THE POLICY PAPER ON SUPPORTING FAMILIES 1999 CDDPC
COLORADO DEVELOPMENTAL DISABILITIES PLANNING COUNCIL
PREFACE

The Colorado Developmental Disabilities Planning Council is pleased to present this revised Policy Paper on Supporting Families. This is one of a series of policy papers that present the consensus thinking of the Colorado Developmental Disabilities Planning Council.

In August 1993, the Council invited people with disabilities, parents, advocates and other professionals to join with them in considering a number of key issues facing people with developmental disabilities in Colorado. An underlying assumption was that families whose sons or daughters with developmental disabilities living at home in Colorado live much of their lives without adequate family support.

After much exploration, deliberation and soul searching, the Colorado Developmental Disabilities Planning Council arrived at consensus and established the Policy Paper on Supporting Families. This Policy set the Council’s focus; dictated Council decisions; permeated all aspects of Council work and established the basis for the use of Council funds. Now, in 1999, this Policy has been revised to allow for continued direction to the Council.

We expect this Policy to challenge the system. We expect to use this Policy to educate our lawmakers. We expect to use this Policy to direct our advocacy efforts. Most importantly, we expect the citizens of Colorado to hold us accountable for our actions based on this Policy.
POLICY

The Colorado Developmental Disabilities Planning Council affirms, promotes and supports within the obligation for good stewardship of public resources the principle of supporting families with "whatever it takes." Families, however constituted, are the greatest natural resource available to children of all ages; the major providers of support, care, and education of children; the experts; and a wealth of diversity in culture and ethnicity. Each family is unique and must drive the planning, implementation and evaluation of the services and supports they receive.
INTRODUCTION

The Mission of the Colorado Developmental Disabilities Planning Council is to advocate in collaboration with and on behalf of individuals who have developmental disabilities, for the establishment and implementation of public policy, which will further their independence and inclusion in the community. The Council works to assure that individuals with developmental disabilities and their families receive services, supports and other assistance and opportunities which respect and value diversity in culture and ethnicity. This policy addresses the concept of supporting families who have a member with a developmental disability. It is meant to cover a greater spectrum than any specific program or service.

"The family is the place for the early education of the child. The child's instruction may be had in school; but his heart and character should be developed and molded at home. Children depend more than ordinary persons do for their happiness and for their support upon the ties of kindred, of friendship, and of neighborhood. All these, therefore, ought to be nourished and strengthened during childhood and youth, for it is then, and then only, that they take such deep root as to become strong and life lasting."

-Samuel Gridley Howe, 1866, eighteen years after he spearheaded the drive to establish the first state institution in America.
PURPOSE

The purpose of this paper is to clearly state the Developmental Disabilities Planning Council’s position and policy on Supporting Families. The Council’s policies guide its work in all areas of advocacy and are used to promote systems change and enhance competency in the provision of services and supports for individuals who have developmental disabilities and their families throughout Colorado.

Historically, the emphasis of public policy had been on institutional care and segregated services for individuals with developmental disabilities. Supporting families in the past meant placement of the child or adult family member out of the home. This resulted in segregated living environments and the loss of family life for the child. Individuals with developmental disabilities were labeled by professionals and often thought of as “sick,” needing a more protective environment. Children and adults with developmental disabilities were frequently placed in institutions providing life long care. The very act of removing children and adult family members with developmental disabilities from their families taught them that they were not good enough to belong. Children and adult family members who stayed within the family unit were sent to segregated schools and workshops with other children and adults with disabilities.
The pervasive philosophy seemed to be one of keeping children and adults separate from the community because they might get hurt, be ridiculed or be deemed a danger to the community.

Today we know that out of home placement is frequently the result of a failure to provide adequate supports to a family rather than the result of the individual’s developmental disability. Since families are generally more capable of providing care than the state, they should be supported in that effort. Supporting families empowers them and protects the integrity of the family.

Overwhelmingly, evidence now shows us that when children who have developmental disabilities live at home, their physical and psychological well being is nurtured. Empowering families and adult family members to live as independently and interdependently as they choose must also be an outcome for supporting families. Supporting families is about supporting the growth and development of all family members. Individuals can then become contributing members of their families, neighborhoods and communities. Supporting families in natural environments is significantly less costly than care provided in a hospital or institution.

Federal legislation lays the groundwork for effective public policy on family support. Public Law 101-496 defines family
support in this way: “The term ‘family support service’ means services, supports and other assistance provided to families with members with developmental disabilities, that are designed to—

(A) Strengthen the family’s role as primary caregiver,

(B) Prevent inappropriate out of home placement and maintain family unity, and

(C) Reunite families with members who have been placed out of home.”

Also, in PL 99-457, Congress finds that there is an urgent and substantial need: “...to minimize the likelihood of institutionalization of individuals with disabilities and maximize the potential for their independent living in society, and to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities.”
Individual Choice In Supporting Children and Adult Family Members within their Families

Supporting families and children and adult family members in communities is most possible when it includes individual choice and self-determination.

Choice gives families control over their lives. Through choice families live and participate in communities. Through the exercise of choice, families are able to contribute to the diversity and the richness of their community.

Families, including those with children and adults with developmental disabilities, know what they want and how they want to live. Choice is a natural part of living in the community. The choices families make are based on their upbringing, personal experiences, current circumstances and the influence of extended family and friends. Families routinely make choices about where they live, who they have as friends, what they purchase, what they do with their time and what goals they set.
If there is only one option presented, there is no true access to the community for the community involves multiple options. Families must be able to choose from among an array of options and they must have information about those options. Access to the community begins with the expression of personal preferences through choice.

The Council believes that choice includes giving families power and control over their lives and their resources. To be supported in community life, families should expect and demand the power to make choices in all aspects of their family life. Family choice must be supported as an integral part of community life. All families, including families with children with disabilities, have the right to live independently with appropriate supports and tools; to be who they are; to make choices that succeed or fail; to act on desires; to choose the nature and scope of community supports and services; and to choose from whom they will receive their services.

Family or individual choice must be balanced against the obligation for the good stewardship of public resources. The obligation to wisely use public resources offers the framework within which individual or family choice must exist. According to Tom Nerney there are four principles governing individual or family choice that
must be applied if that choice is to be supported with public resources. The first governing principle is that a family’s choice cannot do harm to any member of the family, to any other person or to any other family. The second governing principle is that a family’s choice must be an option that is available to all families. The third governing principle is that a family’s choice must not be based on requiring the participation of other families or other individuals with disabilities. The fourth and final governing principle is that a family’s choice cannot create a negative or devaluing image of people with disabilities or their families.
VALUES

The family is the foundation of society. Each family has ethnic and cultural values that must be recognized and respected. Each member of every family is a valuable person who has contributions that should not go unrecognized. Individual and family diversity educates, broadens horizons, and is cause for celebration.

All individuals have abilities, competencies and dreams and must be supported and encouraged to claim their rightful place in society. Individuals who have disabilities enrich the lives of all citizens through their contributions to the social fabric of the family.

We want to insure that American society accepts disability as part of the human condition, part of the human experience. By valuing individuals with disabilities in our lives, we enrich our own experiences. When such a value is not present, the problem is not within people with disabilities but in society.

We, the Council, will continue to oppose programs and services that fail to recognize the value of people with developmental disabilities by isolating and segregating them and their families in policy or in practice.
Supporting Families and Children and Adult Family Members

The following are some examples of the characteristics of supporting families and children:

- All children, regardless of developmental disability, must be supported to live with families and have enduring relationships with adults and siblings.

- Adoption will be aggressively pursued, when children cannot remain with their families, cannot be reunited or when active parental involvement is absent, making every effort to support and nurture the child’s cultural and ethnic identity. When needed, out-of-home placement will be viewed only as a temporary arrangement.

- Emancipation of adults into independent living is strictly a matter of personal choice of the individual with developmental disabilities.

- Support is for the entire family.

- Supports build on existing natural resources.
Support is easily accessible, ethnically and culturally sensitive, flexible and individualized.

Support is timely, proactive and defined by the family.

The need for family support changes over time.

The family controls the services and supports it receives.

Families have options and access to information about the options before making their decisions.

Support facilitates the inclusion and participation of families and children and adult family members with developmental disabilities into the community.

"The flexibility of being able to spend the money the way it needed to be spent at the specific time was really helpful. They didn’t come in and say you have to spend the money in a given pattern. It addressed the needs when the needs arose and that’s exactly what we needed when we needed it."

Bruce Stahlman
Parent
NEXT STEPS FOR THE COUNCIL

1. To raise the awareness of policy makers at all levels.

2. To inform the general public about family support and the values stated in this policy.

3. To promote legislation to implement all aspects of this policy.

4. To use Council funds for projects that support and implement this Policy.

5. Assure that family support is promoted in every aspect of Council work.
DESCRIPTION

The Planning Council

The Colorado Developmental Disabilities Planning Council is a 24 member body appointed by the Governor. At least fifty percent (50%) of the Council members are people who have developmental disabilities or parents of children who have developmental disabilities. The Council advocates for systems change which will support people who have developmental disabilities as they move toward independence, productivity and integration. The Council serves in an advisory capacity to the Governor and the General Assembly.

REVIEW DATE

This is the Council's official policy. The Council, in response to a rapidly changing world, may review this policy at any time. However, the Council must conduct a full review of this policy statement for revision or reaffirmation no later than until December 2002.
DEFINITIONS

Families: "However constituted"

Supporting Families (Family Support):
Flexible supports that work to fill gaps that families experience in their support systems; and help families continue to meet the challenges of parenthood and family life.

Developmental Disability:
As used by the Colorado Developmental Disabilities Planning Council, the term "developmental disability" means a severe, chronic disability of a person 5 years of age or older which—

(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(B) is likely to continue indefinitely;

(C) results in functional limitations in three or more of the following areas of major life activity:
   (i) self-care,
   (ii) receptive and expressive language,
   (iii) learning,
   (iv) mobility,
   (v) self-direction,
(vi) capacity for independent living, and
(vii) economic self-sufficiency; and

(D) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated; except that such term, when applied to infants and young children means individuals from birth to age five, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.
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