New Hope Carolinas in Rock Hill, SC

Outsourcing Our Children: **The Failure To Treat Mental Illness In-State**

By Matthew Herr

Imagine taking your child to the hospital for intensive brain surgery and doctors telling you that his post-operative care would have to take place in another state. Or imagine your child being turned away from an emergency room that could heal her, but won't because she is "too sick" and therefore not profitable to treat. What if your child could no longer receive her cancer treatment because she turned eighteen? This is the reality faced by many families in North Carolina who have children with mental illness. In July 2013, 208 children in North Carolina were sent out-of-state for mental health treatment at a psychiatric residential treatment facility.[1]

Over the past decade, North Carolina largely privatized its mental health system.[2] One particular type of private provider — psychiatric residential treatment facilities (PRTFs) — delivers inpatient mental health services for children.[3] The state operates one PRTF, and 40 others are operated by private providers.[4] The first PRTF opened in North Carolina in 2006 (see sidebar on Eliada Homes). These facilities provide treatment in a physically secure, locked environment (see textbox on levels of care).

The lone state-run PRTF, called the Whitaker School and located in Butner, is an 18-bed, long-term treatment program for teens between the ages of 13 and 17 who are experiencing severe and persistent mental health issues. Children can stay up

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to a year in this alternative education and treatment program.[5] In 2013, 36 children received treatment at the Whitaker School.[6] In July 2013, 365 children were treated at PRTFs across North Carolina.[7]

Although the state's PRTF policies indicate these facilities are supposed to be serving youth through age 21,[8] the North Carolina Administrative Code only allows PRTFs to serve children up to age 18, at which point they are considered "adults" by the state.[9] The Early and Periodic Screening, Diagnosis & Treatment (EPSDT) provision of Medicaid[10] sets the child-adult delineation at age 21.[11] EPSDT requires state Medicaid agencies to cover services, products, or procedures for Medicaid beneficiaries under 21 if the service is medically necessary and addresses a defect, physical or mental illness, or a health problem identified through an examination.[12] EPSDT covers treatment at a PRTF.

"This incongruity between state and federal regulations creates a "doughnut hole" in care for Medicaid-eligible, 18- to 21-year-olds who need intensive mental health services in North Carolina."

However, because PRTFs operate under North Carolina's regulatory definition of children and adolescents, not Medicaid's, these facilities are allowed to serve only children and adolescents until they turn 18. This incongruity between state and federal regulations creates a "doughnut hole" in care for Medicaid-eligible, 18- to 21-year-olds who need intensive mental health services in North Carolina.

Unfortunately, the service gaps do not end there. For children under the age of 18, North Carolina licenses facilities to address either mental illness or developmental disabilities, but not both.[13] As a result, complex, hard-to-serve children — for example, children with both mental illnesses and developmental disabilities — often find themselves without any appropriate EPSDT providers in-state as well.[14] These children are like octagon-shaped pegs trying to fit into a system made up of squares and circles.

In practice, this leaves North Carolina's 18- to 21-year-olds and complex, hard-to-serve children who have severe mental illness with three options. First, they can try to seek in-state inpatient treatment in state psychiatric hospitals, which may be inappropriately restrictive.[15] Second, they can go without essential services until they are sick enough to warrant psychiatric hospitalization — where, once stabilized and discharged, they are back to square one. Or, third, as is regularly the case, they are forced to obtain treatment outside of the state. Sometimes they are sent as far away as Florida or Missouri, which isolates them from their families, excludes them from their communities, and frequently results in the state of North Carolina having little or no

Levels of Care

North Carolina has a graduated service structure for the inpatient treatment of children consisting of five levels, each more restrictive than the last:

Level I provides low to moderate structure and supervision provided in a family setting.

Level II provides moderate to high structure and supervision provided in a family setting, such as a therapeutic foster care, or group home.

Level III provides a highly structured and supervised environment.

Level IV provides a physically secure, locked environment.

Finally, **psychiatric hospitalization** is "designed to provide treatment for individuals who have acute psychiatric problems . . . and is the most intensive and restrictive type of facility for individuals."

Source: N.C. Department of Health and Human Services, State Plan Under Title XIX of the Social Security Act Medical Assistance Program, Attachment 3.1-A.1, 15A.19–20, May 1980. On the Internet at *http://www.ncdhhs.gov/dma/plan/sp.pdf*, accessed on January 25, 2014. See also 10A N.C. Administrative Code 27G.6001.

meaningful oversight over their care. In July 2013, 36 percent of the North Carolina children needing treatment in a PRTF were sent out of state.[16]

For example, Zachary Hamner of Raleigh is a teen that is diagnosed with bipolar disorder and an IQ in the mid-60s, so he has mental illness and a developmental disability. In 2012, he was treated at a PRTF called New Hope Carolinas[17] in Rock Hill, SC, a 3½ hour drive for his parents. When asked why he ended up at New Hope, Zachary says, "I did something bad. I'd rather not go back into the past. I like to think of the future, like when I'll get married and have kids and get jobs."

Eric Harbour at the N.C. Department of Health and Human Services notes that more than 90 percent of the children who were served in PRTFs out-of-state in July 2013 were served in South Carolina. He says, "These youth, in addition to those placed in Virginia and Tennessee, may be in PRTFs that are closer to their home communities than PRTFs in other regions in North Carolina." A statewide initiative called "Bring Them Home" is identifying and working on strategies to reduce the number of youth placed in PRTFs out-of-state.

Before a youth in North Carolina is allowed to seek out-of-state placement, that youth has to apply to, and be rejected from, every PRTF in the state — even from facilities where he or she does not satisfy the age or gender requirements.[18] This process can take weeks or even months. For a family whose child is in crisis, this can be frustrating.

Once youth are placed out-of-state, the state relies on local mental health agencies called Local Management Entity-Managed Care Organization (LME-MCOs)[19] to continue overseeing their care. Unfortunately, this doesn't happen consistently, which is not surprising given that the state does not have an enforcement mechanism to ensure LME-MCOs' compliance with this duty. As a result, North Carolina's children are falling through the cracks once they get shipped out-of-state for treatment.[20]

Madame, I have a confusion,
will you take it away?
Madame, I have a sickness,
will you take it away?
…
Take! For God's sake take!
Mend everything!

—Anne Sexton

These service gaps violate the federal Americans with Disabilities Act and Medicaid's EPSDT provisions. They violate the state's own policies on out-of-state enrollment for residential services, which provide that "in-state placement for the support and continuity of family involvement is the first priority, with [out-of-state] placements as the last option."[21] Sending children who need mental health services to other states should be a measure of last resort, not the state's de facto treatment plan.

This issue provides the state with an opportunity to make good on some of the promises for mental health reform that it made more than a decade ago. North Carolina needs to provide these youth with evidence-based, community-based services. Not only do such services produce better outcomes, they are less expensive than institutionalized treatment.

In July 2013, the United States Department of Health and Human Services released an extensive, multi-state study on the effectiveness of implementing community-based mental health services for youth who met the requirements of being treated in a PRTF.[22] The report finds,

> 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 [from implementing community-based mental health services for children]. In other words, [these] 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.[23]

These states offered an array of community services to meet the needs of these youth who otherwise would have been treated in PRTFs. The core benefit package included traditional services, such as individual therapy, family therapy, and

Early, Periodic Screening, Diagnosis and Treatment: Is EPSDT the Best-Kept Secret in Medicaid for Kids Under 21?

By Mebane Rash

The Center often receives calls from parents whose children have been denied services, and they want to know if there is anything they can do. One option is to submit a "request for non-covered services."

According to the website of the N.C. Department of Health and Human Services, "Early and Periodic Screening, Diagnosis and Treatment (EPSDT) is the federal law that says Medicaid must provide all medically necessary health care services to Medicaid-eligible children. Even if a service is not covered under the N.C. Medicaid State Plan, it can be covered for recipients under 21 years of age if the service is listed at 1905(a) of the Social Security Act and if all EPSDT criteria are met."

What services are covered? "Services must be ordered by the child's physician or another licensed clinician. The service must be medically necessary to correct or ameliorate a defect, physical, or mental illness or a condition that is identified through a screening examination. The service must be listed in section 1905(a) of the Social Security Act. The service cannot be experimental/investigational, unsafe or considered ineffective."

Beginning on April 1, 2014, NC Tracks will process all prior approval requests for EPSDT services for beneficiaries under 21 years of age. NC Tracks is the state's new Medicaid Management Information System where consumers can get information about benefits, and providers can submit claims. Computer Sciences Corporation (CSC) is the new fiscal agent for the N.C. Department of Health and Human Services. Here is the link to the new prior approval form: *https://www.nctracks.nc.gov/content/public/dms/public/pdf/prior-approval/Non-Covered-State-Medicaid-Plan-Services-Request-Form-for-Recipients-under-21-Years-Old/Non-Covered%20State%20Medicaid%20Plan%20Services%20Request%20Form%20for%20Recipients%20under%2021%20Years%20Old.pdf*

For more information, see the EPSDT Policy Instructions Update, May 29, 2010, on the Internet at *http://www.ncdhhs.gov/dma/epsdt/epsdtpolicyinstructions.pdf,* accessed on January 26, 2014.

In our research, the Center has learned that parents are often frustrated when confronted with the distinction between rehabilitative and habilitative services as it applies to EPSDT services for their children.

An attorney at Disability Rights NC explains,

> EPSDT only covers medical or "rehabilitative" services (for example, physical therapy, personal care services, doctor visits, etc.), and it explicitly excludes "habilitative" services. For example, developmental therapy, intensive in-home supports), many of which are only available through home and community-based service (HCBS) waivers.
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> Some services may be open to interpretation. For example, there have been court decisions going both ways on Applied Behavior Analysis therapy for the treatment of autism. It has been characterized as "habilitative" by some courts and "rehabilitative" by others. But if what is needed is something like developmental therapy or independent skills training, many of which are only available through waivers, then EPSDT does not help. However, parents/guardians can request EPSDT services when they receive denials if they have a statement of medical necessity from a treating physician.

EPSDT may be a helpful tool in the toolbox for parents with children needing a service to correct or cure a health issue.

medication management. But the study showed that including a number of other home and community-based services significantly enhanced the positive outcomes. These services included but were not limited to intensive care coordination (often called "wraparound services"), family and youth peer support, intensive in-home services, respite care, mobile crisis response, and stabilization. The funding was flexible and could be used in a variety of ways to meet the needs of the child.[24]

The federal study found that with these home and community-based services kids' attendance in school improved, their school performance was better, they had stronger interpersonal relationships, more positive connections with family members, more self-confidence, more stable living situations, and fewer symptoms of mental illness. They tried to commit suicide less often, their caregivers missed work less, and there were fewer contacts with law enforcement.[25]

When it comes to providing mental health services to 18- to 21-year-olds and complex, hard-to-serve children, outsourcing our children to other states is no longer acceptable. Instead, the state should implement home and community-based services like those in the federal study. This would ensure that every taxpayer dollar that goes to providing North Carolina's youth with intensive mental health services would go to treatments that have been shown to work. It would begin to alleviate the burden on police departments, social service departments, and other service entities that invariably are strained when the state's mental health system fails. And rather than funnel taxpayer money to out-of-state agencies, filling these service gaps would employ

Recommendations

1. On May 7, 2013, the federal Centers for Medicare and Medicaid Services (CMS) and Substance Abuse and Mental Health Services Administration (SAMHSA) issued an informational bulletin on services for children, youth, and young adults with significant mental health conditions inviting states to seek assistance. Certain mental health services allow "children with complex mental health needs—many of whom have traditionally been served in restrictive settings like residential treatment centers, group homes and psychiatric hospitals—to live in community settings and participate fully in family and community life." Federal research has shown that these services are clinically and cost effective. The bulletin says, "Developing these services will help states comply with their obligations under the Americans with Disabilities Act (ADA) and to Medicaid's Early Periodic Screening, Diagnostic and Treatment (EPSDT) requirements, specifically with respect to mental health and substance use disorder services." **The N.C. Center for Public Policy Research recommends that the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services in the N.C. Department of Health and Human Services consult with CMS and SAMHSA to deliver home and community based services for children with significant mental health conditions in North Carolina.**

2. **The N.C. Center for Public Policy Research recommends that the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services in the N.C. Department of Health and Human Services address the doughnut hole in care for Medicaid-eligible, 18- to 21-year-olds, who need intensive mental health services in North Carolina.** While the state's psychiatric residential treatment facilities policies indicate these facilities are supposed to be serving youth through age 21, the N.C. Administrative Code only allows these facilities to serve children and adolescents until they turn 18. This gap in care needs to be addressed by the state.

highly-trained professionals right here in North Carolina. Most importantly, our youth would be treated with community services in the least restrictive setting possible, as required by the U.S. Supreme Court.[26] Keeping the state's promise of mental health reform to these kids is not just the right thing to do, it is the prudent thing to do.

Endnotes

[1] Email from Eric Harbour, N.C. Department of Health and Human Services, on July 3, 2014. See also Mandy Locke, "For mentally ill children in N.C., a weak network of services," *The Charlotte Observer,* Charlotte, NC, August 11, 2013, p. 13A.

[2] N.C. Session Law 2001-437 (House Bill 381). See also Alison Gray, "The History of Mental Health Reform in North Carolina," *North Carolina Insight,* N.C. Center for Public Policy Research, Raleigh, NC, 2009, pp. 76–78.

[3] Psychiatric Residential Treatment Facilities for Children Under the Age of 21, N.C. Division of Medical Assistance Enhanced Mental Health & Substance Abuse Services, Clinical Coverage Policy No.: 8D-1, August 1, 2012. On the Internet at *http://www.ncdhhs.gov/dma/mp/8D1.pdf*, accessed on January 25, 2014.

[4] Whitaker School is the only state-run psychiatric residential treatment facility in North Carolina, although the state runs a similar program for younger children called the Wright School. More information about state-operated facilities is available on the Internet at *http://www.ncdhhs.gov/dsohf/facilitycontacts.htm*, accessed on January 25, 2014. A list of the other PRTFs in North Carolina is available on the Internet at *http://www.ncdhhs.gov/dhsr/data/mhllist.pdf*, accessed on January 25, 2014 (search for PRTF in the list).

[5] On the Internet at *http://www.ncdhhs.gov/dsohf/services/whitaker.htm*, accessed on January 25, 2014.

[6] Jeannette Barham, "Annual Statistical Report, Wright and Whitaker Residential Programs for Children, Fiscal Year 2013," Division of MH/SS/SAS, Raleigh, NC, December 2013, Table 2-A, p. 6.

[7] See note 1 above.

[8] Clinical Coverage Policy No.: 8D-1, note 3 above, p. 1, stating "PRTF services are available to Medicaid recipients under 21 years of age."

[9] 10A N.C. Administrative Code 27G.0103(10) (2012). See also 10A N.C. Administrative Code 27G.0103(9) (2012) (child means a minor from birth through 12 years of age); 10A N.C. Administrative Code 27G.0103(3) (2012) (adolescent means a minor from 13 through 17 years of age); 10A N.C. Administrative Code 27G.0103(4) (2012) (adult means a person 18 years of age or older).

[10] Medicaid is the federal government's state-run health insurance program for low-income individuals. Generally, Medicaid provides health insurance for the poor, long-term care for the elderly, and services for persons with disabilities. Medicaid was established by Title XIX of the Social Security Act of 1965, 42 U.S. Code Chapter 7, Subchapter XIX, §§ 1396–1396v.

[11] 42 U.S. Code § 1396a(a)(43)A (2006).

[12] Assistance Enhanced Mental Health & Substance Abuse Services, N.C. Division of Medical Assistance, Clinical Coverage Policy No.: 8B, November 1, 2012, p. 2. On the Internet at *http://www.ncdhhs.gov/dma/mp/8B.pdf*, accessed on January 25, 2014.

[13] Disability Rights NC, "Kids Caught in a Double Bind: North Carolina's Failure to Care for Children with Dual Disabilities," Raleigh, NC, 2011. This report finds that "[t]he State separates services between Mental Health (MH) and Developmental Disabilities (DD), and the process for getting services for an individual with complex needs is confusing and difficult. Sometimes the services do not exist at all [in-state]."

[14] Generally, mental health providers cannot bill for developmental disability services, and intellectual disability providers cannot bill for mental health services. This disconnect creates a significant barrier to providers attempting to treat complex, hard-to-serve children. The expense of hiring additional staff to bridge the gap must come out of the providers' own profits. That is why it generally does not happen and why "North Carolina has only one in-state specialty provider to treat [children] with . . . dual diagnoses." Telephone interview with Becky Fields, former clinical director of F.A.C.T. Specialized Services, a Level III facility in Jacksonville, on January 23, 2013.

[15] *Olmstead v. L.C.*, 527 U.S. 581 (1999) (requiring treatment in the least restrictive setting appropriate).

[16] See note 1 above. Telephone interview with Iris Green, Senior Attorney, Kid's Team, Disability Rights NC in Raleigh on January 24, 2013.

[17] On the Internet at *http://www.newhopetreatment.com/*, accessed on January 25, 2014.

[18] N.C. Department of Health and Human Services, Compliance Verification Protocol for Client Specific, Time Limited Out-of-State Enrollment for Residential Services, April 2002, pp. 3, 13. On the Internet at *http://www.ncdhhs.gov/mhdd-sas/statspublications/Policy/policy-cf101outofst.pdf*, accessed on January 25, 2014. The protocol requires all in-state resources to be exhausted prior to requesting out-of-state placement, and states that "[i]n-state placement for the support and continuity of family involvement is the first priority, with [out-of-state] placements as the last option."

[19] LME-MCO stands for Local Management Entity-Managed Care Organization. As of Spring 2014, there were nine LME-MCOs in North Carolina.

[20] Telephone interview with Iris Green, note 16 above.

[21] Compliance Verification Protocol, note 18, p. 3. See also 10A N.C. Administrative Code 27G §§ .1303(b)(61), .1706(b), .1805(b), .1903(e) (2012). These code provisions emphasize the need for family involvement at all levels of inpatient placement. See also Susan Stefan, "Accommodating Families: Using the Americans with Disabilities Act to Keep Families Together," *St. Louis University Journal of Health, Law, and Policy,* Vol. 2, No. 1, St. Louis University School of Law, St. Louis, MO, 2008, p. 135, which notes the need to keep families intact in order to have better outcomes.

[22] Kathleen Sebelius, Secretary of Health and Human Services, "Report to the President and Congress Medicaid Home and Community-Based Alternatives to Psychiatric Residential Treatment Facilities Demonstration," Washington, DC, July 2013, p. 1. On the Internet at *http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Downloads/PRTF-Demo-Report-.pdf*, last accessed January 25, 2014.

[23] *Ibid.*, pp. 2 and 3. Nine states participated, including Alaska, Georgia, Indiana, Kansas, Maryland, Mississippi, Montana, South Carolina, and Virginia.

[24] More information about this study is available on the Internet at *http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Alternatives-to-Psychiatric-Residential-Treatment-Facilities-Demonstration-PRTF.html*, accessed on January 25, 2014. See also this federal bulletin on the Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions, on the Internet at *http://www.medicaid.gov/federal-policy-guidance/downloads/CIB-05-07-2013.pdf*, accessed on January 25, 2014.

[25] *Ibid.*

[26] *Olmstead,* note 15 above.