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ABSTRACT

The site visit report describes the Family Support Services program run by the Calvert County (Maryland) Association for Retarded Citizens. The program's goal is to prevent any person 21 years of age or younger from being institutionalized. It provides respite care services, specialized family support, and integrated day care for approximately 50 persons with developmental disabilities and their families. The specialized family support component attempts to help parents obtain any service or piece of special equipment which the family sees as needed to maintain a disabled member at home. Among services provided to families are provision of respite care in either the family's or provider's home, provision of respite care at the integrated day care center, parent counseling, a parent support group, financial support, and information referral and coordination. Cost information is provided. Agency concerns include identifying the best ways to help a family, maximizing resources, agency image problems, and maintaining flexibility. Issues identified by parents include the mother's role in families, conflicting interests, the costs of maintaining a disabled child at home, the sometimes unexpected duration of parental care responsibilities, and the lack of summer programs. Program success seems to be the result of committed leadership, philosophy, small size, commitment to integration and family life, and the parents themselves. (DB)

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Center on Human Policy

SITE VISIT REPORT

CALVERT COUNTY, MARYLAND ARC

FAMILY SUPPORT SERVICES

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Site Visit
to
Calvert County, Maryland ARC
Family Support Services

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This is one of 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 for integrating people with disabilities into community life.

Site Information

Program Name: Family Support Services

Agency: Calvert County (Maryland) Association for Retarded Citizens

Address: Calvert Executive Plaza
P.O. Box 1860
Prince Frederick, MD 20678

Phone: (301) 535-2413

Contact Person: Ms. Kimberly Gscheidle

Summary Description: The intent of this program is to prevent any person 21 years of age or younger from being institutionalized. The program provides respite, specialized family support, and integrated day care to approximately 50 people with developmental disabilities and their families. The specialized family support component attempts to help parents obtain any service or piece of special equipment which the <u>family</u> sees as needed in order to maintain a disabled member at home.

Background

Context of Visit

Prior to the visit, I had spoken with Ms. Gscheidle twice, and she sent me a packet of materials to review.

In March of 1986, I discussed the program with Mr. Jerry Kiracofe, then Director of Calvert County ARC, who was also Director at the time the project began. In addition to the materials mentioned above, he sent me a set of statistical tables from the second year report on the project compiled by the Kennedy Center in Baltimore.

Materials I reviewed included:

Back issues of the Calvert County newsletter
State regulations on Family Support Services
A global description of the CARC
Specific descriptions of other CARC programs such as
  S.O.S., Residential services, educational services,
  and the Respite/day care project
Materials from the state of Maryland about Calvert County

Calvert County

Calvert County is a rural area located on a peninsula in Chesapeake Bay. Major industries include tourism, fishing, and the nuclear power plant. Prince Frederick is the largest city and the county seat. The entire county has only 34,000 residents. The median household income is $27,665--nearly identical to the Maryland mean and above the U. S. mean. There is no public transportation in the county. There is only one major highway, which runs north and south across the county.

Calvert County ARC

A chapter of the Maryland ARC, CARC operates a variety of services: residential, vocational, respite, family support groups, recreation, etc. CARC is staffed with an Executive Director, and Director of Residential, Vocational, and Family Support Services, as well as clerical support personnel. Most of the staff are involved in normalization and PASS training at various levels.

Vocational Services.

CARC operates Calvert Diversified Services (CDS), a sheltered workshop in an old hospital building. Contracts include crabpot manufacture, furniture refinishing, and a professional cleaning work crew in the community. Previously CDS also operated a lawn work business. This project has been "spun-off" to a new provider, who retained the CARC employees, some in supported employment and some as full-time employees with benefits. A total of 52 people currently work in vocational programs.

Residential Services.

CARC owns eight residences (all HUD funded); four of the homes serve 4 people each, and four other homes service 3 people each. Five of the homes were bought, and three were custom built to be accessible. None of the homes use ICF/MR money. No children in the county live in group homes. Only family and foster homes are offered for children.

The state had planned a 114 bed ICF to serve people from a three county region with severe and profound mental retardation. Calvert County and one of the neighboring counties asked for the money to be spent in the community, specifically to return people to the community from institutions. The county was successful in getting the state to build a smaller facility, and to redirect some of the other money into the community. Ultimately, the funds that would have been the equivalent of constructing 9 of the "beds" went to community care in Calvert County. Additional funds for 12 more "places" went to neighboring St. Mary County. The counties had successfully reduced the planned size of the institution by 21 places, and diverted that money directly into the community.

Calvert ARC seems dedicated to small homes, but according to the ARC Director and the Director of the Family Support Project, the state is pressuring Calvert to add people to some homes--make them bigger--to be more cost effective. For example, many people in the county are currently living in groups of three people. The state would like to see them move into clusters of four.

Family Support Services

Involvement with families.

The staff at Calvert County ARC are always conscious of the fact that different families have different needs. In response to this recognition, CARC provides service to families on an "as needed" basis. In terms of frequency of contact, families seem to fall into one of three categories.

1) <u>One time or time limited intervention</u>. Someone comes in for help, they get it and they leave. "Someone has a vision problem," the director says, "we get them the specific services they need, they are 'cured', we may never see them again."

2) <u>Come and Go</u>. These are families that do not need the day to day intervention that other families do, but their need does not go away. For example, a family with a child who needs adaptive equipment. They get set for a while, then the child's needs change, or they out grow the equipment, and they return for more help. In between time they are quite independent. Such a family will have little or no contact with project staff in between time.

3) <u>On Going Need</u>. These families are in regular contact with project staff, and receive a variety of services regularly from financial support, to respite care, to just a friendly person to discuss problems with over a cup of coffee. With these families, if for some reason CARC were to pull out or disappear, it would precipitate a family crisis. This in fact will happen to some families soon when their child turns 22 and they no longer qualify for the service as it is currently offered. CARC has anticipated this problem, and is currently working with the State of Maryland to re-write the legislation under which they operate. Under the proposed legislation, the state would provide "Family and Individual Supports" to adults as well as children.

Regardless of the frequency of the service needed, CARC sees three global benefits to the program:

1) <u>To prevent out of home placement</u>. Many families that might have felt pressure to seek an out of home placement for their son or daughter feel that the added help from CARC has given them the ability to keep the child home for as long as that seems appropriate.

2) <u>To postpone out of home placement</u>. Other families still say that someday they may need an out of home placement for their child, but that the financial, practical and emotional support offered by the project has postponed that decision for the time being.

3) <u>To make life more pleasant while a family waits for an out of home placement</u>. One of the parents I interviewed told me quite frankly that she and her husband were now actively looking for an out of home placement for their daughter. They acknowledged the work of CARC, and stated that they would not have been able to manage for so long without the support. However, they felt that now it is time for their daughter to move to a residential program.

<u>Major types of service</u>.

As a part of the family support services, CARC operates several types of services to meet families needs.

1) <u>Companions come to the family home</u>. In this type of respite, a worker comes to the family home to provide respite and personal attendant assistance. Most of the families have a regular structured amount of in-home respite, such as 20 hours per week. However, this support is also available on an "as needed" basis for specific situations.

2) The child/adult goes to the respite worker's home. In other situations, individuals have agreed to provide respite care for families, but prefer to work in their own homes. Many parents who receive in-home supports point out that your home is always occupied by others, and you lose a sense of privacy. By offering families respite services in another home, families can stay at home for some privacy, or can go away from home knowing that their child is in a caring environment.

3) Respite at the integrated day care center. CARC operates a day care center for the children of their employees. They feel this is part of being a good employer. They also reserve six "slots" at any time to be used by children with handicaps and families in the family support program for a "drop-in" respite center. Parents are expected to call first to make sure that there are not already six other handicapped children there. Non-handicapped siblings are invited as well.

The center is located in a "typical" split level home in a suburban neighborhood. The top half of the house is a rental apartment, rented to a staff member (to defray costs), and the bottom half is the drop-in center.

The staff and parents list a number of positive aspects of the respite center:

* it is parent-need responsive
* it is cost-effective
* it is integrated
* it makes a difference
* it is a good environment for all the kids who come

They were also quick to point out a problem. Ms. Gscheidle says, "the 'theme' is still that the ARC does it." That is, ARC is still seen as the agency responsible for giving families the chance for integrated day care. She would prefer to get generic child care agencies to pick up the project. However, there is the nagging fear that the generic agencies will not do as good a job and will not accept assistance from the ARC.

The original purpose of the respite programs was to fix a crisis. When a family had a problem, CARC would provide respite. They realized that once the family is at the door with a child and a problem, it's <u>too late</u>. More recently, the emphasis has been more on proactive interaction with families to prevent crisis, rather than to try to deal with it after it occurs.

4) <u>Parent Counselor</u>. Essentially, the family support services to an individual family are coordinated by the parent counselor, that is, a person who is herself the parent of a child with a disability who works as a counselor for the project. Most of the parents say they have found it easier to communicate with another parent. "Not that our professional staff are not nice people," one mother told me, "but they are not parents."

According to the project director, "We try to cultivate an image of the Parent Counselor as more of an advocate and a friend, not a professional staff member." A major part of what the counselor does is to check in with families as frequently as needed. Some families may require daily contact during periods of stress.

5) Parent support group (Share Our Support). S.O.S. is a parent group that currently involves some 40 families, although not all of them come to every meeting. Although the group is not officially a part of the ARC, CARC staff support the organization by doing periodic mailings, and "networking" for them. S.O.S. is an advocacy group and feels that it is important that there be some distinction between the two.

S.O.S. has a coffee and conversation meeting about once a month, and the ARC provides a guest speaker. They make sure that the speaker limits their remarks to 30 minutes to provide plenty of time for discussion. The rest of the time is spent on questions and answers, and informal socializing.

6) Financial support. For many families, the extra costs involved in supporting a child with a disability can be a major force for an out-of-home placement. CARC offers financial support to families who are interested in keeping their children at home. Based on financial need, families can be reimbursed for up to 100% of the costs of the disability-related expenses of items ranging from adaptive equipment to diapers. Most of the families in the CARC program receive 80-100% reimbursement of eligible costs.

7) Information referral and coordination. Many of the families that come to CARC for help need information as well as services The CARC staff provide information about educational rights of children with handicaps, referral to existing services, and coordination of the various services being used. By giving

information, referral, and coordination to existing services, the project saves its own limited resources, and involves the family in more generic services in the community.

Cost information.

For all the services the project offers, the budget is quite small. This year their total budget is $113,000. Of that, some $32,000 comes from the Maryland Family Support Program. The balance is supported by the agency which is funded in part by the United Way and the county. They also receive $15,000 from the Department of Human Resources for respite services.

Families do make a financial contribution toward the services they receive, based on their ability to pay. The respite workers are paid from $3-5/hour, and the family pays part of the cost. Families pay for services on a sliding scale. Most of the families in the program have low incomes so they do not pay any of the costs. The same holds true for the financial support. Families receive assistance in paying for diapers, medicine, and the like. The family buys the supplies, and they are reimbursed for up to 100% of the costs.

At the drop-in respite program there is only a cost to the families who use the service for full-time child care. There are only two such families, and they each pay only 20% of the cost. The families who use the center on an intermittent basis pay nothing for their handicapped children or the nonhandicapped siblings who are welcome. Part of the cost of the center is subsidized by fees charged to the employees of CARC who use the center as a day care center. They each pay $30/week to use the program. This serves to integrate the program, as well as to reduce costs.

Major Issues: Agency

1) Making a Difference

"We ask ourselves, 'What would make a difference for this family'? and then we find a way to do that." This is the director's philosophy. But, she says there are problems: the first, the obvious, is the real limit of resources--money, time, staff energy. She admits that there are practical limitations to the philosophy of "what ever it takes." Also, she is afraid that if the agency does too much for a family, that may in fact "create dependency" as she says. By this she seems to mean that the agency and staff need to help people as they need it, but to do so in ways that respect and empower the family rather than take over for the family. She is quite clear that she does not want any family to go without assistance just because they fear that they are asking for too much help. A third potential problem she raises is a concern that the "specialized " service provided by the ARC may keep people away from more "generic" forms of assistance. If the ARC does things for the family, she fears that the family may become isolated from these more generic services which in the long run offer greater participation in society at large.

2) Maximize Resources

Although they did not seem to have an articulated plan, there is a procedure in place to maximize resources and to decrease any dependency. The first response to "What will make a difference?" is to look to other programs--federal and state programs (Medicaid, food stamps), charities, etc. In this way, the family services project functions as a referral and coordination agency.

If the agency cannot get another agency to do what is needed, or pay for it, CARC will. Their priorities, however, are to get people involved in the community, to get the benefits they are entitled to, and as a last resort, to use CARC resources to help them.

3) Image Problem.

Both the project director and parent counselor mentioned a problem with the fact that the family services project in this county is operated by the ARC. They say that many parents of non-retarded but severely handicapped children will not want assistance from a mental retardation organization. At the state level, a new organization, NRDD (Non-Retarded Developmentally Disabled), has developed in response to the fact that the office of MR/DD has focused so much on MR.

The days I was visiting, a referral was in process from a local hospital. The professionals and the parent counselor made sure that no one "got around" to telling the family the name of the agency yet. They wanted to have a bit more time to "sell" the program before the family found out about the retardation connection. I was told that this was not usual procedure, but that people at the hospital who referred the family said that they were very adamant about avoiding an "MR" affiliation for this family. "I know of at least one family right now that needs our services but won't come to us because of the retardation affiliation" a staff member said.

4) Being Flexible: Doing Whatever It Takes

With one family, the issue was the wheelchair. The medical insurance program would not commit up-front whether they would pay for the chair or not. They needed a diagnosis, a recommendation, and the cost in advance, then they would consider payment. The wheelchair company does the assessment, diagnosis and recommendation as a part of the service, and does not commit to a cost until all the work is done. They also require 50% of an estimate in advance. The estimate was for $5,000, and the family was expected to pay first and get insurance reimbursement later. There might have been no chair without up-front money from CARC. The family did get reimbursed for most of the cost. They reimbursed CARC so the money could be "reused" to help another family.

In another family, the child had retinitis pigmentosa, and needed an expensive optiscanner to keep up on his school work. CARC approached several foundations, and put together $6,400 for the machine. Staff time and legwork got the job done, without an expensive purchase.

5) The Future

"We realize that some day our group homes will become community institutions," Ms. Gscheidle says, "and we need to plan now for that day". This clear understanding of progressive change seems to be a major strength of this agency.

6) Advocacy vs. Service

Kim has a strong tolerance for advocacy, and is a strong advocate for integration. She has a real interest in the agency doing more advocacy, and less service provision. This too seems part of the vision.

7) What do you do when all you can do is not enough?

Right now, CARC would like to stick to family support services, and not offer group homes for children. However, the director says "we are losing kids..." When family supports are not enough, kids go to group homes, all out of the county and all "large"--four to five or more. "Maybe we should explore some two person group homes."

She has also been exploring other new service ideas. "Maybe we should subsidize live-in nannies for about $150 per week."

"So far we have never said 'no' to anything. Someone has to think about what to ask for...what is needed."

Major Issues: Parents

Through discussion with staff and five families, several issues/patterns emerged.

1) The mother's role in families. "Dads wear out; Moms aren't allowed to" said one mother. She explained that while Dads may begin by being interested and helpful, they soon wear out, give out, and/or leave. For each family I reviewed, Moms were the primary contact, not just for my interview but for the agency also. In each family, the mother clearly fulfills at least two roles: primary caregiver/nurturer and what could be called "unpaid case manager." The mothers I interviewed spent a great deal of time and energy coordinating benefits, services, activities, and people involved with their sons and daughters.

2) Conflicting interests. Several families pointed out dilemmas that can only be described as intra-family conflicts of interest. "Since she has been getting a high calorie bollus through the G-tube, she gained 15 pounds. The doctor is pleased, but I can hardly lift her now." Often what is good for the child means more work for the family.

3) Basic needs can be expensive. Each family but one mentioned the costs involved in the daily needs of their sons and daughters; costs which other families do not experience at all or experience for a shorter time or to a lesser degree. The most common example was adult size diapers. After about 50 pounds, needs can no longer be met with "grocery store" diapers. Brand name adult diapers, "Attends" and "Depends", cost a great deal more. Some families spend up to $100 per month for diapers.

Other expenses include seizure medication (three or four prescriptions for some). Surgical tubing and Betadine for people using G-tubes are cheap--unless you use them several times a day, year after year. One family I visited spends $185/month on diapers and medication. They say that without the financial support from CARC, they could not afford the "luxury" of keeping their daughter at home.

4) Unexpected duration. No one wants their child to die. Many families were told that their child would live only six months to a year. On that basis, they made a decision to do all they could for the child and to literally center their lives around the child. In many cases, this mental, emotional, physical, and economic commitment for a year has continued for up to 16 years. This is far more than many had been led to believe at the time they made a family decision to keep the child with a handicap at home.

One mother said "She's 11 now, and they said she would not make it a year. I remember the night the doctors gave up on her and said that there is nothing else to do." As in the conflicts mentioned above, the families are thankful for the health of their children, but the rules of the game have changed. The same mother reflected on a time a few years ago when the family discussed the possibility of her daughter moving out. "We all discussed it, my husband, my son and I and we really all decided--and my son was really involved--we decided that we are building our lives around her. She is so rewarding...the more love you give to Pamela, the more she gives you back."

Another mother tells a story about when she adopted her son with a degenerative condition. At the time he was a foster child, and she was told that he would not live out the year so he was to be placed in an institution to die. That prompted the decision to adopt him, and now 4 1/2 years later she says "He's still alive, he is much heaver, and much harder to care for."

5) Summer. Every family expressed problems over the summer. As school lets out, the family suddenly must fill an additional six to eight hours in their child's day. CARC operates a summer program, but even with that, there are several weeks between the time school ends and when the summer program begins and again between the end of the summer program and the return to school. Children and adults seem to find this a difficult time.

6) "Professionals are good...but a parent is really helpful." Parents were all thankful for the role played by the good professionals in their lives, but mother after mother mentioned the special relation-ship with the various "parent counselors".

7)"Parents Need All Kinds of Help." Some parents need help in lifting and transferring their children. Others need training on how to do the lifting and transferring themselves without getting hurt. One family had to drive to Baltimore to the Children's Hospital quite often. The travel expenses were a burden, and there was a risk that needed medical treatment would be stopped because the family could not afford the gas. CARC now pays the mileage, and the family does the rest.

Conclusions.

This program has several major goals, and it seems to be succeeding at each of them. There is clear evidence that the existence of these family supports prevents or postpones out of home placements for children with disabilities, and that the quality of life is enhanced for families even if they are waiting for an out of home placement. It is difficult to pinpoint the reasons for the success of the project, but based on my visit, there seems to be an interaction between several factors:

1) Committed leadership. The state has a commitment to family supports (even though their financial contribution to this agency is modest), and the CARC staff are clearly dedicated to assisting families in the ways that families say they need to be helped.

2) A philosophy of "whatever it takes." This is not a program limited to one or several forms of support. Although CARC offers the most common category of family support, respite, this is clearly not just another respite program. Families get what they need whether it is information and referral, a friendly ear to chat with, or financial support. A clear priority is placed on what the family sees as the need.

3) Small size. One might be tempted to want to expand the Calvert County Project and have these same staff members support a greatly expanded number of families. After all if they are doing so much good now on such a small budget, why not triple their size and help three times as many people? Quite frankly, I do not think it would work. As I discussed the project with the

parent counselor, the project director, and even the executive director of the CARC, it was clear that they really knew about the families that they were supporting. Everyone is on a first name basis, staff could give me addresses and phone numbers from memory, and there was a sense of teamwork between the families and the staff which would be lost in a larger agency.

4) A commitment to integrated community and family life for everyone regardless of their level of disability. There is no need here to discuss questions that seem to plague other projects. No one questions if children are be better off at home, rather they ask themselves how they can improve the life at home. No one asks if there are some kids who will need institutions or group homes, rather they say that children belong with families and ask how they can keep each child with the family. This commitment clearly contributes to the success of the project.

5) The parents themselves. CARC works with the families and provides support as needed, but the prime responsibility still lies with the families. As one parent put it, "The ARC provides the material things." Even though she needs a great deal of financial support, she has her priorities elsewhere. She says "My heart rules me...money does not buy the things I want out of life. You can't buy a child's life, you can't buy that child's smile to have a family. There is no price tag on that." By removing or at least softening the financial pressures on the families, CARC frees up the family to concentrate on their lives as a family, and as members of neighborhoods and communities.