North Carolina’s Mental Health System:
Where We Have Been, Where We Are, and Where We Are Headed

by Mebane Rash
Executive Summary

This article is an overview of North Carolina’s mental health system—its past, present, and future. In 1999, the U.S. Supreme Court handed down the *Olmstead* decision, which required states to place people with mental disabilities in the least restrictive setting possible and in community settings rather than in institutions. This decision paved the way for mental health reform nationwide. North Carolina’s mental health reform legislation passed in October 2001.

To comply with the Court’s decision, the state began to treat more people in the community instead of in institutions. From 2001 to 2011, the number of persons served at the state’s psychiatric hospitals declined from more than 17,000 people to fewer than 6,000 people. At the same time, the number of those served in the community increased by 46 percent. A large network of private providers was built up to increase service capacity in local communities across the state, but questions were raised about provider quality. However, the biggest problem with mental health reform in North Carolina has been the state’s endless stream of changes in policy, funding levels, and leadership. One national expert described it as “continuous, disconnected change.”

More than a decade after mental health reform legislation passed in North Carolina, significant changes are still underway. Changes in policy include the implementation of a **new provider model**, called CABHAs or Critical Access Behavioral Health Agencies, and a **new funding model**, the federal Medicaid waiver. The waiver will move the state from a fee-for-service model to a capitated model, where the state will pay a set amount of money each month for each consumer served. The waiver has thrown the entire mental health system into flux as local mental health management entities consolidate to meet the requirements for managed care organizations. Since reform, the state has shifted its **local governance model** for mental health services from 39 area mental health authorities to 23 local mental health management entities to 11 managed care organizations. The reformed mental health system also has been on a **roller coaster ride of state funding**—from $581 million at the start of the reform effort in 2001–02 to a high of $743 million in 2008–09 to a low of $664 million in 2009–10. **Shifts in leadership** in the state’s Department of Health and Human Services and at the legislature further complicate this issue and compromise the stability of the system.
In the 1840s, Dorothea Dix began crusading for the establishment of state psychiatric hospitals to treat mental health patients rather than throwing them in local jails or state prisons with no treatment. Ironically, this issue reverberates into our current policies as patients in need may end up in the criminal justice system instead of the mental health system. Another unintended consequence of mental health reform plays out in hospital emergency rooms across the state and across the nation. Emergency rooms are on the front lines of mental health care, even though they are not funded or staffed to serve that function and even though the chaotic environment of the emergency room is the opposite of what many mental health patients need. As states wrestle with these questions, their answers ultimately will determine the success of the policy established by the U.S. Supreme Court in its *Olmstead* decision — serving people closer to home, in their communities, which almost always is less expensive than the alternatives.

Based on the Center’s research and analysis of mental health reform in the 50 states, we conclude that the key to building a solid mental health system is settling on a strategy, implementing it, evaluating it, and funding it. North Carolina’s mental health system needs to settle on a course and then stay the course long enough to evaluate its success or failure.

The issues of mental illness, developmental disabilities, and substance abuse do not discriminate. They touch the lives of the rich and poor, those living in urban and rural areas, all ages and races, both genders, and people belonging to all political parties. Mental health reform touches all of our lives.

My uncle, Leland Ray, is autistic and developmentally disabled (see pp. 12–15). Born in Oxford, he attended public schools and was placed in the one special education program that was offered there. Sometime after he graduated with a certificate of attendance, he was placed in the Murdoch Developmental Center in Butner. Leland then moved into Person County Group Homes, Inc. — years before the U.S. Supreme Court’s *Olmstead* decision would have required the least restrictive setting for him. He lived in a group home in Roxboro, and he worked in a sheltered workshop until he retired. A woman named Queenie ran the group home as if it were her own home, and she was the supervisor the last eight years Leland lived there. After retirement, Leland was moved to a more independent living situation, a boarding house in Roxboro, where he lives today. Leland has had the same case manager, John Noland, for more than nine years, and David Forsythe has been the director of Person County Group Homes.

Mebane Rash is an attorney and the editor of the Center’s journal, *North Carolina Insight*. The Center has been conducting a study evaluating the state’s mental health reforms since 2009. Much of this commentary draws directly from the Center’s research, with particular thanks to Alison Gray, author of “The History of Mental Health Reform in North Carolina,” *North Carolina Insight*, N.C. Center for Public Policy Research, 2009, and Christine Kushner for her research on privatization. This commentary was first published in part in the *North Carolina Medical Journal*, Vol. 73, No. 3, May/June 2012, pp. 185–88, by the North Carolina Institute of Medicine and The Duke Endowment.
Homes, Inc. since 1984 — as long as Leland has been in Roxboro. Forsythe’s commitment to service is such that he spends his vacations working to repair the homes under his care.

My uncle is fortunate that his community-based care has included appropriate and adequate services provided on the local level in long-term placements, a medical and behavioral health care home, caretakers with experience who stay on the job, and adequate funding for the services he needs. His community-based treatment has been his community-based life. But Leland’s experience with the mental health system in North Carolina is not typical. It is hard to find others who have had the positive experience he has had — even after the Olmstead decision and the state’s mental health reforms. The question is, “Why?”

Mental Health Reform in North Carolina: Where We Have Been

President John F. Kennedy and his brother, Attorney General and U.S. Senator Robert F. Kennedy, had a special interest in mental health care because their sister Rosemary was developmentally disabled. In the early 1960s, they helped get legislation passed that encouraged a nationwide move toward deinstitutionalization — an effort to move those with mental disabilities out of state institutions and into local, community-based treatment.
The community-based movement gained further strength in the 1990s as a result of two significant events. In 1990, Congress enacted the Americans with Disabilities Act (ADA) to eliminate discrimination against those with disabilities. The act applies to all public entities and the use of public funds; therefore, it has implications for the provision of publicly-funded Medicaid services to people with mental disabilities. Then in 1999, the U.S. Supreme Court handed down the *Olmstead* decision, which required states to place people with mental disabilities in the least restrictive setting possible and in community settings rather than in institutions. This decision paved the way for mental health reform nationwide.

North Carolina’s mental health reform legislation, An Act To Phase in Implementation of Mental Health System Reform at the State and Local Level, passed in October 2001. Underpinning mental health reform were two ideas: deinstitutionalization and privatization.

**Deinstitutionalization**

Even after reform, the state has continued to operate 14 inpatient facilities statewide, including three state psychiatric hospitals, three alcohol and drug treatment centers, three developmental centers for people with intellectual and developmental disabilities, two residential programs for children, and three neuro-medical treatment centers. Together, these facilities, served 12,815 persons in FY 2011. The number of persons served at the state psychiatric hospitals has decreased over the past decade. While the state’s psychiatric hospitals served 17,160 persons in 2001 — the year mental health reform legislation was enacted — they provided care to just 5,754 persons in 2011.

The intent of mental health reform was to separate management functions from functions of providers of services for area programs providing community-based mental health services and to create local management entities (LMEs), with strong ties to county government and with oversight and assistance from the state. Previously, the 39 quasi-independent area programs, called area mental health authorities, were created in the 1970s to provide direct services to one or more counties and had served both as providers and payers — that is, they both delivered services and oversaw public dollars that were allocated to mental health services. They were autonomous public agencies governed by citizen boards, and they were not accountable to elected county commissioners because their service areas often covered several counties.

Under the 2001 legislation, these area programs morphed into LMEs, shedding their direct services and becoming the local entities that manage both providers and public funds for local consumers. Many individuals who had been staff members of the area programs became contractors with the newly-formed LMEs. Consolidation also occurred: The 39 area programs were replaced initially by 33 LMEs, resulting in savings in administration costs and overhead. By July 2010, there were only 23 LMEs, serving all 100 counties. In 2001, 246,039 persons were served through the LMEs, but by 2011, the LMEs were coordinating services for 360,180 persons statewide.

**Privatization**

Privatization of clinical services — which gathered steam on the national level throughout the 1970s, 1980s, and 1990s — originally was not a central premise of North Carolina’s 2001 reform legislation. Private providers already were involved in delivering some services. Only after the reform bill passed in 2001 did private providers and LME staff begin to say that the goal was to privatize. In theory, North Carolina’s approach was supposed to accomplish four things: to increase administrative efficiency by segregating management and oversight of mental health services from the actual provision of services, to promote innovation and utilize new technologies, to enhance provider quality, and to stimulate competition among providers. But the transition has not been easy. For consumers, the loss of a
one-stop shop has been tough. Many consumer advocacy groups, who had served as watchdogs over quality, expanded their role under reform to provide services, creating a potential conflict of interest for themselves. This led to concerns that the private sector might not be sufficiently responsive to the needs of people with mental illness and that the profit motive could result in a reduction in the quality or quantity of services, particularly for those with severe and persistent mental illness.

Based on the Center’s research and analysis of mental health reform in the 50 states, we have found that the key to building a solid mental health system is settling on a strategy, implementing it, evaluating it, and funding it. North Carolina’s reform effort has seen major changes in policy, funding levels, and leadership so frequently that often it seems the biggest problem with reform is the state’s inability to stay the course—any course. More than a decade after reform legislation passed in North Carolina, significant changes are still underway.

The Mental Health System in North Carolina: Where We Are

Changes in Policy

A New Provider Model: Critical Access Behavioral Health Agencies

Reform created a large network of providers and corresponding service capacity, but there were questions about provider quality.\textsuperscript{11} Late in 2009, the N.C. Department of Health and Human Services proposed a new provider classification for mental health services in North Carolina called CABHAs, short for Critical Access Behavioral Health Agencies. These large providers deliver mental health and substance abuse services. This approach was developed to ensure appropriate medical and clinical treatments and to reduce the potential for ineffective or unwarranted services. As of August 2012, there were 210 certified CABHAs statewide.\textsuperscript{12}  

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The story of XDS is a story about providers of mental health services and how they cope with the seemingly constant changes in state policy, how to pay for services, and the real impact on consumers and providers.

Thava Mahadevan (above) is the executive director of XDS in Pittsboro, a nonprofit provider of services to more than 130 consumers. XDS stands for “cross disability services,” which means the people Thava serves have both mental illness and developmental disabilities. Consumers with dual diagnoses routinely fall through the cracks because they need long-term care that costs a lot of money, and they are not going to get better. The budget for XDS is $2 million.

Thava is a refugee from the island of Sri Lanka in southeast Asia. Ethnic and political conflict has plagued the island, and Thava’s family fled to Southern India after their home was attacked and burned to the ground. With the help of a Hindu monastery, the family began to rebuild their lives. After graduating from Madras Christian College, Thava received a full scholarship to attend Davidson College in 1988 on a music and cultural exchange. After Davidson, he moved to Boone. He worked for a small mental health agency providing direct care at two group homes to the first group of Thomas S. patients leaving Broughton Hospital. Thomas S. was a lawsuit on behalf of people with mental retardation that had been served in state psychiatric hospitals instead of their communities. Thava says he loved his work there, and so he decided to go to graduate school at UNC-Chapel Hill in rehabilitation counseling. He then went to work at John Umstead Hospital in Butner, as the Thomas S. specialist, transitioning patients back to their home counties. Five years later, he became the Thomas S. coordinator for the Orange-Person-Chatham local mental health management entity.
After the mental health reform law passed in 2001, XDS was established, and Thava has been there ever since.

Thava’s laugh is infectious. His energy and passion fill the room. He has figured out how to roll with the system. He has decided that serving his clients is all that matters. He figures out what is best for them, and then he figures out how to make that happen.

XDS rents 60 apartments in the Triangle for its clients. Thava knows that without housing he can’t keep his clients out of crisis. His clients use a federal government subsidy to pay for rent and food stamps to pay for food. But how were they supposed to pay for utilities? Thava went to the N.C. Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, and he made sure that their coverage would include the other costs of independent living so his clients could live on their own in the community in an apartment of their choice.

When his clients missed appointments over and over again because of transportation issues, Thava bought a fleet of cars for XDS. Now XDS is able to take services to its clients. Even the psychiatrist goes to the homes of those she treats and provides her services there.

To monitor all of the constant changes in billing and coverage, Thava set up a war room. On one screen, he monitors incoming money to provide services. On another screen, he monitors the Division’s almost constant communications with providers. He pays bills at the same time with his handheld device. There is a notebook computer on his desk that does everything else. He takes it with him everywhere.

Thava lost hope in 2011 when the state’s shift to Critical Access Behavioral Health Agencies (called CABHAs, these are large providers of mental health and substance abuse services) was announced. He stopped laughing, and for the first time he worried about his clients and his staff and whether he could figure out this latest obstacle. He knew the numbers didn’t work. Unwilling to shut down, he moved XDS from Durham, where he was paying $8,000 in rent, and bought property in Pittsboro that costs him only $2,500 a month. XDS then was approved as a CABHA. Thava had figured out a way to keep XDS going.

XDS has merged now with the UNC Center for Excellence in Community Mental Health so that together they can provide a true continuum of care for consumers — from hospital emergency room services, to inpatient hospital beds, to mobile crisis teams, to high-level services needed to keep clients living in the community and out of hospitals, to community support. Thava remains the executive director of XDS, and he serves as the Director of Operations for the Center for Excellence.

Thava now wants to establish a clinic on the XDS property so that medical and behavioral services are integrated at least for his clients. He wants to create a therapeutic farm on his 35 acres and build a music, art, and pottery therapy center for his consumers.

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CABHAs may be for-profit, non-profit, or public health agencies, but they are required to provide three core services—comprehensive clinical assessment, medication management, and outpatient therapy—and at least two additional services from a list of 14 services, creating a continuum of care. The goal is to establish a strong clinical foundation on which to build community capacity. To that end, the state also requires certain staffing for CABHAs—a medical director (full-time for CABHAs serving more than 750 consumers), a clinical director, and a quality management/staff training director.

The interplay of the federal Medicaid waiver (see below) and CABHA policies is worth watching closely. One of the goals of the waiver is to allow LMEs to pick providers based on performance and to give the providers incentives to provide needed services. But the CABHA policy eliminates many smaller providers in favor of fewer, larger providers. Some areas of the state do not have many CABHAs. Whether local management entities will be able to encourage competition and lower prices in areas where a few providers essentially have a monopoly on services is unclear. Also, this provider network is still in flux with the number of CABHAs likely to come down. If further budget cuts are made by the 2013–14 N.C. General Assembly that affect the provision of mental health services, then the CABHAs that are operating close to the margin of profitability may go out of business.

A New Funding Model: The Federal Medicaid Waiver

Medicaid is the state-run federal program providing health insurance for individuals with low incomes, long-term care for the elderly, and services for person with disabilities. It is the largest funder of mental health services nationwide. In North Carolina, it is also the fastest-growing program in our state budget.\[13\]

North Carolina is currently trying a new funding model—a federal waiver for our Medicaid program. Federal waivers allow states to operate programs outside normal federal Medicaid guidelines. The federal Medicaid guidelines are waived, thus the name of the program. Particularly since the economic downturn began in 2008, the waiver is a crucial element in running an effective and cost-conscious system. According to David Swann, chief clinical officer for Partners Behavioral Health Management, “The objective is not to limit services for individuals, but to manage a system so that a person is guided to the appropriate level of care.”\[14\]

The waiver eventually will apply to all mental health, developmental disability, and substance abuse services in North Carolina funded by Medicaid. The technical name of the 1915(b) waiver is the N.C. Mental Health, Substance Abuse, and Developmental Disabilities Health Plan. 1915 is the section of the federal Social Security Act that authorizes these waivers.\[15\] The (b) part of the waiver allows the state to contract with a managed care vendor, a local management entity-managed care organization (LME-MCO),\[16\] for oversight of mental health, developmental disability, and substance abuse services in their counties. In theory, this will save money allowing for expanded services. The technical name of the 1915(c) waiver is N.C. Innovations. The (c) part of the waiver allows for home- and community-based services to be provided in lieu of institutional care for those with developmental disabilities. Through this part of
the waiver, the state will be able to offer habilitation—the teaching or training of a person to be independent in their daily living.

Initially, the state had planned to expand the waiver to one or two LMEs each year, allowing expertise to be provided to each LME and giving the state time to learn from each implementation. But in 2011, with Medicaid costs rising and the state revenues down due to the recession, the North Carolina legislature passed a bill to expand the waiver statewide by July 1, 2013, in hopes of saving $10.5 million in fiscal year 2012 and $52.5 million in fiscal year 2013.¹⁷

This has thrown the entire mental health system into flux as local management entities consolidate to meet the requirements for managed care organizations (MCOs). State officials currently expect the 23 LMEs to merge into 11 MCOs.¹⁸ For this model to work, each MCO has to cover a sufficient number of consumers to be financially stable. From area agencies to LMEs to LME-MCOs, North Carolina needs to stick with a local governance model. “Don’t hit reset too soon,” cautions Mike Hogan, the Commissioner of Mental Health in New York.

Not unexpectedly, implementing the waiver statewide this quickly has been difficult. The Mecklenburg County LME requested a 90-day reprieve from working towards an anticipated July 1, 2012 start date of the waiver as the leadership and financial management of the LME was reorganized. The waiver in Mecklenburg now is scheduled to be implemented in January 2013. The Western Highlands Network began administering services in January 2012. By July 2012, it had amassed a $3 million deficit, and its board of directors fired the CEO.

There are pros and cons to the waiver approach. On one hand, it allows the state to use Medicaid and state funds more effectively by giving the state the ability to predict and control costs. Instead of receiving a fee for a service provided, LMEs will receive a set amount of money each month for each consumer served. The federal waiver also gives the LMEs the ability to pick providers and set rates. The hope is that LMEs will be able to create incentives for providers to make available the mix of services consumers need in their region, including services for consumers who may have been undertreated historically. According to Kelly Crosbie, who is in charge of implementing the waiver statewide for the Division of Medical Assistance, waivers can be used to:

- increase access to preventive and maintenance care;
- decrease the use of avoidable inpatient care;
- expand provider networks and services;
- shift the emphasis to recovery, rehabilitation, and work;
- provide more focused and goal-oriented treatment; and
- increase reliance on best practices.¹⁹

On the other hand, the waiver approach continues to carve out separate provision of mental health services for consumers in North Carolina instead of following a national trend to integrate the provision of mental and physical health care services through one health care provider.²⁰ Under the waiver, LME-MCOs also will assume the risk. If services cost more to provide than projected, the LME-MCOs will have to use risk reserves to cover those costs. Furthermore, the promise of additional services depends on three variables. First, LME-MCOs need to be able to save money, which may prove difficult now that the primary source of savings—moving people out of institutions and into the community—has occurred.²¹ Second, the federal government will have to approve any extra services provided with savings, a process that does not always happen quickly. Third, although the waiver moves LME-MCOs to a capitated system where they receive a set amount for each consumer served, the providers remain in a

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Nestled on a small hill in Roxboro, surrounded by ancient oaks and pecan trees, is a beautiful 1930s-era farmhouse with a long front porch, occupied by well-worn rocking chairs. On one bright and sunny morning, the front door is wide open, and “Hot Stuff” by Donna Summer is blasting into the carefully-tended garden on the front lawn. Inside, gathered in a long, spacious dining room, “Mama Jo” Shotwell is leading a group of a dozen developmentally-disabled men and women in dance. Mama Jo is a bubbly and vibrant woman who has been working with this group for more than 15 years. As she dances around the room clapping and singing, she calls out each person’s name, pulling them further into the activity. Those that can stand up are shaking their hips and swinging their arms. Those who are wheelchair-bound raise their hands into the air and smile and laugh with their companions. This is Generations Adult Day Services, which provides care and therapies for Roxboro residents with developmental disabilities and severe dementia. At Generations, those with mental retardation, autism, and dementia get a mix of socialization, physical therapy and activity, and education from 8 a.m. until 4 p.m.

After Mama Jo gets the group’s blood flowing with some dancing and stretching, she immediately jumps into the first activity of the day, which varies from one person to the next. A young man in a mechanized wheelchair is shown flash cards with images of different animals by an aide, which prompts him to try and name the creature. While the young man cannot verbalize his answers well, the aide continues to prompt him and then gives him the correct answer if he misses. Sitting across the table from him is a quiet woman in her 70s who has severe Alzheimer’s disease. Her activity is a word-finding puzzle. She glances around the room smiling at everyone.

Just down the table sits another older gentleman. He is working on the same type of puzzle as the woman, but his focus is intense. This is Leland Ray (above), who has mental retardation and autism. Leland is an avid walker, making his way to many of the local shops and public spaces in Roxboro, often catching a ride home with anyone from the police, to the fire department, to local store employees, and even other shoppers. Leland lives just up the hill from Generations, a short walk for him. He lives in a small house with four other developmentally disabled men, part of the independent living program of Person County Group Homes, Inc.

Mama Jo looks over at him and says, “Leland, tell me what time it is?” Leland pauses and refocuses his attention on the clock in front of him. “One minute past 10, Mama Jo,” he says quietly, flashing her a big smile.

Joyce Riley, who is the Program Director of Generations Adult Day Services, says that each member of this group has a set of tasks and goals that they must complete. All of their tasks are set up to challenge them and improve their ability to take care of their own life needs. Some of Leland’s
tasks include serving and cleaning up breakfast, helping cook some of the lunches, planning the event and activity calendar with Mama Jo, and working on his ability to tell time, among others. Riley says that on a typical day, the Generations staff tries to provide five types of activities to challenge individuals in the program; passive activities, such as watching TV; active tasks, such as working on a puzzle or game; exercise, such as dancing; communication, such as working with a staff member on a project; and educational activities, such as being read a short article about health and wellness.

Leland and the Generations group will spend the morning hours in this large, old dairy farmhouse participating in these types of activities, watching “The Price is Right” on TV, and cooking a family-style lunch. Once a month, they have the Roxboro Fire Department over for a few games of bingo, and just recently the group donated a rose bush to a local retirement home. When Mama Jo and the other staff mention the fish fry they are planning for Father’s Day, the whole room buzzes with excitement. “I try to mix things up for them, to get them excited, and to provide variety,” says Shotwell. “This place is their whole world. For most of them, after they leave here in the morning, they go home and get dinner and a bath and that’s it. At [Generations] these folks at least have a chance to be part of a close group, learn skills, and to interact in a way they may not normally.”

After Leland Ray finishes a busy morning at Generations, he walks up the hill and returns to his home, but his day is far from over. On this particular afternoon, Leland is late returning home from Generations and John Noland, the qualified professional that oversees the operation of several independent living programs and adult care homes, is worried Leland might have gone out for one of his famous long walks. Noland, a retired high school teacher from West Virginia, has been with Person County Group Homes for nearly eight years and knows Leland’s habits well. “I used to worry about Leland walking around on his own,” says Noland. “But he’s pretty careful about where he goes, and now people all over Roxboro know him and know where he lives. I’ve followed him home in my car on several occasions just to be sure he’s all right.”

Noland says that Leland is just one of more than 80 Roxboro residents living in Person County Group Homes, Inc., and 50 in their day services programs. The five men in this particular group home receive funding at various levels from the N.C. Community Alternatives Program for the Developmentally Disabled (CAP MR/DD) as a means of paying for their services, says Noland. Each individual in the home also is employed in the community, earning their own money to spend on food, hobbies, and vacations. Employment for the members of this group can range from working in a restaurant to a supportive workshop at Person Industries, a county-sponsored work program which recently began handling the processing of all of Person County’s recyclable materials. The other four members of the home work either full- or part-time jobs. Leland, at age 64, is what Noland terms “retired.”

“He still does some work around the house apart from his normal tasks, and he gets paid for doing things like raking leaves in the yard,” says Noland.
Noland then turns away and cups his hand over his furrowed brow as he scans the road leading toward the house for any sign of Leland. Then, a red pickup truck comes rolling up to the house. John Noland smiles wide, and out pops Leland and Mike Jones, a supervisor, who oversees the daily activities in Leland’s house. “Sorry we’re late. Leland was getting his glasses fixed,” says Mike, a middle-aged man with a Southern drawl and neatly trimmed, graying mustache.

Mike has been working with the developmentally disabled for more than 18 years. In his current position with Person County Group Homes, Inc., Mike oversees the daily activities of the five men in Leland’s home, including helping them learn and develop life skills, assisting them with their finances, and transporting the group to doctor appointments and shopping. Mike only stays through dinnertime, making sure everyone in the house has completed their tasks and chores and has received any one-on-one time they need. At night, the residents are on their own, but rarely call upon Mike or John Noland for assistance. “I’ve had only a few serious incidents at night in the time I’ve been here,” says Mike. “Usually if there’s an issue, it’s because someone has switched medications and is having an adverse reaction or something like that.”

Leland leads the way into the house, a small brick ranch home divided into five individual suites — each with a living area, bedroom, large closet, and shared bathroom. Leland’s suite is clean and well-kept except for the small hobby table in his living room, which is covered by countless batteries, broken electronics, and tools. Mike says that Leland is enormously interested in the inner-workings of everyday electronics like clocks, radios, and small toys. In fact, Leland carries a handheld radio in his pocket everywhere he goes. The rest of his suite is sparsely furnished with a TV, couch, bed, dresser, refrigerator, and homemade art that Leland has crafted during his time at Generations.

The house is old and worn but also quite homey, with a large communal kitchen and dining area. In the kitchen hangs a small laminated list of chores that each member of the house must complete daily, such as vacuuming the common areas or cleaning the kitchen. On one wall of the kitchen, from floor to ceiling, is a mural of geese flying over an expansive lake and forest. Mike says that the mural is something to brighten the room up, and Leland smiles and nods approvingly. It is here in the kitchen that
Leland has recently been doing a lot of work, learning how to cook new dishes with Mike’s help.

“I’ve been trying to teach Leland how to cook scrambled eggs for a couple months now,” says Mike. “He’s gotten better, but we’re not quite there. I try to keep him from burning himself or flipping the eggs onto the burner.” Along with these skills, Mike has been helping Leland improve his verbal communication as well. Due to Mike’s poor hearing, he says that Leland has been forced to speak louder and more clearly when they work together. Mike chuckles and says, “I never intended to work on that with him, so that’s a happy accident.”

Sitting down at the kitchen table, Leland immediately begins pulling out picture albums and souvenirs from the group’s latest vacation — a trip to Myrtle Beach. John Noland says that every year they give each individual in their communities an opportunity to go on a vacation. Everyone saves up the wages they earn throughout the year to afford the trips.

Closer to home, the staff of Person County Group Homes makes sure there are plenty of opportunities for fun. Some residents enjoy barbecues. Others have a membership in a sports club. Still others try out for the Special Olympics. Leland, prior to his retirement, was on the Person County Special Olympics Equestrian Team and also possesses several trophies from local bowling clubs. Each resident of the group homes is offered opportunities to live a full, active life.

With this blend of oversight and autonomy, structure and independence, Leland Ray has been given the opportunity to live his life as an integrated, active member of the Roxboro community. This was the goal of mental health reform, but it’s not everyone’s experience. "Leland Ray has been given the opportunity to live his life as an integrated, active member of the Roxboro community. This was the goal of mental health reform, but it’s not everyone’s experience."
fee-for-service system. According to Marvin Swartz of the Duke University School of Medicine, this may “misalign incentives between the MCO and providers, undermining joint planning.”22 Ultimately, Swartz warns the waiver may shift the incentives for LMEs-MCOs from over-treating to under-treating consumers.23 “The cost to treat these consumers may end up just being shifted to the criminal justice system, for instance.”24

To increase the likelihood that the implementation of the waiver statewide will be successful, Swartz has three recommendations. First, despite the political consequences or feasibility, the state should slow down its implementation of the federal waiver. Second, the state should engage private MCOs to teach the public LME-MCOs the business and then exit after implementation. Third, the state should extend the current pilot25 and try different approaches.26

Michigan’s experience provides another cautionary tale about waivers and the risk of relying exclusively on Medicaid to fund mental health services. Michigan also implemented its waiver statewide, but with mixed results. As hoped, the state has been able to save money and increase provider quality, but it has struggled to match federal dollars with state dollars because of the auto industry’s troubles and the state’s damaged economy during the recession. To receive Medicaid coverage, a consumer must be in dire circumstances. As one Michigan area mental health director told us, “We’ve had to tell people who ask for help to come back to us when they’ve lost their job, their house, and their support—because at that point they will qualify for Medicaid and get the services they need.”

Foreshadowing yet another policy change, in April 2012, North Carolina requested approval from the federal government to provide personal assistance services (services that assist with daily living skills, such as eating, bathing, and dressing) to mental health consumers through a 1915(i) State Plan Personal Assistance Services (PAS) program. If approved, these services will be available beginning on January 1, 2013.

**Unstable Funding**

The funding for the public mental health system in North Carolina comes from Medicaid, state appropriations, county funds, and other sources. More than $3 billion annually is spent on services.

But the reformed system has been on a roller coaster ride of state funding, with the Great Recession taking its toll on North Carolina’s state budget revenues and thus funding for the system. State funding for the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services totaled $581 million in fiscal year (FY) 2001–02, increased to $743 million in 2008–09, decreased to $664 million in 2009–10, increased to $705 million in 2010–11, decreased to $666 million in 2011–12, and increased to $696 million in 2012–13.

Three years ago in FY 2010, the state had a revenue shortfall of $4.6 billion dollars. The Governor had to impose cuts after the legislature adjourned to keep the budget in balance. Overall, the Division of Mental Health’s budget was cut during that year from $820 million27 to $664 million, or by 19 percent. Two years ago, the state had another revenue shortfall of $1.2 billion. In FY 2011, $40 million in funding for community services administered through the LMEs was restored. But, this increase was more than offset by cuts in other parts of the budget—in particular, the budget for the Division of Medical Assistance (DMA), which runs the Medicaid program in North Carolina and pays for a lot of mental health services. To save $41 million, the legislature required DMA to use rate and utilization management for mental health services—that means lower rates paid to providers and fewer services for consumers. To save an additional $7.7 million, independent assessments were required for some mental health services paid for with Medicaid funds. The upshot of this was also fewer services for consumers. And, to save an additional $51 million, the in-home personal care services program now will provide care at home only to those individuals at the greatest risk of being sent to more expensive institutional care.
A man undergoing substance abuse detoxification for heroin addiction groans as the drug works its way out of his system. A teenager’s addiction to alcohol is treated in a chair where he may sit for 23 hours under medical observation because beds for adolescents who need long-term substance abuse treatment are few and far between in North Carolina. In another building, a 30-year-old woman sits in a halfway house crying with gratitude. After going through detox three times and being discharged back to the streets, she is ashamed of her struggle but thankful for the support she is finally getting to overcome her addiction. Here, she will learn basic living skills, get her first job, and find permanent housing. Recovery is about much more than being drug-free.

These life-altering services are provided at Freedom House Recovery Center in Chapel Hill, a mental health provider for 37 years. Three years ago, Freedom House had built up almost $1 million in cash reserves—enough to ensure adequate cash flow when the state’s payments were delinquent. But, those reserves were reduced as the economy tanked. Feeding their residential clients costs one-third more than it did a year ago due to the rising costs of groceries. Then, they had to reorganize as a Critical Access Behavioral Health Agency (or CABHA), the state’s new designation for large providers of mental health services. This required having a full-time medical director on staff. And, the organization has suffered through three years of state budget cuts—cuts both to the services they can provide, and the amount they are paid to provide them. Providers are feeling the effects of the economy, changes in state policy, and state budget cuts in a way that could undermine their ability to provide services going forward.

As one of the state’s best private providers of mental health services, Freedom House employs 252 people, and it served almost 10,000 mental health and substance abuse consumers in 2011. Their outcomes are better than both state and national outcomes.
Yet Marvin Swartz of the Duke University School of Medicine notes that most provider organizations are already under financial strain with severe cash flow problems. Providers like Freedom House have had to ask themselves hard questions during the past several years. How will we make payroll? Should we cut services? In a speech in August 2012, Swartz cautioned that additional cash flow problems created by the transition to the federal Medicaid waiver could send provider organizations into insolvency.¹

Trish Hussey, the executive director of Freedom House, says the transition to Cardinal Innovations, formerly Piedmont Behavioral Healthcare (PBH) and one of the new LME-MCOs, “has been a positive experience for us financially so far. They are paying quickly and efficiently for the services we provide, and this has made all of the difference in the world to us.”

In FY 2012, the state was short $2.5 billion. Despite this shortfall, some of the mental health dollars cut in FY 2010 continue to be restored, so for FY 2013, the Division’s budget increased to $696 million. Some important provisions of the FY 2013 state budget as it pertains to mental health reform include:

- A $20 million reduction in funding to the state’s LMEs. $345 million remains in the budget for this purpose;
- An $8.5 million reduction in funding for the administrative budgets of the LMEs;
- A $2.25 million reduction in funding for drug treatment court services;
- $9 million in additional funding for the three-way contracts to purchase 45 more beds; and
- 124 additional beds funded at Cherry Hospital, and 19 additional beds funded at Broughton Hospital, both of which are state psychiatric hospitals.

**Shifts in Leadership**

Just keeping up with who the policymakers are in this field can be challenging for those interested in the issue. Lanier Cansler was Secretary of the Department of Health and Human Services (DHHS) from January 2009 until he stepped down in February 2012. Al Delia, formerly the Governor’s senior advisor on policy, is now the acting Secretary—probably until a new governor takes office in January 2013.

On June 19, 2012, Delia announced a re-organization of his leadership team. Dr. Craigan Gray, the former director of the Division of Medical Assistance, the state’s Medicaid office, was fired. Mike Watson, formerly the chief deputy secretary of DHHS, is the new state Medicaid director. Beth Melcher, formerly the assistant secretary for the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MH/DD/SAS), is now chief deputy secretary of DHHS. Soon after these changes, Steve Jordan, the director of MH/DD/SAS, was killed by a logging truck while riding his bicycle. Jim Jarrard has been named acting director of the Division. Jarrard has been deputy director of the division since October 2010. The elections in November 2012 are likely to precipitate another round of changes.

Turnover at the North Carolina General Assembly further complicates the issue. In the 2011–12 legislature, there were 46 freshman legislators (27 percent). And, 61 more legislators serving in 2011–12 will not be returning at all or to the same chamber in 2013 as a result of deaths, resignations, redistricting, or defeats in the 2012 elections. In the 2013–14 General Assembly, 102 legislators (60 percent) will not have been there just three years ago. This will result in a loss of institutional memory around the goals of mental health reform and create another hurdle for stable funding and consistent policies. For example, the 2011–12 legislature allowed the Joint Legislative Oversight Committee on Mental Health, Developmental Disability, and Substance Abuse Services to expire. Thus, the most prominent forum for discussing mental health policy issues no longer exists. And, when bills affecting mental health services were discussed in committee meetings, legislators did not even realize that they needed committee rooms that would accommodate people with disabilities.

**Nationwide Trends: Where We Are Going**

As the Center has looked at what other states around the country are doing to comply with the U.S. Supreme Court’s *Olmstead* decision and serve those with mental disabilities, two trends are apparent.
Dealing with Mental Illness and Substance Abuse: In the Criminal Justice System or the Mental Health System?

One trend is for states to deal with mental illness and substance abuse in jails and prisons rather than in the mental health system. This is an echo of the policies in place when Dorothea Dix began crusading for the establishment of state psychiatric hospitals to treat mental patients rather than throw them in local jails or state prisons. There is no better example of this trend than the state of Georgia, where one in every 13 adults is under correctional control. It is estimated that 75 to 80 percent of those inmates require either mental health or substance abuse services, and some require both.

Dr. Tony Frasca, a psychiatrist who works in western North Carolina, says that state governments have two options when it comes to serving their mentally ill populations: Either the Department of Correction can be the unseen arm of mental health system, housing people in prisons with little or no treatment, or the mental health system can be the unseen arm of the Department of Correction, with citizens being served at a much lower cost in the community with treatment that prevents them from ending up in jail. He asked, “Which system do we as a state want to fund?”

Hospital Emergency Rooms on the Front Lines

Another trend that emerged in our 50-state study is that visits to hospital emergency rooms by patients with mental illness or substance abuse are increasing. This unintended consequence of mental health reform plays out in emergency rooms (ERs) across our state every day. In 2011, at one community hospital with 24 beds in the emergency room, there were about 2,000 visits by patients with mental illness or substance abuse—on average, about five visits each day. In June 2011, things got so bad that for two weeks, there were nine or more patients in this ER at all times with mental health or substance abuse issues. Patients also are staying in the hospital emergency rooms longer and longer as they wait for beds in mental health facilities to become available. There have been as many as 15 people held in this particular ER for mental health issues, taking up more than half the capacity of the emergency room. The longest stay has been 10 days. Just imagine waiting in a hospital emergency room for 10 days.

By contrast, in New York, the mental health system was designed to put emergency rooms on the front lines. Each of their regions has a psychiatric ER for the provision of mental health services; it provides a single portal of entry into the mental health system. Psychiatric ERs are the home base for Assertive Community Treatment teams in New York, which are designed to provide comprehensive, community-based psychiatric treatment, rehabilitation, and support. These ERs are funded and staffed to identify who needs mental health care the most, what care they need, and where they should get it.

Stay the Course

“Y’all never stick with one thing,” said Mike Hogan, the Commissioner of Mental Health in New York, of North Carolina’s mental health system, during his keynote address at a mental health care conference sponsored by the N.C. Institute of Medicine in August 2012. He described one of North Carolina’s long-standing challenges with mental health reform as “continuous, disconnected change.” He said there was “lack of agreement on the playlist.” His advice? “Problems will occur. Expect them, deal with them. Stay the course.”
Brianna came to live with Linda McDonough when she was seven weeks old, gaining a family, including a big sister, and a home. Linda then adopted her at age two. McDonough adopted Brianna even though by then it was clear Brianna’s mental health issues would shape the life the family would share. Brianna is 13 now.

In some ways, Brianna is lucky. Medicaid pays for Brianna’s treatment, thanks to an adoption insurance package for families taking in high-risk children. And, she has a mother that loves her for the beautiful, challenging child that she is. “I love my daughter,” says Brianna’s mom. “But I can’t cure her, nor can I fix her. I can only love her as she is and work to shape her world so that she can be successful. Sometimes it works. Much of the time it doesn’t.”

Brianna was expelled from her first day care center. Her first interaction with the mental health system in North Carolina was through her local mental health management entity, which placed her in therapeutic day care. Brianna has been mainstreamed — where students with special needs are educated in regular classes. And she has been pulled out of regular classes and educated in a self-contained educational environment. She has attended public and private schools. Her first psychiatric hospitalization was in third grade at UNC Hospital in Chapel Hill.

Brianna personally has experienced most of the options our mental health system has to offer children her age. She spent eight months at the Wright School, a state-operated facility offering residential treatment for children aged 6–12 with serious behavioral and emotional disorders (see p. 45). She spent five months in a therapeutic level II foster care facility with a caretaker she called Aunt Jackie. She spent six weeks...
at Central Regional Hospital in Butner. She has been in more than one psychiatric residential treatment facility (PRTF). She has spent time in multiple emergency rooms across the state. She knows that sheriffs in the criminal justice system take her from one place to another.

In March 2011, Brianna spent 6½ days in a hospital emergency room, 80 miles away from her hometown and her mom. Staff from a psychiatric residential treatment facility had dropped her off and left her in the ER. She was given medication, but she still needed to be restrained at times. She did not have access to books or school work or exercise — because these things just aren’t possible in an ER. She began to self-mutilate, and her hand had to be bandaged. Finally, it was Brianna herself that picked up the phone and called 911. She told the operator she needed a ride to Butner.

Brianna’s primary diagnosis is Disruptive Behavior Disorder, a little worse than attention deficit hyperactivity disorder (ADHD), but not quite so bad as conduct disorder, according to her mom. She also has Anxiety Disorder, NOS (not otherwise specified), which means it doesn’t look like most people’s anxiety. And, complicating it all is a brand new diagnosis of severe receptive-expressive language disorder.

“When people talk, Brianna drowns in an ocean of words,” says her mom. “Kids with this disorder have a very hard time in classrooms because teachers talk so dang much. You know how the adults in the Charlie Brown videos sound? That’s how she hears language.”

Brianna’s mom hopes to find a PRTF that is able to treat her daughter for an extended period of time, maybe a year or two, and that Brianna then will be able to come home and live with her. “The truth is that I am proud of both my daughters. I have no desire to trade either one of them in. They are who they are, and I am honored to share their journeys. Even the one who tells me she likes Butner because their padded room is nicer.”