog but to translate words and intent into action.

DCFS cannot do it alone. Even if we rescue every child from hospitals when they are stable, we need the community-based programs and services that only the private sector in Illinois can build and operate.

The past decade has been economically challenging – for children, for families, for local neighborhoods and communities, for systems like DCFS. We will continue to do what we can – to serve as the emergency room for families, while others are helping us more fully understand the problem and build the solutions. ■

we rush and put youth in any open bed we have, they are more likely to return to the hospital. The issue of BMN would disappear overnight, as youth are no longer in hospitals, but we haven't met the clinical needs of the children. The process of moving in and out of homes, returning to hospital stays, is damaging to the psyche of children, often reinforcing negative feelings of being "unlovable."

The challenges in placement are the level of care needed, the unique and complex needs of many of those youth, the gender of the youth, and wait lists at the best suited facilities. In some cases, for example, court orders require that the youth be in a locked facility; Illinois has no such facility, so we must search out of state, which entails more investigation and additional court approvals.

NEW PROGRAMS IN 2018

DCFS is working with a number of private agencies to create additional capacity tailored toward specific categories of needs. The following are new in 2018.

Community Services

- Integrated Health Home pilot program with Lurie Children's Hospital and Aunt Martha's to provide one stop for families needing a range of physical and behavioral health care [Dr. Cummins from Lurie mentions this in his testimony]
- Secure transportation for youth when it is clinically determined that transport by standard means is not safe
- Youth Advocate Program capacity increased from 65 to 150 youth, to serve Cook County and parts of Central Region
- After-school programming to support youth struggling with mental and behavioral health challenges

Residential

- Southern Region: 8 bed Group home for females ages 13-18
- Chicago: 8 bed group home for males ages 13-18
- Central Region: capacity increase to serve 3 additional males with sexually problematic behaviors
- Redesign of two high-end residential units to enhance the services to better serve females with high-end mental health needs and another for females for high-end mental health needs who are also intellectually delayed
- 10-bed residential program for re-entry of dually involved youth
- Short-term foster home stabilization program between CHASI Rice residential program and CHASI foster care to provide respite services for therapeutic foster parents
- Group home for girls involved in Human Trafficking

Specialized Foster Care

- Southern Region: New capacity to serve up to 20 youth.

Transitional Living Program

- TLP for males and females to serve up to 8 youth ages 17-20.

INCREASING COMMUNITY-BASED SERVICES

1115 Medicaid Waiver

On May 7, 2018, the federal Center for Medicare and Medicaid Services approved federal funding amounting to about $1.3 billion for Illinois, beginning July 1, to improve community-based treatment of people struggling with mental and behavioral health and keep them out of hospitals and other institutional care. The waiver programs last for five years and include an evaluation of the results.

Programs will include Medicaid funding for the following:

- Residential and inpatient treatment for individuals with substance use disorders
- Case management to help people with substance use disorders access needed medical, social, educational, and other services
- Peer support programs for substance use treatment to help prevent relapse and promote recovery
- Crisis intervention programs to intervene in extreme behaviors without psychiatric hospitalization
- Home visiting programs, including postpartum home visiting services and child home visits to postpartum mothers who gave birth to a baby born with withdrawal symptoms
- Intensive services in a home or a home-like setting to support and stabilize a child or youth exhibiting extreme behaviors
- Employment services to help people with behavioral needs find sustainable employment
- Respite services to provide a break to caregivers of people with intensive behavioral needs.

Managed Care for Youth in Care

The statewide expansion of managed care for Medicaid recipients, now streamlined with seven providers instead of a dozen or more under the previous plan, is focused on whole-person care coordination and strong oversight that will bring new resources to youth in care.

Youth with intense needs for psychiatric and mental health services will have care coordinators, who will be focused on a systematic approach to each youth's needs, finding local health providers, and helping ensure the right medications are used consistently and medical appointments are kept.

When Medicaid will not cover a needed service, DCFS will continue to pay for it from its own funds.

Medicaid services to youth in care are NOT diminishing under managed care. Instead, they are being enhanced. IlliniCare, the designated managed care organization for DCFS youth, will be obligated to provide these services and make them available throughout the state. That is extremely important to keeping young people out of psychiatric hospitals and residential facilities.

Managed Care for DCFS youth is targeted to begin October 1, 2018.

More than 80 percent of the state Medicaid population has already been through the new enrollment process, so we have experience to build upon in managing the transition for DCFS youth. DCFS, HFS and IlliniCare are thoroughly working through the transition to ensure that there is no disruption of medical care for any of the children and youth in care. ■

Youth Entering Foster Care from Psychiatric Hospitals

	Total	Lockout	Dependency/Chg to Dep	Abuse/Neglect	Other	#BMN at entry*
FY 2015	**48**	34	0	0	14	21
FY 2016	**49**	36	5	2	6	43
FY 2017	**88**	35	42	10	1	70
FY 2018	**80**	13	50	15	2	65
TOTAL	**265**	**118**	**97**	**27**	**23**	**199**

**BMN status is subject to later appeals to Medicaid for authorizing additional days of care, thus reducing or eliminating BMN days.*

Level of Care Prescribed for BMN Youth[1]

	Biological Parent	Relative/ Fictive Kin[2]	Traditional Foster Care[3]	Specialized Foster Care[4]	TLP/ILO/ YIC[5]	Residential Facility	Different Psych. Facility[6]	Total
FY 2015	0	2	5	31	1	74	0	**113**
FY 2016	2	7	10	72	3	167	1	**262**
FY 2017	0	8	2	74	0	169	4	**257**
FY 2018	0	8	5	81	7	199	9	**309**

[1]Some youth may be counted multiple times because of repeat hospitalizations. 2015 data is based on initial use of psychiatric database and may be incomplete. [2]Includes 1 "self-select" in 2018. [3]Includes pre-adoptive Foster Home. [4]Includes Therapeutic Foster Care. [5]Includes Transitional Living, Independent Living, Youth in College. [6]Includes different psychiatric hospital and psychiatric residential treatment facility.