

Filling the Gaps through Partnerships, Collaboration, and Flexible Funding

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Like many states, North Carolina has experienced budget woes, reductions in rates for services, program shutdowns, and forced layoffs or furloughs for employees. It's clear we are not operating in an environment of "business as usual" these days. The good news is that reduced resources doesn't have to equal diminished opportunities or services. Often, the time to create new community initiatives is when changes in state and federal funding cause a reprioritization of resources.

The North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services allocates funding each year to Local Management Entities (LMEs) to address behavioral health needs of the designated counties under each LME. The LME, in collaboration with stakeholders, decides which services they will offer within the financial resources available for individuals without Medicaid or other insurance coverage. East Carolina Behavioral Health (ECBH) is the LME for Beaufort, Bertie, Craven, Gates, Hertford, Jones, Northampton, Pamlico, and Pitt counties in eastern North Carolina. East Carolina Behavioral Health works creatively with several different partners to improve the system and funds innovative options for consumers and families, working to achieve the best services in the most cost-efficient way.

Historically, North Carolina has favored funding for institutional, rather than community-based, services for people with intellectual or developmental disabilities. Institutional levels of care are not only more costly but also serve fewer people; these levels of care reduce the amount of funding available to serve people locally in their own communities. North Carolina could successfully fill funding gaps by closing the residential component of state-operated mental retardation centers and allocating dollars for more appropriate community-based services, as many other states have already successfully done.

There are waiting lists for developmental disability services, and ECBH is working hard to develop solutions to shortages and gaps in funding. Respite care, developmental therapy, adult day programs, and group living are some of the greatest needs that have been identified by families of disabled children and adults. ECBH developed resources and alternatives within available funding to meet these and other growing needs of communities. Unfortunately, due to limited financial resources, there is not enough for everyone to get what they want or, in some cases, need. For example, in the ECBH area, more than 4,200 people with intellectual disabilities and other developmental disabilities receive state-funded developmental disabilities services. As

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of November 2009, 328 people were waiting for funding for the Medicaid Community Alternatives Program for Mentally Retarded/Developmentally Disabled Individuals (CAP-MR/DD) program. ECBH works closely with consumers and their families to meet the needs of individuals who are waiting for a Medicaid waiver slot by offering funding to provide for the purchase of needed equipment and supplies that they might not otherwise be able to obtain without this funding. Annually, ECBH spends \$128,000 in the purchase of individual equipment and supplies for people who are

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waiting for CAP-MR/DD waiver funding. This is in addition to other services that the person may receive while waiting for CAP funding. ECBH provides a parallel state-funded system of supports for consumers while they wait to receive the benefits of the more robustly-funded Medicaid waiver.

There are many people with intellectual and developmental disabilities (I/DD) who need support in a variety of residential settings. The annual cost to support a person to live in a group home setting is about \$27,010 per year in the ECBH area, not including the cost of room and board. Increases in support for these programs are rare, and ECBH, like other LMEs, has many people who are on waiting lists for these types of services. Now more than ever before, people are seeking group home placements as parents age and families need a place for their adult family members with I/DD to live. Consumers and families also want options as each person is unique and needs a different level and type of support. ECBH currently supports 105 people living in group home settings, at a total aggregate cost of \$2.9 million.

In an effort to extend the options for housing supports, ECBH recently purchased eight duplex apartments through The Arc of North Carolina. These duplexes will expand less restrictive housing options in the area for our clients and offer the opportunity for people to live in their own apartment with wraparound supports based on individual needs. The cost to support these 16 individuals to live in apartments is projected to be \$10,555 per person per year.

ECBH has a strong focus on the rehabilitative needs of individuals who have survived a traumatic brain injury (TBI). However services currently offered do not adequately or appropriately address the unique needs of this population. Last year ECBH developed an alternative service definition to address the long-term residential and rehabilitative needs of TBI survivors. This service currently supports seven individuals living in residential settings. The cost to support these individuals to achieve their recovery potential is \$333,620 per year, in aggregate. Support for the needs of this population cost an average of \$51,100 per person per year. This cost supports requesting a waiver for this population as the needs are intensive and the potential for rehabilitation is great if the right type and amount of services are available within the first year after the initial trauma.

Flexible funding is not a new concept. Simply stated, this means that the person decides how to use the funding to get the services or support they need. The individual might create a specific service, take a class, buy equipment, make renovations to support independent living, or interview and hire a job coach who works directly for them to support employment. Flexible funding is one part of self-determination. Self-determination is a conceptual idea that allows people to choose the services and the providers they want and control other decisions because they themselves know best about what they need and how to make sure they get what they need. ECBH, now in its third year of collaboration with The Arc of North Carolina, supports

eight individuals to be more self-determined. Each of these individuals has been able to design services that are unique to meet their needs.

Collaboration is the key to success for each of these individuals. Of course, the idea of collaboration isn't new; rather, it is the identity of the collaborators and the process of designing individualized services that takes this project beyond business as usual. In addition to family, friends, personal assistants, and agency personnel, new participants include church members, daycare operators, retailers, housing agencies, and a range of business, professional, and private citizens. It is this idea of rethinking and expanding our community connections that we believe is significant, especially in this era of shrinking resources. This is one of the most innovative projects ECBH has worked on since reform began; it is about new resources, new partnerships, new points of view, and new relationships.

Partnerships

Here are examples of the individualized solutions we have developed:

Janey designed her own service to assist her in maintaining employment with a local retail store. Janey's needs did not fit within the context of currently defined services. Janey needed more than personal care and more than supported employment but needed both services at the same time. She had secured her own job but was unable to maintain it without supports. The project director at The Arc of North Carolina worked with Janey, her family, and Easter Seals UCP to develop Janey's service, which combines the elements of a personal care service with elements of supported employment and which revolves around Janey as a unique person. This service has supported Janey to maintain her employment for the past three years.

Dana designed respite services to help support her to live in her own home while her father, her primary caregiver, works shift work. Dana and her father live in a rural area, and her father works out of state approximately two weeks each month. Dana does not have any other natural supports since the death of her mother, and she receives minimal services when her dad is in town. The Arc of North Carolina worked with Dana, her dad, and RHA Health Services to develop Dana's service to support her to remain in her home when her father had to go out of state. If this service had not been available, Dana may have needed to move to a group home or other higher level of care.

Charles designed his own services to support his transition from a state institution back to his mother's home. Charles was living at Caswell, a state-operated developmental center. Charles's mother desperately

wanted him to move home. In order for Charles to move home he required overnight awake staff within his home to maintain the safety of other family members until the transition was successful. The Arc of North Carolina and ECBH, through flexible funding, created an overnight awake service to ensure the safety of Charles and his family. Over time, this evolved as Charles became more stable at home, and the service has now become a PRN crisis response service available to the parent within 10 minutes.

While change is happening simultaneously throughout the behavioral health system in North Carolina, it is important to point out the successes that are occurring within the ECBH region. Working in partnership with consumers, families, and other stakeholders to create and design

services which meet the needs of people is paramount. We know that when we give people the ability to design exactly the supports they need, we are saving financial resources and supporting the person to have the life they want. What is provided, who provides it, how and when it is provided, and where it is provided all impact a person's life.

As more people move out of institutions or decide to live more independently in communities, they will be looking for services that meet their unique individual needs. Options such as those being carried out in the East Carolina Behavioral Health region of the state offer exciting opportunities for success in supporting people to live in the community. Our belief is that by sharing our vision of possibility, sharing resources, and collaborating in new ways toward one common goal of improving quality of life for each person, we encourage people toward success. **NCMJ**

my friend's got mental illness.

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