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ABSTRACT

Special Training for Exceptional People (STEP) is a private, nonprofit agency serving children with developmental disabilities (0-22 years) and their families in the south-central section of Montana, encompassing Billings and a Crow Indian Reservation. One of the services provided by STEP is specialized family care, to prevent placement out of family settings for children with intensive needs and to create movement to family settings from more restrictive environments. Program services include home training; in-home assistance; contracted services (occupational therapy, physical therapy, speech, etc.); architectural modifications; adaptive equipment; foster care; and extended respite. Case profiles demonstrate utilization of each of the types of support services by the 51 children receiving family training and support services, including 3 Crow Indian children. Issues in providing family support on the Indian reservation are discussed, such as the poverty level, distance from Billings, and the need for cultural sensitivity. Strengths and limitations of the program are outlined. (JDD)

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REGION III: SPECIAL TRAINING FOR
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FAMILY SUPPORTS IN MONTANA: REGION III: SPECIAL TRAINING FOR EXCEPTIONAL PEOPLE (STEP)

INTRODUCTION

Special Training for Exceptional People (STEP) is a private, nonprofit agency serving children with developmental disabilities (0-22 years) and their families in Region III in the State of Montana. This region contains eleven counties covering approximately 140 square miles in the south-central section of the state. Other than the city of Billings, with a population of nearly 70,000, the area is predominantly rural, with small towns and hamlets scattered throughout it. A Crow Indian Reservation lies in the southwestern part of this region.

A program description states that the "major thrust of STEP is to prevent institutionalization of children who are developmentally disabled by providing community-based programs, services, and public education." The objective is "to maintain children in their natural or foster homes and to nurture their positive growth and independence within the family."

There are four major types of services provided by STEP: (1) family training and support; (2) respite care; (3) specialized family care; and (4) children's group homes. This case study focuses particularly on the specialized family care (SFC) program, as well as the family training and support services provided on the Crow Reservation in this region. It is based on a site visit to STEP between July 20-24, 1987. The information contained in this report reflects observations of the program as it was at that point in time, and not any changes that may have occurred since then.

THE SPECIALIZED FAMILY CARE PROGRAM

Introduction

The purpose of the specialized family care (SFC) program is "to prevent placement out of family settings for children with intensive needs, and to create movement to family settings from more restrictive environments. This program offers a wide range of services, including: home training (home teachers), in-home assistance (habilitation aides); contracted services (occupational therapy, physical therapy, speech, etc.); architectural modifications; adaptive equipment; full-time foster care; shared foster care; and extended respite. Supports are funded through both the Medicaid waiver and state dollars. To be eligible for this program, a child must be 0-22 years old, labeled developmentally disabled, and determined to be "at risk of institutional placement." A child can be considered "at risk" due to a number of factors, such as: severe or profound mental retardation, including deficiencies in self-care skills; significant maladaptive behaviors; or severe medical/health problems. Even if a child does not meet these more specific diagnostic requirements, he or she may be considered "at risk" due to "environmental" factors, such as a stressful family situation. A state committee makes the final eligibility determinations. As of July 1987, STEP served 16 children through the SFC program. There were 73 "slots," statewide, for SFC. According to state regulation, the average cost for each family cannot exceed 80% of the average annual group home cost per child in Montana, which is $25,000. In Region III, the average annual cost per family for SFC supports is $10,400, significantly below the 80% figure of $17,000.

One child who receives supports through the specialized family care program is Tim*, who is 9 years old and lives in the Billings area with his parents and younger brother and sister. He has cerebral palsy and severe mental retardation, uses a wheelchair, and needs assistance in most daily activities and routines. According to a staff member, his family was considering out-of-home placement, but as an alternative decided to keep him at home with support from SFC. A "habilitation aide" comes to the home 15 hours per week (3 hours a day, 5 days a week) to help provide direct support to Tim and his family. She is at the house when Tim comes home from school. While there, she assists Tim with some self-care routines (i.e., bathing), the development of increased communication skills, and other activities. For example, when he has an after-school snack, he helps to feed himself. She assists him to use the direction of his eye gaze to indicate either "yes" or "no" responses. This support person stays through the family dinner to assist Tim with eating.

Once a week, a "home teacher" comes to Tim's house both to discuss any concerns with his parents and to observe and give assistance to the direct support provider if necessary. Tim's family can use up to 48 hours of respite per month (it can be used by the hour, or by the day); they choose to have the "hab aide" provide this respite. The family enjoys going for evening bike rides. Tim can now join them, since through STEP they have acquired a cart that attaches to the back of a bike.

From the perspective of Tim's parents, the family benefits from the SFC program in a number of ways. Tim's mother commented that, "With the hab aide

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*All names throughout this report are pseudonyms.

helping Tim with things like feeding, dressing, and bathing, this way, I have more quality time with him." The support from SFC allows him this time to himself. Respite support gives Tim's parents the opportunity to take his brother and sister places that Tim either does not enjoy or is not able to go to--such as a day at the rodeo. And, adaptations, such as the bike cart, give Tim the chance to join family activities in which he could not previously participate.

Another family who receives supports from the SFC program are the Martins. Joanne Martin is an 18 year old woman who lives with her father for two weeks of every month and in a foster home for the other two weeks. She is labeled mentally retarded and has severe cerebral palsy and a hearing impairment. According to a staff member, when Joanne's parents lived together her mother provided nearly all the care for her due to her father's illness. Her parents have now separated, but her father's health has improved and Joanne lives with her father while her sister lives with their mother. Joanne goes to school during the day, and will continue to do so until she reaches the age of 21. When she is with her father, a hab aide comes to the house several hours per week to spend time with her. Joanne's father talked about his preferences in terms of hiring hab aides, saying that "past experience is good, but I also go with my gut feeling about people, and whether they have a sense of excitement about being here."

There are a variety of types of adaptive equipment in the house that have been provided through STEP. These include remote control for the television and lights, a special blender to blend food for Joanne, close captioned television, and a special communication device called a "communi-clock." With this, Joanne can push a switch, which moves a clock like hand in a circle until it is pointing to the word she desires among several words placed around the perimeter of the clock. Some of the words on Joanne's clock now include: Dad, Mom, eat, school, like, want, and so forth. Joanne is also learning sign language at school, and her father and the hab aide are both learning it too. On weekends, Joanne and her father go out often. As her father described, "We go to baseball games, camping, shopping, I get season tickets for us for hockey..." And, even though neither Joanne nor her father knows a lot of sign language, he talks about their ways of communicating with each other. "Joanne has certain things she likes. She'll let me know what she wants and what she doesn't want."

For the two weeks out of the month that Joanne is not with her father, she lives with a foster mother and that woman's daughter. The daughter is hearing impaired, so the mother already knows sign language. She also works part-time as an aide at Joanne's school. Joanne and her father were both involved in meeting with this foster parent as part of the selection process. Her father was particularly pleased to find someone who lives nearby, three blocks away. When asked if he thought the moving back and forth was disruptive for Joanne, her father suggested, "I don't think it is...I think it gives her the same thing it gives me...a break, a chance to be around different people." And, in terms of future living arrangements, Joanne's father commented, "I'd hate like hell to put her in a group home, but I suppose that's where she would go if she left here. But with the situation as it is now, there's no need for her to move."

Types of Supports Provided by STEP

Families who are part of the SFC program are eligible for a number of different types of supports, including: in-home training, in-home habilitation assistance, foster care, respite, and in-home adaptations. Families who do not qualify for SFC receive more limited types of support such as in-home training and/or respite as well as some other types of assistance and support, but not in-home habilitation. Each of the types of support is described below.

In-Home Training

All families who are in SFC are eligible for family training and support. As the primary part of family training and support, home teachers provide training in the home to assist the family in supporting their child. In working with the family, state regulations for the program spell out the necessity to include both "family-focused" and "child-focused" objectives. Family focused objectives are aimed at "enabling family members/caregivers to function as independently as possible in providing/obtaining services, so the need for support services is eliminated." The child-focused training should enable the "family/caregiver to conduct specific interventions (educational, behavioral)."

According to staff members of STEP, the state Division of Developmental Disabilities places a primary emphasis on "skill training" for families. However, staff maintain that "some families don't want that, they can't deal with it right away, or they don't need it, they just need service coordination." The state does allow for a small percentage of families in the program to go without skill training; current state regulations mandate that 90% of the families served by STEP must have skill objectives. This set percentage does not totally solve the problem, and staff still face dilemmas over having to create skill objectives for families who they feel really do not need them.

Home teachers typically have backgrounds in early childhood education, child development, rehabilitation, developmental disabilities, or behavior analysis. An agency staff member indicated that it is preferable, though not mandatory, that home teachers have a Master's degree. Also, they must demonstrate the ability to write behavioral objectives, do task analyses, and develop teaching sequences. She said it is difficult to find people with a background in education since the pay is not comparable to what they can earn in schools. Home teachers generally are in contact with anywhere from about 8-12 children and their families. If the children are in shared foster care arrangements, this involves contact with both the foster and natural families.

In addition to home training, home teachers offer much more to families. They provide case management and information and referral services, including coordination with schools and other agencies, information about adaptive equipment, training materials, and supportive counseling. Family training and support services also include a lending library of resource materials and educational toys. Parent support and training groups are formed from time to time, based on request.

Some families receive only home training, and are not part of the SFC program. To be eligible for this service if they are not eligible for SFC, a family must: (1) have a child 0-18 years with developmental disabilities; or (2) have a child 0-5 years old who is considered "at risk" for developmental disabilities. "At-risk means a child who is birth through five years of age who may become developmentally delayed or developmentally disabled due to an established developmental risk, an environmental risk or a biological risk." This "at risk" designation provides significant flexibility for the agency to serve families with young children who would not otherwise be eligible for support. For example, one of the home trainers is providing training to a married couple with developmental disabilities who are expecting a baby. Because the prospective parents have disabilities themselves, the child was considered "at risk" and home training was begun even before the birth of the child. As of July 1987, this program, which is state funded, served 51 children in both natural and foster families. The statewide average annual costs for this service equal approximately $2,800 per family.

In-Home Assistance

"Habilitation aides" provide direct in-home assistance to families in the SFC program. Families can hire/fire the hab aides, although they are considered contract employees of STEP. They spend about 15 hours per week with the family, typically something like 3 hours per day, 5 days a week. The habilitation aides generally have some training in areas such as developmental disabilities or rehabilitation, but this is not a requirement. Families participate in the selection of hab aides, and this person could be someone the family already knows, such as a friend or a neighbor. For example, in Tim's case, the family asked a neighbor to be the habilitation aide, a woman who knew the family and had previously babysat for the children. In another case, Greg, who is 16 years old and has muscular dystrophy, and his mother both make the decision about hab aides for him. Greg's mother talked about his involvement in hiring the hab aides, explaining, "They are his hands and feet." She mentioned some characteristics she looks for in hab aides. "They must be flexible, and willing to do things with other teenagers in the neighborhood, not just Greg...I want someone who is young enough, and has enough energy to pile in the van with a group of six teenagers and go do something...Greg needs to do things with other kids, not just his mother or a hab aide alone." She talked further about some of the types of things the hab aides did with Greg. "They do things that I wouldn't do, like going roller skating. Also, things that are part of being a teenager that mothers don't necessarily approve of and wouldn't help their children do. Greg want with one hab aide and 'burned the point,' hot rodding around in their cars at the local teen hangout. You have to let go, and give him a chance to be a kid, and do things regular kids do."

The only required training for all hab aides is in cardio-pulmonary resuscitation (CPR). Aside from this, all other training is geared to the needs of the specific child that he or she will be working with. Home teachers may do the training of the hab aide. However, one staff member indicated that "In many cases, the parents do the training of the hab aides."

Foster Care

As part of the SFC program, STEP offers different foster care options, including full-time foster care and shared foster care. Currently, of the 16 children in the SFC program, three are in full-time foster placements and six have shared foster care arrangements. One staff member commented that, "Shared foster care is becoming the most popular option." She said this option usually involves the child spending from two to five days per week out of the natural home and in a foster family home.

Foster families are recruited by the posting of leaflets in various human service type offices, such as visiting nurses and welfare, as well as through ads in the local newspaper. Applicants are interviewed by an agency staff member as part of the selection process. Also, natural families participate in the selection of foster families for their children. Some families have requested shared foster care for weekends-only; however, the agency finds it most difficult to find foster families who are willing to do this.

The maximum rate paid to foster care providers is $900 per month--which includes $400 from SSI and up to $500 from the specialized family care program. This amount beyond the SSI varies based on the needs of the child. Some agency staff members suggested that this rate is inadequate, particularly for children with severe disabilities. For example, one staff person talked about a nurse who is a foster parent for Vicky, a child with severe and multiple impairments, who needs tube feedings and other medications and treatments throughout the day. The staff member commented how the pay equalled "less than $2.00 per hour" for this foster parent.

After they are recruited, foster parents are given a foster parent manual, which includes lists of community resources, and an orientation to the STEP foster care program. This orientation includes information on the organization of STEP, description of their duties as foster parents, program policies (i.e., client rights, aversive procedures policy), information about pay and benefits, instructions about record keeping (medical, training, behavioral, etc.), and review of emergency procedures. All foster parents are required to get CPR certification. The agency will also contract with consultants to provide any specific training in physical therapies, and the like.

A staff member from STEP who is the "case management supervisor" for all children in the SFC program, has contact "on behalf of each family at least twice monthly." This involves speaking or meeting with either the home teacher and/or the family. She is in each home a minimum of twice per year. Also, foster homes are licensed by the state Department of Social and Rehabilitation Services. This agency comes once per year to each home to check for compliance with fire regulations and safety standards. The state would like STEP and other private providers to become the licensing agents for these homes.

Other Supports

In addition to home teaching, habilitation aides, and foster care, STEP also offers many other types of supports to natural and foster families.

Respite. STEP's respite program serves 111 families. Each family receives $360 of reimbursement per year to pay respite care workers. However, families who qualify for the SFC program can receive up to twice this amount. A staff member pointed out that the rate of $360 per year equals an average of $30 of respite per month, or "two and a half weeks of respite at $1.12 per hour." She continued, "There is an assumption that parents pay the rest...It's hard to recruit respite providers at that rate...The best bet is to find a friend." Fortunately, the program incorporates the flexibility for families to do just that--hire friends, relatives, or neighbors as respite providers. However, the agency also keeps a list of people who are willing to provide respite. To have their name placed on this list, people need three positive references, and training in first aid and CPR. Beyond this, the families give respite providers any additional information or training.

Adaptations. Primarily through use of state funds, STEP is able to help families obtain many different types of adaptations, including home modifications and adaptive equipment of all sorts. The adaptations are provided in a very individualized fashion, based on the child's needs. They include things, such as Tim's bike cart, that are not strictly medical in nature, but which contribute to a child's social integration as well.

As the program changes to one that is solely Medicaid funded, it may be more difficult to assist families with these many types of needs. This seems particularly likely in an area where staff at STEP report that the regional Medicaid office considers the expense for ramps into houses and lifts into vehicles as "recreational expenses." To compensate for this impending loss of state funds and the anticipated loss of flexibility which will accompany it, staff are preparing to investigate other sources of support, including community organizations and grants.

Educational aides. STEP uses federal Chapter I education funds to provide supports to families with children labeled developmentally disabled or at risk for developmental disability who are not receiving any other types of services. The family can get $600 per year for services such as physical therapy, habilitation aides, or educational aides. STEP currently supports 15 children through this program.

Other materials/equipment. STEP provides a variety of other miscellaneous types of supports to families, including their lending library of written materials and educational toys and games. Upon request, STEP will coordinate support group meetings.

FAMILY SUPPORTS: THE CROW RESERVATION

Introduction

Included among the 51 children receiving family training and support services are three Crow Indian children. Ann Fisher, a home teacher, drives the nearly 200 mile round trip two or three times a month to visit and assist these children and their families.

One of the children who is just beginning to receive supports from the program is Eddie. He is just 5 months old, and has Down syndrome. He lives with his mother, Kim, who is 21, Kim's mother, and two of Kim's cousins. They live in a small house in the town of Crow Agency. Although they are just now signing up for the program, Susan has visited them once before and has begun to give Kim some suggestions. For instance, she has shown Kim some range of motion exercises to do with Eddie; recommended giving him water sometimes instead of just milk so he doesn't gain any more weight; and advised Kim about such things as not leaving him in his walker for extended periods of time.

Christy is another child on the reservation with disabilities who receives support from STEP. She is 7 years old and labeled severely mentally retarded. She has epilepsy, and has shunts for hydrocephaly. Christy lives out in the country, several miles from any town or village. She and her parents and three brothers and sisters live in an old mobile home set back off the main road in a cluster with two other houses.

Christy currently goes to the Head Start program on the reservation. STEP pays a woman, Patsy, who works for the Head Start program, to come once a week and spend additional time with Christy working on skill development. One of the things they are working on is feeding, and Christy now eats with a much greater degree of independence. Also, at school and at home, communication is a major goal, and Christy is beginning to learn a few signs. In the coming year, STEP will begin paying someone at Head Start to give Christy extra assistance while she is there. Ann made two trips with the family to see the pediatric neurologist in Billings. Now, the family does not mind going on their own. According to Ann, since the most recent visit Christy is no longer taking phenobarbital, and seems to be much more alert.

In addition to Ann and Patsy, there are a few other sources of support available for Christy's family. Ann helped organize a parent support group on the reservation. Christy's mother said she had not been to it because of the recent birth of her latest child. However, she expressed an interest in going at some point. Christy's grandmother lives next door and helps take care of the children, though "she is nervous being left alone with Christy because of the seizures." Finally, the community health nurses from the reservation come to visit about twice a month. Christy's mother said they were a good source of support, "I can talk to them if I have a question or problem."

Issues in Family Support on the Reservation

There are a number of issues about family support on the reservation which make it different from the supports that STEP does for families in and around Billings.

1. In working on the reservation, there is a great need for cultural sensitivity. This involves all aspects of support, including how families are approached, and how

supports are designed and delivered. For example, Ann feels that it is important to take into account that, "People here are very family oriented and private in the way they function...There is the assumption that the family will take care of things...It is culturally difficult to leave a child with a nonfamily member for respite, or to pay a family member." Therefore, some of Ann's efforts involve both increasing the number of family members (both immediate and extended family) involved in support of the child, as well as encouraging the involvement of certain nonfamily members with whom the family is already connected and comfortable. For supports to be successful, it is necessary to take into account these cultural preferences, and design the supports in ways that fit into the culture rather than around it. One possible means of increasing cultural sensitivity would be for the agency to include among their staff some members who are themselves Native American.

2. The poverty on the reservation demands additional flexibility and resourcefulness in the way supports or provided. Many of the families do not have telephones and, on occasion, Ann will arrive from Billings to find that a family is not at home. Rather than readily giving up on a family, she explores ways to improve communication, leaving notes for them and/or coming back later in the day. Most of the families also do not have cars, so Ann either helps with transportation herself (i.e., to appointments, stores, etc.) or helps families find others (i.e., neighbors, friends, social service workers) who can help.

3. The distance of the reservation from Billings also affects the ability of STEP to provide support services there. Ann cannot spend intensive time with a family, therefore the contacts that she makes and supports she develops within the reservation are particularly important. In addition to her direct support of families,

Ann has gotten to know many other people on the reservation, including those employed by already existing social service programs such as the health clinics and Head Start program. By working together with them, she assists them to provide support to the children with disabilities and their families.

Up to this time, most of those children with severe disabilities have moved to the Billings area, either with their family or into a foster home. The flexibility in ways that supports can be provided by STEP, however, would seem to allow the potential for development of intensive in-home supports on the reservation. What would be needed would be to work together with the family and other local agencies and individuals to determine both the specific child and family needs and the ways which they could be met through use of the combination of local and STEP resources.

CONCLUSIONS

There are a number of strengths in the ways that the STEP program provides supports to families of children with severe disabilities. These include the following.

1. **Staff are committed to their work and to the families they help support**. As one staff member described her relationship to the families: "I'm able to work out a balance where I'm also a friend. I don't come in to judge families. I can come in not just as a professional, but as a peer." Many staff members go far beyond just the requirements of their job, providing significant moral support to families as well. One father described that it took him awhile to get to know staff from the agency. "At first, when I got custody of Joanne, I thought people were checking up on me. It took awhile for me to trust them...but since I have gotten to know them better, the moral support has been tremendous." And, another parent, a

mother of one of the children on the Crow Reservation commented that the support staff have "been like a backbone for me."

On occasion, staff face dilemmas over how to support families in making their own choices, even when they are not necessarily in agreement with the choices that are made. One example is Tim's family, who have chosen their next door neighbor for a hab aide. STEP staff members feel that this neighbor probably does too many things for Tim, rather than helping him do things himself. However, they do not feel that Tim is being harmed by this and they feel the benefits of having someone the family knows and likes outweigh the lack of skill development. Therefore, staff are supportive of this family's choice. A second example is of a woman with a child having severe disabilities. The woman has a drinking problem, and tends to make spontaneous decisions, such as that of moving out of town and then back again. Though staff do not feel she always makes the best choices or decisions, they continue to support and assist her as best they can to find services.

2. **Staff at STEP promote significant family choice and control in the determination of what supports a family needs and how these supports will be provided.** To begin determining what support a family will get, Ann, the "case manager supervisor," begins by asking families what they want and need. "I get a wish list from each family." Families are involved in hiring and training of hab aides, foster families, and respite providers. Funds are used in a flexible way, such that a family can select a respite provider of their choice, including a friend, relative, or neighbor. In this way, recognition is given to the choices and preferences of families, and to their expertise in caring for their child. The support services that are provided build on the family's already existing networks and sources of support.

3. **The agency has developed some positive strategies for recruitment, training, and support of foster families**. First, staff employ a variety of strategies in order to recruit foster families. Second, most of the training that foster families receive is very individualized, based on the needs of the specific child who will be part of that family. And third, the agency attempts to support foster families in a variety of ways, with things such as in-home adaptations, in-home training, respite, equipment, and so forth.

Overall, the agency has been successful in recruiting foster homes for children, including some with severe and multiple impairments. Staff members consider one of the challenges for the future to be recruitment and support of foster families for children labeled emotionally disturbed or those with both mental retardation and mental health labels. For example, one staff member reported she was nervous about this since she is not trained in these areas. However, use of their already developed expertise at finding and supporting foster care for children with severe handicaps, as well as consultation and cooperative effort with those who are more specifically trained in these areas where necessary, should alleviate or prevent some of the anticipated problems.

4. **There is a creative and flexible use of and search for resources to help support families.** In its distribution of resources among families, the agency attempts to both meet as many families needs as possible as well as to provide individualized and flexible levels of support based on differing child and family needs. While there is a maximum average funding level per family, the agency pools this money and offers more than the average level of funding to those who need intensive supports, and less to those who require less. In addition, agency staff

seek additional sources of funding from grants, community organizations, and so forth to obtain needed equipment and supplies for families that they could not otherwise afford to purchase.

5. **The agency is currently making efforts to support families on the Crow Indian reservation.** There are numerous difficulties associated with this, including the poverty and lack of resources on the reservation, as well as the distance of the reservation from both the STEP office as well as other resources in Billings. Significant effort has been made to develop rapport and trust with families on the reservation, and to establish connections with and use of local resources and services to help support families.

In addition to these strengths, there are two broad areas in which STEP could improve and increase its efforts toward community integration and support.

1. **While the agency has a mission of supporting children and families in the community, this vision should extend to include all children.** Staff expressed the opinion that group homes are necessary for some children. Further, they support the right of parents to choose group homes for their sons and daughters. As an alternative, the agency philosophy should recognize the right for all children to a home. Then, they need to spend time figuring out what this means for agency practice--that is, intensive and creative ways to support children who present more challenges and the elimination of group homes as an option. This still leaves the family with some options (home care with support, foster care, adoption), and at the same time ensures the right of the child to a home and family.

2. **There are a few agency practices which are problematic.** One is the titles of staff such as "home teachers," and "habilitation aides." In general, the role

of home teachers and habilitation aides is much more broad than just teaching or habilitation. These staff members were observed to give families a wide range of support, including advocacy, coordination of services, emotional support, and so on. Yet, the current job title conveys the message that their primary role is one of teaching or habilitation and, consequently, that the primary need of families having children with disabilities is for teaching and habilitation. An alternative title, such as "family support assistant," "family support coordinator," or whatever would reflect both the broader role that these staff members currently play and help promote the idea that families may need different types of support, not just teaching and habilitation.

Second, there is a need to examine the context for the use of shared foster care. Shared foster care is an important alternative to offer families and children to help prevent institutionalization, help during a crisis period, or offer ongoing respite. However, when used as a long term, ongoing arrangement, effort should be made to ensure both that (a) the movement is not disruptive to the child; and (b) that this arrangement maximizes and enhances the child's relationship with his or her family. Shared foster care and other family supports should be used within the context of "permanency planning," assisting children to have stable, permanent family relationships. When this is not possible with the natural family (i.e., if shared foster care is disruptive or is not enhancing the child's relationship to the natural or birth family), then other options such as adoption or permanent foster care should be considered.

At the state level, the policies created for the Specialized Family Care Program have some very positive features. First, the way the family support program is defined as both a child and family centered program recognizes the need to provide support to the whole family, not just the child with disabilities. Second, there is significant flexibility built into the program, giving the regions the opportunity to offer families varying types and levels of supports based on family needs. Flexibility in funding mechanisms encourages family participation and control of the supports they receive, so families can hire/fire their habilitation aides, and can use friends and neighbors as respite providers.

However, there are also some problems or issues with the way family supports are conceptualized and provided.

1. As the basis for the family support program, there is a significant emphasis on training and intervention. Ninety percent of families who are served must have skill objectives. This creates a context in which the primary need of families is seen as one of learning skills and behavioral interventions. At the regional level, the search for staff gives priority to those who can "demonstrate the ability to write behavioral objectives, do task analyses, and develop teaching sequences." The emphasis on training is reflected in staff titles such as "home teachers" and "habilitation aides" rather than a more general family support one.

The problem is that training and habilitation is only one of many types of support that a family may need, and should be one component of a family support program, but not the basis on which the program is defined and built. Staff members of STEP recognize that all families do not need skills training, and are permitted, by state regulation, to serve a small percentage of families without this component. However, this only allows them a small bit of flexibility, and not enough to really look at each family on an individualized basis and determine whether they need skill development or not.

2. Part of the way the program is defined, at the state level, includes the intent of enabling families to function "as independently as possible in providing/obtaining services, so the need for support services is eliminated." While it is fine to assist families to become as independent as possible, there must also accompany this the recognition that some families will always need supports, and will never become totally independent.

3. The "slot system" of services in the state restricts the regional agency's ability to provide supports based on the needs of the family. If a child needs intensive supports, through the SFC program, but there are not slots for this, then he or she will not receive this type of support. An alternative design for services would be to eliminate the slot system, provide a set amount of funding to the each region for the SFC program, and let them determine the numbers of people they can serve based on the individual needs of a given child and his or her family. The state might also establish a special, separate pot of funds to assist a region with a child/family with very intensive needs who exceeds what that region can afford for any given child or family.

4. The state continues to put funding into group homes for children, while at the same time allocating limited funding to family support--such as for foster providers, respite providers, and so forth. There is a limit to how good community-based family supports can become while a state continues to support a group home system also. Other states, such as Michigan and Wisconsin, are moving toward the elimination of institutional and group living for children; instead, they are putting their

time and resources into finding families for all children, including those with severe and multiple impairments. Community supports are both cost effective at the same time that they support the value that children belong with families. If children cannot remain with their natural families, support should be given to adoptive or foster families. It is notable that Montana has included in its state constitution provision for the right to "lifegiving services" for people with disabilities. The state should go one step further to promote "permanency planning" and the right to a home and family for all children, including those with severe disabilities. Along with this, then, is the need to devote more time and resources into assisting regional agencies like STEP to figure out how to support children who they currently have difficulty supporting, including those who are older and may present particular behavioral challenges, those with medical needs, and those labeled "mentally ill" or "emotionally disturbed."

Overall, the combined strengths at the state and regional levels have produced many positive features in the support of children with severe and multiple disabilities and their families in the community. At both the state and regional levels, a philosophical commitment to supporting all children at home, accompanied by the movement of resources in this direction, will build upon the already existing strengths and help create opportunity for all children in Montana to live with families.

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