

# Policy Research Brief

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## Do We Really Mean Families for *All* Children? Permanency Planning for Children with Developmental Disabilities

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### ■ Introduction

The Caswell\* family is a household of five, including Marianne and her husband Joe, two children by his former marriage, and Stephanie born since their marriage. The Caswells use nurses 16 hours a day to help care for Stephanie who has a disability including significant health problems. Marianne worries about her little girl waking up in the night and seeing a stranger. One of her current nurses has a strong personal bond to Stephanie, a relationship that is encouraged and appreciated by her parents. Marianne refers to the caregiver by the kinship term “Aunt Ruth” and describes her as “like extended family.” Marianne and Ruth would be happy for Stephanie to spend the weekend at Ruth’s home, but nursing agency rules prevent her from taking Stephanie out of her birth home. Instead Stephanie will spend the weekend with two other staff from the nursing agency.

\*Family names are pseudonyms.

The O’Briens\* describe themselves as a family of five including parents John and Jan and their three children. This family has also used nurses to assist them in daily care of their son JJ who has significant health-related disabilities. Despite 16 hours of help a day they feel overwhelmed. When they began to talk about the possibility of seeking out-of-home placement for their son, one of the nurses expressed an interest in adopting JJ. They interpreted this as a staff person who had become too emotionally involved and was overstepping professional boundaries. Shortly after this exchange, John and Jan placed their seven-year-old son in a geriatric nursing home where they visit regularly.

These two families have very different perspectives about the meaning of family for their children with disabilities. Both families love their children and want what is best for them and their family. Embedded in their views are permanency issues. Each family has used extensive family support to assist them with the daily needs of their children with significant disabilities. Despite receiving such support, neither family has been asked to plan for permanency by the service system that provides the support. For lack of that conversation, one child has lost the opportunity to grow up in a family. The other child is prevented from sharing extended family life by regulations intended to protect her.

Though family support has become the dominant form of services for children with developmental disabilities, non-family residences still exist for these children. The statement that “all children should grow up in families” is far from including all children. Permanency is a concept that seeks to assure a permanent family living situation for

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children. Permanency is why we do family support. This brief looks at why and how family support policies are missing permanency and what might be done to embrace it.

## ■ Good News and Bad News

Despite dramatic decreases in residential facilities, a large number of children with developmental disabilities still do not live with families, and admissions to non-family residences continue (see Table 1). It is a cultural expectation that children should grow up in families, but this expectation has often been waived for children with disabilities. In previous generations, parents were urged to place their children with disabilities in specialized residences, whether they wanted to or not. Traditional residential placements for children with disabilities meant that children would never again experience a stable family home life. More recently policies have discouraged residential placement. Between 1977 and 1997 facility residential care for children and youth from birth through 21 decreased by 65,000 (Lakin, Anderson, & Prouty, 1998, p. 4). In 1998, at least 13 states had no large state facilities with children under age 15 (Prouty & Lakin, 1999, p. 4). Hidden in this good news is the fact that admissions of children in 1998 (the most recent available data) exceeded discharges. In 1998, the net change in large public and private facilities was an increase of 332 children and youth (Anderson, Lakin, Prouty, & Polister, 1999). In 1998, mental retardation and other developmental disability (MR/DD) agencies reported serving more than

twice as many children under 18 in non-family facilities as in foster care (Hemp, 2000). Despite policies discouraging institutional placement of children with disabilities and dramatic reductions in the number of children in institutions, admission to large state facilities is growing faster than discharges for a small but alarming group of children with severe disabilities. In addition to more than 5,600 children under age 18 living in large institutions, state MR/DD agencies report at least 9,000 children with developmental disabilities living in other non-family residences (Hemp, 2000).

## ■ Permanency, Child Welfare, Disability

### Differences Between Systems

Children living in residential facilities operated by the disabilities sector have been denied the permanency protections assured to them if they were served by child welfare services. Permanency is a concept that emerged in child welfare systems to describe the philosophy and practices involved in securing a permanent family living situation for children. Child welfare services are required by law to provide permanency for children and youth unable to remain with their birth parents. The Adoption Assistance and Child Welfare Act of 1980 and its successors, the Family Preservation and Family Support Act of 1993 and the Adoption and Safe Families Act of 1997, assure permanency planning. Under these pieces of legislation children are assured pursuit of three things:

**Table 1: Children with Developmental Disabilities in Non-Family Residences**

Good News				Bad News		
Children and youth receiving public and private out-of-home residential services sponsored by developmental disability agencies <sup>*</sup>				Discharges from large state MR/DD facilities in the year ending 6/98 <sup>**</sup>	Admissions and readmissions to large state MR/DD facilities in the year ending 6/98 <sup>**</sup>	Net change
age	1977	1987	1997			
0-14	38,161	15,085	11,403	113	171	+58
15-21	52,781	31,448	14,438	263	537	+274
0-21	90,942	46,533	25,841	376	708	+332

Source:

\* Lakin, K. C., Anderson, L., & Prouty, R. (March 1998). *Policy Research Brief (9) 1*.

\*\*Anderson, L., Lakin, K. C., Prouty, R., & Polister, B. (1999). Ch. 4. Characteristics and movement of residents of large state facilities. Tables 1.20, 1.21, & 1.22. In R. W. Prouty & K. C. Lakin (Eds.) *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1998*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. <<<http://ici2.umn.edu/rct/risp98tables.html>>>

- A safe and nurturing family home.
- A permanent family home.
- Entitlement to securing both of these in a timely manner.

Permanency activities include family preservation, family reunification, and finding alternate families for children who cannot remain with their birth families. Permanency planning involves:

- Identification of minor children.
- Permanency assessments.
- Family preservation planning services.
- Family reunification planning services.
- Recruitment and preparation of alternate families.
- Adoption and post-adoption support.
- Liaison with agencies, organizations, and school systems that provide out-of-home placements for children.

These legislative mandates apply to children served by the child welfare system, but do not extend to the developmental disability system. Children with developmental disabilities served by disability services have not routinely been afforded this protection. The family support movement and family policy must embrace more fully the issue of permanency. The benefits of family life are denied to the more than 14,500 children with developmental disabilities reported to live in non-family residential situations and the unknown number of others who are not reported by current tracking systems (Hemp, 2000). Failure to address their permanency needs endorses them as a different kind of child in less need of protection. In fact, they are the same kind of child in more need of protection.

## The History of Permanency Policy

The history of permanency policy (or lack thereof) affecting children with disabilities and their families paints a distressing picture. Bergman and Singer (1996) outlined three major shifts in services for people with developmental disabilities over the past 50 years. The parent movement originated in the 1950s and brought a shift from custodial institutional care to deinstitutionalization and public education. A second shift occurred in the profusion of specialized community programs and habilitative treatment in what has been called a services paradigm. A third shift now underway is described as the emergence of a support paradigm. Family support is part of this emerging trend. This third paradigm focuses on natural settings. Its vision is that adequate support will enable all children to grow up in a typical home with a family. The natural supports movement rejects the notion of a continuum of care and treatment as the primary focus of services. The first two movements concentrated attention on the individual with a disability. The third movement focuses on the social context – in the

case of children, on the family as the unit to be supported.

According to Bergman and Singer (1996) the values underlying the new family support programs were first articulated at a meeting sponsored by the Center on Human Policy at Syracuse University in 1986 by a group of forward-thinking advocates and parents with experience in pilot projects aimed at developing family support. The group developed the *Statement in Support of Families and Their Children* (see Appendix A) that called for family home life for every child and identified commitment as the motivating force behind family support services. The statement is a clear expression of permanency and is widely referenced in the disability literature and family support literature.

Interestingly, the family support movement emerged in reaction to the tendency to separate a child with a disability from the family (Turnbull, Garlow, & Barber, 1991). Family support literature focuses on efforts to keep children with their birth families, but the application of permanency principles has not generalized to children with disabilities served in non-family residential facilities. A review of 120 professional articles from various disciplines identified the key concepts used in defining the term “family-centered,” a hallmark of family support (Allen & Petr, 1996). Although maintenance of children in their own homes was a key concept, so also was a community-based continuum of care and family choice. With no explicit rejection of non-family care, the implication is that non-family care is acceptable for some families or permanency does not apply to some families. With more than 14,500 children with developmental disabilities living in non-family residential situations (Hemp, 2000) we must ask what family support offers them.

Federal protection requiring permanency for children in the child welfare system emerged in the 1970s and was codified in legislation in 1980. The *Statement in Support of Families and Their Children* was widely circulated and endorsed by the late 1980s. In 1991, the National Conference of State Legislatures’s (NCSL) Task Force on Developmental Disabilities recommended that state legislatures create and fund family support principles that adhere to the guiding principle that “all children, regardless of disability, have the right to grow up with a family, biological or otherwise” (NCSL cited in Bergman & Singer, 1996. p. 459). Twenty years have passed since permanency became accepted practice in child welfare. Ten years have passed since the call went forward for its application to children with disabilities. Permanency policy has yet to be embraced as an imperative in services for children with disabilities. Children with disabilities who are living in non-family residences operated through disability services have been predominantly excluded from the protections of a policy that has been deemed important for other children. Conceptual problems and contradictory practices have hampered application of permanency for children with disabilities. Following is a discussion of the conceptual threats to permanency impeding practice, and suggestions for policy.

## ■ Threats to Permanency

### Faulty Assumptions

Failure to assure permanency for children with disabilities suggests two underlying faulty assumptions. The first is an assumption that some children with disabilities (or children with some disabilities) are fundamentally different from other children and therefore do not need the family life that our society values for other children. The second is an assumption that the questions posed to other parents who are unable or unwilling to raise their children should not be asked of parents of children with disabilities. Both assumptions are related to the negative way our society views disability. Disability is seen as an undesirable burden that invokes a responsive wish to provide relief. Fitting this image, unwilling parents should not be obliged to raise their children with disabilities, should be relieved of this responsibility if they desire, and should not have their already difficult situation exacerbated by asking difficult questions. Related to these notions is the expectation that no one would choose to raise a child with disability. In this view, a child who has a disability is a special form of child requiring a special form of care other than the usual societal arrangement for child rearing. Seeking alternate families is seen as a charitable and expectedly unsuccessful venture. Rethinking of permanency policy regarding children with disabilities requires challenging these views.

Questions that need to be addressed to redirect our permanency policy to include children with disabilities include:

- What does it mean to be a child and what should a good childhood look like?
- How do current policy and practice facilitate or hamper good childhoods for children with disabilities?
- What policy changes are needed?

The answers to these questions for children with significant disabilities lie in the view that permanency is a developmental requirement for well-being. As such it is a developmental right, a human right. That absence of permanency is detrimental to human growth and development has been well researched. The most vulnerable children are those with the most severe disabilities, yet these are the children most at risk of not having permanency.

### Misplaced Treatment Strategy

Struggling families are often steered toward non-family placement through a misplaced treatment strategy. If we look closely at residential placement of children who do not or cannot live with their families, their admission path has usually followed one of two courses:

- Out-of-home placement has followed parental abuse, abandonment, or mistreatment as a child welfare issue.
- Out-of-home placement has been framed as a problem located in the child and handled as a health care or treatment issue.

Under the first approach, the child's permanency needs are protected by child welfare legislation. However, child welfare systems that are uncomfortable or unfamiliar with children with severe disabilities do not pursue the permanency options they would for a more typically developing child, but instead refer to a disability facility. Under the second approach "treatment" needs overshadow permanency needs. In either case, children who leave their birth homes are likely to enter non-family residences. At issue here is not whether to provide treatment or a family. The child's right to treatment can be met within the context of a family residence given adequate in-home support and an adequate local school program. While it is true that children in large residential facilities tend to be adolescents and have more severe impairments (Anderson, et al., 1999), rather than interpreting this fact as a problem located in a child, this fact needs to be interpreted as a problem of adequate supports to a willing family.

While treatment can occur in a family, family cannot occur in a facility. When children are placed into non-family residential treatment settings, the qualities sought in caregivers are competence rather than continuity. Treatment is judged by professionalized intervention standards rather than longevity. Caregivers are interchangeable rather than consistent. Lack of continuity prevents the security of a long-term enduring relationship. Since treatment is the goal, admissions judgements are linked to the ability of the facility to meet treatment needs, not permanency needs. The question of permanency goes unaddressed. Families not confronted with a discussion of permanence may feel or are led to believe they are doing the best thing for their children. In many cases families report that the move toward non-family placement is, in fact, initiated and pushed by professionals.

### New Supports in an Old Paradigm

Family support programs for children with disabilities have been inherited from a services paradigm oriented to a placement perspective. From this frame of reference their goal is seen as preventing out-of-home placement. Framing the issue as prevention implies that placement is a likely occurrence and can serve as a self-fulfilling prophecy. The family home itself becomes an alternate form of placement. System interventions mimic placement activities by coordinating caregiver arrangements that focus around the family home as a place. Quality outcomes are related to the competence of the caregivers, both family members and support staff. With the focus on holding the "placement" together,

there is little distinction between children and adults. Activities focus on immediate issues and escalate at points of crisis. The guiding principle of the placement perspective is good case management coordinated via adherence to eligibility categories, procedures, and regulations.

A permanency perspective takes a very different frame of reference (see Table 2). From a permanency perspective, the goal is promotion of a sense of belonging and focus on the child's experience. This perspective is oriented to enduring relationships. Quality outcomes are lifelong relationships. The activities of the system are directed to making and nurturing relationships through invitations and life-sharing commitments. An emphasis on child development directs attention to the difference between children and adults in a child's need for a nurturing parental figure in day-to-day care. The guiding principle underlying permanency is the simple concept that all children need to grow up in a family. A permanency perspective is much more in line with the supports paradigm of the family support movement than the specialized services paradigm of the placement perspective. But the family support movement has not yet fully embraced permanency.

### Conflicting Family Member Needs

For some families the needs of one family member are in conflict with the needs of others. Planning for a child to leave her or his home begins when the needs of the child and the needs of other family members become incompatible. What may be most desirable for the child may not be most desirable for the rest of the family. The Turnbull, Garlow, and Barber (1991) policy analysis of family support for families with members with disabilities refers to this as "a well-recognized paradox" (p. 755). They state that conflict exists because the issue is not just a matter of site, but a matter of relationships, roles, responsibilities, and satisfaction of the needs and preferences of all members of the family. Disability service professionals "may walk a fine

line between respecting the family choice and supporting decisions that they feel may be inappropriate or even harmful for one or more family members" (p. 764). Unquestioned parental choice assumes the child belongs *to* a family rather than *in* a family.

Family support has been framed as a parental right to make decisions about a child. A core principle is that services be family-centered. Although the principles of family support take a holistic view of the family, in actual practice, decision-making is located with the parent. Understandably, the parent is the decision-maker for children who are too young or otherwise unable to meaningfully participate in decisions of the group. Nevertheless, between a parent and a child there are two vantage points. The existence of multiple vantage points does not require that they be adversarial. They need not be and often are not. But they may be. When a parent chooses an aversive behavioral intervention, the question of the compatibility of the parent/child vantage points can be raised. Similarly when a parent chooses to place a child in a non-family setting when other viable alternatives exist, then the compatibility of the parent/child vantage points may be questioned.

The family support movement asks that families be considered as complex units involving multiple members with individual and collective strengths as well as needs. The family support movement emerged from criticisms that services took the singular view of the child's disability as central. Services fail families when the focus of attention is limited to the child's "deficit." Similarly services fail families when the focus of attention is limited to the parents' stress. As the shift in perspective has pulled away from the centrality of the child toward the family as a unit, it may have inadvertently obscured the individual experience of the child with a disability. Embracing permanency within family support is a balancing stance. Neither the perspective of the parent nor the child is the "right" perspective. They are simply different perspectives that ask us to consider different aspects of the lived experience of each individual

**Table 2: Placement vs Permanency Paradigms**

Placement Perspective	Permanency Perspective
<ul style="list-style-type: none"> <li>• Goal to prevent out-of-home placement</li> <li>• Orientation to caregiving arrangements</li> <li>• Focus on location</li> <li>• Quality outcome viewed as competent care</li> <li>• System tasks               <ul style="list-style-type: none"> <li>To coordinate staffing patterns</li> <li>To secure placements</li> </ul> </li> <li>• Focus on present – reference point is a crisis</li> <li>• Little distinction between children and adults</li> <li>• Guiding principle: case coordination and adherence to compartment boundaries, funding streams, and regulations</li> </ul>	<ul style="list-style-type: none"> <li>• Goal to promote a sense of belonging</li> <li>• Orientation to child's experience</li> <li>• Focus on relationships</li> <li>• Quality outcome viewed as lifelong connection</li> <li>• System tasks               <ul style="list-style-type: none"> <li>To connect people in life sharing patterns</li> <li>To secure relationships</li> </ul> </li> <li>• Focus on the future – reference point is the lifespan</li> <li>• Distinction between child and adult needs</li> <li>• Guiding principle: All kids belong with families</li> </ul>

member of a family. The preponderance of the family support literature is currently focused on a policy perspective that reflects the parental vantage point. Raising the profile of permanency is called for as family policy matures.

### Parental “Choice” of Non-Family Placement

Parental “choice” of a non-family placement prevents pursuit of a different solution to incompatibility – the child living with another family. An understanding of parental choice must more fully take into account the complex interaction between parents and multiple actors with multiple roles and responsibilities in support systems. An overly simplistic view assumes that choice is about willingness to parent a child with a disability, and ability is about parental skills related to disability. Unwillingness or inability alone applies to a limited portion of families. Permanency issues are clearest for this group. The larger proportion of families requires another view. A deeper appreciation of choice has more to do with availability of supports coupled with willingness to accept the intrusion necessary to use the supports within the family home. For example, the support of a child may require nurses around the clock. That level of intrusion into the privacy of the family home presents an enormous disruption to lifestyle.

Families vary widely in their willingness to accept such disruption. Some families feel their home is no longer a family with that kind of intrusion. Other families are able to construct their home life to include the intrusion. A key to accepting the level of intrusion is the personal relationship that forms with the “intruder.” The importance of relationships once again reiterates the framework of the permanency perspective rather than the placement perspective. What permanency asks is that birth parents who are unwilling to accept intrusion or unable to define their homelife as a family not prevent their child from experiencing family life in another family that is willing to accept intrusion or is able to construe themselves as family despite the intrusion. It is failure to translate the discussion into these terms that contributes to the failure to apply permanency principles to children with disabilities.

A debate around parental choice has emerged in which permanency has been misunderstood as “a current zeitgeist that disparages the decision to place” (Blacher, 1994, p. 214). It is not the decision to place, but the decision to place in a non-family alternative that is at issue for permanency policy. A recent article by a father captures this missing distinction in the way “debate” about parental choice is framed. In an article entitled “*Children with Severe Disabilities: Options for Residential Care. Is Living Under the Same Roof Necessary for a Nurturing Relationship?*” Bain (1998) suggests that permanency has gained “professional favor” (p. 1) but its requirement of family life is not applicable to all children and families. He describes a group home with shift pattern staffing as an “attractive option” with the

“potential for long-term security and staff attachment to the child” (p. 5). He cites Blacher’s (1994) finding of active involvement of parents with children in residential settings to support his argument that regular visits to and from the birth family “can allow important objectives of permanency planning to be achieved, if high levels of family involvement are encouraged” (p. 6).

Such arguments do not say that the shift pattern also prevents other important objectives of permanency planning from being met. Such arguments confuse attachment with fondness and affection. The term permanency is mistakenly applied to a stable *residence* rather than a stable continuous *relationship* with an adult parental figure. The misunderstanding assumes a regular visitation pattern by a parent is an adequate substitute for the day-in-day-out continuity of nurturing parental guidance required by children for security and well-being. The fact is that a shift pattern home with interchangeable staff is not a family, and does not fit the meaning of the phrase “grow up in a family.”

### Mismatched Resources and Needs

Family problems that lead to placement frequently reflect a mismatch between resources and needs. A system that has not embraced permanency probably does not provide families with the level of support they require. Wide differences exist among states in their provision of support to families. Ten states spent more than \$5,000 per family in 1998, while 12 spent less than \$1000 (Braddock, Hemp, Parish, & Rizzolo, 2000, p. 27). Spending in 1998 ranged from a low of \$8,535 per 100,000 citizens in one state to a high of \$1,243,636 in another (Braddock et al., 2000, p. 27).

Incompatibility between support needed and support received is related to inadequate resources, but it also occurs where there is difficulty delivering theoretically available support. Parents who are accepting of their child’s disability and willing to accept the level of intrusion necessary to support their child at home too often find inadequate support because available funding is insufficient for the assistance they need or because even with funding they find available support unreliably provided.

### Crisis Management of Placement

Crisis management of placement decisions ignores the fact that decisions to place emerge over protracted periods, as do successful support relationships and the development of alternate families. Birth families go through a protracted process of two years or more in coming to a decision to seek out-of-home placement (Blacher, 1994). Successful recruiters of alternate families identify a protracted process of two years or more by families making the decision to include a child with a disability. Recognition of these timeframes fits the permanency perspective that relationships take time to develop and nurture. The placement perspective does not

attend to relationships; it also does not attend to these time-frames and fails to build them into preparation of a response. Many families state a preference for alternate family care, but without alternate family recruitment find no such families available and end up placing in non-family settings through a crisis. Many families also prefer the possibility of support through a shared arrangement with another family recruited for that purpose. Recruitment of alternate families holds much untapped potential.

The complex and sometimes conflictual aspects of these issues highlight the practical problems of a broad-based permanency policy. What impedes family-only alternatives? Why aren't alternate families more readily available? Why aren't families presented with family-based alternatives? These are the topics of the next section.

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## ■ Implementation Issues

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There is a significant disparity between the rhetoric that "all children belong with families" and the reality. There is great variability nationally. Eight states reported 10% or more of their large facility residents as 0-21 years of age (Anderson et al., 1999, p. 5) while seven states operate no large state facilities. Five states report more than 450 children under age 18 living in public or private institutions of 16 or more beds (Hemp, 2000). While the impediments each state experiences are complex, three common beliefs are present in the folklore of difficulties expressed at the "street" level of implementation of permanency policy:

- Some children cannot live with families.
- Alternate families can't be found.
- Birth parents won't accept another family.

### Misconception: Some Children Cannot Live With Families

While there is broad consensus in favor of children with milder disabilities living with families, skepticism that children with more severe levels of impairment can live with a family is part of our folklore. The impression, sometimes stated outright and sometimes merely implied by our practices, is that some kids are "just not family material." This myth is best dispelled by the fact that a child with every kind and severity of impairment is currently living successfully with a family. While one family finds a child's needs too great or their lifestyle too restricted, another family with a child with identical impairments is doing well. The impairment alone is not the reason for non-family life. We must look beyond the child for an explanation. A more complex understanding leads to consideration of two broad areas: (1) the nature of supports to families and (2) the recruitment of alternate families.

Family support has grown dramatically in the past decade. Between 1993 and 1998 funding for family support increased 93% (Braddock et al., 2000, p. 26). In 1998, over 327,000 families were served (including families with adult members) at a total expenditure of \$736 million (Braddock et al., 2000, p. 26). As dramatic as the increase is it falls far short of the needs of some families. Tremendous differences exist among the states in the level of their commitment to supporting families, with 11 states spending more than \$500,000 per 100,000 citizens in 1998, while 16 spent less than \$100,000 (Braddock et al., 2000, p. 27). Clearly a commitment to families as a priority requires a commitment to funding and designing supports that will provide whatever it takes to make that possible. Importantly, whatever it takes does not mean whatever it costs, but equally importantly it does not mean whatever is available.

### Misconception: Families Can't Be Found for Children with Significant Disabilities

When no amount of resources or creativity will make it possible for a child to remain with her or his birth family, then an alternate family needs to be found. There is a common belief that, however desirable, alternate families cannot be found for some children. The evidence usually cited to support this claim is the difficulty that child welfare systems experience in finding enough families. As the logic goes, if you can't find a family for typically-developing children, then you surely cannot find a family for a child with severe disabilities. This logic fits the negative societal image of disability as something no one would voluntarily seek and its corollary that a person with a disability is someone no one would voluntarily include in her or his family or close personal network.

This mistaken belief is dispelled by three sources of evidence:

- An estimated 1.9 million individuals with developmental disabilities live with families (Braddock et al., 2000, p. 41).
- At least 6,000 children with developmental disabilities live with foster families (Hemp 2000).
- Alternate families are successfully recruited by organizations that have devoted significant energy to the process.

The availability of alternate families is directly related to the energy put into seeking and preparing them. Where energy has been great, families have been found. Where families have not been found, energy has either not been great, has been diluted by competing responsibilities, or has employed ineffective strategies. The success of programs like Macomb Oakland Regional Center in Michigan (Taylor, 1991) and Every Child, Inc. (formerly Project Star) in Pennsylvania (Taylor, Racino, Walker, Lutfiyya, & Shoultz, 1992) in finding families for large numbers of children with severe

disabilities gives testimony to its feasibility. The fact that the MR/DD agencies in nine states report no children with developmental disabilities under age 18 living in facilities with over 16 beds, and over 1,000 children (in aggregate) living in foster care, gives testimony to the feasibility of family residences (Hemp, 2000).

There is a cycle at work here. If you believe you cannot find families, you will not find them, and then use your failure to confirm what you believed to be true. Systems that have put serious energy into recruitment and preparation have reversed this negative cycle to a positive one. Believing good families exist leads to serious pursuit, which finds families, which confirms the belief. The more success, the more motivated the recruiter, the more energized the search, and the more success, thus repeating the cycle.

### **Misconception: Birth Families Won't Accept Another Family**

As the logic of this misconception goes, even if alternate families could be found, birth families will not accept them. It is true that many birth families initially believe that if they who love their child cannot continue to have her or him live at home, then no other family could either. At first blush this seems reasonable and logical. It is dispelled however by the fact that many families do come to accept that an alternate family can raise their child. Experiences in Michigan (Shultz, O'Connor, Hulgin, & Newman, 1994), Pennsylvania (Taylor et al., 1992), and elsewhere (Center on Human Policy, 1987) have provided clear practical advice about how to handle the emotionally charged and potentially conflictual issues involved in coming to this acceptance. These experiences have helped develop successful strategies since the mid-1980s, strategies that have, however, seen relatively little generalization. In a joint project, the National Foster Care Resource Center, The National Resource Center for Family Based Services, and the National Resource Center for Special Needs Adoptions (1993) collaborated to identify good permanency practice materials. In an extensive literature search, they reviewed 1,400 entries to identify 100 highly recommended books, articles, and special journal issues. Only five items identified issues in working with children with disabilities. A more recent search of material on permanency and disability found a similar dearth of material.

Experiences of places such as Macomb Oakland Regional Center (Rosenau, 1990; Taylor, 1991) and Every Child, Inc. (Taylor et al., 1992) where alternate family placement is made by voluntary agreement with the birth family demonstrate the feasibility of the approach. A closer look at their strategies finds three important elements at work: a) high quality alternate families are readily available, b) the relationship between the birth family and the person who works with the birth family is carefully built through trust and longevity, and c) the birth family retains the

decision about a particular family for their child.

The process of conversion from reticence to acceptance involves helping the birth family to see how an alternate family differs from them. Presenting the possibility of alternate family care requires an explanation of how another family can do what a loving birth family cannot. This involves pointing out differences such as the choice to raise a child with a disability, the choice of type of disability, preparation prior to having the child, and beginning at a peak of readiness and energy. While those differences can make alternate family care more palatable to consider, experience has shown that the real convincing comes when the birth family is introduced to a particular alternate family. If the recruitment process has been done well, the very attributes of the alternate family will sell themselves. In the experience of Macomb Oakland Regional Center, hundreds of birth families have made the choice voluntarily.

The family support movement calls for recognition that families are competent. Families can make responsible decisions about permanency, but questions about permanency need to be posed. Too frequently parents are steered toward residential placements by professionals who are themselves reticent to confront the issues. Parental choice of a residential facility cannot be treated simply as a preference out-of-context with its permanency implications. Failure to address permanency is a disservice to the family as well as the child. Parents who are respectfully engaged in a discussion of permanency can and do seek to place their children with other families. Where supports are inadequate or no alternate families exist, facilities may represent the only alternative. Where facilities exist without viable alternatives or no opportunity is offered to work through reluctance, parents may "choose" a residential facility. That is not a choice, but a default position.

One problem is that facilities for children exist. By their very existence they come to be justified and admissions continue. When a family is struggling, rather than reviewing which facility is most appropriate, the issue should be with which family the child should live. That review is related to what kinds of support a family can accept. Which family can accept the child *and* the child's needs *and* the intrusion that may be required to meet the child's needs *and* the lifestyle that accompanies the intrusion? Permanency planning will help to sort out what the birth family needs and when an alternate family is needed. Permanency planning will help sort out how birth and alternate families will relate to each other and share in making a secure family home for every child. Respectful but assertive exploration of permanency can allow a mutually satisfying arrangement that fulfills the vision that all children grow up in a family.

### **Reality: Lack of Data Hampers Policy Assessment**

The acid test of permanency is how many children do not live with permanent families. We currently have no system-



atic way to track children with disabilities in order to judge the security and nature of their family situation. We do not reliably know how many children do not live with families. Our data keeping is not organized to indicate whether children live with families and whether their family life reflects permanency principles. None of the readily available national data sets tracking trends for persons with developmental disabilities clearly identifies the total number of children living in non-family settings. Data about out-of-home placements may not be reported or is reported for large facilities only; where data is collected, it may fail to distinguish family from non-family residential settings and/or between children and adults. A recent General Accounting Office (2000) report on *Medicaid Managed Care: Challenges in Implementing Safeguards for Children with Special Needs* acknowledges that there is no system to identify and track this “uniquely vulnerable population of children” (p.34) which includes children with developmental disabilities. The report focuses on health care broadly defined to include all aspects of a child’s life, but it makes no reference to residential facility care. The comments of the Department of Health and Human Services in response to the report identify the importance of a “medical home” (p.61) but do not make a similar point about the importance of a family home.

Over the past 20 years, data collection on a national scale has improved dramatically. Data collection not only identifies trends, it steers them. By asking questions at a national level, agendas are set and priorities identified. What is asked, and what is not, tells much about what is considered important in developing services for people with disabilities. If we don’t track where children are, we are less able to judge how well our systems are doing in providing for permanency for children with developmental disabilities to assure all children grow up in a family.

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## ■ Recommendations

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The United States as a nation and the individual states should invest in permanency. They should:

- Adopt permanency as a policy for all children.
- Include permanency policy within family support policy for children with disabilities.
- Assure implementation of policy through mechanisms to track non-family placements of children, require a written permanency plan for all children served, and require periodic administrative review of permanency plans and non-family residential placements.

States, local governments, and service providers should invest in relationship-based family support. They should:

- Review policies that inhibit relationships.

- Support strategies that enhance relationships.
- Increase the match between needs and responses.

States, local governments, service providers, and advocates should invest in alternate family recruitment. They should:

- Recognize the protracted process involved in family decision-making.
- Provide dedicated energy to recruitment.
- Disseminate successful strategies.

All stakeholders, policymakers, advocates, and community members should work together to connect permanency, family support, and alternate family recruitment as inseparable elements of policy and practice to assure a family home for all children

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## ■ Conclusion

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Return to the Caswells and the O’Briens who opened this discussion. Each family has received significant family support. Yet the personal relationship between the Caswells and the people who support them is hampered by organizational rules that prevent them from operating like extended family. The personal relationship the O’Briens rejected means that their son is growing up in a nursing home. Neither family has been asked by the systems that work with them to think about the issues of permanency or to strategize about how to affect the future for their children. The current situation for each does not need to remain as it is. As things stand service systems are intricately woven into their lives. People within those systems can either continue in the current sub-optimal direction, or work with them to make a difference that will help Stephanie and her family enjoy the family lifestyle they prefer and help JJ and his family find a way for JJ to get back into family life, quite possibly an alternate family.

Both our policies and our practices for children with developmental disabilities are too little directed to permanency. Partly this results from a misplaced conceptualization that sees children from a placement perspective rather than a permanency perspective. Placement identifies a typology of kinds of settings. Permanency focuses on an emotional experience. A child’s experience of childhood has relevance for her or his experience of adulthood connections. We have experience with a generation of adults with disabilities who were separated from their families in residential institutions. A sense of unrequited longing and searching for reunification is a compelling part of their stories. The children for whom we do not plan permanency today risk losing the sense of belonging that is so much a part of the experience of well-being.

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## ■ Appendix A

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

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:

**All children, regardless of disability, belong with families and need enduring relationships with 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."**

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 position 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 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 possibility 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 seldom provides children the continuity and stability they need in their lives. While foster families may be called upon to assist, support, and occasionally fill in for families, foster care is not likely to be an acceptable alternative to fulfilling each child's right to a stable home and enduring relationships.

*Center on Human Policy, Syracuse University, Syracuse, New York • 1987/88*

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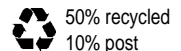
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