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A Report to the Governor, the Legislature and the citizens of Colorado  
from The Colorado Developmental Disabilities Planning Council

**The Colorado Developmental Disabilities Planning Council affirms, promotes and supports the principle of “whatever it takes,” is what constitutes family support. 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. (December 1993)**

#### **Statement in Support of Families and Their Children**

All children, regardless of disability, belong with families and need enduring nurturing relationships with adults to achieve their maximum human potential...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.

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

...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.

Family Support Bulletin

United Cerebral Palsy Associations, Inc.



*Heather grew up in group residential care.*

*She used to bounce with hesitant hops on the little trampoline in the playroom, giggling. Her brown pigtails would tap against her shoulders and helmet. Frequently, she would collapse as her legs and arms jerked out of control. A protective volunteer would reach for her slender body, but she determinedly pushed herself to hands and knees, straightened her legs, then slowly lifted her arms until she was hopping and giggling once more.*

*Each time a staff member would enter the room, she stopped her play, and with thick words, pleaded,*

*"Will you be my mommy?"*

*She was eight years old, a child with developmental disabilities, waiting for a forever family. She never gave up hope.*

*Neither should we.*

The statements on the facing page strongly advocate for our society's support of families. The need for a permanent home for all children is urgent — especially for those with developmental disabilities. Time is a precious commodity in the lives of children; they cannot afford to wait. Children like Heather cannot afford to wait. Their young years are lost as their pleas fade.

*"A child shouldn't have to ask for a 'for keeps' family."*

*-Alice Spencer*



*"I believe that every child is adoptable... there is a family out there and eventually you find them."*

*-Cecilia Duggan*

Children have a critical need for family. Families nurture them, establish trust, teach them how to get along with others, provide a place for them to grow and cope with change; families teach children to value themselves. Growing up in a family is the norm. Every society recognizes the vulnerability of its children and strives to provide them with safety and nurturance within a family setting.

A child with developmental disabilities has an even greater need for family. Family members are the child's only lifelong (and most invested) advocates to make sure the child gets all available services and supports to maximize his or her potential.

However, parents of children with developmental disabilities care for their children at home against overwhelming obstacles. Many require around-the-clock parental supervision, often with minimal help. Hospital stays and extensive medical testing are common. Parents continually struggle to balance work, caring for their other children, and never-ending medical appointments. In addition, private insurance companies frequently have a lifetime cap; medical coverage may be exhausted by the time the child is two or three years old. It is no



wonder that parents sometimes wear down from lack of sleep, financial, and emotional stress.

In most families, parents concentrate their time and efforts into caring for their children during the early years. By age five, children are in school and parents help them develop increasing amounts of independence and autonomy. This movement really takes off during adolescence and winds down with the young adult's emancipation somewhere between ages eighteen and twenty-two. That's when parents re-focus

some of their time and energy into other interests.

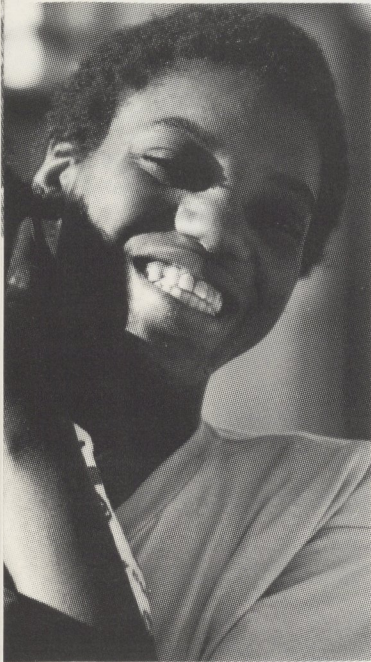
Yet parents caring for children with developmental disabilities must deal with a completely different reality — their children may remain dependent for the rest of their lives. Adult services, which can assist with independent living, are scarce. Waiting lists stretch to eight, nine, or ten years. As parents also age, they worry about what will happen if they die or become incapacitated before their child can receive adult services — another major concern for already heavily laden parents.



Jamie Grafton-Wright has four children; these two youngest she adopted as a single parent.

*“Every child has a right to a family, period...I don't care what level of disability the child has... It's a basic right, like oxygen.”*

*-Dee Hodapp*



Families can apply for support funding from the local community center board and for Medicaid. However, waiting lists are long, funding is diminishing, and when services are available, they often are temporary. Children with developmental disabilities need lifetime advocacy. A few hours of respite care a year or a one time modification to the home is not sufficient. For example, a child may need a wheelchair ramp when he is young and lifts to assist getting in and out of bed or the bathtub when he is a teen. Children with developmental disabilities need periodic and cyclic assistance.

In the end, many families eventually wear out and seek

placement for their child. If they choose not to take their child back home, the local county department of social services may take custody of the child. Judges can terminate parental rights if parents do not wish to stay involved with the child. Once in out-of-home care, children with developmental disabilities rarely leave the system. The 1989 Colorado Foster Care Study showed that children with developmental disabilities stayed **ten times longer** than the average child in the foster care system.

Because of their special needs, the placement of a child with developmental disabilities in out-of-home care is an even heavier burden for taxpayers.



*The costs of such placements are high; family members are emotionally drained; society assumes a one million dollar debt for an individual's lifetime care, and the handicapped person, who is the pawn in the game, suffers the loss of loved ones as well as the loss of opportunity for normal development. (Skarnulis, 1979)*

National organizations monitoring foster care costs in all 50 states estimate that the average cost per child in out-of-home care is \$20,000 per year.

Their estimates include costs for:

- foster care or other group care (group homes and residential care facilities)
- social workers and their supervisors
- court costs for regular hearings on the child's care
- attorney costs
- medical care for the child while in the custody of the state or county

All children have a right to a family and a permanent home. However, too many times, a child with developmental disabilities is denied this right.

*Children with developmental disabilities spend **ten times longer** than the average child in the foster care system.*

*-1989 Colorado*

*Foster Care Study*

*"We as families interact with a lot of systems, but systems don't talk to each other so there is a chance for families to fall through the cracks."*

*-Ellie Valdez Honeyman*

Unfortunately, the very structures that were designed to help our children sometimes create the biggest obstacles. For instance, in Colorado, several different systems may provide services to one child with developmental disabilities (child welfare, developmental disabilities, mental health, and education). Each system has separate funding, eligibility criteria for services, and terminology. State officials are attempting to streamline these services with a mandate for reorganizing. In July 1994, a new Department of Human Services united the Division of

Developmental Disabilities, the Department of Social Services, and the Division of Mental Health. However, systems barriers remain.

One major obstacle is that service systems cannot agree on which children they will serve. For example, the Colorado developmental disabilities system restricts services to children who are mentally retarded (IQ less than 70). Thus, children affected by severe to profound cerebral palsy, muscular dystrophy, or other life-threatening conditions which require 24 hour support cannot obtain services if their IQ is in the normal range. It is interesting to note that other state services do not have this restriction nor does the federal definition of developmental disabilities.

Another barrier surfaces when workers, supervisors, or administrators have minimal or no expertise in fields other than their own. Children with developmental disabilities need service coordination across several systems throughout their lives; however, few systems are prepared to deliver cross-agency organization and advocacy. As a result, children (and their families) do not get the full range of services they need.







A third factor working against a child with developmental disabilities growing up in a family can be the attitude that the child is not adoptable. This may be the strongest factor in whether or not caseworkers, judges, and attorneys enable the child to leave foster care. If attitudes

prohibit this effort, children will remain in foster care for the rest of their growing up years. Many in our society view foster care as “good enough” for children with developmental disabilities. After all, they ask, does the child really know any better?

*“He was in the system for four years because everyone was afraid to take him...because of his disabilities...We decided as a family team to do whatever it takes to keep James as a member of our family.”*

*-Melanie Kennedy*

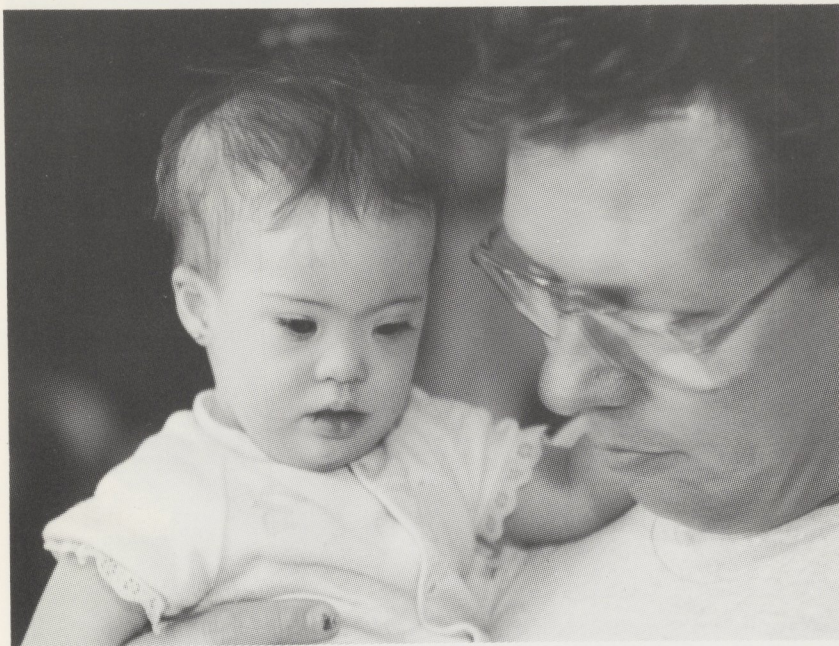
*"When our children  
change from foster  
status to adoption  
status, we lose  
half of the money  
we are paid."  
-Foster mom  
who adopted nine  
children with multiple  
special needs.*



*The Honeymans have adopted five of their seven children and are informally co-parenting eight-year-old twin girls.*

Unfortunately, the scarcity of support services (which probably contributed to the child's entering out-of-home care) may also help to keep the child in the foster care system. Foster families who wish to adopt discover that the child will lose services or financial benefits as a result. For instance, they may find

that their income will preclude the adopted child from receiving SSI benefits. Parents also lose a monthly stipend for respite care. Although adoptive parents can receive subsidy (equivalent to monthly foster care payments), it does not completely cover the child's expenses.



Another disincentive to adoption is that children in the foster care system skip waiting lists and have preferential access to adult services as soon as they turn twenty-one. Conversely, children who have remained at home or have been adopted are added to waiting lists that are eight to ten years long. This preferential access sometimes motivates foster parents **not to** adopt and birth parents to seek out-of-home placement before their child turns sixteen. Thus, larger numbers of children come into the child welfare system in order to obtain preferential access to those adult services.

*"Families who adopt are in a way penalized because they're keeping the child...then when it's time to emancipate, there is no place for them to go because all the services are taken up by people who have been in the system all their lives"*

*- Mary Erickson*

*"Information in itself  
is a family support."*

*-Ellie Valdez Honeyman*



#### WHAT CAN BE DONE?

Changes are essential in the following major areas to ensure that Colorado children with developmental disabilities grow up in permanent families:

- **Respite care**
- **Adoption services for children that are mandated statewide**
- **Training for caseworkers**
- **Education for families**
- **Equitable access to adult services**
- **Open adoptions and voluntary co-parenting arrangements**

## RECOMMENDATIONS

**1) Give families who adopt a child with developmental disabilities a minimum of 24 hours of respite per month.**

Respite care is a number one service priority for all families parenting children with developmental disabilities. It should be provided as both a prevention and a crisis intervention service and should be a part of mandated core services. Funding mechanisms can include Family Support and Family

Preservation programs, programs in the community centered board system, and mental health or early intervention initiatives. Flexible access to these services can prevent yet another move for a vulnerable child. In addition, families need trained respite workers to care for their child who is medically fragile. Many of these children require care by a registered nurse so parents can leave just long enough to see a movie or to have dinner.

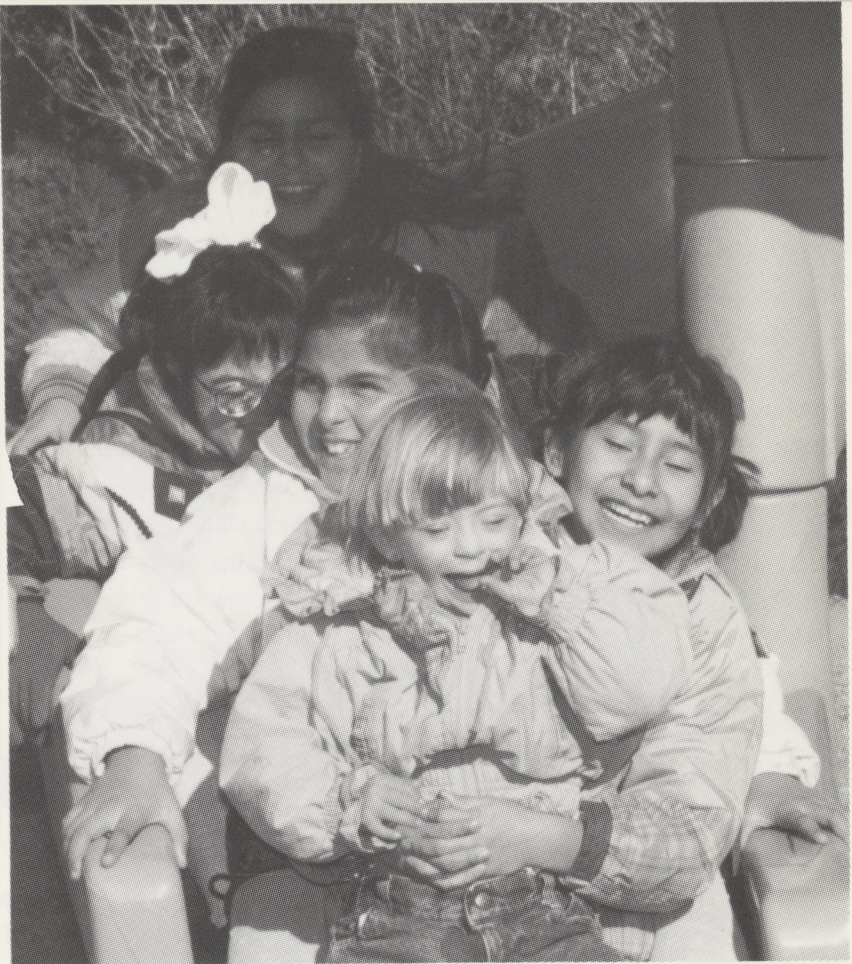


*"Absolutely respite care is the number one need stated by families, whether they are foster families, adoptive families, or biological families."*

*-Mary Erickson*

*"Coming from a county where there were no adoption services, we had to contract for our home study... that took six months."*

*-Melanie Kennedy*



**2) Require that adoption be a mandated service for families applying to adopt children with developmental disabilities.**

Under current Department of Human Services regulations, adoption is a mandated service **for all children** who are not returning to their birth parents. However, it is not a mandated service **for families who want to adopt children with developmental disabilities.** The impact of whether or not these services are mandated can be the

difference between a child like Heather living with a forever family or staying in residential care for the rest of her life. Because adoption services are not always available, prospective parents frequently cannot get a home study — the necessary first step to adopt a waiting Colorado child. If this change is implemented, families could be studied and approved to adopt the more than 100 children with disabilities currently waiting for a permanent home.



*The Hodapps have adopted nine of their twelve children; two are foster children.*

**3) Expand training for caseworkers on how to get children with developmental disabilities into permanent adoptive families.**

Workers in child welfare, developmental disabilities and mental health systems know little about service programs in fields other than their own. The children they work with could receive services from many different systems. Adoptive and foster parents frequently find their most knowledgeable resources are not professionals in the field but other

parents. A key factor in the successful adoption of children with developmental disabilities is awareness of community resources, and this is not routinely being provided.

Training for social workers will allow them to better serve the children in their care and the families who will adopt them. In this case, training will serve to keep families together and help them get needed support services as well as to improve the quality of services workers can provide.

*“Workers are where it gets made or broken... they don’t know just what a crucial role they can play for families.”*

*-Ellie Valdez Homeyman*

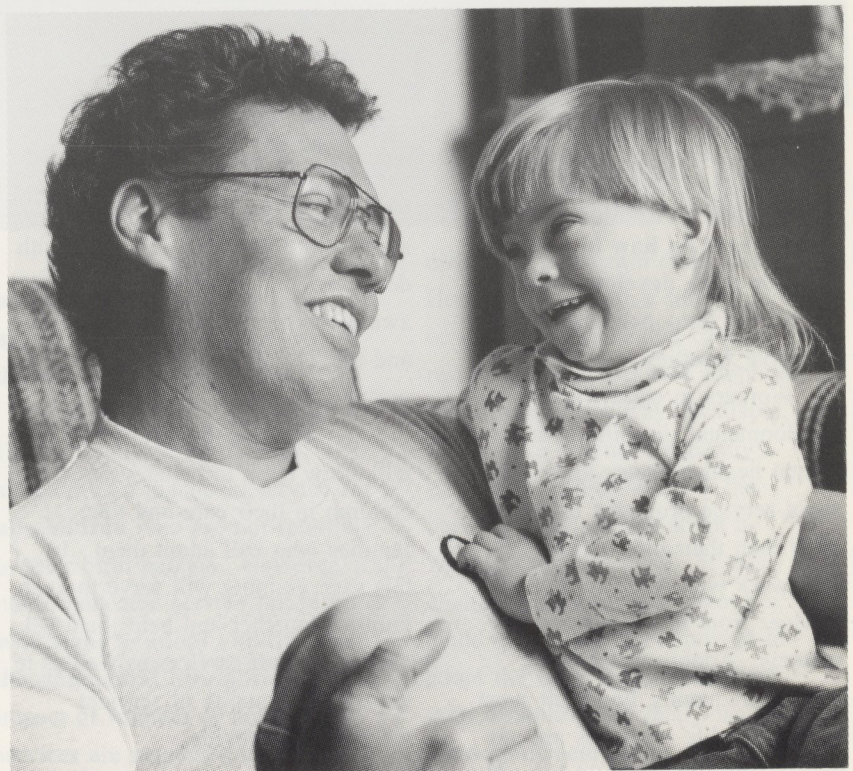


**4) Ensure that adoptive families receive education in services available to them across all systems.**

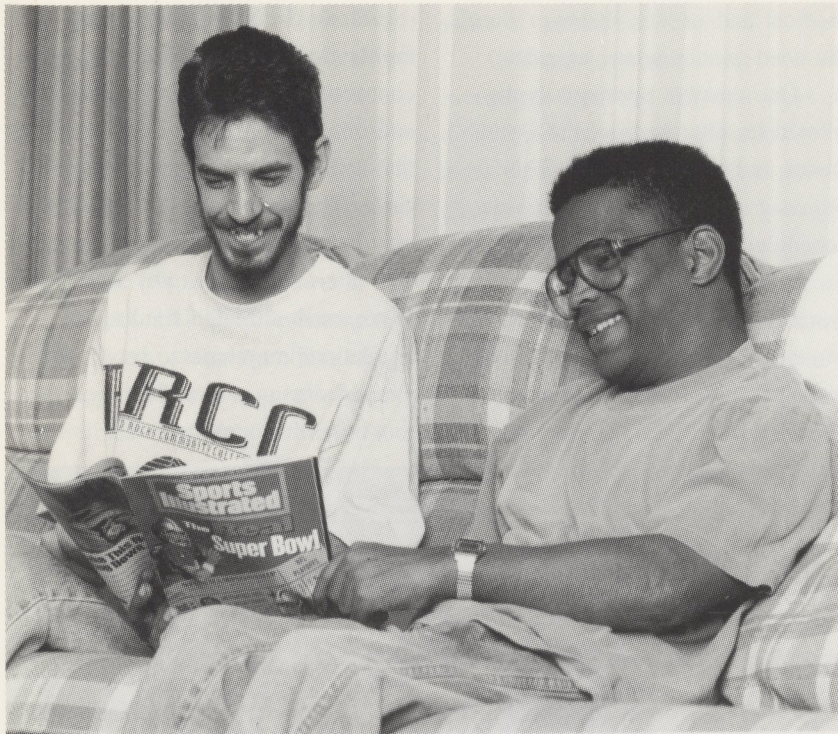
Families who adopt a child with developmental disabilities commit themselves to lifetime advocacy so the child can receive all available services. Knowledge is power and it plays a critical role in the child's long-term prognosis. Adoptive parents need ready access to information which will help them best parent the child coming into their family.

*"Adoptive parents shouldn't have to call other adoptive parents for resources. There should be a central referral resource number for adoptive families to find resources for whatever their child needs."*

*-Alice Spencer*







**5) Investigate methods to equalize access to adult services for adopted children with developmental disabilities.**

Children with developmental disabilities who have been adopted are penalized because they lose preferential access to adult services. Children who grow up in foster care are able to receive adult services much more quickly but are denied a family. Creative approaches must be developed to allow some flexibility for adopted children with developmental disabilities to access adult services in a more equitable fashion.

**6) Amend policy and practice standards within the Colorado Department of Human Services to allow informal co-parenting arrangements and open adoptions.**

Research has shown that adoptions of children with developmental disabilities are more successful when the adoptive parents receive thorough information regarding the child's history and special needs. Open adoptions offer children the opportunity for birth parents and relatives to maintain ongoing contact. It also offers the adoptive family a wealth of information on the child's

*"Rather than open adoption, we see it as the best of all worlds... we have an extended family and our daughters' birth parents have the reassurance that the girls are growing up in a family they know."*

*-Ellie Valdez Honeyman*

*"We're also involved in a co-parenting situation which has been very rewarding for us...By the third or fourth weekend, she wasn't talking adoption any more but was talking instead about 'the next time you take the girls'."*

*-Ellie Valdez Honeyman*

developmental milestones and challenges as well as ready access to medical and genetic histories should the need arise at some later date.

One creative approach being piloted in other parts of the United States is "co-parenting." This allows a second family to provide scheduled and periodic respite care for the child. The child benefits from the chance to enjoy the stability of one predictable family who will care for him or her when parents need a break. Birth parents have a

chance to rest and recoup their emotional and physical energy on a regular basis. The co-parenting family makes a significant contribution to the life of a child and often becomes the single reason that a child does not go into foster care. This innovative approach may have much to offer as a lower cost alternative to lengthy stays in foster care, although funding regulations may have to be expanded to accommodate these more flexible arrangements.



## CALL TO ACTION

The recommendations detailed in the preceding pages are offered as first steps to address some of the barriers to growing up in a family for children with developmental disabilities. They were developed after a study of programs and practice across the U.S.

Project staff identified programs of excellence which are effective in crafting adoptive placements for children with severe to profound developmental disabilities. These programs (public and private) utilize flexible funding streams and flexible family support services for adoptive families throughout the child's youth. Families receive expanded respite services on a regular basis. Any family applying to adopt a child with developmental disabilities can get homestudy services through either public or private agencies. Specialized placement units hire workers with training in both developmental disabilities and placement skills so that they can effectively assist adoptive families at every step to get needed services. Families are linked with workers and advocacy training organizations for ongoing help.

Some agencies have helped families develop open adoptions as well as co-parenting arrangements. These services alone have enabled children to avoid the foster care system entirely—saving taxpayers

years of public support costs.

Colorado systems must investigate new and different ways of doing business so that Colorado's most vulnerable children have a chance to grow up in stable, loving, permanent families.

### Needed changes include:

- a minimum of 24 hours of respite per month
- mandated adoption service for families applying to adopt children with developmental disabilities
- expanded social worker training
- adoptive family education in services available across all systems
- equalized access to adult services for adopted children with developmental disabilities
- allow informal co-parenting arrangements and open adoptions.



*The Spencers adopted six of their seven children. Photo by Louis Landa.*

*"I don't think from my  
checkbook, I live  
from my heart."*

*- Alice Spencer*



JoLynn Osborne and her son David befriended David Eaton 12 years ago.

#### A STORY OF TWO DAVIDS

*"When I see a kid  
hugging his dad, I think,  
'Man! I wish I had that'  
...But I don't know  
what it's like to have  
a mom and dad."*

*-David Eaton*

Meet David Osborne and his mom JoLynn. David is 19 years old and recently graduated from high school. He just started classes at a local community college a couple of weeks ago. David Osborne has developmental disabilities and lives at home with his mother and his sister when she is not away at college. David is a handsome young man who likes playing wheelchair basketball, is fiercely competitive at whatever he tackles, and has a finely developed sense of humor.

David Osborne looks forward to living on his own at some point. He lives in Jefferson County which has a waiting list that is currently 8 to 10 years long for adult services through the developmental disabilities service system. His mom put his name on the waiting list a few years ago. It is uncertain how long it may take before David will be able to move into his own apartment.

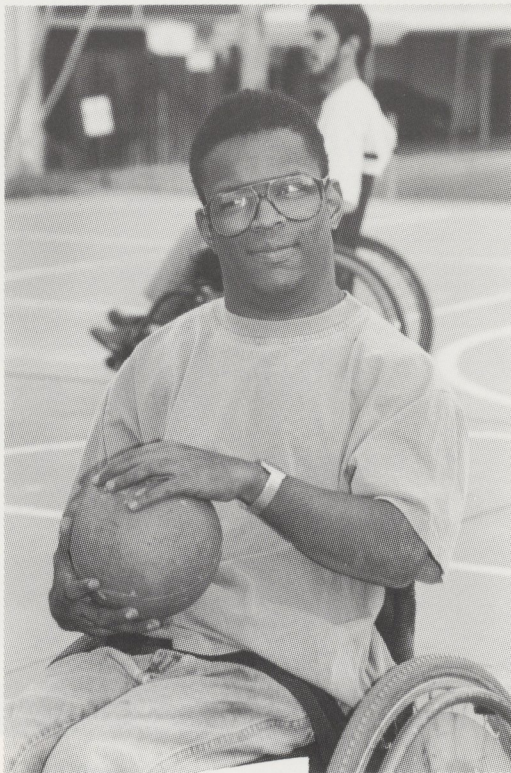
David has a close friend, also named David — David Eaton. David Eaton has been his friend for the past 12 years. David Eaton entered foster care when he was seven years old and spent the rest of his youth

in foster care and group homes. At the age of 22, David Eaton lives in his own apartment with his brother. He has a part time job as an aide in a local elementary school. From outside appearances, David seems like he is on the road to making it in this world.

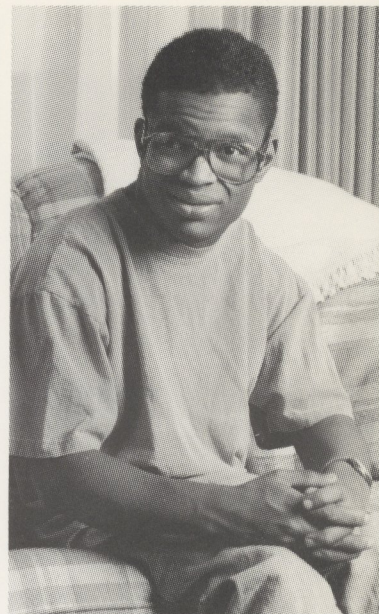
There is only one problem — David Eaton still yearns for a family, a mom and a dad who will care about him. He talks about how it hurt so much that there were no permanent parents in his life. The people in his life were group home staff and social workers; his memories are that they cared about him for a while and then moved on. David says that ache has built a wall around his feelings — a wall that protected him somewhat from the hurt of not having family. David envies his friend David Osborne who has a lifetime family.

David Eaton represents over 100 children with developmental disabilities who are legally free and waiting for adoptive families right now in Colorado. He speaks for

untold other children in the foster care system who are not legally free but who continue to grow up in out-of-home care because no one has worked to enable them to be placed with adoptive families. All the children want to grow up in a family. Family connections sustain them during rough times and happy times.



David Eaton's plea is that **“everyone will work to get those kids families so they won't have to grow up like I did.”**



*“For the kids with disabilities who are out there now, I wish that...someone would reach out a hand and take them in.”*

*-David Eaton*

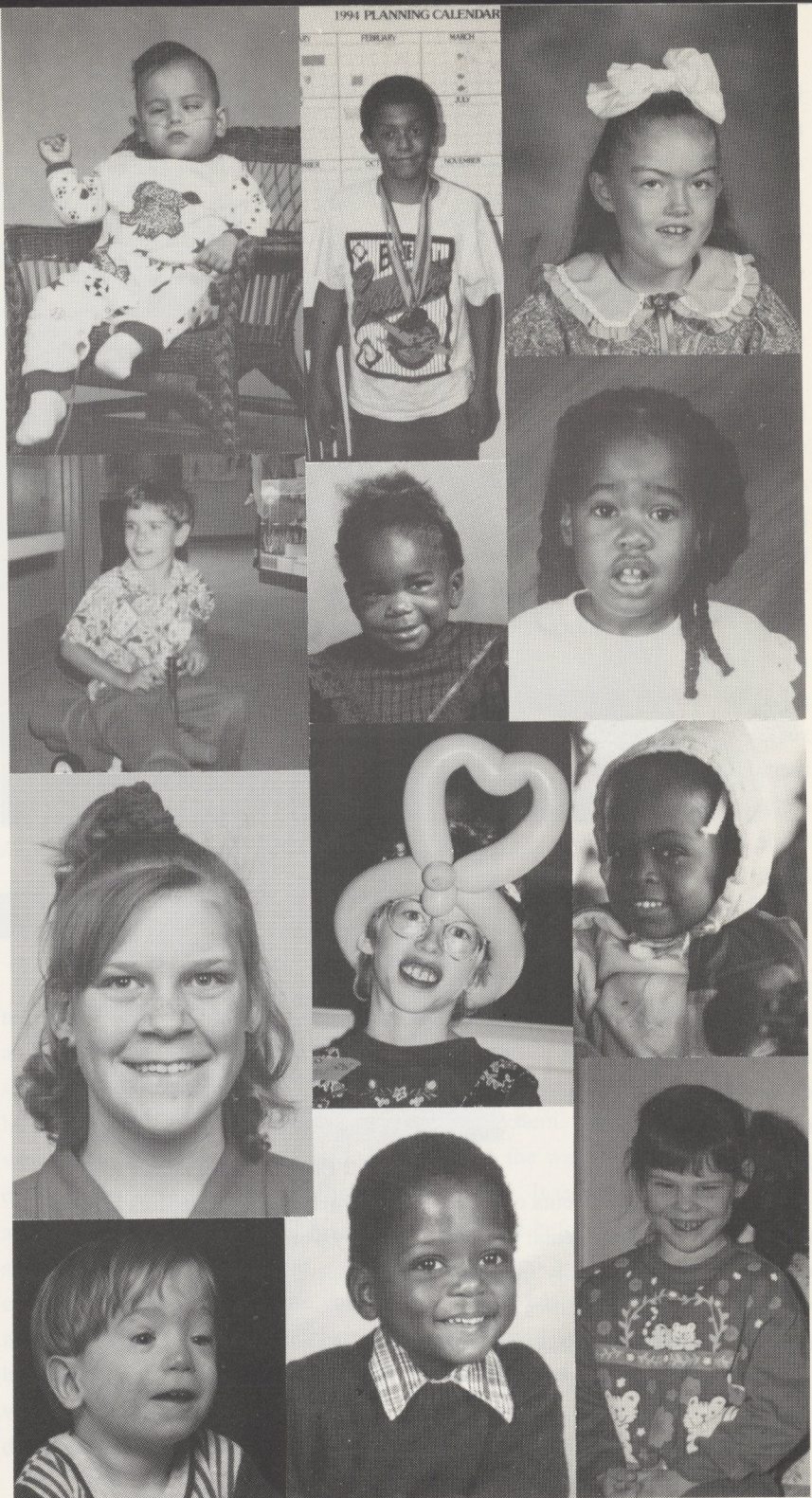
*These*

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*The Duggans adopted their daughter Penny when most of their children were grown.  
Photo by Randall's Photography*

## ACKNOWLEDGEMENTS

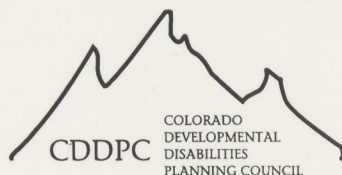
Our sincerest thanks and appreciation is owed to the following families who gave so generously and unselfishly for interviews, videotapings, and photo sessions for this project. Their love makes family a reality for each of their children every day:

*Mike and Ellie Valdez-Honeyman  
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Connie Brothers  
Wayne and June Turner*

A special thank-you to David Osborne and David Eaton who speak for many other young people with developmental disabilities.

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For more information about this project, call or write:



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## A Place to Call Home...Forever

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Planning Council.

*As the old man walked the beach at dawn, he noticed a young man ahead of him picking up starfish and flinging them into the sea. Finally catching up with the youth, he asked him why he was doing this. The answer was that the stranded starfish would die if left until the morning sun. "But the beach goes on for miles and there are millions of starfish," countered the other. "How can your efforts make any difference?" The young man looked at the starfish in his hand and then threw it to safety in the waves. "It makes a difference to this one," he said.*

*- Anonymous*

