DOCUMENT RESUME

ED 323 683 EC 232 109

AUTHOR	Shoultz, Bonnie
TITLE	Supporting Individuals within Their Families or in Homes of Their Own: The CAP-MR/DD Program in Raleigh, North Carolina.
INSTITUTION	Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	Jun 89
CONTRACT	G0085C03503
NOTE	30p.
AVAILABLE FROM	Syracuse University, Center on Human Policy, 200 Huntington Hall, 2nd Floor, Syracuse, NY 13244-2340 ($2.25).
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	*Community Services; Delivery Systems; Family Involvement; *Family Programs; *Home Programs; *Human Services; Individualized Programs; Program Implementation; *Severe Disabilities
IDENTIFIERS	North Carolina (Wake County)

ABSTRACT

Findings are presented from a site visit to a Raleigh, North Carolina, program that provides in-home support to children and adults with severe disabilities and their families. The program, the Wake County Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities, is administered by the North Carolina Department of Human Resources under a Title XIX (Medicaid) waiver. The program's three components include a client screening procedure, a plan of care, and a set of locally developed community-based services. Positive program practices include responsive case management; family involvement; building supports around the individual's specific needs; individualized programming in the home; contracting with individual "providers"; attention to issues of cultural and racial diversity; and emphasis on positive relationships among case managers, caregivers, and the people they support. Program limitations are also noted. (JDD)

SUPPORTING INDIVIDUALS WITHIN THEIR FAMILIES OR IN HOMES OF THEIR OWN: THE CAP-MR/DD PROGRAM IN RALEIGH, NORTH CAROLINA

SUPPORTING INDIVIDUALS WITHIN THEIR FAMILIES OR IN HOMES OF THEIR OWN: THE CAP-MR/DD PROGRAM IN RALEIGH, NORTH CAROLINA

by Bonnie Shoultz

Research and Training Center on Community Integration
Center on Human Policy
Syracuse University
200 Huntington Hall
Syracuse, NY 13244-2430

Preparation of this case study was supported by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability Research and Rehabilitation, under Contract No. G0085C03503 awarded to the Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University. The opinions expressed herein do no necessarily reflect the position of the U.S. Department of Education, and no official endorsement should be inferred.

June, 1989

This is one in a series of reports on programs and services that support people with severe disabilities in the community. The purpose of the series is not to evaluate programs or services, but rather to describe innovative practices in integrating people with disabilities into community life.

SUPPORTING INDIVIDUALS WITHIN THEIR FAMILIES OR IN HOMES OF THEIR OWN: THE CAP-MR/DD PROGRAM IN RALEIGH, NORTH CAROLINA

by Bonnie Shoultz

Over the past three years, staff and associates of the Center on Human Policy have visited programs that provide individualized services and supports to children and adults with severe disabilities and their families. We learned about one such program while carrying out a technical assistance agreement with Wake County Mental Retardation/ Developmental Disabilities Services, whose office is in Raleigh, North Carolina. We decided that a site visit to this program would be worthwhile after having visited several families and one adult who were extremely enthusiastic about the in-home support they were receiving through the program. I spent three more days with staff members, five families, and three adults in April, 1987.

Anthony and His Family

In 1987, Anthony Adams* was a five year old who lived with his grandmother, a sister, a brother, and a couple of

---

*All names used in this report, except for names of the case managers, are pseudonyms.

cousins ranging from two to ten years old, and his great-grandmother in a public housing project. Anthony's mother had recently moved from this house to an apartment with two of her sons, one of whom was an infant. Another of her children was living with his other grandmother. We arrived at Anthony's home one afternoon around 4:00 p.m. Anthony and his family are black, and the case manager, who is also black, respectfully called his grandmother "Miss Lillian" and his great-grandmother "Miss Bea" throughout the visit. Miss Bea greeted us at the door and told us that everyone else was "out back." We went through their home to the back door, which looked over a wide field in back of a school. The school's backyard had been turned into a carnival, with areas for games and rides, and it was full of children and adults, black and white.

As we neared the people, a young woman and a very worried-looking boy came toward us. One was Anthony, who wanted to stay and have fun at the carnival, and the other the caregiver working with him under the auspices of CAP (Community Alternatives Program). To Anthony's visible relief, we all turned around and went back to the carnival. There, we also found Anthony's grandmother, Miss Lillian, who heads the household, and his siblings and cousins, including the brother who lives with his other grandmother.

Anthony's caregiver stood with Anthony in several lines for games and prizes while we watched and talked. The other family members joined us, left, joined us, and left again.

When Anthony was about 3 1/2, his mother's household came under the scrutiny of the Department of Social Services. Because Anthony was hyperactive and impulsive, the developmental evaluation center referred him to Amos Cottage, a home for behavior management in Winston-Salem. While he was there his mother and her other children moved in with Miss Lillian and Miss Bea, and Miss Lillian visited Anthony as often as possible. CAP-MR/DD, a relatively new program at that time, became interested in bringing Anthony home, and worked with his mother and grandmother to make that possible. He came home in April, 1986. CAP hired a caregiver to work with him at home, and placed him at Learning Together, an integrated preschool, with another child served by CAP-MR/DD (one staff member funded by CAP-MR/DD worked with these two children in the integrated setting). Anthony was in the custody of the Department of Social Services until January, 1987, but was then placed in the custody of Miss Lillian.

Rachel, Anthony's caregiver, worked in the home from 5:00 p.m. to 9:00 p.m. Monday through Friday. A CAP Parent-Caregiver Trainer worked with her and Miss Lillian to develop a schedule and routines for Rachel's work with him. Their routines included self-care and simple housekeeping tasks, meals with the family and going out in the community together or with other family members. Both she and the Parent-Caregiver Trainer spent time with Miss Lillian talking about family matters. They often posed suggestions for working through problems arising with Anthony. Other services could be provided if they were needed by the family. At the time of the visit, Miss Lillian was very happy with the arrangements. She remarked, "I reckon if Rachel stopped coming to see him, I don't know what he'd do." Anthony is still doing very well. With Rachel's involvement, Anthony has made great progress both at school and at home, and his family enjoy him and are proud of what he can do. His grandmother spontaneously said, during the interview, "He's something! I love him. My friends do too."

John's New Life in the Community

I met John's mother one morning when Ilean, the case manager, stopped by at her place of work to have her sign some papers. She spontaneously and enthusiastically told me how happy she was because of what is happening in John's life. She seemed optimistic about his future, and said that for years she had had no hope for John ever living in the community.

John, a white man in his late 20s, had a history of acting out violently against those close to him and against people who worked with him. Because there were few support services available at that time for him or his family, his parents reluctantly placed him at O'Berry Center, a state institution, while he was an adolescent. Since then he had moved back to the community several times, but each time there was an escalating series of incidents which ended up with John returning to O'Berry Center. The last time he came out, he lived in a group home operated by a private agency in Wake County until the home said they could not handle John. He was sent once again to O'Berry Center, and stayed there until CAP brought him back in May, 1986. UntilCAP's involvement with him, the supports and environments John needed were not available to him.

To bring John back home, CAP worked with the Residential Coordinator for Wake County Mental Retardation/ Developmental Disabilities Services. She located an apartment for John and another man, and CAP recruited someone to live with them. This has worked very well for John. The three men get along very well, and John has had no major problems. The man who first lived with them left after nine months, and Doug, who lived with them when I visited and is still there now, was hired. The apartment is seen as "belonging" to John and his roommates, not to the agency.

John has a job hauling trash for a company. This is a supported employment position coordinated Wake Enterprises, an agency in Raleigh. He has done well on this job and intends to keep it.

Doug and John get out a great deal. They go to self-advocacy meetings once a week, to Doug's home (40 minutes away, it is a farm with an orchard and a fishing pond where John fishes) on the weekends, and many other places. The apartment is within walking distance of a shopping center, a grocery store, a bank, and other resources. John has learned to deposit his check and withdraw money from the bank, a skill the staff at O'Berry Center said he would never be able to learn.

After years of trying to make John fit a variety of programs, what has worked has been a program designed to fit him. He no longer has to struggle for control over how he lives and what he does during his day.

Background on the CAP-MR/DD Program

The North Carolina Department of Human Resources administers this flexible program, which provides home and community based services under a Title XIX (Medicaid) waiver. The program developed by the state is called the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD). As such, it is a program intended to support individuals within a variety of community settings, including the families into which they were born.

According to "A Pamphlet for the Operation of the North Carolina Medicaid Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities," a manual developed in 1985 by the Department of Human Resources, "The primary focus of CAP-MR/DD is to provide an alternative to institutional placement through community living if non-institutional community services are feasible, financially viable and preferred by the person" (p. 2). The manual goes on to state that the objectives of the program are "to deliver necessary services in the most cost-effective way and to assist persons with mental retardation/developmental disabilities to lead lives in the community with as much dignity and independence as possible."

Two divisions within the Department of Human Resources are responsible for the program: the Division of Mental Health, Mental Retardation, and Substance Abuse, which is the lead administrative agency for CAP-MR/DD, and the Division of Medical Assistance, which is the division responsible for administering the Medicaid program.

There are 41 area programs in North Carolina; these are public agencies providing community based mental health, mental retardation and substance abuse programs for a catchment area under the governance of area boards appointed by county commissioners. In April, 1987, the month of my visit, the CAP-MR/DD program was operated by 35 area programs. In 1988, 39 area programs operated CAP-MR/DD.

According to the manual referred to above, "the program consists of three main components: (1) a client screening procedure, (2) a Plan of Care; and, (3) a set of locally developed community based services" (page 2). The client screening procedure assesses the person's strengths and needs and can involve a variety of evaluations, including medical, dental, speech, physical and/or occupational therapy evaluations. The Plan of Care responds to these evaluations and contains goals and objectives for serving an individual. It is developed by the local program and must be submitted to the state, which may approve the Plan of Care or return it to the local program for revisions. After it is approved, the Plan of Care can be revised, but each revision must be approved by the state.

A large part of the Plan of Care is the specification of the locally developed community based services a person will receive. A wide variety of services can be provided to CAP-MR/DD clients. The state defines these as case management, homemaker services, home health aide services, personal care services, adult day services, personal habilitation services, respite care, home mobility aids, durable medical equipment, registered nursing services, and supplies (such as diapers and other disposable supplies needed for the individual). These services can be purchased from existing providers, or new ways of providing these services can be developed locally.

Wake County's CAP-MR/DD Program

Wake County Mental Retardation/Developmental Disabilities Services is one of the 41 area programs. In 1987, Wake County's CAP-MR/DD program provided individualized services to 27 children and adults who were at risk for or had been institutionalized. No more than 27 people in Wake County could receive services through CAP-MR/DD in fiscal year 1987-88 (July-June), because the state allocated only 27 "slots" to Wake County. Each "slot" could be used to purchase services not to exceed $19,382 per year for one person.

The number of people served and the ceiling amount for each "slot" may change from year to year, but the financial restrictions described here are still in effect. According to North Carolina's Medicaid waiver agreement that was approved by the federal government, a "slot" is considered filled for the fiscal year as soon as a claim for an individual is reimbursed for a waiver service, whether that be screening for eligibility or full time residential and day services. Thus, if only $500 is spent on an individual in a fiscal year (for example, if the person moved or came into the program late in a fiscal year), the remaining funds cannot be spent to meet another person's needs. The program is not permitted to serve more people at a lower average cost per person or to use one person's unspent funds to supplement the allocation for another person.

Wake County MR/DD Services, like most of the other area programs, has made conscious efforts to reserve use of its CAP-MR/DD funds for people whose service needs are high and who will be using the service(s) for more than just a few months. They feel that providing CAP-MR/DD services to people who need less means that the money available will go unused. Eligible individuals with fewer needs may receive the other services funded through Wake County MR/DD Services using local, state and federal funds. These services range from infant stimulation and preschool services for children to employment and community living services for adults but do not include the in-home support and wide array of other services available to those served through CAP-MR/DD.

Each area program operating a CAP-MR/DD program may develop or contract for services. Wake County MR/DD Services provides some services directly and contracts with existing or new providers for others. The program operates as follows: A CAP-MR/DD Coordinator/case manager coordinates the program and supervises a case manager. The Coordinator is case manager for 13 people and the case manager for 14 people. Case management includes screening, eligibility determination, development of the Plan of Care, purchase and coordination of services. The case manager role is critical to the success of the program.

Arrangements for Paying for Services and Goods

As long as they are listed in the individual's Plan of Care and are allowable under the Medicaid waiver guidelines, services, supplies and equipment can be provided through a variety of arrangements ranging from direct purchase or provision to contractual agreements between Wake County MR/DD Services and providers. Durable medical equipment (for example, wheelchairs, standing tables, and braces) and supplies are purchased directly for individuals. Professional services such as physical, occupational and speech therapy and medical consultations and services are provided under contracts with professional providers.

Some persons are served in day programs operated by contract agencies funded by Wake County MR/DD Services; these include supported employment programs, sheltered workshops, segregated preschools, and integrated preschools. CAP-MR/DD clients with medical or behavioral needs may receive one-on-one staffing in these programs, funded by the CAP-MR/DD program. In these instances, the caregiver or worker supporting the person may be employed by the contract agency through funding provided by CAP-MR/DD or may work directly for CAP-MR/DD as an independent contractor.

Many of the children served by CAP-MR/DD receive in-home care on a regular basis (e.g. 20-40 hours per week), as do a few adults. The caregivers in these homes work as independent contractors under contract agreements with Wake County Mental Retardation/Developmental Disabilities Services. Many of these situations are supported by a Parent-Caregiver Trainer, a woman who works with the parents and caregivers to develop programs and activities to be carried out with the individual. The Parent-Caregiver trainer may visit the home on a weekly or biweekly basis, depending on the need for her services.

CAP-MR/DD also supports some adults in their own apartments; John, described above, is an example. In these cases, the staff who live in are independent contractors with CAP-MR/DD who are "hired" with the involvement of the people supported in this way. This involvement can range from an opportunity to meet with the person to an opportunity to be involved in the interviewing process. A caregiver's contract can be terminated fairly easily if there are problems between the caregiver and the person receiving CAP services. The caregiver can be given 30 days' notice or can be terminated immediately if fraudulent or unprofessional behavior has occurred.

Wake County's CAP program can create or develop services based on individual needs and wishes, as long as those services are allowable under the state's guidelines and as long as they cost no more than $19,382 per year. Depending on the services needed by a person, the program may recruit, hire and supervise independent contractors, contract with an agency, or do both. For example, the program may contract with a preschool that agrees to serve a child with medical needs or very challenging behaviors at a higher rate than is ordinarily paid for children in its program; it may also hire an independent contractor to work with the child in the home and community. A high degree of flexibility is allowed, as long as the services can be provided for less than the ceiling amount.

Waiver of Parental Income

Until 1987, the federal Secretary of Health and Human Services could waive parental income deeming requirements as part of a waiver request; the Omnibus Budget Reconciliation Act that year left this provision out, and the Health Care Financing Administration gave the states until July 1, 1987 to remove middle income children from Medicaid funding. North Carolina was using the option more than any other state, because its CAP-MR/DD program served a large number of middle income families whose disabled children live at home. In April, 1987, efforts were being made to lobby for restoration of the provision, and parents and staff were very worried. National and local advocacy groups advocated for the restoration of the provision and were successful before any of the six Wake County families that would have been affected lost their services. Thus, it has been and still is possible for middle income families with minor children living at home to receive these services.

Positive Program Practices

Responsive Case Management

Because of the way the program is set up, the case managers are critical to the success of the program. Their role is to work with all the parties involved to ensure that services are really meeting people's needs. Pam and Ilean, the case managers, believe that case management means responsiveness, and are available to families and individuals whenever they are needed. For example, two weeks after my visit, Sidney's mother, a single parent who had appeared quite stressed during our time with her, called Pam because she needed to go immediately into a drug/alcohol rehabilitation program. Pam took five-year-old Sidney home with her; for the next few weeks Sidney stayed with Pam or with other families Pam solicited, and his mother completed treatment. The fact that Sidney has many challenging behaviors and very limited communication skills did not prevent his being taken care of while his mother was in treatment. Sidney still lives with his mother and continues to receive CAP MR/DD support.

Responsiveness also means completing necessary paperwork, arranging meetings, obtaining and coordinating services, monitoring programs that serve CAP MR/DD clients, and identifying, screening, contracting with, and supervising caregivers. Finally, responsiveness means attentiveness, noticing when a need exists that can be met by the program and offering to meet that need. I saw many instances of this while I was there.

Family Involvement

The CAP MR/DD program actively involves families from the beginning. Many if not most of the referrals come directly from families who are experiencing problems serious enough to cause them to consider placement of their child out of the home. After acceptance into the program, families are actively involved in the meetings with agencies where the individual may receive services. Families help to develop the goals that are required for the Plan of Care, and often recommend changes in the goals proposed by professionals. Families must sign the Plan of Care before it can be sent to the state Medicaid agency. Revisions to the Plan of Care can be made at any time, and are often suggested by the families. For example, the family may feel that a goal is too ambitious, not ambitious enough, or inappropriate for the individual.

Finally, if one or more caregivers will be working with an individual in the family's home, the family can rely on the program to assist in resolving any problems that may arise. Theoretically, this could include termination of the caregiver, although this has not been necessary since the program's inception in 1985. Even in the cases where adults are served in apartment and work settings away from the family home, the families remain actively involved when that is their and their son or daughter's desire.

Like some of the family support programs we have visited, this program serves some families whose values and beliefs about their son or daughter differ from those of the program staff. In these cases, staff struggle with whether and how much service to provide to families who resist or are unable to use their suggestions and advice, and for whom the services offered appear to be ineffective. To date, however, no family or individual has been terminated from the program due to disagreements over the family's way of handling situations. Instead, the staff offer services that they feel would meet the individual's needs, but support the family's decisions even when there is disagreement. In at least four situations I learned about, staff and families had very different ideas about meeting the individual's needs. In each case, the families have prevailed and are receiving the services they wanted.

For example, early in 1987 CAP offered to develop an apartment setting for Barry, a young black man who was living with his family and in jeopardy in the community.

CAP staff, professionals, and community agencies involved with Barry felt that he needed to move from his family's home so that his entire day could be structured and consistent. His parents disagreed and felt that he should live with them; after all, his older brother and sister, both of whom had chronic illnesses, still lived at home. Why should Barry be the first to leave? This disagreement resulted in conflict that lasted for quite a while before it was resolved.

Pam, the Coordinator, explains her current thinking about Barry this way: "We were projecting Barry's needs as we saw them. But they needed the opportunity to try it their way, and we provided the services and structure for him. It wouldn't have been fair to him or them to terminate services. Now they are asking us to find an apartment and roommates for him, so we will be working on that soon. We feel our work with him in his home over the past two years was positive and will help us meet his needs in the future."

Building Supports around an Individual

When a child or adult is being considered for the CAP program, the case manager meets with the family or the adult to define the services and supports the person will need. After acceptance into the program, the Plan of Care is developed to include specific types of supports for the person. Some limitations are imposed by state and/or federal Medicaid regulations (for example, transportation can no longer be provided through the program), and some types of services (for example, supported work for people with very challenging needs) are not available within the county. Notwithstanding these limitations, however, a high degree of flexibility is allowed and pursued by the program. The possibilities are communicated to the families or individuals to be served, who are heavily involved in the meetings held to develop the Plan of Care. Supports of many kinds are discussed and tailored to meet the individual's needs.

The supports designed for Barry can serve as one example. Everyone agreed that he needed support in his home so that his parents could keep their jobs and so that he could have positive experiences in the community. The young men hired to work with him in his home, Blair and Thomas, were very positive about Barry. They knew what to do when he became angry and destructive, but that was not the focus of their work with him. When I asked Thomas to describe Barry, he said "He loves basketball...more like a mixture of basketball and soccer. His favorite, though, is riding in the car...He loves pleasing those that are his peers, he loves attention, that's probably the best way to put it...He loves videos, he knows every word to every kind of video he sees on tv!" After he had spent several minutes describing Barry's likes and dislikes, Thomas got around to a short description of the ways Barry acts when he is angry or upset about something. Thomas was a young man hired to be on call, to come over any time Barry's parents called. For Barry, supporting him meant hiring people who genuinely liked him, and it meant building in many activities Barry enjoyed. It meant building in the capacity to have someone they trusted there when needed. It also meant developing a consistent way of being with Barry, and working with the whole family so that everyone understood. Finally, it meant going along with the family's wishes even when the "professionals" disagreed with them about what was best for him.

Individualized "Programming" in the home

The Parent-Caregiver Trainer's job is to develop individualized activities for parents, caregivers, and the person with the disability to carry out in the home. The activities I learned about were appropriate to the age of the person, and were appropriate to the situation in which they were engaged. For example, it was impossible for five-year-old Tony's mother to take him out in the community because he would kick, scream, scratch her face, and try to run away. With the Parent-Caregiver Trainer's help, the caregiver learned how to take him to the grocery store, to the park, to the clothing store, and to other community sites. These activities became part of his "program," as did eating at the table at home, folding his clothes, buttoning, and other self-care activities. After his mother developed confidence in the caregiver and in Tony's responsiveness, she also learned how to take Tony to the grocery store and other community sites.

In another instance, Gina, Deirdre's caregiver, spent her time assisting Deirdre to use the bathroom, to learn to sit and work on a task for a few minutes at a time, to say a few words and understand their meaning, and to play ball and engage in other outdoor activities. Gina introduced Deirdre to her sister, a typical child Deirdre's age, and helped them learn to play together. They became friends. Other than Deirdre's brother, this was the only typical child Deirdre had ever played with. Gina also worked hard to improve the relationship between Deirdre and her brother.

Contracting with Individual "Providers"

Most agencies solve the problem of staffing by hiring employees and deploying them in ways that meet the needs of the agency. The Wake County CAP MR/DD program, in contrast, provides support to individuals through contracts with people who are seen as self-employed. These caregivers are selected for a particular individual and are assisted in working with the individual and his/her family. Although they are not involved in the selection of the caregiver, families and individuals can turn to the case managers if problems arise, and can have a caregiver removed if they find they cannot trust, respect, or get along with the caregiver. In the three years of the program's existence, only one family has made such a request. In this instance, the mother, who was very poor, did not like the way the caregiver, a college student, looked and dressed, and the Coordinator worked with her to resolve the problem. That caregiver was still with the family at the time of my visit. The families and individuals I met unanimously appeared to be very pleased with the caregivers working in their homes.

Relationships

One of the most positive aspects of the program is the emphasis placed on positive relationships between case managers, caregivers, and the people they support. Relationships within a family are seen as important and are supported and encouraged as much as relationships between the caregivers or case managers and the family or individual. Pam and Ilean, the case managers, appear to have excellent relationships with the families and individuals. They and the families related many stories which incidentally revealed the high degree of trust and affection between them and the people with whom they work.

The caregivers are selected partly for their personal qualities, including their abilities to establish and maintain trusting relationships with the families or individuals they support. In describing her relationship with Shelly and her family, for instance, Kara said "Since Christmas, I've noticed that the older son thinks of me as part of the family. The other day he said, 'You might as well be part of the family, you're here every day, Dad might as well be your dad, and Mom be your mom. . .' Our relationship has grown, we're close and everything." Being such an intimate part of someone else's home can be very demanding, but the caregivers who do this under Wake

County's CAP-MR/DD program are encouraged and assisted to develop the kinds of positive relationships that make it work.

Attention to Issues of Cultural and Racial Diversity

Raleigh is a city of many races and cultures. As in any city, there are many upper, moderate, and low income people, and it has a high proportion of black people. Wake County's CAP-MR/DD program attends to the needs of these diverse groups in at least two ways. First, its hiring practices are sensitive to the needs of these groups: its staff members, Pam and Ilean, are black women, and many of the caregivers are black as well. Second, positive and respectful attitudes are promulgated among the staff. Pam and Ilean appear to understand and relate equally well to low-income whites and blacks and middle income people, and have worked for good matches between caregivers and families or adults living in their own apartments. These matches are not made by race--a number of black caregivers work in the homes of white families, and vice versa--but by other characteristics such as ability to communicate and respect between the parties.

"We ask ourselves, 'Where is this person?' I know I can't go into someone's home as superior to them." says Pam. "If I go in there acting like a middle class white social worker, it won't work. We get their background, the history of what's happened to them with other agencies. If it's been hurtful, and often it has been, we ask them not to compare or assume we'll be like the others. We ask them to give us a chance. It even extends to how we dress. If I'm going to a low-income home, I may wear my jeans. One of the mothers, a single mother, recently was talking to me just like she'd talk to one of her friends, telling me about her social life, and I thought 'well, this is good, she doesn't see me as a middle class professional.'"

Pam goes on to say, "Right now, we're having a harder time dealing with some of the upper income whites. It's racism, unfortunately--there's one family who will call and try to talk with my supervisor or another social worker here, who are white. This family has been treating the caregiver who works with their daughter as though she is their nanny, so we are planning to hire a white caregiver to work in their home. I hadn't seen this as a problem until recently, but it is one. With the lower income families, we've tried really hard to fit in, and it has worked well for everyone."

I explored some of these issues with the woman who had been the Wake County MR/DD Services Director during the time CAP-MR/DD came to Wake County. "We didn't really think it out ahead of time, we hired Pam for her qualifications and her values. Pam came to us with experience in another CAP program in the state. She wanted to move to Raleigh, and we had just received approval to begin our program. I had met her at conferences, and I knew she was excellent. After she came on as Coordinator/Case manager, people in her network of friends and acquaintances heard about and applied for the positions that were opening up. Many of the independent contractors are people in her network. I think that the reason so many of the people she has hired or contracted with are so good has to do with Pam's values. The Church in the black community is very strong, too, and emphasizes values and service, and this has had a positive impact on human services."

Program Limitations

The most noticeable limitation of the program is that, for basic services such as preschool and adult day services it often works with what already exists in the county. For example, if a sheltered workshop or a segregated preschool (serving only children with disabilities) is the only agency that will agree to serve a person (or, if the parents or guardians insist on such a setting), then services are created there instead of in an integrated setting where people without disabilities work, learn, or play. The program philosophy, however, values integration, and agencies offering integrated services are usually approached first.

The fact that segregated services still exist in Wake County is an issue for Wake County MR/DD Services to continue to struggle to resolve; it definitely impacts on the people served by the CAP-MR/DD program. To its credit, Wake County MR/DD Services is pushing for both its preschool and adult services to move toward integrated settings, and is achieving success, especially in the preschool area.

Although Wake County is moving in the direction of greater individualization and integration in more of its service settings, it still has a way to go. Old ideas (for example, that people need special schools or special residential programs) do not disappear overnight.

Another program limitation has to do with the fact that for some individuals, even with the flexibility built into CAP-MR/DD, the program had not yet resolved some significant problems. Program staff and families were struggling to meet people's needs but did not have the resources with which to do so. In some cases, an outside consultant might have helped to provide better ways of serving some individuals with very challenging behaviors.

Another limitation is common to most service agencies across the country, and is something that many people in the field are just beginning to struggle with. While Wake County's CAP program places much emphasis on quality, respect, meeting needs, and other values having to do with caring and service, less conscious thought is given to the need by individuals and families for relationships with typical community members who might already be or who could become involved in some way in their lives. Some questions the program could consider include: What is the role of paid professionals in promoting relationships between the people they support and typical people in the community? Can paid people support relationships so that they have a chance to become stronger? Can they do this without getting in the way? While I saw much evidence that program staff and caregivers believed in the importance of community ties (for example, Rachel goes to church with Anthony and his family so that Miss Lillian can sing in the choir) and friendships (e.g., the friendship between Deirdre and Gina's sister that was fostered by Gina), I did not hear these beliefs articulated as part of the program's value system. The program might benefit from ongoing discussions of these issues.

Another limitation has to do with restrictions in what can be purchased with program funds. For example, Jan lived with his family in a rural area where the public transportation system serving people with disabilities did not go. CAP-MR/DD had been paying for his transportation by taxicab until the state office ruled that transportation costs could no longer be purchased with CAP MR/DD funds. For a while, this worked out well for Jan, because his CAP case manager found a woman from his area who was willing to drive him into Raleigh and drop him off at his work site, a sheltered work program. After several months, however, she was laid off and no longer drove to Raleigh. Jan was not able to get to work, and his case manager was trying to find other ways to meet his need to have meaningful activities during the day. If the program could be supplemented by state dollars, serious problems such as this could be avoided and the program could more fully meet its goals.

A final limitation has to do with the fact that the available money is divided into "slots" with an expenditure ceiling for each "slot." Some other states' Medicaid waivers are more flexible in regard to these financial issues. The "slot with a ceiling" restriction plays itself out as follows in Wake County: people with developmental disabilities who need services that would cost substantially more or less than $19,382 a year are not accepted into the CAP program. This means that people with higher service needs might still be institutionalized, although that had not happened for two years prior to my visit. Those with lower service needs might be placed on a waiting list or in community settings that are less integrated and less individualized than those provided through CAP MR/DD. While change in the "slot with a ceiling" restriction would not correct all the problems in the system, it would allow greater flexibility in serving those deemed eligible for the program.

Conclusion

Wake County's CAP-MR/DD program is one example of a creative approach to use of the Medicaid waiver. Other examples also exist in North Carolina, but were not visited by Center on Human Policy staff. The program uses some promising approaches in supporting individuals and, usually, their families, including responsive case management, a focus on the family or individual, an emphasis on relationships, building supports around the individual rather than forcing the individual to fit into a program, and attention to cultural and racial diversity. The people receiving services presented real challenges to the system of services, whether behavioral or medical, and need a high level of support to remain in the community. Wake County's CAP MR/DD program provides the support they need.

For more information please contact:

Pam Flowers
Wake County MR/DD Services
3509 Haworth Drive, Suite 105
Raleigh, NC 27609
(919) 755-6456