

A Personal Perspective on the Future of the Developmental Centers in North Carolina

Alexander M. Myers, PhD, LP, HSP

"The future belongs to those who believe in the beauty of their dreams." —Eleanor Roosevelt

The future role of the developmental centers in North Carolina is a controversial topic. Discussions on this issue are always spirited, with opinions ranging from those who view the centers as sites of excellence in the field of service provision for the most needy of North Carolina's citizens with intellectual/developmental disabilities (I/DD), to those who abhor the centers' very existence and advocate for their elimination. I must acknowledge that I hold the former opinion. The views presented here may be shared by others, but are attributable solely to myself.

"The future ain't what it used to be." —Yogi Berra

Before forecasting the future, it is helpful to take a quick glance at the past and describe the role of developmental centers in the state's I/DD service delivery system. Prior to the 1970s, the centers (then known as training schools or institutions for the mentally retarded) were the primary residential option for this population outside of the family home. Conditions were deplorable by today's standards. In 1972, a new service known as intermediate care facility services for persons with mental retardation (ICF/MR) and related conditions was added to the Medicaid program. The introduction of this program allowed developmental centers to begin shifting their emphasis from warehousing clients to creating therapeutic homes that provided active treatment that prepared individuals to move back into the community.

"The future is here. It's just not widely distributed yet."
—William Gibson

During the last 30+ years, developmental centers in North Carolina have downsized their resident populations and evolved into homelike communities while developing a unique expertise in serving persons with I/DD who have increasingly complex needs. The centers have served as a valuable public safety net for persons whose needs exceeded the available supports and services in the community.

North Carolina once had five regional developmental centers—it now has three. Black Mountain Center was converted into a neuromedical treatment center providing skilled nursing care a few years ago, and the O'Berry Center is in the process of transforming into a neuromedical treatment center also providing skilled nursing care.

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The remaining three developmental centers have dramatically reduced their populations from their historic highs, working with Local Management Entities (LMEs) to prepare persons for life in a community setting. Caswell Developmental Center in the eastern region of the state has reduced its population from 2,045 to about 430. Murdoch Center in the central region has decreased from 1,660 to 525. The J.I. Riddle Developmental Center in the western region has seen its census lowered from 840 to approximately 350.

Alexander M. Myers, PhD, LP, HSP, is the director of the Murdoch Developmental Center in the Division of State Operated Healthcare Facilities, North Carolina Department of Health and Human Services. He can be reached at [aleck.myers \(at\) dhhs.nc.gov](mailto:aleck.myers@dhhs.nc.gov).

It should be noted, however, that most of this downsizing occurred in the 1980s when community-based residential options were being developed. In recent years, community placements have become less frequent.

As they downsized, the centers continued to develop expertise in serving populations with significant challenges. Riddle Developmental Center is renowned for its cutting edge research and training in the area of I/DD and has recently developed a rapid response team in a collaborative consultative effort with Broughton Hospital, a state-operated psychiatric hospital. Caswell Developmental Center has developed a specialized, time-limited program serving adults with I/DD and mental illness. Murdoch Developmental Center is renown for its program library, its innovative vocational programs, and its three time-limited statewide specialty programs. These programs include (1) Partners in Autism Treatment and Habilitation (PATH), serving children age 6 to 16 with autism spectrum disorder and extreme behavioral challenges (this program includes two community PATH homes); (2) Specialized Treatment for Adolescents in a Residential Setting (STARS), serving adolescents age 13 to 17 with diagnoses of I/DD and mental health and behavioral issues; and, (3) Behaviorally Advanced Residential Treatment (BART), serving young adult males with I/DD and extremely challenging behaviors.

All three developmental centers are nationally recognized ICF/MR residential treatment facilities that continue to serve an ever-changing population. Each is now serving a general population of aging persons who primarily have severe/profound intellectual disabilities and who are viewed as hard to serve in the community due to either extreme medical needs or challenging behaviors. The list that follows gives the proportion of persons in the centers with each of the following needs:

- Severe/profound impairment (cognitive or adaptive) —97%
- Routine medications—99.4%
- Medications/treatments provided per day (Murdoch) —8,717
- Psychotropic medications—37.5%
- Non-ambulatory—33%
- Seizures—48%
- Fed by tube—14.4%

"Predicting the future is easy. It's trying to figure out what's going on now that's hard." —Fritz R. S. Dressler

Currently the developmental centers anchor the North Carolina service delivery system for persons with I/DD, providing specialized care and expertise for the most difficult to serve individuals. A strong, specialized training and consultation program providing support to the community was offered for many years until eliminated by the legislature several years ago. It was disappointing to

lose this program as it helped maximize the effectiveness of community supports and prevented some admissions to the developmental centers. However, in their safety net role the centers continue to offer short-term therapeutic/diagnostic respite services to persons with I/DD when those services are unavailable in the community. The developmental centers have been especially important during the recent challenges presented by North Carolina mental health reform. During this period LMEs have gone through dramatic changes and the economy has worsened. The result is fewer dollars being available in the community to support persons with challenging behaviors. Also during this period the number of unserved or underserved individuals has continued to increase. In a time of great upheaval, the community has continued to depend on developmental centers as a source of stable services, as well as a nurturing home for many individuals with I/DD.

Moving Towards the Future

"We don't like their sound and guitar music is on its way out."
—Decca Records rejects The Beatles in 1962

The persistent goal of some critics is the elimination of the developmental centers. However, until needed community resources can be established as safe, stable, and reliable and until providers demonstrate their willingness and ability to effectively serve even the most challenging individuals with I/DD, the services offered by the centers will be essential, especially given their specialty services. Given this reality, the centers are committed to the following:

1. Admissions committees at the centers will view the centers as placements of last resort. It is not easy to get someone admitted; LMEs must demonstrate that they have exhausted all community options.
2. Any person currently residing in the centers, regardless of level of need, could be served in the community if sufficient supports and resources are provided.
3. Active and persistent efforts have been and will continue to be made by the centers to work with families, LMEs, and providers to find adequate community placements for those who seek them.

While the developmental centers are committed to supporting community placement, a number of obstacles must be addressed. First, communication barriers must be eliminated. The LMEs, community providers, and the centers must share information about available openings, persons actively desiring placement, and the specific needs and supports for each individual. This collaboration must be maintained at least through a six-month transition period. Second, case management services during the transition process must be improved. Case managers must be skilled and available for thorough transition planning so they can work with the LME, the center, the individual/

family/guardian, and the chosen provider to develop and coordinate the transition plan. Third, both LMEs and residential providers need better incentives to move people out of the centers and into the community. Many LMEs see downsizing the centers as a low priority, given other pressing issues and the lack of resources. They tend to view the centers as providing a safe and secure home to individuals from their area and do not view them as a priority unlike those individuals in their catchment area who are underserved and who are clamoring for community-based services. Residential providers are also selective about who they serve. Not surprisingly, individuals with less complex support needs are easier and less expensive to serve than those coming out of the centers. Additionally, there is little disincentive for terminating a community placement for an individual with little or no warning when problems are encountered; this places the person in a crisis situation and the LME is often forced to turn to the developmental center (or the psychiatric hospital) for placement. There needs to be greater incentives for providers to continue to serve individuals who can be more challenging.

Fourth, families and guardians of individuals residing at the developmental centers also indicate a preference for continued center living. For many people, the centers have been home for many years; these people are aging in place and are content with their lives at the centers. The centers are viewed as stable, safe, and committed to person-centered programming; have ready and timely access to professionals, supports, and services; have relatively low turnover rates; and are protected by well-established advocacy programs, human rights committees, and continuous quality control protocols. Families and guardians are concerned that community providers are unable to meet the same standards as centers and as a result will not consider community placement. The community must acknowledge this mistrust and develop creative ways to

reach out and build trust. Developmental center staff can continue to work with families and guardians to consider community options, but cannot build the needed trust. That must come from the community.

"I've read the last page of the Bible. It's all going to turn out all right." —Billy Graham

The developmental centers will continue to partner with the LMEs and other community providers to help North Carolina deliver top quality supports and services to citizens with I/DD. The centers should be considered as one part of a service continuum and serve as a safety net for people with significant I/DD. The centers' expertise can also be used to train direct care and professional staff in the community and students in the university system and to provide consultative support to families, LMEs, and providers. As the centers' population ages and community supports are strengthened, the centers will continue to become smaller and more focused on providing specialized services. Within 10 years, the centers will reach a point where their residential capacity represents a public safety net for persons with extreme I/DD needs within each of the three regions. Additionally, specialty programs for specific populations will help stabilize persons in crisis and help develop habilitative plans to assist community providers in the provision of long-term safe, secure, and therapeutic homes. Finally, working with community I/DD crisis teams (such as the new NC-START teams), LMEs, providers, advocacy groups, and the psychiatric hospitals, the developmental centers will replace emergency rooms, prisons, and the psychiatric hospitals as the last-resort safety net for persons in crisis. Working hand-in-hand to support all persons with I/DD, the goal will be to ensure safety, security, dignity, respect, and happiness throughout their lives in North Carolina. **NCMJ**

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