



# **Kids Caught in a Double Bind:**

## **North Carolina's Failure to Care for Children with Dual Disabilities**

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# North Carolina's Failure to Care for Children with Dual Disabilities



Photographs in this publication are for illustrative purposes only and the persons depicted in them are models.

Imagine being angry all the time but not having the words to express it or the experience to understand it. Imagine being raped or beaten by an adult who is supposed to love and take care of you. Imagine being so traumatized by being the victim of violence—or watching it happen to another—that flashbacks are as commonplace as computer games. Imagine hearing voices in your head that tell you to do things that will get you in trouble at school. Imagine being so sad that you don't want to live into adulthood. Imagine having an intellectual or sensory disorder on top of the mental illness, making it even more difficult to grasp the complexities of the mental illness as well as the world around you. Imagine you also have a fragile medical history.

Imagine trying to survive under these conditions without having necessary support, services and treatment. If survival is difficult, recovery is nearly impossible.

These are not imaginary scenarios, as demonstrated by the four real-life stories highlighted in this report. These four stories occurred in North Carolina this year, in 2011. They are not isolated instances; rather they are illustrative of all-too-common problems child advocates at Disability Rights North Carolina see in this state: A lack of necessary and appropriate services for children with complex needs, the state's failure to hold Local Management Entities (LMEs) accountable for the provision of services in their catchment areas, and the North Carolina General Assembly's debilitating funding cuts in recent years.

These funding cuts and lack of necessary and appropriate community services mean North

Carolina's children increasingly face institutionalization, many in other states. While most children still receive mental health services in a private residence (e.g. their home, a relative's home), a significant number of children receive services in out-of-home settings, including psychiatric residential treatment facilities, community residential homes, foster homes, youth development centers (e.g. training schools) and state psychiatric hospitals. While the percentage of children treated in out-of-home residential treatment facilities has fallen nationally, statistics suggest that North Carolina's children are not experiencing the same trend. North Carolina more than *quadrupled* the number of locked residential placements from 117 in 2005 to 494 in March 2010.

The State recently presented a plan that requires community-based services be tried before a more restrictive out-of-home placement is used. This plan uses a model called the System of Care, which is built on the involvement of children and families, the development of individualized treatment plans that meet the unique needs of each child and family, and the coordination of services among multiple providers of services. Yet each of these provider systems is facing devastating budget cuts. The System of Care may be a great model, but where are the funds to pay for the staff to implement it?

Reduced spending for North Carolina's children with disabilities will only increase the pressure on an already strained system of care—resulting in more costly outcomes for everyone. Cuts to the system have been counterproductive. Emergency room visits continue to

rise, as does the number of out-of-state placements.

Clearly, these are extremely difficult times for the State, but North Carolina has both a legal and moral obligation to meet the basic needs of the most fragile among us—children who have complex needs directly related to their disabilities.

It is time to develop a more balanced approach to the crisis. The Department of Public Instruction and the Department of Health and Human Services must develop an interagency agreement that promotes a comprehensive set of services and supports that is coordinated and based on the needs of the whole child. The services must include: care coordination, early intervention, robust transitions, and individualized supports in the least restrictive environments that engage youth and their families.

Vicki Smith  
Executive Director  
Disability Rights North Carolina

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*Upon request, information is available in alternate formats.*

## **The Story of CS: Out of State, Out of Mind?**

With no community-based care appropriate to meet their 17-year-old adopted son's needs, a family in a rural western North Carolina county took the only route they knew to get help—they took their son to the emergency room (ER) at their local hospital.

The young man has both autism and mental illness, which complicates his situation: North Carolina has only one in-state specialty provider to treat those with these dual diagnoses. The 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.

This family waited for seven days in the ER before a bed in a private psychiatric hospital in central North Carolina was available. However, once they stabilized his condition, the hospital tried to discharge the young man without a plan for community-based follow-up care. Disability Rights NC worked with the hospital to complete this integral step prior to discharge.

Back in the boy's home county, a team of representatives from the Local Management Entity (LME) and The Arc of North Carolina met with the family. All agreed that the young man needed residential services to gain the skills he needed to become an independent adult. Since North Carolina did not have an opening in its program to address the needs of those with both autism and mental illness, they identified a psychiatric residential treatment facility (PRTF) in Virginia that could provide the appropriate treatment. After an extensive process, the young man was able to get treatment from the Virginia provider. He thrived there, showing great progress. However, the North Carolina LME stopped participating in his continued treatment and discharge planning.

Tragically for him, the Virginia PRTF has stopped accepting North Carolina Medicaid. Therefore, this young man and all other young patients from North Carolina have been sent back to their respective counties with little or no supports in place.

The family is once again in crisis since the young man's discharge from the Virginia treatment facility. The new wrinkle in the case is that the young man has turned 18 and his adoption assistance has ended. He is currently without medical insurance. Disability Rights NC continues to work with all relevant agencies to promote a favorable outcome, but the lack of insurance and necessary services makes a satisfactory resolution unlikely.

## Playing Rough with the Rules

*During a visit with her son, NP's mother noticed severe bruising on his legs, arms and torso. The boy told her that hospital staff had physically restrained him.*

In an effort to avoid further juvenile court involvement and on the advice of a mobile crisis unit, a mother took her son to the local emergency room to be assessed.

Instead, without a complete assessment and identification of appropriate community-based services to keep him in the least restrictive environment, he was involuntarily committed to a psychiatric hospital five hours away from home.

NP's mother sought treatment for him so that he would not be further criminalized for behaviors caused by his disabilities. NP had exhibited aggressive behaviors toward his older brother in the home, oppositional behaviors toward adults, and symptoms of Asperger's Syndrome, a form of autism. NP had also suffered sexual abuse by an older relative. As with many families with a history of sexual abuse, the local Department of Social Services (DSS) has been involved with the western North Carolina family for some time.

NP's mom conducted extensive research of various psychiatric residential treatment facilities (PRTF). These facilities, which are spread throughout the state, treat youth aged 6-18 with behavioral and emotional problems. The average length of stay is six to nine months.

The hospital agreed with NP's mother that a PRTF would better fit her son's treatment needs. A facility was identified and an admission date scheduled. In the meantime, NP stayed for nearly two months at the state hospital.

During a visit with her son, NP's mother noticed severe bruising on his legs, arms and torso.

The boy told her that hospital staff had physically restrained him. The mother immediately took pictures of the bruising with her cell phone camera; she also called 911.

Physical holds are a legal means of controlling individuals who become out of control and might hurt themselves or others. In this case, hospital staff did not notify NP's mother of the physical restraints or the bruising. In addition, he had not been seen by medical staff until the mother raised the issue with the hospital. The mother filed a complaint with the hospital's internal advocacy office. While admitting that the amount of bruising NP suffered was an area of concern, the hospital's internal investigation determined that no abuse to NP had occurred during physical holds. NP's mother has appealed that decision.

At a subsequent treatment team meeting, a Disability Rights NC child advocate identified ways in which staff could work with NP to eliminate the power struggles between the boy and staff that always preceded the restraints.

On the day NP was scheduled for discharge from the hospital and admission to the PRTF, his mother was present at the PRTF as his legal guardian. NP was transported to the facility by hospital staff. In an effort to ensure that her child would not be mistreated at the PRTF, NP's mother raised a number of questions and concerns about physical holds before she would agree to sign documentation for admission at the PRTF. This lengthened the admission process.

Approximately two hours after the admission process began, hospital staff who transported

NP and had been standing by contacted the hospital to report the mother was causing problems. Subsequently, and without any communication with NP's mother or the PRTE, the state hospital cancelled the admission and took the boy back to the state hospital, a three-hour drive. Disability Rights NC maintained the hospital had no legal authority to take this action, and a judge subsequently agreed, ordering the boy's immediate discharge.

However, caught in an ensuing legal snare among the state hospital, the PRTE, and the DSS, the mother was forced to sign paperwork to voluntarily re-commit NP to the state hospital. If she did not sign the voluntary commitment paperwork, the consequence was that DSS would take custody. Rather than give up her custodial rights, NP's mom signed a voluntary agreement to keep NP in the hospital while he again waited for placement at the PRTE.

Disability Rights NC filed a grievance with the hospital's advocacy office regarding the lack of communication between the hospital's clinical staff and NP's guardian. The report was substantiated citing that the actions of clinical staff complicated the patient's discharge and created barriers for the parent. The investigation determined that NP's treating physician failed to communicate with the guardian prior to readmitting the child to the hospital.

The boy was given a new admission date to the PRTE. The Disability Rights NC child advocate drove to the PRTE to assist NP and his mother with the admissions process. He was admitted, but his treatment was delayed for two weeks due to the hospital's actions.



## Compounding the Trauma

One mother who sought medical help for her daughters in southwestern North Carolina encountered a nightmarish chain of events instead.

After being dropped by their medical provider because they were late for their third appointment, the financially strapped mother of 10-year-old twins needed medical care and prescription drug refills for her daughters. Both girls have intellectual disabilities and problems with attention and anxiety. The girls had not received any prior community-based services.

The mother herself was ill with a stomach virus when she sought help from a privately operated walk-in clinic that offers mental health and substance abuse services. While she was in the restroom, her daughters became frightened and unruly, and threw some magazines in the clinic's waiting area.

The provider staff separated the twins, exacerbating their distress, and one child ran out of the building and onto the road—whereupon the agency

called the police and had the twins involuntarily committed (IVC) to the local hospital.

The mother, still very ill herself, followed the police car to the hospital, where she was subsequently admitted due to her own viral illness. She was not permitted to see her children, and was helpless to fight orders from a magistrate and a doctor that kept the girls confined in the hospital emergency room (ER). Without her consent, the children received shots of Haldol, a powerful anti-psychotic medication, and Ativan, a benzodiazepine used to treat anxiety. One child was restrained by being strapped to a bed.

Their nightmare had only begun. Due to a lack of available and appropriate placement options, the children endured not days, but more than two weeks, at the ER. Finally, they were transferred to separate institutions—one under IVC to a state-operated psychiatric hospital and the other to a state-operated treatment program for children with intellectual

*Continued on page 6*

*As of tomorrow we only have 2 days left to find a safe, suitable placement for our son. Is there anyone out there that can help us??? I do not want my son being taken to a homeless shelter by a member of our local LME staff!*

*I really just want some help, please help, I love my son dearly and do not want anything to happen to him. If you know of a therapeutic foster care home that can handle PRT holds or a group home that specializes in Autism, please help me.*

From an e-mail message sent to state and local officials and copied to Disability Rights NC in early November, 2011

## **Compounding the Trauma**

*Continued from previous page*

disabilities (ID) and/or autism who are in crisis. Following standard operating procedure in North Carolina for the transport of people with mental illness or developmental disabilities who are under IVC, that child was forced to ride in a police car with her hands and feet shackled. The other child was transferred to the ID crisis program by her parents.

Eight days after the children were admitted to the ER, the mother called upon Disability Rights NC to look into the allegations of mechanical, physical, and chemical restraints used on the children, the egregious wait time in the ER, and lack of appropriate discharge planning by the agencies involved. Working on the family's behalf, Disability Rights collaborated with the treatment team to identify placement options and back-up plans; communicated with hospital staff to increase awareness of the twins' disabilities; advocated for safer medications; supported the effort to transport the children without traumatizing them; and obtained assistance from

the NC Department of Health and Human Services' Division of Medical Assistance to expedite the treatment and ensure the children's safety.

Both girls were released after a single week of appropriate treatment, but because their car needed major repairs, the family could not make the eight-hour drive to pick them up. The local chapter of The Arc intervened to solve the transportation problem. The twins are now at home and receiving community-based services, but due to a lack of available funding for ID services they are receiving help currently from a mental health provider. This provider's staff are not trained to support the developmental issues that significantly complicate the twins' mental health symptoms. The twin who attended the ID crisis treatment center is doing better than the twin who remained under IVC and was admitted to the psychiatric hospital. However, the girls are still traumatized by their experiences in the ER and are apprehensive of any medical provider and fear they will be separated and removed from the care of their mom.



## The Story of RH:

# Administering Medical Treatments That Can Cause Permanent Damage to Children

RH is a 12-year-old boy with autism, mood disorder, intellectual disabilities and post-traumatic stress disorder. At the time RH was adopted, RH's father knew that his six-year-old child would need services because of the neglect he had suffered. But he was unaware of the developmental and psychiatric problems that were to come.

When the family moved to rural southeastern North Carolina in August 2009, they had no idea how difficult it would be to access community-based mental health services for a child with complex needs. The lack of available mental health services led to long waits in emergency rooms and multiple hospitalizations just to stabilize his condition.

In April 2011, RH's father contacted Disability Rights NC when he was unable to access community-based services. At that time, the lack of services led to RH waiting in the emergency room for seven days. After the seven-day wait, RH was transferred to a psychiatric hospital in central North Carolina. During his stay there, his parent became very concerned about the medications being administered—Zyprexa, Risperdal and Thorazine—and the use of excessive physical restraints. Disability Rights NC intervened and assisted in getting the hospital's doctors to reconsider the medications, though they continued administering high doses of Thorazine, an antipsychotic drug. Eleven years old at the time,

RH received the Thorazine orally and into the muscle. During this hospitalization RH developed motor coordination problems, drooling, sleepiness, and tremors in his hands for the first time.

Due to the concerns with the physical and chemical restraints, Disability Rights made a report to the North Carolina Division of Health Service Regulation (DHSR). DHSR substantiated many of the allegations, including the following: (1) Failure to debrief the individual within 24 hours following a physical restraint; (2) Failure to promote and protect the patient's rights by failing to ensure informed consent for non-consenting minors and safe use of restraint and seclusion; (3) Failure to ensure safe medication use practices; and (4) Failure to obtain parental consent for psychotropic medications.

In June 2011, RH was discharged and accepted to a psychiatric residential treatment facility (PRTF), which discontinued the Thorazine. He began to make progress once his medications were stabilized. He learned skills to help him cope better with his behaviors. However, when he was ready to be discharged, RH encountered the same problem of lack of community-based services for children with complex needs. In the area where he lives, such services are non-existent. The PRTF was forced to discharge him to home with no supports in place except for individual counseling and medication management. The case

manager attempted to get services from four separate private agencies, all of whom denied services, stating that RH's low developmental functioning in conjunction with his mental illness was not something they could handle.

RH's father continues to push for services and medical assistance to keep his son stable. RH continues to see medical doctors to address the continued physical symptoms that remain following the administration of medications he was given at the psychiatric hospital last spring. A neurologist recently informed RH's father that RH most likely has "Tardive Dyskenesia," a lifelong condition which manifests like cerebral palsy and can be caused by the use of some psychotropic medications.

As a result, medications that were keeping the child stable have been discontinued, and now he is once again in need of more intensive community-based services. RH is undergoing additional medical testing to assess whether his physical symptoms are permanent side effects of the psychotropic medications and also to determine if he had a stroke from the stress of being restrained and medicated at the psychiatric hospital.

RH now weighs 106 pounds, down from 138 at the time of his admission to the psychiatric hospital. He has difficulty eating because his tongue remains swollen. Doctors have now ordered him to be on a diet consisting of liquids and soft foods.

## Summary: These stories present a sampling of the critical issues.

### Problems

1. LMEs lack accountability and uniformity.
2. Case management and care coordination are underfunded and of inconsistent quality. Quality case management is crucial to the ability to serve the whole child by coordinating multiple facets of a child's care.
3. Children in rural areas and those with complex needs do not have access to appropriate providers.
4. While the number of PRTF beds soars statewide, providers are not serving the children with the most complex needs.
5. The State has dramatically cut funding for our most vulnerable residents, including children with mental health needs.

### Recommendations

The State of North Carolina must:

- ◆ Require that all LMEs/Managed Care Organizations (MCO) ensure continuity of care for children in need of mental health/developmental disabilities/substance abuse services in their catchment areas. Every LME/MCO must be responsible and accountable for working across systems, coordinating between counties and possibly across multiple LMEs/MCOs. There must be consistent LME/MCO contract requirements to promote uniformity, decrease confusion for stakeholders and promote a statewide continuum of care for children in need of MH/DD/SA services. LMEs/MCOs must provide stand-alone case management services to Medicaid-eligible children who require mental health treatment.
- ◆ Establish policies, procedures and practices that facilitate the availability and competence of professionals providing case management. Case management professionals should be required to meet minimum experience and training qualifications and be cross-trained to provide services for mental health, developmental disabilities and substance abuse populations.
- ◆ Establish and implement policies, procedures and practices to ensure that children with complex needs promptly receive medically necessary services, including professionally-adequate assessments and crisis services.
- ◆ Establish and implement policies, procedures, practices, and reimbursement rates to ensure that a variety of qualified providers are available throughout the state of North Carolina to offer intensive home-based services, including professionally-adequate assessments, crisis, and case management services to children with complex needs.
- ◆ Ensure that adequate residential services within the state of North Carolina are available for children with complex needs.
- ◆ Provide meaningful notice to Medicaid-eligible children and those with private insurance about Medicaid-funded mental health, developmental disabilities and behavioral service availability under EPSDT and private insurance.
- ◆ Track and centralize data about children's care using case management and billing data to ensure that all of a child's providers are able to access a complete picture of the child's care history. It would be especially valuable to indicate when the child's care team is seeking placement in a different level of care, how long a child has been waiting for a change in level of care, and when such a change has been completed. Records must be coordinated to serve children in juvenile detention facilities and jails. This information would provide the State with very specific information about how long a child is waiting for appropriate, medically necessary services and assist the State in resolving lengthy delays.
- ◆ Conduct professionally-adequate assessments of all Medicaid-eligible children awaiting mental health services in detention and jail and adequately fund treatment for these children.