ALTERNATIVES TO INSTITUTIONALIZATION: APPLICATION OF PERMANENCY PLANNING PRINCIPLES TO SERVICES FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

Prepared for:

The Colorado Developmental Disabilities Planning Council

Under Contract Number C600061

By:

Applied Management Corporation
Denver, Colorado

and

Human Services Research Institute
Cambridge, Massachusetts

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INTRODUCTION

Since the early 1900s, the State of Colorado, like most other states, has acknowledged that children with developmental disabilities represent unusual burdens on families, and the State has an obligation to assist such children and their families. Fifty years ago, the only assistance to these children and families literally was in the form of commitments to institutions. Today, institutionalization is not an acceptable placement decision in all except the most unusual of situations (Paul & Porter, 1981; Beckman-Bell, 1981; Turnbull, 1981; Turnbull & Strickland, 1981.)

Now, in the late 1980s, there is a broad and growing array of services and programs in use that have all but replaced institutionalization as the settings of choice for children with developmental disabilities. The characteristics of these programs vary, but typically they have the same broad purposes: (1) to ensure that children (through age 21) with developmental disabilities receive needed 24-hour treatment and services in family or family-like settings that provide continuity in relationships ("permanency planning principles"), and (2) when possible, to prevent the disintegration of families caused by the stresses of meeting the special needs of their children.

Organization of this Report

Permanency planning principles represent the philosophical foundation for this policy analysis. Thus, Section I begins this report with an extensive description of permanency planning principles and a discussion of the theoretical and historical framework surrounding the emergence of permanency planning for child welfare services in general and for services for children with developmental disabilities. Section II reviews the array of alternatives to institutionalization -- the options that comprise the spectrum of programs and services implied by permanency planning principles, namely: family support services, temporary foster care and various forms of adoption. Section III presents alternative decision-making criteria for selecting among these program options. Section IV analyzes the current status of funding and program alternatives to institutionalization in Colorado. Section V describes a "model" permanency planning service system developed by the Michigan Department of Mental Health. Section VI looks at barriers to changing the current system status. Section VII concludes this analysis with recommendations for implementing a system in Colorado that reflects permanency planning principles.

SECTION I

THE PHILOSOPHICAL BASIS: PRINCIPLES OF PERMANENCY PLANNING

Permanency planning is a principles-based approach to child welfare services, the goal of which is to assure permanent caregivers for children. Permanency planning is defined by Maluccio and Fein (1983) as:

> .... the systematic process of carrying out, within a brief time-limited period, a set of goal-directed activities designed to help children live in families that offer continuity of relationships with nurturing parents or caretakers and the opportunity to establish lifetime relationships.

Thus, under permanency planning principles, a child's right to a permanent home and a stable relationship with one or more adults is an end, a value to be pursued, a highest-order system outcome. The child's right is neither a process nor a means to some other outcome, but a result (an ultimate) that is sought for its own worth.

Permanency planning implies an array of interventions. (See Section II.) The first priority is to prevent disruption or disintegration of the natural family and to keep the child at home. However, if the family situation does not permit the safe or healthy maintenance of the child at home, the child may be removed to a temporary out-of-home placement. Out-of-home placements however, must be accompanied by a detailed plan stipulating the conditions under which the child can return home. If after a designated period of time, it appears that the natural family cannot provide an appropriate care-giving environment, then steps are taken to develop an alternative permanent family environment. This usually involves some form of adoptive arrangement. The main goal is to prevent or reduce the time a child spends in temporary foster care arrangements.

Several historical trends have contributed to the emergence of permanency planning in child welfare. The removal of children from parents who were perceived to be neglectful or abusive, and the subsequent placement of the child in a foster family, used to be an accepted practice. Thus, since the beginning of this century, foster care placements have burgeoned. Although reunification of the natural family is an explicit goal of foster care, influential studies in the 1960s and 1970s revealed that many foster care children never return to their families. Studies have documented that large numbers of children spend five years or longer in foster care, and the average length of stay may be as high as three years. Once placed, children tend to "bounce" from one foster care placement to the next until they attain majority. Further, children often "drift" into foster care, meaning that a variety of often temporary circumstances lead to the removal of the child from the natural home. Once having "drifted" into foster care, the child's continued foster care placement is made more certain by the absence of a purposeful plan that establishes the circumstances under which the child may return to the family.

These findings have fueled a growing conviction among many child development experts that disruption of the parent-child relationship, especially repeated disruptions, carries significant risks to the emotional well-being of the child. "For the child in extended foster care, healthy emotional growth is often inhibited when the child is in a limbo situation and prevented from making lasting emotional investments and relationships" (Milner, 1987).

This recognition has led to an increasing acceptance of permanency planning principles in child welfare. After five years of testimony on adoption and foster care, Congress passed the Adoption Assistance and Child Welfare Act (P.L. 96-272) in 1980, a benchmark in the move toward ensuring permanent families for children. This act included the following provisions:

- federal matching funds for pre-placement preventive services and family reunification services;
- in order to recieve supplemental federal funds for child welfare, state officials must submit a plan that commits them to making "resonable efforts" to prevent the removal of children from their homes. This plan must establish a process for case reviews by a court or administrative panel every six months to determine whether continued foster care is necessary;
- before a state can get federal reimbursement for foster care for an AFDC eligible child, a judge must rule that "reasonable efforts" have been made to prevent or eliminate the need to remove that child from the home;
- states are required to establish (in law) a cap on the maximum number of children in foster care for over 24 months;
- federal matching funds are available for adoption subsidies for AFDC-eligible children with special needs or for SSI eligible children;

- other fiscal incentives are offered to reduce foster care placements and enhance preventive and reunification services.

Although permanency planning principles have enjoyed support from many child welfare professionals and administrators, there are several reasons why these principles are only slowly being adopted by developmental disabilities professionals. The two most important reasons have been:

(1) In past times, placement in long-term congregate care was the intervention of choice for children with developmental disabilities. The recommendation to institutionalize a child was consistent with the medical model which, until several years ago, dominated the field of developmental disabilities. Even when familes were interested in keeping their children with developmental disabilities at home, doctors prescribed institutionalization. Consequently, placement out of the home was thought to be in the best interests of the child, not because of abuse -- as in the child welfare field -- but because it was assumed better care could be secured. Although there has been documented abuse of children with developmental disabilities by their families, placement of such children out of the home did not proceed from an assumption of fault on the part of the family. As a result, parental rights usually were kept fully intact, even though a family may have chosen to have no contact -- for decades -- with its institutionalized child.

(2) Children with developmental disabilities were considered to be unadoptable. Professionals assumed that no one would voluntarily adopt a disabled child. So, little or no effort was made to do so. This attitude dovetailed with another predominant attitude among developmental disabilities professionals: the "state" is there to "rescue" the family from the child rather than to serve as an advocate for the child or for the family as a whole.

Despite this dismal history, many recent developments have been contributing to an atmosphere which is more open to permanency planning principles. For example:

(1) The most significant of these is deinstitutionalization. Deinstitutionalization begins with the assumption that long-term congregate care is not an appropriate living situation for either children or adults. Gradually, the concept of the appropriate size of a residential arrangement has grown smaller and smaller. For example, the Center on Human Policy at Syracuse University presently recommends home environments of no more than three people for persons with severe behavioral or medical involvements (Taylor et al., 1986).

At the same time, home-based care is increasingly viewed as the most cost/effective and most normalizing care environment for all populations. In developmental disabilities, "habilitation" has replaced the medical model, and even the most severely involved persons are viewed as being able to live with a family when given sufficient supports. Growing efforts to avoid out-of-home placements have accompanied an expansion of family support services. Also, efforts to use foster care families instead of group care placements are becoming more common.

(2) Growing recognition that families can and will adopt children with developmental disabilities. This change in attitude may have been assisted by the "shortage" of white non-disabled children for adoption. Nonetheless, there are increasing numbers of adoption services and strategies targeted at placing the special needs child.

As these services have grown, permanency planning principles have become more salient. It is clear that children with disabilities who are served in foster care are also subject to multiple moves from one family to another. Similarly, children with disabilities are entitled to and are known to benefit from a consistent caregiving relationship and environment. Further, "a permanent family" can serve as a lifetime advocate -- especially for those children who have been abandoned by their families.

As these developments have emerged, explicit expressions of permanency planning principles have also become evident. One example is a recent statement from a "Policy Institute" on Families and Homes for People with Severe Disabilities in Syracuse, New York, sponsored by the Center on Human Policy, University of Syracuse. The statement, "In Support of Families and Children" is very significant and thus is presented virtually intact below (Center on Human Policy, 1986). Another set of permanency planning principles for children with multiple special needs, prepared by the Collaboration for Families, Project Impact (Boston, MA), is in Appendix A.

> In June 1986, the Center on Human Policy's Research and Training Center on Community Integration sponsored a two-day "Policy Institute" on Families and Homes for People with Severe Disabilities in Syracuse New York. The Policy Institute included parents, people with disabilities, professionals and state and national leaders committed to community integration. The following statement came out of this Policy Institute:
>
> ## A Statement in Support of Families and Their Children
>
> WHEREAS: All children, regardless of disability, belong with families and need enduring relationships with adults, and
>
> WHEREAS: States and agencies have traditionally not supported the role of families in caring for children with developmental disabilities.
>
> THEREFORE: These principles should guide public policy toward families of children with developmental disabilities ...and the actions of states and agencies when they become involved with families.
>
> Every child should have the right to a permanent home and a stable relationship with one or more adults.
>
>> When states or agencies become involved with families, permanency planning should be a guiding philosophy. As a philosophy, permanency planning endorses children's rights to a nurturing home and consistent relationships with adults. As a guide to state and agency practice, permanency planning requires family support, encouragement of a family's relationship with the child, family reunification for children placed out of home, and the pursuit of adoption for children when family reunification is not possible.
>
> Families should receive the supports necessary to maintain their children at home.

> Family support services must be based on the principle "whatever it takes" within the limitations of what states and agencies can accomplish. In short, family support services should be flexible, individualized, and designed to meet the diverse needs of families.

Family supports should build on existing social networks and natural sources of support.

> As a guiding principle, natural sources of support, including neighbors, extended families, friends, and community associations, should be preferred over agency programs and professional services. When states or agencies become involved with families, they should support existing social networks, strengthen natural sources of support, and help build connections to existing community resources. When natural sources of support cannot meet the needs of families, professional or agency-operated support services should be available.

Family supports should maximize the family's control over the services and supports they receive.

> Family support services must be based on the assumption that families rather than states and agencies, are in the best positions to determine their needs.

Family supports should support the entire family.

> Family support services should be defined broadly in terms of the needs of the entire family, including children with disabilities, parents and siblings.

Family support services should encourage the integration of children with disabilities into the community.

> Family support services should be designed to maximize community integration and participation in community life for children with disabilities.

When children cannot remain with their families for whatever reason, out-of-home placement should be viewed initially as a temporary arrangement and efforts should be directed toward reuniting the family.

> Consistent with the philosophy of permanency planning, children should live with their families whenever possible. When, due to family crisis or other circumstances children must leave their families, efforts should be directed at encouraging and enabling families to be reunited.

When families cannot be reunited and when active parental involvement is absent, adoption should be aggressively pursued.

> In fulfillment of each child's right to a stable family and an enduring relationship with one or more adults, adoption should be pursued for children whose ties with their families have been broken. Whenever possible, families should be involved in adoption planning and, in all cases, should be treated with sensitivity and respect. When adoption is pursued, the possibilty of "open adoption," whereby families maintain involvement with a child, should be seriously considered.

While a preferred alternative to any group setting or out-of-home placement, foster care should only be pursued when children cannot live with their families or with adoptive families.

> After families and adoptive families, children should have the opportunity to live with foster families. Foster family care can provide children with a home atmosphere and warm relationships and is preferable to group settings and other placements. As a state or agency sponsored program however, foster care cannot guarantee children with the continuity and stability they need in their lives. While foster families may be called upon to assist, support and occassionally fill in for families, foster care should not be viewed as an acceptable alternative to fulfilling each child's right to a stable home and enduring relationships (Center on Human Policy, 1986).

SECTION II

ALTERNATIVES TO INSTITUTIONALIZATION: AN ARRAY OF COMPONENTS IN A SYSTEM OF SERVICES BASED ON PERMANENCY PLANNING PRINCIPLES

Any system of services that is built upon a foundation of permanency planning principles revolves around three essential service delivery components: family support, foster care and adoption. It is useful to envision these components as being a hierarchy ranging from programs designed to help keep children in their homes with their original families, to programs designed to replace the original family with other permanent relationships. However, it is most important to remember that all alternatives to institutionalization are simply a modern form of the State of Colorado's historical commitment to help children with developmental disabilities and their families.

The hierarchy is diagrammed in Figure 2-1, followed by a discussion of each option.

Figure 2-1

A Hierarchy of Program Options Under Permanency Planning Principles

		Some Examples
1.	Family support services	respite care counseling homemaker services transportation information and referral
2.	Adoption	open adoption co-parenting permanent foster care subsidized adoption post-adoption services
--	Short-term, temporary foster care	in a foster home in a group home in a residential child care facility (RCCF)

The hierarchy has several potential uses: for example, organizing information about the availability, appropriateness, costs, organizational and funding arrangements and responsibilities, legalistic barriers and enhancements to the use of eligibility criteria, outcomes, and other programmatic, financial, and moral/values advantages and disadvantages of each option.

The basic public policy issue is how best to meet the goals of:

1) ensuring that children (through age 21) with developmental disabilities receive needed 24-hour treatment and services in a family or family-like setting that provides continuity in relationships,

(2) when possible, preventing the disintegration of families caused by the stresses of meeting the special needs of their children, and

(3) doing so within reasonable state fiscal parameters.

Then, recognizing the State of Colorado's long-standing commitment to children with developmental disabilities and their families, how should the administration, program, and financing of programs be structured?

A first requirement, however, is to determine whether the complex needs of children with developmental disabilities and their families can be met best through placements in or out of the home. (See the discussion of the "reasonable efforts criteria" in Sections III and IV.) Because children, families, and contexts differ, there is no universally applicable answer. For children who need more care than their families are able to provide, the answer is mixed: for some, voluntary out-of-home placements probably are the best answer; for others, alternatives such as family support services or voluntary relinquishment may meet the stated goal -- and several larger goals -- more effectively and possibly at less cost. Colorado needs to be more aggressive in exploring the true viability of such alternatives as part of any effort to arrive at a long term public policy. solution.

A description of each component in the hierarchy of options follows.

Family Support Services

The cornerstone of permanency planning is to provide services that will prevent the removal of the child from the family or that will permit the return of the child to the family from out-of-home care. Often these services consist of intensive activities geared to the family as a whole. In child welfare, recent family support services have been targeted to providing intensive, time-limited casework to the family in the family's home (Edna McConnell Clark Foundation, 1985). Reduced caseloads and flexible shifts allow workers to respond to families in crisis at any time. Parent training, individual and family therapy, plus financial and other concrete services allow families to stabilize, thereby preventing further abuse, neglect or other crises.

Although these generic services are relevant to families with a child with developmental disabilities, there are hosts of specialized services that may also be needed given the unique challenges faced by many such families. Some of these challenges tend to include the following (Agosta & Bradley, 1985):

- adverse reactions to the discovery that a family member has a developmental disability including a sense of shock or numbness, denial, grief, shame, guilt and depression;
- chronic stress;

- social isolation resulting from perceived negative attitudes and/or rejection by kin or neighbors;
- financial costs or lost opportunities for employment, career advancement, and education;
- extraordinary time demands involved with providing personal care to the family member with disabilities and teaching this person adaptive living skills;
- difficulty with physical management (e.g., ambulation, lifting, carrying) and with handling socially disruptive or maladaptive behavior;
- difficulty in undertaking normal family routines such as shopping and house cleaning or in finding ample opportunity for recreation;
- lack of the skills needed to cope with the potential medical emergencies and/or to teach necessary adaptive skills;
- absence of needed community services to complement and enhance the care provided at home.

The following is a partial list of family support programs that attempt to address these needs (Martin & Griswold, 1986). (For comparison, services that are reimbursable under Colorado's Family Resource Services Program, are listed in Appendix D.)

1) Respite Services (in-home/out-of-home)

   a) Child care before and after school
   b) Child care during school vacations
   c) Weekend and vacation care
   d) Emergency placement service
   e) Regular sitters

2) In-Home Services

   a) Assistance in the care of children who have severe physical limitations
   b) Parent training
   c) Behavioral intervention programs
   d) Physical and/or occupational therapies
   e) Home health care

3) Out-of-Home Services

   a) Vocational programs
   b) Preschool programs
   c) Early intervention (e.g., infant stimulation/ prevention activities)
   d) Recreation/leisure services
   e) Parent groups

4) Counseling

   a) Parent support
   b) Family therapy
   c) Sibling support
   d) Individual therapy

5) Financial assistance for services or goods needed by the family which can only be obtained by cash outlay

   a) Special foods
   b) Transportation
   c) Special clothing
   d) Special equipment
   e) Home modifications
   f) Tax incentives
   g) General subsidy

Family support services began to appear in some states in the 1970s as part of the need to respond to needs caused by the deinstitutionalization movement of that decade. Although the history of family support services can be traced directly to families of people who were being deinstitutionalized, many intact families living at home also need such services. In 1985 the Human Services Research Intitute found 25 states that were operating extensive family support programs. Table 2-1 lists the permissable services provided by 22 states who identified the presence of family support programs (Agosta et al., 1985).

Cash assistance is a significant development in family support services. Families are given monies to subsidize the high costs often associated with the care of a family member with disabilities. Table 2-2 provides information about the cash assistance program in eight states (Agosta, et al., 1985). In addition to cash assistance, Medicaid waivers have been used successfully by Michigan and other states to support families and maintain children at home. Other family support services have included: in-home and out-of-home respite care, crisis intervention support and placement, parent support groups, "latch-key" programs which provide working parents school-sponsored activities before and after school, and intensive family treatment for multi-problem families by a private agency.

TABLE 1: Permissable Services in 22 Family Support Programs

SERVICES	STATES																							TOTAL
	CA	CT	FL	ID	IN	IA	LA	MD	MI	MN	MT	NB	NV	NJ	ND	OH	OR	PA	RI	SC	VT	WA	WI	
Adaptive Equipment	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x			x	x	x	x	x	21
Educational or Therapeutic Services for disabled person (examples include physical, speech or vocational therapy behavior management)	x	x	x	x			x	x	x	x	x			x	x		x	x	x	x	x	x		17
Transportation	x	x	x	x	x			x	x	x	x	x	x		x		x			x		x	x	16
Medical or Dental Services	x	x	x	x	x	x	x	x	x	x		x			x				x	x			x	15
Housing Modifications	x		x	x		x	x	x	x	x		x			x	x		x	x	x			x	15
Special Clothing	x	x	x	x					x	x			x		x						x		x	10
Diet or Nutrition Services			x	x			x	x	x	x			x		x	x							x	10
Diagnosis and Assessment	x		x	x					x	x	x	x			x								x	9
Medications		x	x				x	x	x	x		x								x				8
Home Health Care				x			x	x	x			x		x	x									7
Personal or Attendant Care	x						x	x	x			x												5
Recreational Services			x	x											x			x					x	5
Information and Referral											x						x							2
Temporary Respite or Relief	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	22
Family Training or Counseling	x	x	x	x		x	x	x		x	x	x			x	x	x	x	x				x	16
Homemaker	x							x		x		x		x				x	x					7
Chore Services	x							x				x												3
Housekeeping	x							x				x												3
Room/Board for Family (for traveling related to provision of care)			x									x												2
Provisions for permitting unique services not available elsewhere	x	x	x	x	x			x	x		x							x		x			x	11

TABLE 2

Eight Cash Assistance Prorams by Six Areas of Information

STATE	DATE INITIATED	TYPE OF PROGRAM	CLIENT/FAMILY EXPENSE LIMITS	NUMBER OF CLIENTS SERVED	APPROPRIATIONS (FY 1983-1984)	ELIGIBILITY CRITERIA		
						Client	Family	Placement
Connecticut	1981	Cash Program	$2,000 per year	15	$23,106	developmental disabilities	sliding scale based on income and family size; no other public assistance received	at risk of out-of-home placement or returning from such placement
Idaho	1981	Cash Program	$250.00 per month ($3,000 per year)	138	$47,000	developmental disabilities; under age 21		priority to those at risk out-of-home placement or returning from such placement
Indiana	1982	Cash Program	Determined by casemanger, maximum of $500 per month for respite	191	$185,000 (FY 1985)	developmental disabilities		priority to those at risk of out-of-home placement
Louisiana	1983	Cash Program	$375.00 per month ($4,500 per year)	25	$112,500	mental retardation		
Minnesota	1975	Cash Program	$250.00 per month (3,000 per year)	190	$525,000	primary diagnosis of mental retardation; under age 18; priority to severest disability	priority to greatest resource needs	
Nevada	1981	Cash Program	$286.00 per month ($3,432 per year)	67	$110,000	profound mental retardation	insufficient income to cover costs of care; sliding scale based on family income & size	
North Dakota	1981	Cash Program	$15/week for basic care; $35/week for services/ treatment ($2,600 per year)	200	$200,000 (3 year pilot)	developmental disabilities; under age 21		
South Carolina	1974	Cash Program	150.00 per month ($1,800 per year)	15	$23,000	mental retardation	insufficient income to cover costs of care	

Detailed descriptions of family support programs in four model states are in Appendix B. While there is no consensus on exactly what a family support program should look like, there is general agreement that permanency planning begins by supporting the family. Further, there cannot be a successful permanency planning oriented program unless sufficient resources are first allocated to support the natural family to maintain the child. When a permanency planning caseworker can marshall any or all these supports, chances greatly improve that a child can remain at home.

However, in *some cases* even an ideal family support program will not prevent a request for out-of-home placement. For example, some families:

- feel emotionally and/or fiscally unable to care for their child
- have a potential or actual abusive or neglectful environment; or
- due to a variety of circumstances, are unable to provide a consistent caretaker.

In these situations temporary out-of-home placement may be necessary while the family is helped to reunite with the child and/or an alternate permanent placement is planned.

From a Colorado public policy perspective, it is very important to understand that most children with developmental disabilities remain at home. The State does not have a placement role with these children. Presumably, if more family support services existed and if more families were prepared to use family support services, fewer children with developmental disabilities would require out-of-home placements. Yet, between 1977 and 1984, the United States government spent $13 billion on ICF-MR (Intermediate Care Facilities for Mentally Retarded) reimbursement (Braddock, 1984). In contrast, Wieck (1985) estimates that less than one percent of public funding for persons with developmental disabilities (in the 22 states with the most extensive programs) is designated for family support.

Foster Care

Under permanency planning principles, foster care represents only a temporary stop-gap measure to be activated when family support services fail to prevent an out-of-home placement request. Children placed in foster care need to have a permanent plan of care developed and implemented as quickly as possible. To ensure the appropriate care of children while in foster care, the Permanency Planning Work Group, Collaboration for Families (1986) recommends that the program should be comprised of the following:

1) Extensive training for social work staff in:
    - permanency planning for children with developmental disabilities;
    - use of assessment resources;
    - access to funding sources;
    - service provider agencies and their services;
    - adaptive housing equipment; and
    - recruitment of specialized resources.

2) Involvement of case management and service coordination staff from other agencies in addition to that provided by the supervising agency. This is crucial in gaining access to on-going interagency services and planning.

3) A specialized recruitment program which provides community education about the need and advantages of foster care for these children.

4) Skill training for foster families on the medical, developmental, and emotional needs of children with disabilities. This may be contracted through other specialized agencies or provided directly.

5) A clearinghouse for foster families who are available to work with children based on the needs of the child, rather than on the geographical territory, agency or worker providing the home study.

6) A system of reimbursement which establishes fair and appropriate rates for children with extraordinary care needs, eliminating the need for foster parents to struggle over each individual rate or remain under-reimbursed.

7) Reimbursement for adaptive equipment, clothing, frequent travel to medical or developmental programs, or other extraordinary costs.

8) An expansion of respite care beyond the existing ten days per six months available through departments of social services.

9) A recognition that respite care is different from the care provided by home health aides or other support programs. Respite care represents a break.

10) Foster parent support groups.

11) A plan for seeking the termination of parental rights and development of an alternative legal family when the biological family is not able or willing to accept parental responsibility for the child.

(A detailed discussion of model foster care programs is included in the Preliminary Foster Care Policy Analysis prepared for the Colorado Developmental Disabilities Planning Council as part of this grant [Applied Management Corporation & Human Services Research Institute, 1987]).

Adoption

Numerous circumstances may prompt a search for an adoptive placement of children with developmental disabilities. Some of these are:

- neglectful or abusive parents;
- the child has been institutionalized and the family refuses to accept the child back;
- attempts at family reunification via support services have failed;
- the child is in foster care with no movement toward a resolution of the permanent plan;
- the child is in residential care with little or no family contact.

In these cases, the aggressive pursuit of an adoptive family becomes the permanency planning option of choice as noted in the following policy statement from Michigan:

> Adoption often becomes the plan of choice for children who cannot be cared for by their birth families because this alternative most closely simulates the parent-child relationship which exists in the birth family. Indeed, the adoptive parent becomes the legally recognized parent in every sense that the birth parent is, except genetically.
>
> The emotional bonding which occurs between the adoptive parent and child makes adoption an even more important alternative for children with developmental disabilities. Adopting parents who have been well prepared by an adoption worker are committing to parental responsibility exceeding that of a normal child. Adopting parents are aware that their parenting years may be increased (that the child may be totally dependent upon their advocacy, and maybe their care, as an adult) and that the demands on their energy level, time and finances may be greater (Permanency Planning Project, 1986).

As was mentioned earlier, children with developmental disabilities are no longer perceived to be unadoptable, and research shows that a large number of children of all ages with various disabilities are placed in adoption with few disruptions (Coyne & Brown, 1985). For example, the permanency planning project in Michigan operates from the belief that there is a family for everyone. Michigan's statewide reduction of out-of-home congregate care placements for children to under 100 is vivid testimony to that belief.

The adoption of special needs children has received considerable media attention and federal funding support. For example, the National Adoption Exchange in Philadelphia, assisted by a grant from the Office of Human Development Services, provides a nation-wide computerized listing of legally adoptable special needs children. A recent federal initiative is aimed at assuring that workers in state child welfare and developmental disability systems work cooperatively toward the goal of increasing public awareness of special needs children, recruiting adoptive families, and expanding resources for children awaiting adoption (NASMRPD, 1983). Two states have initiated special needs adoption programs utilizing media campaigns and agressive staff follow-up. Numerous television stations and newspapers regularly sponsor advertisments of special needs children who are available for adoption.

Although numerous traditional adoptive arrangements have been successful for many children with developmental disabilities, the unique circumstances and needs of these children have spurred the development of alternative adoptive arrangements. Like birth families, adoptive families require additional supports to maintain their family member with developmental disabilities at home. Thus, state and federal planners have established adoption subsidies to facilitate adoption placements. (See the discussion of "Subsidized Adoption" below.) Another unique circumstance of children with disabilities is that they are often voluntarily placed in out-of-home care by their families. Although birth parents may not feel able to care for the child themselves, they may be equally reluctant to release all of their rights, especially visitation, to an adoptive family. To respond to this need of birth families while ensuring a permanent caregiver for the child, permanency planning workers have evolved other adoptive arrangements. Those discussed here are subsidized adoption, foster parent adoptions, open adoptions, and permanent foster care arrangements.

<u>Subsidized Adoption</u>. Subsidies are intended to offset the additional costs of caring for a child with special needs and are used to encourage families to adopt. As was mentioned previously, P.L. 96-272 offers federal adoption subsidies to children with special needs eligible for AFDC or SSI. In Illinois, adoption subsidies have been used to accomplish the movement of a large number of children from long term foster placement into adoptive situations (Wiltse, 1980). Michigan permits adoption

subsidies that are comparable to the daily foster care payment rate. Even more important, Michigan's subsidized adoption permits children to remain eligible for Medicaid even though the adoptive families' income might otherwise disqualify them.

Foster Parent Adoptions. Many children with disabilities are adopted by their foster families. These families provide a rich resource of adoptive placements.

> Children with developmental disabilities are often adopted by their foster parents. The vast majorty of adoptions which have occured under the (Michigan) Permanency Planning Project have been foster parent adoptions. This has facilitated the adoption of children with highly complex needs because the foster parents have had the child in their care and have become attached as well as skilled in providing for the child's needs. In addition, parents feel more comfortable in releasing their child for adoption when the foster parents intend to adopt, because the potential adopting family is a known entity (Permanency Planning Project, 1985).

Open Adoption. The release of parental rights for adoption is considerably more complicated for children with developmental disabilities than children in abusive/neglectful homes. In the latter, parental rights are often terminated by the court. However, the majority of children with developmental disabilities in foster care are placed voluntarily. Although parents may feel unable to care for their child themselves, they may be reluctant to terminate all contact and responsibility. The use of foster parent adoptions is effective in securing the release of some children. Another adoption alternative that has also been successful in securing release, is "open adoption."

> Open adoption is being established as a viable option for children with developmental disabilities who are mental health clients. Through open adoption, releasing families maintain some type of contact with, or knowledge of, the child in the adopting family. The degree of openness can vary from simply knowing who the adoptive family is and/or being informed of major events in the child's life, to having regular contact with the child and adopting family (Permanency Planning Project, 1985).

Open adoption may require a contract between releasing parents and the adoptive family specifying the rights and responsibilities of each party. The Lutheran Adoption Services in Michigan, for example, permits the adopting family to be certified for adoption prior to the voluntary release of the biological family. In this way, the releasing family is assured of knowing who the adopting family will be. Michigan will not broach parents' voluntary release of rights unless a foster parent or other person has expressed interest in adopting the child.

<u>Permanent Foster Family and Co-parenting Agreements</u>. In some cases, neither return home nor adoption is a viable option. This is often true of teenage children who present greater difficulty in finding adoptive placements or who may attain majority by the time all releases are executed. In other cases, foster families may be committed to the child but are understandably reluctant to extend that commitment through adulthood when community services for adults are uncertain. In these cases, a formalized (and sometimes a non-formal verbal) agreement is reached with the foster family that it will maintain care until adulthood. This non-legal alternative is probably the least

desirable permanency planning option, because it does not guarantee a permanent adovcate through adulthood; however, it does assure a permanent caregiver until then.

The co-parenting agreement is a version of the permanent foster family agreement. This agreement incorporates a plan for the birth family to maintain its involvement in planning and caring for the child and for maintaining a positive relationship while the child remains in the primary care of a particular set of foster parents. Such arrangements typically include weekend care by the birth family, or week-on week-off arrangements.

Post-adoption Services. Post-adoption services are relatively recent additions to the spectrum of services and are not widely available. These services tend to include on-going case management, counseling and support services to the adoptive family. Although disruptions of adoptive placements are infrequent, the provision of services can reduce the potential for such disruptions.

SECTION III

DECISION CRITERIA FOR SELECTING OPTIONS IN A SYSTEM OF SERVICES BASED ON PERMANENCY PLANNING PRINCIPLES

In light of this array of placement options, uncertainty often arises over appropriate utilization of any individual option. For example, decision criteria are needed to determine when a child should be placed out-of-home, when a foster care placement has gone on too long, and/or when parents should be counselled to sign a voluntary release for adoption. Some generally accepted practices have evolved that shed some light on appropriate approaches to answering these and related questions. The following practices are described and discussed in this section: 1) state efforts to implement "reasonable efforts" determinations, 2) model child welfare service standards, 3) case worker professional judgment, and 4) use of parent/agency agreements.

Implementation of "Reasonable Efforts" Criteria

The "reasonable efforts" determination requirement is a key provision of P.L. 96-272. In order for states to be eligible for federal reimbursement under Title IV-E Foster Care Funds, the law requires that for each child entering foster care there must be a judicial determination that reasonable efforts have been made to prevent out-of-home placement and return the child to his/her family. However, no federal guidelines exist for measuring how well the reasonable efforts determination requirement is being met in a state. Nonetheless, state legislatures have been vigorous in their efforts to implement the reasonable efforts determination. As of 1984, 22 states require such action either through statute or other means (Magri, 1984). The Edna McConnell Clark Foundation (1985) has catalogued the methods that different states have chosen to determine whether appropriate steps have been taken to prevent out-of-home placements. These are discussed below.

Judicial Determination. Juvenile and family courts hold legal responsibility for protecting children, and possess the authority to award custody of a child to the state. Traditionally, this accompanies involuntary out-of-home placement. Most state laws which follow the Adoption Assistance and Child Welfare Act reflect that act's requirement that a judge determine in each case whether reasonable efforts were made to keep the child safely at home, so the state can receive the federal foster care reimbursements it needs. These laws are intended to compel the court to pay close attention to each child's entry into foster care. Of course, the courts in each state must institute guidelines and procedures to make sure the laws work.

Defining Standards. Given the federal government's reluctance to define what is "reasonable," states must define the term for themselves and hope the federal government will agree with the definition. It is important to set standards high enough so that families actually receive the services they need. Some states appear to shirk responsibility by defining reasonable efforts in terms of those services already available, however inadequate. Others implicitly define the term by mandating a specific array of services. Washington state law orders the state's umbrella social service department to offer families comprehensive services to reduce the need for out-of-home placements, and sets out some guidelines for how to achieve that goal.

The more points at which reasonable efforts must be made and the more people who have a responsibility to do whatever is reasonable to prevent unnecessary removal, the more likely it is that someone will do it successfully. California is exemplary for the number of these points its law names in the bureaucratic as well as the judicial process. There, probation officers, social workers, protective services staff, and judges must all consider offering services to a family to help keep its children at home.

<u>Court-ordered Services</u>. Some states allow the courts to order the provision of those services needed to keep a child at home. Some states leave the choice of services open-ended, while others specifically stipulate a list of -- or core of -- in-home services the court can order. Wisconsin for example, lists services that include (but are not limited to) individual and group counseling, homemakers and parent aides, respite care, housing assistance, day care, and training in how to be a better parent. Presumably this allows also for the particular combination of family therapy, skills training, and service brokerage which constitutes intensive family services.

Documenting Services Provided. Some states require the court or the child welfare agency to document both the services each family has received and their quality. This is a useful refinement of a section of the federal law which requires a case plan for each child. Such a plan loses most if not all of its usefulness unless it also leads to a report of whether the plan is followed or not. Louisiana, in a "statement of suggested language," asks the court to describe efforts made at prevention and to explain "why further efforts could or could not have prevented or shortened the separation of the family." The requirement mandates careful scrutiny by the courts, and establishes a record which will help future efforts to assess and ensure premanent families for children.

A still undeveloped, but nonetheless important aspect of this process is its potential use in differentiating effective from ineffective or even harmful services. Poorly-skilled homemakers, for example, may provide little aid or even cause harm. Requiring documentation and review can help track such problems.

Establishing a Range of Preventive Services. Despite all of these moves to determine, document, and record whether efforts to prevent unnecessary placement have been made, few states have actually passed laws mandating a range of preventive services and ordered them distributed for reasonably uniform access by the state's population. Diane Dodson of the American Bar Association recommends that state laws should contain certain basic provisions. In her opinion, a state law should:

- require a case plan specifying which services the state will provide to a child and his or her family;
- specify a particular range of services that the state will provide including both hard services and special services for families;
- require the court to report on what services are, or were, available and deemed appropriate;
- allow the court to order removal only if it finds that the child cannot be protected by the provision of services at home; and
- require and authorize the court to order services to allow the child to remain at home.

Model State Child Welfare Service Standards

Recent standards prepared for South Carolina's child welfare system provide an excellent example of how state standards can be used to embrace the intent of P.L. 96-272, orient a human service delivery system toward permanency planning principles, and establish decision criteria for acceptable permanency plans. The rest of this section draws from "Standards on Substitute Care" developed for the South Carolina Department of Social Services by the URSA Institute (1986).

Standard E. Clients shall remain in substitute care only as long as is necessary.

Indicators: 1. The average length of time a case is open for substitute care services is three years.

2. For those cases coming into care since January 1, 1981, the average time the case is open for substitute care services is eighteen months.

3. The average length of placement in Level 1 specialized residential treatment is 15 months; for level II, 12 months; for Level III, nine months.

4. At least 75% of all substitute care cases opened since Jauary 1, 1981 are closed within one year.

Standard F. Each child in substitute care shall be assisted to achieve permanency in a reasonable time period.

Indicators: 1. In at least 50% of the cases in which the case plan is "return home" (family reunification), the child is returned home within 18 months of placement in substitute care.

2. In at least 50% of the cases where the case plan is placement with relatives, the plan is achieved within 18 months of placement in substitute care.

3. For the above two permanent plans, the recidivism rate (within one year of return home) does not exceed 10 percent.

4. In at least 80% of the cases where the case plan is adoption, children are freed for adoption within 18 months of the time the decision is made to make adoption the case plan.

5. 90% of the children who have completed treatment in a specialized residential treatment facility and have returned to their family (birth, foster or adoptive) experience no further change in placement in one year (Kimmich, 1986).

Many standards used to determine appropriate permanency planning revolve around case plans and case reviews. Timelines that govern when cases must be reviewed to determine whether they are proceeding in accordance with permanency planning principles, can be provided. The South Carolina standards also suggest an example of this approach.

Standard C. The agency shall meet all of the federal requirements (427 audit) for substitute care regarding case plans and external reviews.

Indicators: 1. A written plan is developed for each child in substitute care; if the child is placed in a residential setting, both the treatment plan and the post-placement plan are developed in cooperation with staff of the facility.

2. The case record contains a description of the child's placement and the reasons for the placement; the services to be offered to the child and parent(s); and the services to be provided to the foster parent(s) while the child is in care.

3. At least every six months, the Foster Care Review Board or the courts review the case of each child in substitute care.

4. The agency prepares for a dispositional hearing by the courts no later than 18 months from the time a child was placed in foster care and yearly thereafter, in compliance with P.L. 96-272 (Kimmich, 1986).

South Carolina's standards for adoption services also reflect permanency planning principles.

Standard D. The (adoption) agency shall make a concerted effort to place special needs children.

Indicators: 1. The agency has cooperative agreements with other adoption agencies and exchange lists and/or exchange books on children awaiting adoptive placement.

2. In the past year, adoption subsidies were made available to all special needs children who are freed and awaiting adoption and who cannot be placed without a subsidy.

3. In the past year, 100% of the special needs children freed for adoption who had waited three months or more for placement were referred to adoption exchanges.

4. The adoption worker explores the possibility of adoption and assesses the potential for adoption of all foster parents of special needs children (Kimmich, 1986).

Other adoption indicators used in South Carolina include percentage of children placed in adoptive homes within nine months of being freed for or referred to adoption, and percentage of special needs children placed in adoptive homes without disruption.

Case Worker Professional Judgment

The above state standards provide measures of the outcomes of permanency planning. However, guidelines are not provided by which an individual caseworker can make a plan for permanency, or determine what stage the family has reached. These judgments are left to the professional training and discretion of the individual worker. External monitoring agencies have little ability to regulate the decisions of the worker, and so must rely on external measures of the efficacy of the plan (such as, frequency of case reviews). However, some guidelines by which a caseworker can assess whether s/he is adhering to permanency planning principles can be written. One such self-assessment manual is presented in Appendix C. Some examples of guidelines include: "Does permanency planning always begin with an assessment of the child's own home as a possible living situation for him/her?", and "Where appropriate, are ongoing services provided to reunite the natural family unit?".

Parent/Agency Agreements

The following procedures for determining permanency planning options have been developed by the permanency planning project in Michigan.

A foster care or group home placement is available to a child only when services and resources directed toward maintaining the child with their family have proved unsuccessful;

specific, goal-directed foster care, on a temporary basis, is viewed to be in the best interest of the child; or the child's needs cannot be met in the existing home environment.

When a caseworker finds that a referral for temporary foster care is necessary, the caseworker must prepare a Family Assessment and a Resource Assessment. These assessments must include the following information: 1) services and resources that have been provided to the family to support maintenance of the child within the family; 2) the impact of those services and resources on the prevention of out-of-home placement; 3) alternatives to out-of-home placement that have been explored; 4) current family dynamics, 5) documentation that permanency planning has been discussed with the family; and 6) the reason for request for admission into foster care services. The assessment must be current within three months and should include projected permanency goals for the child, including a timeframe for return home.

If temporary foster care is pursued, then the principles of permanency planning are explained to family members. They are advised that this is considered to be a temporary placement, that the family is expected to resume care, share in the care, and maintain regular visits with the child while in foster placement. These understandings are spelled out in a parent/agency agreement signed by the parents, mental health or referring worker, foster care worker, and foster parents. The agreements include the following information:

- factors necessitating placement;
- conditions necessary for the child to return home;
- parent goals, tasks, activities, and time frames for achievement;
- foster care casemanager tasks, activities, and time frames for achievement;
- mental health (developmental disability) worker tasks, activities, and time frames for achievement;
- other possible services to be provided to parent(s) by foster care support staff or outside agency staff;
- foster care provider tasks, activities, and time frames for achievement; and
- shared care plan: (Plan for cooperative sharing of care between birth parents and foster parents, including the nature and frequency of birth parent visits).

Hardin (1983) argues for other components of a parent/agency agreement:

- The parent has the right to refuse to place the child with the agency and to be represented by an attorney if the agency takes the matter to court.
- If the parents cannot afford an attorney, the court will appoint one.
- The parents have the right to visitation, to be given information about the child, and to be consulted in major medical and educational decisions concerning the child.
- On demand of a parent, the agency must return the child or obtain a court order within seventy-two hours.
- Entering the agreement does not prevent the agency from later taking the parents to court to obtain legal custody of the child or to terminate the parent's rights.

- If the child remains in care more than 180 days or after the expiration date of the agreement, the case will automatically be reviewed by the court.
- The agency might file for termination of parental rights if parents fail to make reasonable progress that will permit return of the child.
- The parent can take the agency to court at any time if the agency refuses to return the child home, violates the agreement, or denies the parents any other rights toward the child.
- The parents and agency have the obligation to work together to remedy the problems causing the separation of parents and the child.
- The parents shall maintain contact with the agency and the child.
- The agency shall notify the parents of any change in caseworker or in the location, progress, or condition of the child.
- If the agency and parents have entered into a plan to work toward the return of the child, the terms of that plan shall be made part of the agreement.
- A short statement of alternatives to placement is included in the agreement.

This plan is reviewed by all concerned parties every three months so that the plan can be modified if necessary, and to ascertain progress toward reunification. The overall time frame established for a child's return home is not to exceed one year. The parent/agency agreement and permanency plan is reviewed by an administrative committee of the foster care agency every six months until the permanency goals have been achieved.

Obviously, there are some cases in which family reunification is not possible. Sometimes families refuse to have any further responsibility for the care of the child. In those situations, caseworkers will broach the topic of adoption and request the family to release the parental rights voluntarily so that the child may achieve a permanent home. Reportedly, Michigan caseworkers attempt to avoid this turn of events unless there has been a clear interest on the part of the foster parent to adopt or if the child is likely to be adopted easily. Adoptive subsidies, equivalent to foster care rates, and the use of alternate adoptive strategies described earlier, assist in securing both adoptive parents and the voluntary release of rights by the birth parents.

SECTION IV

THE CURRENT STATUS OF PROGRAM ALTERNATIVES TO INSTITUTIONALIZATION IN COLORADO

Introduction and Overview

Family support services, voluntary foster care placements, and the varieties of adoption are, in fact, simply modern forms of the State of Colorado's historical commitment to assist children with developmental disabilities and their families. Fifty years ago, the assistance to these children and families literally was in the form of commitments to institutions. Today, institutionalization is not an acceptable placement decision. Thus, in 1987, the state's historical commitment is manifested through a variety of in-home and out-of-home placement alternatives (See Section II). Family support services, foster care and adoption are simply less restrictive placements within a hierarchy of care; however, there has been a history of dissatisfaction and frustration, particularly about the course of Colorado's out-of-home placement programs and policies. (Colorado Office of State Planning and Budgeting, 1979). That frustration led to Colorado's current legislation governing child welfare services ("SB 26"). The frustration arose in the mid 1970s out of two separate concerns.

First, foster care costs were rising at approximately thirty percent annually. Legislators and others were fearful that foster care costs were, in fact out of control. Secondly, many people (including advocacy groups, care providers, etc.) were truly concerned that out-of-home placements were not being effective in producing desired results for children and families. Thus, the Office of State Planning and Budgeting convened a group of people from concerned organizations in the spring of 1978 to ameliorate the two concerns (Colorado Office of State Planning and Budgeting, 1979). This group worked to ameliorate the two concerns through "SB 26." First, it was decided to "cap" state foster care appropriations -- to hold costs. Second, the group sought program flexibility to satisfy the concerns about the effectiveness of care. Therefore, "SB 26" allows counties with approved plans to spend some appropriated foster care funds to prevent placements -- on alternatives to out-of-home placements. SB 26 also exempted children who were voluntarily placed in foster care (i.e., mostly children with developmental disabilities) from court reviews. This exemption was reversed by the state legislature in 1987.

Before analyzing the components of the service system in Colorado, it is important to re-raise an issue that is fundamental to permanency planning principles: Are the complex needs of children with developmental disabilities and their families best met through placements out of the home. Because children, families, and contexts differ, there is no universally applicable answer. For children who need more care than their families are able to provide, the answer is mixed: for some, voluntary placements probably are the best answer; for others, alternatives such as family support services may meet the stated goal -- and several larger goals -- more effectively and at equal or less cost.

Thus, Colorado needs to be more aggressive in exploring the true viability of such alternatives -- alternatives that comprise a full array of services which are consistent with permanency planning principles -- as part of any effort to arrive at a long term public policy solution. However, our investigations have led us to three inescapable conclusions about the program of services for children in Colorado:

1) No matter how often or how much Colorado's providers, arrangers and funders of services for children with developmental disabilities may profess to believe in permanency planning principles, those principles are rarely influencing placement decisions (whether or not they are so labeled). Colorado policies and funding allocations provide only token acknowledgement, support and funding for programs and placement options that reflect permanency planning principles. For example, even the highly sought-after Family Resource Services Program (FRSP) commits support to families for a maximum of one year. Does it make sense to remove or divert a child from an out-of-home placement for a support commitment of about $200 a month -- for one year or less?

Few program/placement options are open to case managers and social workers in the developmental disabilities and social services "systems" -- the two systems that work most extensively on living placements (and their funding) for children with developmental disabilities and their families. Further, in conducting interviews for this analysis with (non-randomly selected) case managers and social workers who work with children with developmental disabilities, most had either not heard of the concepts or reported that "we profess to be guided by those principles, but in practice we are not." A few, mostly concentrated in a few county social services departments, provided clear evidence of efforts to make decisions in accord with those principles.

2) Total funding levels and specific funding limits for the system of services for individuals with developmental disabilities (family support programs, foster care and adoption) appear to be woefully inadequate. An in depth "market study" is needed on Colorado's rates and, in particular, their impacts on the ability to attract foster and adoptive families.

For example, in July 1987 the number of FRP "slots" available in Colorado increased from 50 to 65. Most of the increased slots were "funded" by decreasing the maximum monthly support allowance to each paticipating family by $50 a month. And, there are only 50 "Model 50" slots in the entire state. ("Model 50" slots provide funding to people who meet all Medicaid eligibility criteria except financial.) Foster care reimbursement rates depend on the age and special needs of children. The maximum rate for an infant is $185 per month: for an older adolescent, $318 month. Special needs allowances can increase monthly maximums by as much as $137 per month.

3) Those few funded permanency planning-type options (such as FRP, "Model 50," Home Care Assistance allowance [HCA] and subsidized adoptions), with limited numbers of "slots" (e.g., 65 and 50 for FRP and "Model 50" respectively, statewide) that do exist in Colorado are administratively complex to access and are fragmented between service systems with "fuzzy" responsibility boundaries. Once again, the research for this analysis identified few people who actually make decisions affecting children and their families who are knowledgeable of the range of options available, know which options would be most appropriate for different cases, and understand how to access them.

If permanency planning principles are the yardstick used to assess Colorado's system of services that comprise the alternatives to institutionalization, the results are bleak. Long-term congregate out-of-home placement appears to be the placement of choice -- in fact, but seldom publicly espoused -- for most children with developmental disabilities. (It will be interesting to see what impact the termination of the exemption for voluntarily placed children will have on long-term congregate living placements.)

Situation Analysis: Family Support Services

As is the case in many other states, most Colorado children with developmental disabilities remain at home. The state, county or community center board does not have a placement role. If and when the family (or individual members of a family) decides that the stresses and pressures of caring for a child with developmental disabilities are too great to bear, several options are open to it:

- Apply for an out-of home placement, usually through the community center board (CCB). Typically, the application will cause the child to be placed on a waiting list. If the "system" is working correctly, once the child is on a waiting list, s/he receives priority consideration for a FRP "slot." Thus, an application for out-of-home placement may result in at-home support through FRP, an out-of-home placement, or an extended stay on a waiting list. (Appendix D contains excerpts from the Family Resource Services Program Implementation Guide for Community Centered Boards, September 1986 revision, by the Division for Developmental Disabilities.)

- If the family meets Medicaid eligibility requirements, it may be able to obtain a HCA allowance through a county social services department. If the family meets all Medicaid eligibility requirements except income, it might qualify for a "Model 50" assistance slot.

If the "informal system" is working well in a county, an application for assistance to either the CCB or the social services department also should trigger an exploration of services and eligibility through the other agency. Our investigations indicate that this type of informal, cross-system investigation and referral occurs in some counties.

Presumably, if more family support services existed, if family support allowances were more realistic in dollar level and length of commitment, and thus if more families were prepared to use family support services, then fewer children with developmental disabilities would require out-of-home placements. However, those "ifs" are only "ifs" in Colorado. Unfortunately, we see few signs on the horizon to indicate Colorado is philosophically or fiscally seriously inclined to implement a comprehensive family support program similar to Michigan's mental health-type family support model (described in the Section V).

We are not critical of the administration of the family support service programs in Colorado: quite the contrary. Rather, we regret the state's overall lack of commitment and direction, and the limited resources available for use. Without an aggressive, well designed and funded, family support program, the entire hierarchy of services -- as alternatives to institutionalization -- is rendered ineffective. The problem is lack of state commitment, direction and identified responsibility and , thus, the virtual absence of constructive state policy and funding.

Situation Analysis:
Foster Care

Presumably, if more family support services existed and if more families were prepared to use family support services, fewer children with developmental disabilities would require voluntary out of home placements. However, as was discussed in the previous section, family support services in Colorado are very limited.

In Colorado, the State Department of Social Services administers or supervises all public assistance and welfare activities of the state, including child welfare services [26-1-111]. Funds to support adult and child foster care are allocated by the Colorado State Legislature to the State Department of Social Services who redistributes them to county departments of social services. The Department of Institutions through the Division for Developmental Disabilities has lead responsibility for funding and ensuring the provision of services to people with developmental disabilities. A few facilities and services are managed directly by the Department, but most are operated through local, private, nonprofit, community center boards (CCBs) and contracted service providers. Foster care is a noticeable exception (as is the education of school-aged children).

Individual foster care placement and services decisions for children are made jointly by county departments of social services and the juvenile courts. Voluntary placements for children with developmental disabilities were specifically excluded by SB 26 from court involvement by the Colorado Childrens Code until 1987. They now are included. Placements are administered and funded locally by county departments of social services through their child welfare services programs. Voluntary placements have not had the same protections under law as court ordered placements. The impacts of the termination of the exclusion are not yet known.

The Department of Social Services is the primary provider of out of home placements for children with developmental disabilities. Currently, there are 400 children with developmental disabilities placed in the social services foster care system. Approximately one-half of the placements are voluntary and one-half are court ordered. As of September 1, 1986, the Department of Institutions had only 105 children with developmental disabilities in its three Regional Centers.

The $30,000,000 annual state foster care appropriation is allocated to counties according to a formula. Counties have some discretion in allocating these funds among foster care and approved alternatives to placements (e.g., family support, day treatment programs, and family therapy). However, for obvious legal and financial reasons, court ordered foster care placements take priority over voluntary placements. Further, many county departments of social services do not give highest priority attention to voluntary placements for children with developmental disabilities. Thus, children in voluntary placements do not have the same legal protections as do children in court ordered placements.

The consequences of the lower priority given to voluntary placements for children with developmental disabilities, have been predictable. In late spring 1986, several Colorado counties' foster care budgets were depleted, but legal obligations to make and fund court ordered foster care placements continued. Thus, two large urban counties not only stopped making new voluntary placements but also began discharging voluntarily placed children with developmental disabilities. The foster care placements of an estimated 200 children were placed in jeopardy. The situation was temporarily ameliorated by a supplemental legislative appropriation of $312,000, but a permanent solution was not achieved. The situation can be expected to recur, and voluntary foster care placements of children with developmental disabilities again will be jeopardized.

Adults age 18 and over [CRS 19-1-103-2] with developmental disabilities (and who are receiving or are eligible to receive services in programs administered by the Department of Institutions) do not qualify for adult foster care funding or for services through social services [1979 Supl. p. 147; 1977 SB 160]. This legislated prohibition against county departments of social services providing foster care services and placements for adults age 18 and over with developmental disabilities, leaves the status of foster care placements for children ages 18 through 21 in question. (Note: people over age eighteen who are under court order are not defined as adults.)

Thus, although the State of Colorado has had a commitment for more than 50 years to assist children with developmental disabilities and their families, and despite the long term trend in Colorado toward placement of children with developmental disabilities in less restrictive environments, there is a disparity within the social services system. Generally, there are no specified funds for foster care for children with developmental disabilities. Funding for all court ordered and voluntary child foster care is appropriated and allocated as one to county departments of social services. Voluntary foster care placements cannot compete effectively for limited foster care funds within county social services departments. Those funds are allocated first to court ordered placements. Additionally, few county departments of social services have been arranging for foster care placements for children with developmental disabilities as a high priority.

In Colorado, the developmental disabilities system has primary responsibility for funding and ensuring the provision of services to people with developmental disabilities. The system, its organizations, and its services exist solely to serve this population. However, it does not have responsibility for funding or arranging foster care placements for children with developmental disabilities.

At least partially because of the crisis in foster care funding that developed in 1986, the Colorado State Legislature that year appropriated $15,000 to the State Department of Social

Services for a study of foster care funding/administration. The study was not initiated. Now, in summer 1987, the State Department of Local Affairs is preparing to issue a Request for Proposal for a comprehensive analysis of foster care in Colorado. The study's primary funding will be from the Community Development Block Grant, but the $15,000, 1986 legislative appropriation will be included. This Department of Local Affairs-coordinated study will investigate foster care in Colorado starting from the most basic of questions. Although the study's focal issues and questions are being refined, the items to be addressed will be similar to those listed in the study's original statement of rationale, "Rationale for a Foster Care Study," dated October 7, 1986.

- Program policy decisions at the local level affecting foster care expenditures.
- Is the current foster care allocation formula appropriate and equitable?
- Do all children in placement meet the placement criteria?
- What is the effectiveness of placement, by type of facility?
- Are consistent decisions being made around the state with regard to alternatives and placement?
- Are court decisions consistent around the state?
- What is the effect of "special circumstances" in counties upon the potential foster care population?
- Are our current resources and programs within the Department and other child caring programs sufficient to meet the "real" out of home care need in the state?
- What philosphical differences exist between counties that may offset decisions concerning foster care placements?
- What are the available resources and gaps in services?
- What are the rate policies in all relevant Departments?
- What is the fee collection structure in all relevant Departments?

Situation Analysis: Adoption

Under permanency planning principles, adoption (in any of its several forms) should be preferred over long-term foster or congregate care placements. Our research uncovered no evidence that such an ordering of preferences exists among Colorado's service providers and arrangers. Adoption appears to be the placement of last resort for most children with developmental disabilities in Colorado.

Adoption is another weak link in Colorado's system of services. In addition to the philosophical barriers (see Section VI), widespread use of adoption as an alternative is limited by: (1) adoption subsidies may not exceed the cost of foster care reimbursement and thus are not realistic nor attractive, (2) unlike foster care, may jeopardize a child's Medicaid eligibility (but not necessarily so), and (3) conceivably could jeopardize an adopting family's Medicaid eligibilty (Hill, 1982). Also, within county social services budgets, subsidized adoption funds are merged with foster care funds.

Interestingly, subsidized adoption is an active "program" in parts of Colorado. Like so many other "permissive programs" which may be socially desirable but are not legislatively mandated, it is neither widely known nor universally used across the state. Subsidized adoption commitments are subject to annual review but, reportedly, once established they tend to continue, often until the child's 21st birthday. Because adoption subsidies may not exceed foster care rates, representative maximum subsidies are $318 per month for a youth between ages 15 and 21, and $185 for an infant between birth and eleven months of age. In addition, adoptive parents of children with developmental disabilities can receive up to an additional $137 per month for special needs (e.g., serious medical involvements). Despite the overall weakness of the adoption component of the system of alternatives in Colorado, one of the more interesting, subsidized adoption, is under-utilized.

Conclusion

Most of Colorado's components of an alternative system are permissive, non-entitlement programs and thus are used and administered inconsistently across the state. Uncertainties about program responsibilities have plagued Colorado's system of services for children with developmental disabilities for the past several years, and have accentuated the tendency for agencies to be programatically unaggressive -- to not pursue permanency planning-based options.

Section V describes one permanency planning project that Colorado should consider as a "model." Section V's description serves as an lead-in to Section VII's policy recommendations.

SECTION V

A MODEL PROGRAM: THE PERMANENCY PLANNING PROJECT, MICHIGAN DEPARTMENT OF MENTAL HEALTH

The Michigan Permanency Planning Project represents the only widely known, well-developed statewide planning initiative specifically targeted at children with developmental disabilities. As such it is a "state-of-the-art model" of how services can be planned and administered. Several important aspects of the project have already been described in this report, (e.g., the family support program, the use of parent/agency agreements, and the initiative to take all children out of congregate care facilities). Other aspects of permanency planning described in this report are used or were developed by the Michigan project, including adoption subsidies, innovative adoption strategies, and caseworker efforts to ensure permanent care for children. Several other aspects of the Michigan project warrant discussion because these pieces together form a comprehensive demonstration of how permanency planning can be implemented for children with developmental disabilities. The following aspects of the project are described and discussed: 1) fiscal and complementary state supports, 2) staff training activities, 3) practices surrounding the making of permanent plans for previously institutionalized children, and 4) case management practices surrounding the provision of a complete array of services.

Fiscal and Complementary State Supports

As a result of an adoption initiative (assisted by a grant from the Administration for Children, Youth and Families [ACYF]), the Michigan Department of Mental Health (MDMH) decided to change the orientation of its service system from one "that encourages and supports children's estrangement from their families through the use of open-ended voluntary placments, to one that provides services to support the intactness of families" (MDMH, 1986). This reorientation was supported by an additional grant from ACYF and by the following concurrent Michigan initiatives: 1) the allocation of state monies to community-based agencies specifically for the development of family support services/resources, 2) the enactment of the Family Support Subsidy Act that provides a monthly subsidy (of $243.33) to families of children with severe developmental disabilities who are living at home, and 3) the initiation of an individual Medicaid waiver program to provide reimbursement for home-based services as an alternative to out-of-home institutional placements.

Training Activities

Presently, four regional permanency planning specialists and a director are employed to orient Department of Mental Health workers to the principles of permanency planning. Specific regional centers are targeted, and extensive training efforts are conducted for those agencies' caseworkers. Subsequently, a permanency planning specialist is assigned to assist caseworkers in pursuing permanency planning principles and procedures in their casework with families. The MacComb-Oakland Regional Center is the oldest and most well developed of the regional centers in incorporating permanency planning.

Training curricula have been prepared to support this project in cooperation with the Spaulding Center for Children in Chelsea, Michigan. The training is geared toward persons involved in all levels of care for children (e.g., parents, administrators and social workers). Materials are designed to help workers assess children's abilities as well as disabilities. In addition, training is geared to change attitudes that perceive children with disabilities as being unadoptable, creating too much stress on families, or being unable to progress. Project staff serve as role models for case managers, gradually convincing case workers that permanency planning goals are worthwhile, and then gradually shifting case planning reponsibility to the case managers.

Aside from training workers and parents in permanency planning, the project is also engaged in public awareness activities that are very crucial for informing legal and medical professionals, many of whom do not embrace permanency planning for children with developmental disabilities. Many physicians continue to make out-of-home placement recommendations to new parents of children with disabilities. Also, Michigan recently hired an employee to act as a liaison with perinatal hospital units and to explain the permanency planning initiative and the inappropriateness of congregate care facilities for children.

Practices Supporting Permanency Planning for Deinstitutionalized Children

Permanency practices are spurred in Michigan by the presence of an important initiative calling for the removal of all children from out-of-home group care (e.g., group homes, nursing homes and institutions) and into family settings. Michigan has been successful in reducing the number of children in group care facilities to under 100 across the state. The drive to place all children in permanent family arrangements has given Michigan planners experience in some unique circumstances pertaining to the deinstitutionalization of children. The goal of Michigan workers is to take children who may have been placed in out-of-home congregate care for many years, and to attempt reunification with the birth family.

Reunification, however, has sometimes proved to be a difficult process. First, as with any family, fiscal and other circumstances (e.g., single parent family, parental alcoholism, and extensive need for sitter or respite services) may prevent the family from being able to offer adequate care. However, the history of institutionalization poses other unique barriers to reunification. After many years of separation and perhaps many moves of the child to multiple service settings far from home, parents may have little or no emotional attachment to the child. Parents may have moved out-of-state. They may have no confidence in their ability to care for a child with disabilities. They may be content with the services the child has received and see no reason to move the child. Agressive, decisive casework is necessary to help parents see the urgency of decision-making regarding long range plans for the child, and the urgency of permanent care.

When reunification is not possible, adoption is deemed to be the appropriate alternative. In these cases, a parental voluntary release is required to legally free the child for adoption. Staff training materials focus in part on how to encourage and guide parents through the voluntary release process.

However, some parents are unwilling to release their child voluntarily. In these situations, it is necessary to make children legally free through the filing of a neglect petition. By the end of the project grant period, two Michigan children were adopted by involving protective services and making the child a permanent ward through the child welfare process. An alternative presented to Michigan workers is to file neglect petitions when parents refuse to voluntarily release children but will not participate in permanency planning. It can be argued that parents who have placed children in congregate care and have no or little involvement for many years, have effectively abandoned them. This can provide a sufficient basis for a neglect petition.

This strategy however generated strong opposition. The Department of Social Services may be reluctant to accept these cases for referral on the basis of abandonment because, in their view, the parents have made plans for the children by placing them in out-of-home congregate care. Judges and others may deem the neglect petitions "unfair" because some families may have been simply following professional advice and practice when they placed their children. Project personnel anticipate that barriers to freeing children for adoption through court terminations on the basis of neglect will be eliminated through: 1) successful completion of termination in one or two pilot cases, and 2) development of a state policy and adjustment of state mental health codes.

Case Management Practices Surrounding the Provision of a Hierarchy of Services

Michigan has a unique and powerful policy that greatly assists in permanency planning endeavors. Parents simply are not offered the option of long term congregate care or long term foster care. They are prepared to either keep the child at home or to release the child for adoption. To complement this seemingly restrictive policy, Michigan permanency planning caseworkers adopt the attitude of "do whatever it takes" to make family reunification possible. This stance is possible and defensible only because of Michigan's rich family support service options (including cash assistance) described in Appendix A. Permanency planning is provided for every child with developmental disabilities (including those with severe physical or behavioral challenges) who request assistance from the Division of Developmental Disabilities.

When a family indicates interest in a voluntary placement, the first task of the social worker is to put as many family supports into place as possible to alleviate family stress and thereby maintain the child at home. However, some families require temporary foster care. Foster care efforts are supported by Michigan's aggressive and innovative recruitment of foster parents, relaxed policies regarding the types of families that can serve as appropriate placements (e.g., single parent families and elderly foster parents) and by the higher foster care rates paid to foster families with children with disabilities than those paid by the Department of Social Services.

As was described earlier, before a child is placed in foster care, a parent/agency agreement is written that defines the conditions, timelines and responsibilities necessary to return the child home. Six month administrative reviews of parental agreements are made by project staff to assure that progress is being maintained on the permanency plan. Continuous assessment is expected of case managers.

If a child is young (under age 5) caseworkers will not push for voluntary release for adoption unless there is no hope for family reunification. Nor will caseworkers seek voluntary releases for other children unless someone has expressed a clear interest in adopting them. However, when adoption looks possible for a child and when foster care has exceeded (or is about to exceed) one year then caseworkers will agressively seek parental release.

The potential for securing an adoptive placement is enhanced by the numerous adoptive strategies that caseworkers have at their disposal in the interest of a permanent caregiver for the child (i.e., open adoption, permanent foster care and co-parenting). Michigan also provides substantial adoption subsidies for children with special needs and efforts have been initiated to begin post-adoptive support services.

When all of these practices and services are taken together, Michigan clearly provides a model example for Colorado to consider when planning to implement permanency planning for children with developmental disabilities.

SECTION VI

BARRIERS TO CHANGING THE CURRENT SYSTEM STATUS IN COLORADO

Philosophical Barriers

In addition to the multitude of difficult public policy and fiscal issues that family support, foster care and adoption programs raise, the fundamental philosophical issue of individual family versus government responsibility for the care of children with developmental disabilities, poses a serious dilemma. There are two basic perspectives on the balance between family autonomy and government intervention. The one side argues that public assistance to families preserves human dignity while reducing the need for more expensive program alternatives (Featherstone, 1979). The opposing argument holds that families are responsible for their children, and government intervention (including support) is wrong morally, philosophically and financially (Berger & Neuhaus, 1977).

If the primary goals are to strengthen families and ensure continuing relationships for children, and if one accepts the principles of permanency planning, then it makes sense to define eligibility very broadly for family support services. In this vein, for example, Moroney (1981) advocates the universal provision of support services to families caring for a member with developmental disabilities at home. In contrast, most of Colorado's family support program eligibility requirements tend to be quite stringent. (For example, see Appendix D.)

Fiscal Barriers

In many ways, family support programs are most difficult to deal with in practice. The "bottom line," the strongest argument against broad eligibility for family services, is fiscal. Although strengthened family support programs undoubtedly would enable some people to be at home who otherwise would be in a more expensive out-of-home placement, it is not known how many families who already are caring for a member with a disability at home would accept support. The same fiscal impact fears have hounded the numerous proposals that have been advanced for financing at-home care for the aging population through Medicare and/or Medicaid (Rowland, 1987). Reportedly, the widespread fiscal concerns in Colorado also have led to adoption of a relatively limited array of reimbursable family support services. (See, for example, Appendix D)

Other fiscal barriers have been discussed earlier in this analysis, particularly in Section IV. Some are barriers to public sector funding while others are barriers faced by potential adoptive parents. Primary among them are the permissiveness of Colorado's legislation (the absence of a mandate) coupled with mingled (or merged) county foster care-subsidized adoption funds; fees charged to parents by county departments of social services, for example, for foster care but not by the Department of Institutions, for example, for Regional Center services; and, the absence of adoption incentives (some would argue the presence of disincentives) involving rate levels and potential loss of Medicaid eligibility.

Resistance from Institutional Providers

Further, as one would expect, current providers of institutional services often tend to resist the spread of family support services -- but typically are less than candid about their true reasons for resistance. The current structure of human service delivery is primarily institutional, and the problems and opportunities families present seem to confound or be confounded by that structure. The family often is both the provider and the consumer of services at the same time. Government regulations, policies, guidelines, and funding formulas do not typically or easily deal with the somewhat simultaneous overlap of roles that occur in providing family support services.

One response to these issues has been an increase in the number of family support programs that are using cash subsidies and/or vouchers. Fourteen out of the seventeen states included in the 1984 survey conducted by the New York State Office of Mental Retardation and Developmental Disabilities (Bird, 1984) used a cash subsidy and/or voucher mechanism -- although they tended to be limited in scope. Voucher-type approaches for family support services are philosophically compatible with the principles of "privatization" (Savas, 1982). In contrast, Colorado's FRP permits spending only in accordance with a carefully structured spending plan and, in most cases, service providers are reimbursed directly from vouchers submitted to the CCB. (For example, see Appendix D)

Judicial Barriers

Although this analysis has not focused on judicial barriers, two are evident: first, reportedly, judically-caused adoption delays of as much as four years have been experienced in Colorado. Second, the annual rotation of family court judges in Colorado appears to prevent the development of judicial expertise in this complicated area.

Summary

The information presented in Sections III and VI says clearly that the barriers to changing the current system status in Colorado are pervasive and formidable:

1) The system needs overhauling -- not just finetuning,
2) philosophical opposition to intervening in families,
3) fear of an uncontrollable fiscal burden,
4) absence of clear responsibilities and, thus, leadership at the state and local levels, and
5) resistance (not always forthright) from existing institutional providers,
6) judicial barriers, and
7) the pervasive problem of parental resistance.

(For additional information about system barriers, particularly regarding adoption of children with developmental disabilities in Colorado, see Hill, 1982).

SECTION VII

POLICY RECOMMENDATIONS

The following policy recommendations are made to the Colorado Developmental Disabilities Planning Council regarding further changing the Colorado system of care for children with developmental disabilites to embody a permanency perspective. The recommendations reflect the philosophies and values that have been explicitly stated throughout this report and the cumulative experiences in this and other states. The policy recommendations and conclusions presented in the Preliminary Foster Care Policy Analysis (Applied Management Corporation & Human Services Research Institute, 1987) are repeated in Appendix E. The authors also urge the readers to review and reconsider the recommendations that have been made in other analyses of Colorado's system of alternatives, such as Hill (1982, chs. 6 and 7).

Recommendations and Rationales

1. Organization of the System

The system of services for children with developmental disabilities needs to be organized so as to substantially reduce the ambiguity and confusion about agency management/administrative responsibilities at the state and local levels.

A. Neither the Department of Institutions/Division for Developmental Disabilities (and the CCBs) nor the Department of Social Services (and county departments of social services) is adequately staffed, funded or clearly legislatively empowered to administer and monitor on its own the total system of services for children with developmental disabilities. Social services and developmental disabilities agencies need to fill important system roles but, clearly, a designated strong lead agency is needed. Between the existing agencies, we slightly favor the Department of Social Services, but only if the Division for Developmental Disabilities provides strong programmatic input and the CCBs are involved in the delivery of services. (See Appendix E.)

B. The two most important considerations in deciding about agency designation are (1) desire and motivation, i.e., which agency really wants to be responsible and will work hard to make the system function well for children and families?; and (2) philosophical commitment to permanency planning principles.

C. The upcoming analysis of foster care in Colorado, sponsored by the Department of Local Affairs, should investigate the desirability of a Children's Bureau in Colorado. Several states have established "Children's Bureaus," using quite different models, which may or may not be helpful in Colorado. Typically, Children's Bureaus tend to house administration of services for children because such services tend to involve and require cooperation among multiple state agencies. Children's Burueaus may include functions often found in departments of education, developmental disabilities (or mental retardation), health, mental health, and social services.

D. Whichever state agency ends up with lead responsibility should administer both the foster care and the family support service programs for children with developmental disabilities. (See Appendix E for rationale.)

E. Designation of lead agency (between the Department of Institutions and the Department of Social Services) also will affect the need for state legislation to deal with children between 18 and 21. (For additional information see, "Foster Care for Children With Developmental Disabilities: Preliminary Policy Analysis.")

2. <u>Formal Commitment to Permanency Planning Principles</u>

Prepare and adopt a state policy expressing formal commitment to permanency planning principles and objectives for children with developmental disabilities. Colorado's permanency planning policy statement should include the following principles:

A. Permanency planning principles should be applied to interventions with families having children with all types of disabilities (e.g., developmental, medical, physical and behavioral).

B. Long-term out-of-home placements in congregate care facilities are not acceptable placements for children with developmental disabilities. Permanent family-based caregiving arrangements for children should be developed for children as alternatives to institutionalization.

C. The natural family is the first residential setting of choice for children with developmental disabilities.

D. Foster care placement is acceptable only as a temporary measure until a child's permanent plan has been executed.

E. When continued residence in the natural family is not possible, adoption is the placement of choice. To facilitiate adoption, innovative adoption strategies should be pursued. Parents should be actively encouraged to voluntarily free the child for adoption if they are not able to reunite with their children.

3. <u>Establish and Fund a System of Components</u>

Establish, implement and fund the service components that make up a successful permanency planning-based service system. Formal statements supporting permanency planning are valueless unless the components comprising such a system are in place.

A. Permanency planning begins with comprehensive family supports that can prevent out-of-home placement requests. Family supports need to be flexible enough to help the needs of individual families. Families need to be empowered by family supports and be given the opportunity to use cash assistance at their own discretion. Services that families may need to purchase (e.g., respite care and parent training) must be available.

   1. Colorado's rules and mechanisms for obtaining respite care need to be reworked. Respite care is perhaps the system's "best bargain" and should be aggressively "marketed," but it tends to be managed and authorized rigidly and inflexibly.

   2. The state should encourage, train and support local agencies to develop and use "multi-jurisdictional pools" of service resources (such as foster care families and specialized group homes) as an efficient method for filling gaps in the hierarchy of services.

B. Aggressive foster care recruitment techniques and substantial foster care rates are needed to develop an adequate pool of appropriate foster care placements.

1. Foster care rates need to be raised to a level that attracts competent people into the foster care system.

2. Gaps need to be filled in the array of out-of-home placements in virtually all catchment areas across the state. The most frequently cited gaps involve:

   - older children (as they approach 18 and 21), particularly children with serious medical involvements; and
   - children with "dual diagnoses."

C. Successful adoption of children with developmental disabilities require more liberal adoption subsidies, and subsidy commitments longer than one year; and adoptive families must know that a child's (or the adoptive family's) Medicaid coverage will not be lost by accepting an adoption subsidy. State guidelines must permit flexible adoption arrangements.

4. <u>Implement Decision Criteria</u>

Establish and implement criteria that convert principles and concepts into effective and appropriate decisions and decision processes.

A. State child welfare standards need to reflect permanency planning outcomes. These may include, for example, maximum duration of stay in foster care, percentage of children returned home or placed in adoption, reduced number of placement disruptions for any one child.

1. The state system decision criteria presented in Section III and the individual case manager/social worker decision criteria in Appendix C may serve as models for building criteria for use in Colorado.

B. In compliance with P.L. 96-272 and the 1987 action of the Colorado State Legislature, judicial reviews should be (1) conducted to ensure that reasonable efforts have been made to prevent out-of-home care and (2) carefully designed and implemented to ensure that continued out-of-home care is warranted. Judicial reviews should be complemented by regular supervisory casework reviews to ensure that progress is being made to achieve permanent placement for children.

1. The Colorado Developmental Disabilities Planning Council (or a similar concerned but independent agency) should commission a longitudinal study of the impacts of judicial reviews of voluntary placements on length of out-of-home placements and related quality of service variables.

C. Upon acceptance into foster care, parent/agency agreements should be written specifying the timelines, services and responsibilities of each party in ensuring the return of each child to the home, or in establishing an alternate permanent plan. Parents need to be advised from the start that long-term foster care or congregate care is no longer an option available to them.

D. Guidelines should be developed to help caseworkers assess and identify the permanent plan option of choice for various circumstances.

E. Quality assurance mechanisms must be activated to ensure on-going quality of care in foster care and adoptive settings.

5. <u>Values-based Training for Professionals and the Public</u>

Extensive training is needed to educate child welfare and developmental disabilities workers that permanency is a viable option and right of all children. Permanency planning for children with developmental disabilities is still novel.

A. Public awareness activities also need to be focused on parents and legal and health professionals.

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Guidelines for application of criteria for selection of families for participation in FRSP:

1. Out-of-home placement:

   (a) child is on waiting list for out-of-home placement (Regional Center, HCB-DD facility or for placement through social services) and it is the opinion of the committee that child would be placed as soon as an opening occurs; or child is not yet on waiting list(s) for placement but placement is being actively pursued by family.

   (b) although family is not pursuing placement, it is the judgment of social services or CCB professionals that child is at risk of placement within the year without addition intervention.

2. Type and severity of handicapping conditions/behaviors:

   (a) decisions regarding level of cognitive functioning should be based on available test results.

   (b) decisions regarding physical disabilities are to be based on available medical information

   - where a range in scoring is indicated, a higher score should be given for a more severe condition.

   - higher weight of nonambulatory should be given to older children and/or children whose weight and size contribute significantly to the burden of care.

   - other factors can be considered as determined by the committee: examples of these could include degenerative nature of syndrome/disease, other medical/physical factors such as severe allergies, frequent respiratory infection, etc.

   (c) decisions regarding this should be based on review of all available information including information from families, reports from referral source, professionals, etc.; examples of other severe behaviors could include prolonged screaming, crying, self-abusive behavior, aggressive behaviors, etc.

   (d) level of care required:

   - points should be given for older children lacking toileting, eating, dressing, and/or other basic self-care skills

- examples of factors for the committee to consider are need for frequent positioning, inability to assist with transfer to/from bed, chair, lack of wheelchair mobility, need for constant supervision due to severity of self-abusive or other dangerous behaviors, etc.

- decisions regarding this should be based on available information. Consideration might be given to need for suctioning, gastrostomy feeding, frequent need for oxygen.

3. Age of child - self-explanatory.

4. Single parent family - self-explanatory.

5. Financial expenses of the family -

   expenses to be considered here are those that a family might have due to having a child with a developmental disability and that are not covered by insurance or public funds. (Expenses that would be considered "out-of-pocket" expenses.)

6. Financial resources of family -

   general economic resources available to family should be considered here.

7. Other characteristics of families -

   the scoring of this will require significant judgment by the committee and needs to be weighed very carefully. Examples of items that should/could be considered under this section are: supportive resources available to family, extent of support by extended family, family relationships, employment status, number of siblings in home, extent of family involvement with handicapped child, overall stress of family, other special needs in home, health status of family, etc.

8. Potential for success of Family Resource Services -

   What are the anticipated needs of family and the child with developmental disabilities; is it the belief of the committee that these needs can be addressed by the Family Resource Service Program?

   Can a plan be developed that will maintain the child with the family?

What is the likelihood that these types of services will be successful in preventing or delaying out-of-home placement?

9. Contribution of services available through FRSP to progress of child and family and/or prevention of regression of child and/or family.

What is the expected impact of these services on the family?

What is the expected effect on child and family if these services are not provided.

FAMILY RESOURCE SERVICE PROGRAM
CRITERIA FOR SELECTION OF FAMILIES

Family Name: ______________________ Child: ______________________ DOB: ______________

Date Reviewed: ______________________ Committee Members:

____

____

____

____

____

	WEIGHT	SCORE
1. Probability of out of home placement:		
a. child is currently on waiting list for out of home placement and/or out of home placement is being actively pursued (application for placement has been made with DSS or CCB)	5	
b. child is determined to be "at risk" of placement within next year by Social Services or CCB	3	
2. Type and severity of handicapping conditions/behaviors:		
a. Level of cognitive functioning		
Mild	1	
Moderate	2	
Severe	3	
Profound	3	
b. Physical disabilities:		
Severe hearing impairment	1	
Severe sight impairment	1	
Cerebral palsy	1-3	
Uncontrolled seizures	1-3	
Semi-ambulatory	1	

APPENDIX E

EXCERPTS FROM

FOSTER CARE FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

PRELIMINARY POLICY ANALYSIS

for

The Colorado Developmental Disabilities Planning Council

by

Applied Management Corporation
Denver, Colorado

and

Human Services Research Institute
Cambridge, Massachusetts

January 1987

but it requires restating the issue from who should administer a program to how it should be administered, what is acceptable/ desirable quality? What is desirable quality in Colorado? What do we need to do administratively to achieve desirable quality? Thus, the HSRI part of the analysis concludes with an assessment of some of the supports and strategies which could allow exemplary foster care programs and services for children with developmental disabilities to be administered in a generic child welfare system (See "Alternative Solutions").

APPLIED MANAGEMENT ANALYSIS

Policy Issues

The basic public policy issue is how best to meet the goal of ensuring that children (through age 21) with developmental disabilities receive needed 24-hour treatment and services, while preventing the disintegration of families, within reasonable State fiscal parameters. Then, recognizing the State of Colorado's long-standing commitment to children with developmental disabilities and their families, when out of home placement is the only alternative, how should the administration, program, and financing of voluntary placements be structured?

A first requirement, however, is to determine whether the complex needs of children with developmental disabilities and their families can be met best through placements out of the home. Because children, families, and contexts differ, there is no universally applicable answer. For children who need more care than their families are able to provide, the answer is mixed: for some, voluntary placements probably are the best answer; for others, alternatives such as family support services may meet the stated goal -- and several larger goals -- more effectively and at less cost. Colorado needs to be more aggressive in exploring the true viability of such alternatives as part of any effort to arrive at a long term public policy solution.

The second requirement is to determine which of two human services system will do a better long-term job of meeting the complex needs of these children and their familes. Each service delivery system has advantages.

Social Services System:

1. The structure, procedures, and people experienced in making foster care placements, already exist in the social services system. The social services system carries the mandated role of child protective agency. Major system changes are disruptive to everyone involved. No system change should be initiated unless substantive, service and/ or administrative advantages clearly will result.

2. Because the social services system is a "generic system" (responsible for the welfare of all children), foster care for children with developmental disabilities will be less segregated. Social services agencies are more likely to place children with developmental disabilities in settings designed for children as people -- rather than clustering children with like disabilities.

3. Although voluntary foster care placements have not competed effectively within some county social services departments, funding for voluntary placements may be less vulnerable as part of a larger purpose funding pool than if it was separate and more visible. Placements for these children may not receive any more legislated funding if they are separated from the larger pool. (Conversely, it can be argued that children with developmental disabilitites have a potent lobby that would be more successful in securing funding if foster care was separate and visible.)

4. County departments of social services also have access to federal and county funds for foster care placements. Transfer of responsibility out of the social services system may decrease the total amount of funds available for voluntary foster care placements (IV-B, IV-E, XX, and [illegible].

5. In most counties, services for children are provided on a sliding fee scale/ability to pay basis. This is not necessarily true of services provided through community center boards.

Developmental Disabilities System

1. Children with developmental disabilities are an integral part of this system's target population and will receive higher priority in competition for funds.

2. The community center boards, through their case management systems and personnel, are intimately knowledgeable with the needs of persons with developmental disabilities and the community resources that can meet them.

3. Under current legislation, community center boards already determine eligibility of children with developmental disabilities for voluntary out of home placements. And, CCBs are responsible for making eligibility determinations on court-referred children with developmental disabilities [pursuant to article 10.5 of title 27, C.R.S.]. Transfer of funding and responsibility to the developmental disabilities system would involve fewer agencies and, thus, simplify administrative procedures.

4. The developmental disabilities system has clear criteria for determining services eligibility (i.e., definitions of who is eligible to receive services through the system). The social services system does not use the developmental disabilities system's definitions or criteria. Transfer of responsibility to the developmental disabilities system would eliminate confusion and "catch 22" situations involving client eligibility.

5. The developmental disabilities system has an established program and (limited) funding for providing family support services. For some children and families, family support services and out of home placements are fungible alternatives. If voluntary foster care placements also are made by community center boards, the probability of making best choices among the alternatives would increase.

6. The developmental disabilities system would not be legislatively restricted in its ability to serve children ages 18 through 21.

Conclusions

The arguments are not convincing for transferring administrative responsibility for foster care for children with developmental disabilities and their families from the State Department of Social Services to the State Department of Institutions, Division for Developmental Disabilities. On the other hand, a clear need remains for clarifying and strengthening state policy and the existing program as administered through the generic child welfare system. For example, the current arrangement lacks for programmatic leadership ("vision," if you will): there is no apparent mechanism for keeping people in the foster care program abreast of the state-of-the-art and incorporating state-of-the-art into Colorado's programs. The Colorado Developmental Disabilities Planning Council should be actively involved in supporting such improvement efforts. Some beginning suggestions are included in the following analysis by Human Services Research Institute.

HUMAN SERVICES RESEARCH INSTITUTE ANALYSIS

Alternative Solutions

Given some of the strong commitments and resources required to adequately provide examplary foster care services for children with developmental disabilities, it appears that a specialized developmental disability agency can best provide these services. To cull from the practices of the model programs described, the following qualities and resources are required:

- a commitment to place all children with disabilties in a permanent family situation;

- specialized knowledge to access all available funding and other resources;
- specialized training of foster parents in the exacting physical and behavioral needs of some children;
- reduced caseloads in order to properly "cultivate" families to care for children with disabilties; and,
- an active recruitment effort.

Nonetheless, with certain supports and strategies, it may be possible to acheive this level of service quality in a generic child welfare system. Five of these strategies are: 1) specialized units; 2) specialized training; 3) expanded legal mandates; 4) technical assistance; and, 5) interagency collaboration.

Specialized Units

One solution to the problems encountered by generic child welfare services in administering foster care for children with developmental disabilities is the creation of a separate unit within the child welfare agency that deals only with children with disabilities. Such a unit would be able to develop the resources, expertise and specialized knowledge necessary to assure comprehensive services. Further, workers in this unit could have reduced caseloads in order to have the time necessary to cultivate foster care families. These workers could undergo specific training in normalization and other disability-related concerns. A specialized unit could spearhead progressive services for children with disabilities within the context of the generic child welfare mandate. One potential problem with this arrangement, however, is that specialized units are often the first to fall subject to budget cuts.

Specialized Training

Another alternative is to increase training for all workers in specialized disability-related needs and services. As was mentioned previously, the University of Washington has developed a program that has prepared training materials for precisely this purpose.

Expanding Legal Mandates

One option available to Colorado planners is to increase the protection of voluntary placements by assuring them the same court mandates that are available to neglected or abused children. However, while this may prevent the types of crises recently experienced, it does not solve the broader issue of the necessity for specialized knowledge as well as a concerted effort to make permanent family care placements available to children with disabilities.

Technical Assistance

The New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) has developed new initiatives designed to provide technical assistance to the State's Department of Social Services (DDS) in the care of children with disabilities who remain in foster care services under DDS licensure.

As a result of studies over the past several years, more than 2,000 mentally disabled children in DDS programs were identified who qualify for care in the Office of Mental Health (OMH) and OMRDD systems. A number of the DSS foster care facilities were serving such high concentrations of disabled children that the agencies made a joint policy decision that these facilities should transfer licensure and supervision from DSS to certification by OMH or OMRDD systems.

However, only 45% of the children found in the DDS rolls to be sufficiently disabled to warrant care in either the OMH or OMRDD systems are being cared for in the facilities recommended for transfer by the Interagency Transfer Action Plan. The residential sites recommended for transfer from DDS to OMRDD house ten or more children. The 1700 certified family caregivers in the OMRDD family care system who care for more than 3000 disabled persons, may serve up to six clients but most have only one or two clients in order to enhance the home-like environment which the program seeks to provide. A significant number of mentally disabled children will remain in the DDS foster care system, even after all recommended transfers occur. The state agencies hold regular ongoing discussions regarding their appropriate roles in serving the OMRDD eligible and OMH eligible children who remain in the DDS foster care system.

Because of the specialized expertise available in OMH and OMRDD, the agencies have considered actions that could be taken to ensure that all children with disabilities who are in DDS foster care services receive specialized support. Both mental hygiene systems have contributed to the social service agency's development of compliance standards for the assessment of agency operations. OMRDD has requested additional resources in order to:

- provide training to DDS caseworkers and foster care families.
- provide technical assistance to foster care agencies serving children with mental retardation and/or developmental disabilities for development of service relationships with community-based agencies that can provide support to the children and their families.
- provide appropriate screening, assessment, and program planning mechanisms for new referrals.
- create and maintain a centralized registry to guarantee continuity of services and to facilitate new program and residential resource development as children grow into adulthood.

Interagency Collaboration

Another alternative to transferring services from one department to another is the purposeful design of interdepartmental collaboration. Massachusetts is presently piloting a project in which permanency planning objectives for children with developmental disabilities are prepared by interdepartmental collaboration. Representatives from the Department of Public Health, Department of Social Services, and the Department of Mental Health join in case review and planning. Each department contributes its unique perspective, resources, and expertise. Previous studies had determined that many children with developmental disabilities "fall through the cracks", i.e., either a specific department did not have a clear mandate to serve that child or an individual agency did not possess the range of services required by children with disabilities. With interagency collaboration, multiple supports can be assembled for the purpose of achieving permanent nurturing family ties. In the following case example foster care services were avoided through interagency collaboration.

> This child was referred to the Department of Social Services at 10 months of age by the hospital where she had resided since birth. Because of cystic fibrosis and a chronic lung disease she had multiple medical care needs, including constant oxygen and a feeding tube. Her parents were very involved with her but hesitant to deal with her medical care at home with two other pre-schoolers. They were requesting an interim placement until she could be weaned from the special equipment. The case was referred to the Collaboration for Families for permanency planning. With the establishment of multiple support services, and with supportive casework the parents were able to bring their daughter directly home from the hospital. Services were funded through the Department of Public Health or Medicaid included twelve hours of home nursing each day, special equipment and supplies, day care for the other children during the transition and early intervention services. Case management by the Collaboration for families was funded by the Department of Social Services. Once the transition plan was successfully completed and services in place, the case was discharged to the Department of Public Health for on-going case management and the Department of Social Services for respite care. The child has made extraordinary developmental gains by living with her parents. Family stress has been largely relieved through reunification and the provision of adequate support services. (Collaboration for Families, 1986)

The Massachusetts Collaboration for Families has subsequently written a draft paper designed to enable each individual Department to implement a shared philosophy of permanency planning for children with developmental disabilities. The paper spells out ways that each agency can work to implement a permanency planning philosophy and suggests interagency strategies for coordinated planning that better meet the needs of these children.

Three areas issues have been identified as needing inter-agency collaborative efforts. These are:

1. Case Management services for children in out-of-home care served by the three agencies.
2. Need for a specialized foster care system particularly designed for children with disabiliteis...
3. Preventive services for families such as respite, case management and all types of in-home supportive services need increased funding. Innovative models of interagency coordination of service delivery could be designed to demonstrate the effectiveness of such intense family services. (Collaboration for Families, 1985)

Use of Private Agencies

One final option available to state planners concerned with foster care services for children with developmental disabilities is the use of private contracted agencies to provide these services. This option may be more feasible in those states that have a standing tradition of the use of private agencies. Nonetheless, contracted services can help assure that developmentally disabled children are receiving an active, agressive case management that is tempered with the special expertise needed for working with this population.

State of the Art in Foster Care Services for Children with Disabilities

Although one department may have certain advantages over another in the administration of foster care services, certain "best practices" became evident in the course of this study, which are important irrespective of the particular agency in which foster care services are delivered. The adoption of these practices can help ensure that children with disabilities are placed in a family rather than in a group setting, and that, to the extent possible, permanent placement is achieved. To conclude, the following is a list of such practices. Many of these have been drawn from recent testimony given by the Massachusetts Collaboration for Families to the State Legislative Special Commission on Foster Care and from various materials of the Community Integration Project of the Center of Human Policy, Syracuse University.

- Extensive training for social work staff on permanency planning, adoption procedures, access to funding sources, generic community services, adaptive equipment, and principles of normalization;
- Involvement of case management from other agencies in addition to that provided by the supervising agency. (This is crucial in gaining access to ongoing interagency services and planning.);
- Skill training for foster families on the medical, behavioral, developmental, and emotional needs of children with disabilities;
- A clearinghouse of foster families who are specifically available to work with children with disabilities;
- A system of reimbursements that encourages families to consider foster care and which establishes fair and appropriate rates for children with extraordinary care needs. This should include timely reimbursement for special adaptive equipment, travel to medical services and other extraordinary costs;
- Substantial access to and availability of respite care including policies that permit paid in-house respite care by family friends and neighbors and other non-institutional respite alternatives;
- Foster parent support groups, and other means of parent-to-parent support;

- Adoption of a formal policy of permanency planning for children with disabilities including a plan for seeking the termination of parental rights and development of an alternative legal family when the biological family is not able or willing to accept parental responsibility for the child;
- Active support of alternative permanent arrangements such as shared care or open adoption;
- Reimbursement policies that encourage adoption of children with disabilities by foster parents;
- Extensive in-home support of foster families including professional services, home health services, and 24 hour emergency response;
- Clear separation of policies, training and procedures for foster care placements of children versus adults with disabilities;
- Innovative and aggressive recruitment of persons who are interested in and suitable to provide foster care for children with disabilities.

ALTERNATIVES TO INSTITUTIONALIZATION: APPLICATION OF PERMANENCY PLANNING PRINCIPLES TO SERVICES FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES