CONGREGATE CARE
FOR CHILDREN WITH DISABILITIES

LITERATURE REVIEW

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INTRODUCTION

Whether congregate care is necessary, appropriate, beneficial, and productive of cost-effective outcomes are issues of interest to child advocates nationally. Issues around congregate care are complex and the literature that might inform them is also complex. Framing this literature review are the following parameters:

Premise of the literature review. Child well-being is tied to family well-being. To understand the lives of children with disabilities who live in congregate care, we need to understand the complex context in which congregate care exists and the alternatives that have and have not been available to support children with significant needs and their families.

Questions which guided the literature selection:

- What do we know about what children with disabilities need to grow and thrive?
- What do we know about congregate care for children with disabilities?
- What do we know about families with children with disabilities?
- What do we know about systems of support for children with disabilities?
- What do we know about family-based alternatives to congregate care for children with disabilities?

Operating definition of disability for this literature review: A severe or chronic physical, developmental, behavioral, or emotional condition manifested before age 22 and likely to continue indefinitely, that results in substantial limitations and an ongoing need for individually planned and coordinated services.

Operating definition of congregate care for this literature review: A configuration of resources and people organized in a living arrangement that is shared by multiple individuals with disabilities, where care is provided by multiple individuals who do not include a parent(s), and is intended to provide a stable residence of more than short-term duration. Multiple terms are used in the literature and in this review to refer to congregate care, including institution, residential or facility care, or residential placement.

Congregate care is fundamentally a caregiving arrangement. Congregate care has two components: (1) care by adults with responsibility for providing day-to-day supervision, direction, and assistance to minor children and dependent adults who are in need of such assistance, and (2) congregation of multiple numbers of people needing care into a residential setting in order to receive needed care and/or treatment from multiple individuals who are organized in particular ways to carryout that function.

The logic of this literature review is as follows:
1. To understand the impact of congregate care, it is necessary to understand what children with disabilities need.

2. To understand what children with disabilities need, it is necessary to know what all children need and what children with disabilities need that is different or additional.

3. To understand the use of congregate care, it is necessary to understand why congregate care exists as an alternative to families raising their children with disabilities at home.

4. To understand families’ experience, it is necessary to understand what is needed to be able to provide beneficial care to children with disabilities in a family home.

5. To judge whether congregate care is necessary, appropriate, and beneficial involves a comparison, which requires an understanding of what alternative caregiving arrangements are possible.

6. To make recommendations about changing or maintaining services and supports for children with disabilities and their families, it is necessary to understand the design and organization of the current system in contrast with alternative ways to design and organize support to caregiving endeavors.

A word of caution is necessary about the literature and this literature review. The potential amount of relevant literature is vast and varied. Any search/selection strategy is fraught with dilemmas. In part the task is complex because this review includes a range of disabilities. In part the task is complex because of the way services have been organized and subsequently studied. Following are some of the dilemmas that pervade the literature:

- Much of the literature relevant to congregate care is compartmentalized according to service systems that are most often compartmentalized according to disability.
- Literature about congregate care in the developmental disabilities services system exists but it is not necessarily specific to children.
- Literature about residential care in the mental health services system exists but it does not always distinguish short-term treatment settings from long-term living arrangements.
- Literature about congregate care of children in child welfare services exists but often does not specifically address children with disabilities.
- Literature about children who are placed in congregate care by child welfare systems involves children removed from families due to abuse and/or neglect, thereby confounding effects on children that result from the maltreatment that preceded placement.
- Literature about children placed voluntarily in congregate care has tended to focus on parental decision-making rather than the subsequent effects on children.
- Literature about congregate care and family decision-making does not always address the socioeconomic or cultural influences that affect families.

Given the multiple issues that are compartmentalized or confounded in the literature, neat assessment is difficult. Acknowledging these dilemmas, the selection of materials in this literature was based on what might be most relevant, informative, and contribute to further discussion. The intent of the literature review is not to polarize debate about the merits of congregate care versus family care, but rather to provide a context for problems to be solved to better support children with disabilities and their families.
WHAT DO WE KNOW ABOUT CONGREGATE CARE?

Trends away from congregate care

Residential services for children with disabilities are found in four major service systems: (1) developmental disabilities (inclusive of intellectual disability/mental retardation), (2) child welfare, (3) mental health, and (4) health. Each service system maintains or supports residential components. No overarching framework guides all four systems, however over the past thirty years each system has embraced some kind of disinclination toward long-term large congregate housing. Such disinclinations have been motivated by legal and/or funding issues, as well as by philosophical and/or clinical perspectives.

1. Overall a family support movement has been growing nationally since the mid 1960s which became acknowledged in federal legislation in 2000 (Bornheim, Goode, & Jones, 2006; Bryant-Comstock, Huff, & Vandenberg, 1996; Kagan, 1996; Parish, Pomeranz, Hemp, Rizzolo, & Braddock, 2001).

2. Developmental disabilities and mental health share a twentieth century movement toward deinstitutionalization which seeks to move individuals from large institutions toward smaller community-based housing. (Braddock et al., 2005; Prouty, Smith, & Lakin, 2005; Shoultz, Walker, Taylor, & Larson, 2005).

3. Developmental disabilities, health, and child welfare have been guided by legislation and judicial mandates for least restrictive settings (Braddock et al., 2005; Lerman, Apgar, & Jordan, 2005; NCD, 2005; Taylor, Lakin, & Hill, 1989).

4. Health and mental health have been moving from inpatient to outpatient care whenever possible and to short-term treatment in residential settings (Kastner & Walsh, 2006; Kiesler, 1994; Koyangi & Boudreauaux, 2003).

5. Child welfare, developmental disabilities, health, and mental health have been moving to a preference for family-based care rather than facility care (Johnson & Kastner, 2005; Shonkoff & Phillips, 2000; Stroul & Goldman, 1996; Taylor et al., 1989).

These national trends can be seen in legislation, judicial decisions, policy decisions, and data regarding residential patterns.

- Between 1997 and 2005, children and youth in out-of-home placements through the intellectual or developmental disability (ID/DD) service system decreased from almost 91,000 in large institutions to less than 26,400 for youth under age 21, and less than 8400 children under age 18 in congregate care (Breedlove, Decker, Lakin, Prouty, & Couucouvanis, 2005; Prouty, Lakin, Couucouvanis, & Anderson, 2005).

- Funding for “at home” services has fundamentally changed the age profile of persons with ID/DD in residential care from 36.8% of individuals under age 21 in 1977 to 7.1% in 1997 (Doty, 2000).

- According to the Surgeon General, family preservation and intensive home services have been well-researched and have been shown to be effective (Bazelon, 2001).

- The passage of the Adoption and Safe Families Acts of 1997 and 1980 increased accountability of child welfare systems to prevent unnecessary removal of children from their families and reasonable efforts to reunify children after removal.
• The Olmstead Supreme Court decision of 1999 provided legal support for states’ efforts to rebalance long-term services toward home and community supports (NCD, 2005).

• A national public health agenda developed by the Centers for Disease Control and Prevention called Healthy People 2010 established specific objectives and rationale calling for the elimination of congregate care for children under 18:

"Reduce to zero the number of children aged 17 years and younger living congregate care facilities."

"Institutions and other forms of congregate care are inconsistent with positive public health policy and practice."

Trends maintaining congregate care

How far these shifts away from congregate care will go or can go is a matter of considerable debate. Not all trends are moving away from congregate care. Some countervailing trends are maintaining congregate care or resisting its elimination.

• Funding patterns demonstrate a federal bias towards institutional placements with more than 50% of Medicaid resources continuing to support congregate care facilities (Keisler, 1994; NCD, 2005; Parish et al., 2001).

• While out-of-home placements of children and youth aged 0-14 with intellectual or developmental disabilities have slowed substantially, if not ended, the trend toward decreasing numbers of children 14 years and younger has been offset by an increase in the number of youth aged 15-21 in congregate settings of four or more people (Prouty, Lakin et al., 2005).

• While there has been a significant decrease in the number of individuals with intellectual or developmental disabilities living in state operated institutions, there has been an increase in privately operated congregate facilities (Leman, Apgar, & Jordan, 2005).

• The American Medical Directors Association reports at least 100 pediatric nursing facilities and that the number is growing (AMDA, 2004).

• Although most foster children live in family settings, 27% of foster children ages 8-17 live in congregate care and a majority of them have disabilities (NACAC, 2005).

• Residential group care for children with serious emotional disturbances is more common than family foster care and the number of children placed in residential treatment centers has increased in recent years (Bazelon, 1999; Curtis, Alexander, & Lunghofer, 2001; Landsman, Groza, Tyler, & Malone, 2001).

A small firestorm was set off in 1994 when the Speaker of the U.S. House of Representatives called for reopening “orphanages” as an alternative for disadvantaged youth and families (Shealy, 1995). Although the proposal was short-lived, it touched off a national policy debate about the place of congregate care in U.S. human service systems. While proponents of congregate care for “typical” children represent a small minority, the same cannot be said for children with significant disabilities. The maintenance of long-term congregate facilities is largely advanced for those individuals with significant and specialized needs presumed to be unable to be supported in the community (Shoutz et al., 2005). Individuals usually identified as requiring congregate care have needs that fall into four groups: (1) behavioral support needs; (2) complex medical needs; (3) psychiatric disabilities, or (4) some combination of the three (Shoultz et al., 2005).

Factors which come into play as to whether congregate care is “needed” extend beyond the specific
characteristics of an individual with a disability to include external issues such as the cost of care, workforce recruitment and retention, efficiency of resource use, and policy decisions about the way services are organized (Shoulztz et al., 2005).

The remainder of this literature review of congregate care looks at some of these complex and interrelated issues, examining clinical, policy, economic, and philosophical issues. It addresses large system issues as well as issues affecting individual children and families.

Research evidence and limitations

The literature around congregate care outcomes is complex, contradictory, and fraught with methodological dilemmas in design and consequent interpretation. Despite the face value logic that congregate care is needed for some individuals with complex and high levels of need, there is a remarkable lack of current rigorous outcome research that residential group care and treatment is more effective than family-based alternatives (Curtis, Alexander, & Lunghofer, 2001; Hardin, 2002; Keisler, 1994; Meadowcroft, Thomlinson, & Chamberlain, 1994).

Methodological dilemmas abound in research design. Critiques of sampling procedures, randomization, control groups, validity of measurement tools, and absence of longitudinal data can be raised about most studies. Complicating design and interpretation of outcome studies of congregate care settings is the need to sort out the contribution of pre-placement factors such as the age of the child at placement, the nature of the parent-child relationship prior to placement, the pace of removal (i.e., emergency or careful transition), the presence of abuse prior to placement, and the number of placements preceding the congregate setting (Shealy, 1995).

Additional methodological conundrums lie in sorting out the contribution of post-placement factors such as the type of treatment, quality of treatment implementation, characteristics of the setting and logistics of caregiving, and clarity and measurement of the purported benefit of placement. Rather than attempt to use this literature review to evaluate this complex and unsatisfying literature, I have chosen to focus instead on findings from selected studies that might inform productive discussion. However, it would be remiss not to touch on the findings of existing studies which address congregate settings, especially those that compare congregate care with other living arrangements. Despite methodological limitations in available studies, a good deal is known about congregate care.

Attachment

Some of the earliest studies and instigating challenges to congregate care were raised by John Bowlby from observations of children separated from their parents in residential nurseries due to the large-scale disruption of World War 11. Bowlby looked at three conditions associated with young children in nurseries
(Berlin, Ziv, Amaya-Jackson, & Greenberg, 2005):

1. Physical separation from parents
2. Absence of a specific bond to a specific figure due to inconsistent institutional staffing
3. Deprivation of the institutional environment

Subsequent research has examined the effects of separation and residential care through careful observation of children and longitudinal studies following children for many years (Harden, 2002; Kobak, 1999; Zeanah, 2000; Zeanah et al., 2003).

The theory that evolved from these investigations became known as “attachment.” Attachment theory is one of the broadest, most profound lines of research in modern psychology and provides one of the most robust measures in the field of socio-emotional development (Berlin et al., 2005; Spieker, Nelson, DeKylen, & Staerkel, 2005; Ziv, 2005). Empirical studies that span four decades and multiple countries and cultures provide cross-cultural evidence of attachment as a universal and normative phenomenon (van Ijzendoorn & Sagi, 1999). Evidence from attachment research has implications for current practices and policies regarding congregate care of children with disabilities.

Attachment is a psychobiological theory that posits the primacy of the parent-child relationship for optimal development (Carlson, Samson, & Sroufe, 2003). Attachment theory asserts two interrelated features (Carlson et al., 2003):

1. Differences in qualities of caregiving lead to differences in attachment
2. Differences in attachment significantly influence later social and emotional development

Meta-analysis studies have established that securely attached children have an early advantage in cognitive and language development and develop fewer behavioral problems compared to insecurely attached children (Spieker et al., 2005). Studies of children with special needs including autism, premature birth, neurological difficulties, Down syndrome, and eating and sleeping difficulties have found that attachment relationships form in ways that are comparable to nondisabled children (Carlson et al., 2003).

While attachment highlights the importance of a bond of parental affection, affection alone is not sufficient to create a secure attachment. Attachment is not simply a matter of affection displayed by a caregiver during episodes of caregiving. Continuity of the caregiver is important, that is, the attachment relationship is with a specific caregiver over time. Furthermore, attachment security also involves times when the child is not with the caregiver. Attachment involves the child’s felt sense of security even in the absence of the beloved caregiver based on an expectation of their sure return. Attachment involves the child’s exploration of the environment in ever increasing physical distance from the beloved caregiver as the child develops (Cassidy et al., 2005). During early childhood these periods are very brief (a few minutes) and distance is short.
(across the room). Time and distance increase through childhood.
Security develops in the course of everyday intimate interactions between the child and the primary attachment figure. Attachment theory asserts that the child’s attachment security is determined by the extent to which the attachment figure provides a “secure base” (Zeanah, 2000; Ziv, 2005), that is, a psychological, emotional relationship that holds in both presence and absence. A secure attachment involves the child’s ability to safely venture out and have a felt sense of security in the caregivers’ availability if needed. Lack of reliable availability or interference with exploration can each contribute to insecurity and have an impact on emotional development and adult emotional health.

The important contribution of attachment research is that it calls attention to the essential role of a primary parental figure in optimal child development. A parent who is predictably present, emotionally available, nurturing, responsive, and remains consistent over time offers the secure base that is necessary for healthy development and for later adult emotional health. Absence, infrequent or unpredictable availability, unresponsiveness, or harm or the threat of harm contribute to insecure attachment with repercussions in suboptimal development.

**Brain science/neurological evidence**

There is increasing convergence in the multiple fields of attachment, child development, trauma, and child mental health regarding the neurobiological underpinnings and behavioral consequences of early life experiences and disrupted attachments (Berlin et al., 2005; Putnam, 2005; Simpson, Jivangee, Koroloff, Doerfler, & Garcia, 2001). Recent technological advances have contributed empirical evidence of the underlying neurobiological processes of early childhood experiences (Zeanah et al., 2003). Brain imagery scans of children reared in institutions compared to family-reared children have noted significant differences in areas of the brain associated with cognitive and emotional regulation (Zeanah et al., 2003). Neuroscience research confirms the growth-fostering importance of close relationships for brain development in young children (Shonkoff & Phillips, 2000). Lessons from developmental neurobiological evidence have elevated attachment to a leading public health issue (Putnam, 2005; Healthy People 2010).

**Child development**

A review of the explosion of child development research in the past decade was commissioned by the National Research Council and the Institute of Medicine (Shonkoff & Phillips, 2000). Nationally recognized child development experts evaluated and integrated the research advances in neurobiological, behavioral, and social sciences. The final report describes the central role of parenting as the focused and differentiated relationship that the young child has with the adult (or adults) who is (are) most emotionally invested and consistently available to him or her.
The report identified what all children require from an early and abiding parental relationship. This special adult is not interchangeable with others. To be optimally beneficial, this relationship requires stability, consistency, sensitivity, love, availability, reliability, responsiveness, protection, affection, and unflagging commitment to the child’s well-being. Early development is, therefore, inextricably tied to the interpersonal context of the growing child, that is, to his or her caregivers and home (Carlson et al., 2003). The scientific evidence about the significance of early experiences and relationships for development was described in the report as “incontrovertible” (Shonkoff & Phillips, 2000, p. 6).

Congregate care compared to family care

A large body of research has been devoted to comparisons of institutional care and family care for infants and young children (not necessarily children with disabilities). A special article instigated by the 1994 congresswoman’s call to reopen orphanages examined a century of pediatric and child psychiatric research (Frank, Klass, Earls, & Eisenberg, 1996). The review identified five areas of potential biological and social risk for infants and young children in congregate care. The authors concluded that for young children, the research is clear that the risks of institutional care are inescapable and cannot be reduced to tolerable levels even with massive expenditures:

- **Institutions are inherently unsuitable for the emotional needs of human infants . . . inevitably depriving infants of the flexibility and reciprocity in interaction with stable, noninterchangeable caregivers, which are essential for adaptive emotional development.** (p. 574)

- **There is no realistic way to assure caregiver continuity for institutionalized children.** (p. 575)

In particular, the following risks were enumerated in the review (Frank et al., 1996).

1. **Infectious mortality**—Even with meticulous compliance with immunization schedules, infants and young children who are brought together in groups for care have a higher rate of infection and increased risk for acquisition of resistant organisms. The risk is increased when there are more than 3 children in a childcare setting.

2. **Physical growth and nutrition**—Findings of institutional care have documented chronic growth stunting and life-threatening marasmus (a form of serious protein-energy malnutrition). Debate continues as to whether this is related to poor appetite reflecting depression or subtle neurochemical changes reflecting a lack of tactile stimulation.

3. **Cognitive development**—Research shows universal descriptions of progressive deterioration by the second year of life in most institutionalized children. Efforts to provide increased staff ratios, time out of cribs, and increased stimulation without permitting infants to form relationships with a few specific caregivers were noticeably ineffective. Even with optimal ratios of 1:3 for children younger than 24 months, infant residential care exacts a developmental cost.

4. **Socio-emotional development**—Children who are most at risk are those who experience multiple changes of parent figures or who are reared in institutions with many attendants who have no special responsibility for individual children. Even the best trained caregivers cannot replace the level of interaction and reciprocity which young children achieve when cared for by parents. Even living in small groups with high staff-to-child ratios and abundant stimulating play materials,
young children with large numbers of different adults who looked after them were more anxious, fearful, aggressive, and quarrelsome at age 16 compared to children who had never been institutionalized.

5. *Maltreatment*—Physical and sexual abuse is more likely to occur in residential settings than families. In addition, some maltreatment is institutionally sanctioned as a necessary discipline practice despite the strong opposition of the American Academy of Pediatrics to corporal punishment.

Better outcomes are consistently found for children raised in a continuous family home by responsive parents compared to children raised in congregate care by rotating staff (Smyke, Dumitrescu, & Zeana, 2002; Zeana, Smykes, & Settles, undated). However, much of the research on institutional care is dated. In one of the few current U.S. studies comparing more adequate settings than earlier orphanage care, Harden (2002) compared three programs serving young children (not necessarily children with disabilities): (1) group settings of 4-8, (2) a large setting of 57 children, and (3) foster home settings. The programs tended to perform equally well on personal routines, health and safety, feeding and diapering, scheduled activities, furnishings, and caregiver listening. The children in two of the smaller group settings had ratios of 1:2 adults to children, while the other facilities had ratios of 1:5 or 1:6. Children in two of the small facilities had ‘house mothers’ who resided on the premises. The other facility-reared children were exposed to larger numbers of caregivers, greater ratios of caregivers, and more frequent rotation of caregivers.

Differences were found on child outcomes related to the number of children in the home and the practice philosophy of the home (Harden, 2002). Higher scores were found in settings with more highly trained and supervised staff, with smaller groups, with lower total number of children, and arrangements that included house mothers. Children reared in foster care fared better than their group-reared counterparts on mental development and adaptive skills. Foster parents had higher scores for responsiveness, involvement, and variety of stimulation. Both small and large congregate settings had worse outcomes compared with children in foster care. Children in the congregate settings were more likely to experience a multitude of caregivers who changed depending on the day and shift. By virtue of the structure of the facility, congregate caregivers were less available to react to the child’s signals, to spontaneously follow the child’s cues in play and affect expression, and to adapt their responses to the child (Harden, 2002).

This study highlighted how optimal child development unfolds in the concrete details of everyday life. Congregate care arrangements create an environment of non-contingency where it is difficult for children to learn the consequences of their actions—a fundamental necessity to cognitive, emotional, and behavioral development. From the child’s perspective, in congregate living arrangements, caregiver attention “just happens” without the child doing anything to elicit it (Zeana et al., undated). The logistics of caregiver assignments in congregate settings prevent timely and spontaneous reactions to children’s subtle and unique signals and expressions, the very hallmark of caregiving qualities required for optimal growth and development.
Both historical and contemporary investigations have noted a set of interrelated features inherent in congregate care that are problematic for optimal development:

1) Limited opportunities for a primary caregiver
   a. Shift care
   b. Responsibility for multiple children
   c. Understaffing
   d. Turnover
   e. Limited time with an individual child
   f. Non-individualized responses to children
   g. Lack of psychological investment in a child by caregivers
   h. Lack of caregiver continuity over time

2) Care on a schedule rather than in spontaneous response to a child
   a. Regimented daily schedules
   b. Paucity of stimulation
   c. Long stretches of inactivity
   d. Competing needs of many children of similar ages and needs

3) Inadequate care and protection
   a. Higher prevalence of poor quality physical care
   b. Higher prevalence of maltreatment

The irreplaceable distinction between congregate care and family life is the parent-child relationship. While the relationship need not necessarily be with a birth parent, it entails much more than rotating staff can offer.

International research

Classic studies from the 1940s to the 1960s established developmental delays and socioemotional deficits in institution-reared children. A resurgence of interest in attachment research has been stimulated by the “natural experiment” of institutional practices in Eastern Europe given widespread exposure to these practices following the fall of communism in the early 1990s. Recent research around international adoptions of children raised in Eastern European institutions has found numerous deleterious behavioral and developmental outcomes that persist into later childhood and beyond (Harden, 2002; Zeanah, 2000).

A problem in relating recent studies of Eastern European institutions to U.S. institutions has been that the Eastern European settings involve both the effects of parental separation and the effects of institutional deprivation. By contrast, Vorria, Pickles, Wolkind, & Hibbsbaum (1998) conducted a study in Greece of children raised in higher quality long-term residences with stable staff compared with children raised in two-parent families. Children were admitted to residential care for parental financial reasons (rather than because of maltreatment). About one third of the children in residential care saw their parents on a regular
basis (at least once a month) while others had no contact or very infrequent contact. The presence of family cohesion and stability prior to admission to residential care was the single most powerful predictor of the child’s functioning. Frequency of parental visits was unassociated with outcome measures. Although children in these residential settings had had unusual continuity in residential caregivers, they exhibited numerous problems in late childhood and early adolescence. Children with stable early family upbringing showed lower emotional and behavioral difficulties, but when compared to children raised in families, children raised in residential settings were disadvantaged in school experience and peer relations.

Another “natural experiment” from international research that has provided a unique opportunity to control for the effects of deprivation and intensity of parental involvement is the Israeli kibbutz system of caregiving (Aviezer, Sagi, & van Ijzendoorn, 2002; Sagi-Schwartz & Aviezer, 2005). Kibbutz care over the last two and half decades involved middle-class families who chose congregate child-rearing as part of a child-minded ideological belief about the potential benefits of a highly organized out-of-home environment. Kibbutz children were cared for in groups by multiple caregivers in residences where they were visited daily by their parents or returned to their family home every afternoon from 4:00 to 8:00 before returning to sleep in the children’s residence.

The kibbutz system has been closely studied in longitudinal studies following children from infancy into adulthood. Studies compared Israeli children in kibbutz care with Israeli children in typical families. Kibbutz children had substantially higher rates of attachment insecurity compared to children who lived and slept in their family homes (Sagi-Schwartz & Aviezer, 2005). Negative effects persisted into young adolescence with school ratings of less emotional maturity (Aviezer et al., 2002). Although parents in both groups were comparably sensitive in observed interactions with their children, distinct differences were found in communal-sleeping children compared to family-sleeping children. Only in the family-sleeping samples was higher maternal sensitivity associated with higher infant attachment security.

Researchers concluded that the higher rate of insecurity of kibbutz children was tied to the practice of communal sleeping and the resultant inconsistent responsiveness inherent in the logistics of nighttime care. Researchers noted that children’s nighttime experiences in communal-sleeping arrangements were characterized by maternal inaccessibility and non-availability, combined with exposure to numerous adults responsible for numerous children who were unable to respond promptly and sensitively to children’s needs (Sagi-Schwartz & Aviezer, 2005). The kibbutz communal sleeping practice has since been discontinued.

**Developmental disabilities “movers and stayers”**

A significant body of literature has compared different kinds and sizes of institutional settings for individuals with intellectual and developmental disabilities (primarily adults). A number of studies have
compared individuals who moved from congregate care to community settings with matched individuals who remained in institutional settings. Lerman et al. (2005) conducted a large systematic review of research about deinstitutionalization and identified the most rigorous studies. In 12 of the 8 most rigorous studies, so-called ‘movers’ were compared with matched ‘stayers.’ Improvements in overall adaptive behavior and self-care were significantly better for movers. The review found only one recent study in which researchers examined the longitudinal effects on adaptive behaviors of persons who remained in institutions. A random sample of 150 movers matched from a random sample of stayers with no significant baseline difference between movers and stayers in 1994, found significant decreases in 2000/2001 in the scores of stayers in areas of social and emotional skills and increases in the scores of movers in the areas of community and household skills. The investigators suggested that continued residence in an institution has long-term socioemotional detriment (Lerman et al., 2005).

**Abuse and neglect**

There is a significant body of literature that suggests congregate care increases the risk of harm from abuse and neglect.

According to the National Clearinghouse on Child Abuse and Neglect Information, children with developmental disabilities and mental impairments in general are at greater risk of being maltreated than children without disabilities (NCCANI, 2001). Estimates of maltreatment suggest 31% to 69% children with disabilities are maltreated in comparison to 9% of other children (NCCANI, 2001); because of recording and reporting methods, even this may be an underestimate of the real extent of the problem (Bruhn, 2003; NCCANI, 2001).

Available data suggests children with disabilities tend to be maltreated multiple times in multiple ways (Bruhn, 2003; NCCANI, 2001). Once in care, children with disabilities are at risk of subsequent maltreatment (Bruhn, 2003; Sobsey, 1994). Children with disabilities experience increased risk in congregate care settings both from caregivers and from other individuals with disabilities with whom they come in contact (Sobsey, 1994). Although there is disagreement about the precise percentages, significant numbers of offenders are disability service providers (Sobsey, 1994). Studies have identified the following categories of offenders (Sobsey, 1994):

- disability services providers 28.0%
- acquaintances and neighbors 16.5%
- family members 15.6%
- peers with disabilities 9.1%
- strangers 6.6%
- transportation providers 5.8%
It is important to understand the factors that contribute to these disturbing statistics. The National Clearinghouse on Child Abuse and Neglect Information (NCCANI, 2001) suggests the following contributing factors:

1. Attitudes and beliefs that devalue children with disabilities
2. Segregation, distance, and isolation of children with disabilities
3. Lack of attachment and bonding
4. Professional messages that discourage attachment and bonding
5. Children’s impairments that inhibit self-protection, escape, communication of threats, and ability to discriminate; and that promote learned compliance with authorities
6. Living arrangements with paid caregivers characterized by
   a. power and control inequities
   b. dehumanization of care recipients
   c. detachment of caregivers
   d. abusive subcultures

In one of the most comprehensive analyses of factors related to abuse and neglect of individuals with disabilities, Sobsey (1994) identified similar factors from reviews of the literature and research:

1. Isolation. The general public knows little about the realities of institutional life.
2. Administrative structures. Direct care staff have little power and influence. Administration is managed in large, distant bureaucracies.
3. Detachment and dehumanization of caregivers. Attachment of caregivers is actively or implicitly discouraged by caregiving assignments and time spent in meetings and record keeping.
4. Clustering. Vulnerable individuals who are known to be aggressive are congregated and mixed.
5. Unrealistic expectations. Beliefs that institutions provide safe havens that protect vulnerable people from society while offering sophisticated educational and rehabilitative services inhibit development of safeguarding practices.

The very nature of congregate care unintentionally but unavoidably includes factors that increase the risk of maltreatment (Sobsey, 1994). Increased and long-term dependency needs of individuals with disabilities require intimate exposure to multiple persons over the course of scheduled coverage. Staff are responsible for social control and protection of multiple individuals in conditions that group individuals together who are known to be aggressive or destructive. Known characteristics of abuser profiles include motivations of control and depersonalization of victims, both situations that are fostered in group care. Management and administration of group settings further contributes to risk through procedures for behavioral control that require physical management.

A large body of research indicates that isolation from society increases the risk of maltreatment while inclusion decreases it (NCCANI, 2001). Remote locations, locked doors, infrequent contact with the general public all contribute to isolation. Less risk is associated with small social units with stable members and stable, continuous caregivers (Sobsey, 1994). Strong bonds inhibit abuse. Staff turnover,
rotating shifts, rotating client assignments all contribute to weak bonds rather than strong ones. Weak bonds between staff and the people they serve cannot be expected to deter abuse to the same extent as stronger bonds (Sobsey, 1994). Organizational needs for interchangeable staff for efficient management inhibit the growth of strong bonds which in turn inhibit maltreatment.

Research has found preventive factors include the active involvement of families of children placed in out-of-home care. A large national study of outcome measures involving 3630 individuals served by 552 organizations across 36 states found that maintaining ties with natural support systems and having intimate relationships and friends may be the best predictor of personal safety and freedom from abuse and neglect (Gardner and Carran, 2005). Family involvement decreases risk, especially when families know the individual caregivers who work with their children (NCCANI, 2001). Environments that welcome and encourage and facilitate family involvement add a preventive element as does community involvement (AAP, 2001). Factors such as distance and interpersonal interactions that discourage visits reduce this protective feature.

Family involvement post-placement

In early research about family involvement after out-of-home placement, studies found that once an individual is placed in residential care, parents maintained little involvement (of note these studies focused primarily on adults) (Blacher, 1994a, b). In a later study of family involvement after placement of their minor children, Blacher and Baker (1994a) made a distinction between visitation patterns and parental feelings of attachment. Their study of parents of children two years after placement found 75% of families continued to feel strong attachment. A majority of families also reported family life was better after placement.

A study that examined family involvement for 266 children in mental health and mental retardation residential care (Pfeiffer & Baker, 1994) found wide variation of involvement, although 80% had contact less than 4 times a year. Of the children studied:

- 12% had “no families”
- 19% had no visits from their families
- 50% had contact three or four times a year,
- 20% had contact 30 or more times a year

Another study which looked at the visitation patterns for 53 families of children aged 2 to 18 living in a variety of placement types (Blacher, Baker, & Feinfield, 1999) found:

- 17% had visits fewer than six times a year
- 52% had visits once a month
- 31% had visits more than once a month
This study found that parental visits tended to decline over time. The study found that parental involvement after placement was influenced more by facility practices than by family or child characteristics. The number of visits to the facility was predicted by the opportunities provided by the facility, and the number of times the child had visits home was predicted by the distance from the facility. Children under age twelve had no different visitation patterns than children over age 18. When asked about their perception of attachment ties, 47% of families felt that their attachment was lessening over time. When asked about their ideal placement for their child, two-thirds felt it was the facility and one-third felt the child being home would be ideal, although 82% felt the child being at home would make family life worse.

Other studies have also found that the strongest predictor of family involvement was the opportunities provided by the facility that facilitated such involvement (Pfeiffer & Baker, 1994). Lower socioeconomic status and greater distance have been found to be predictive of family involvement, however, an evaluation of a project where staff facilitated family involvement found distance was less predictive of decreased involvement (Landsman et al., 2001).

Parental involvement has an impact on the child while in care, but also has an impact on whether the child remains in care. Data consistently finds that parental involvement is associated with better outcomes for children while in care and that increased involvement is associated with reunification (Landsman et al., 2001).

**Staffing issues**

The very attribute of congregate care that is touted as its benefit; that is, the availability of multiple staff as contrasted to burnout in families with fewer caregivers is, in fact, problematic. Serious workforce issues face congregate care providers including shortages and turnover (Braddock et al., 2005; Seavey, 2004). A study of the cost of turnover in direct care workers in long-term care concluded that turnover presents a significant quality of care problem (Seavey, 2004). One study estimated the annual turnover rate in nursing facilities is nearly 100% (NCD, 2005). Another study identified turnover rates in nursing homes at 71% and turnover in community disability residences at 28% (Seavey, 2004). An economic analysis estimated the national cost of turnover in direct care at $4.1 billion (Seavey, 2004).

The future looks even more problematic. A study by the U.S. Department of Health and Human Services projected that the need for direct support staff to assist individuals with developmental disabilities will increase 37% by 2020 and that recruitment and retention to meet future demand will become even more difficult (ASPE, 2006).
Turnover is exacerbated by workplace conditions. Direct care workers in long-term care settings experience some of the highest injury rates of any group of workers in the U.S. economy (Seavey, 2004). One-fifth of direct care workers earn incomes below the poverty line and the majority of long-term care workers have no health insurance (NCD, 2005). For the worker, co-worker absences, turnover, and shortages mean covering for unfilled hours or inexperienced colleagues. Deterioration in working conditions and lack of incentives increase the likelihood of quitting, further contributing to the problem so that turnover leads to more turnover.

For the recipient of care, turnover means disrupted continuity of care. It means a continual adjustment to new caregivers who don’t know preferred routines and with whom recipients lack relationships. It means interference with development and individualized care and therefore depersonalized care (Seavey, 2004) which is a risk factor for abuse and neglect (Sobsey, 1994).

SUMMARY

We know from research about attachment, early childhood development, and comparisons of various caregiving arrangements that a parental relationship is key to child well-being. There is clear evidence of the developmental benefits of family life with a readily available, responsive, nurturing, reliable, well-supported primary parental caregiver whose relationship is consistent over time. On the other hand, there is a lack of outcome-based research about the benefits of congregate care. There is little evidence to suggest benefit to a child of sharing living arrangements with other individuals with similar disabilities. There is little evidence to suggest benefit to a child of having multiple interchangeable caregivers. There is, however, evidence to suggest that the absence of a primary parental relationship has negative developmental consequences and that there is an increased risk of maltreatment in congregate settings where multiple caregivers are inherent. The effect of congregate care for a child, therefore, presents developmental risk without offsetting benefits.

The merit of congregate care (if any) may lie elsewhere. It may be argued that congregate care is needed for parents and families who have been inadequately supported, or for economic reasons or management ease. While families may (arguably) benefit from the removal of their children, their children may not benefit from removal (Blacher & Baker, 1994a; Blacher et al., 1999). Congregate care has filled a gap when support is unavailable for families, inadequate or ineffective for a particular family, or not wanted if available. We turn next to look at families of children with disabilities and their needs.
WHAT DO WE KNOW ABOUT FAMILIES WITH CHILDREN WITH DISABILITIES?

What congregate care settings cannot provide is the very feature which promotes an optimal growth environment for children—a quality parental relationship. However, not all families are able or willing to provide the necessary responsive environment—some because of parenting deficits, but a great many more because of inadequate support. The parent-child relationship is affected by the parent’s availability to the child. Parental availability can be hampered by physical separation, as when a child lives in congregate care. It can also be hampered for a child who lives at home by the parent’s physical exhaustion even though physically present to the child. It can also be affected by the child’s availability to the parent’s ministrations, as is the case with some children’s temperaments or impairments which affect sensory or tactile responses, activity level, or behavioral expression.

What many families with children with significant disabilities find they need is the support of additional caregivers beyond their immediate family members. Additional caregivers are the very feature which congregate settings offer. Historically, families’ needs for supplemental caregivers have been answered by moving children to locations where alternate caregivers are available. More recently, family support initiatives have tried to bring support to families to supplement and enable caregiving within a family home.

Family responses to disability

Families have diverse responses to raising children in general and equally diverse responses to raising children with disabilities. Families’ responses are shaped by multiple factors ranging from their values and beliefs, to competencies and parenting skills, to the sources of support (both formal and informal) that affect their ability to raise their child.

Early research findings regarding parenting a child with disabilities assumed that disability was inherently negative with unavoidable adverse effects on family life. However, methodology challenges were raised that comparison samples of parents of children with disabilities were not random, but were drawn from families who had sought assistance because they were struggling, thereby virtually assuring findings of struggles (Glidden, 1993; Shelton, Jeppson, & Johnson, 1989). Another criticism was that measures were taken after the child with a disability had entered the family; hence parent/family characteristics prior to the child’s diagnosis were not known or taken into account when interpreting negative findings (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001).
Criticisms also suggested flawed methodology failed to disentangle demands, stresses, and strains; confusing demands (the external environment), from stress (the relationship between the external force and the family), from strain (the actual negative effect as a result of stress) (Glidden, 1993). Greater demands do not necessarily transfer to greater stress or strain. Furthermore, some stress can be manageable, even positive. Failure to disentangle these issues contributed to the perception of maladjustment and chronic sorrow and masked positive adaptation of families rearing children with disabilities (Ferguson, 2002; Seltzer & Heller, 1997).

Seltzer et al. (2001) noted that early findings of negative responses also involved different cohorts of families than later studies with findings of positive accommodation, suggesting the impact of availability of services such as public education and increased spending on family support services. A large body of literature has now identified numerous positive responses to family life with a member with disabilities (e.g., Ferguson, 2002; Hastings & Taunt, 2000; Scorgie & Sobsey, 2000; Trute and Hauch, 1988). Families’ positive responses, however, do not mean they do not have difficulties. A more complete view of families recognizes that the source of difficulties is not limited to the child’s impairments, but includes the environments in which they live their lives.

*Families live, love, and survive within social contexts and these contexts influence their physical, emotional, and social well-being.* (Krahn, 1993, p. 245)

**Multiple caregivers**

Children’s well-being depends on the health and well-being of their parents (Shonkoff & Phillips, 2003). Extensive or protracted care needs of children can present demands on parental time and energy. Parenting stress and fatigue can reduce their responsiveness. Parental circumstances (e.g., single parenthood or illness or competing childcare demands) can result in an imbalance between what a disabled child needs and what a parent can provide (Shonkoff & Phillips, 2003). How well families function is dependent on how well they are supported to provide a nurturing environment, which is in turn affected by the way society organizes assistance.

Support from additional caregivers to supplement parental care can be helpful in (1) moderating the effects of a child’s atypical needs, and (2) providing a rest for parents to re-energize, allowing parental expressions of sensitivity towards the child that might otherwise be unavailable from an overburdened parent (Carlson et al., 2003). The effect of multiple caregivers on a child is dependent on both the quality of the primary parental relationship and the quality of the secondary caregiver (Carlson et al., 2003; Shonkoff & Phillips, 2003; van Ijzendoor & Sagi, 1999). Evidence about the implications of multiple caregiver arrangements is emerging from extensive research findings regarding out-of-home day care. Evidence suggests that routine out-of-home childcare is not harmful when care is sensitive and responsive in both the home and the care
setting. Conversely, early full-time day care presents risks when quality is poor, and especially when poor quality day care is combined with poor quality care in the home (Carlson et al., 2003; Shonkoff & Phillips, 2000).

Parental selection of alternate caregivers is influential in a child’s life, but parental selection is constrained by external factors such as income, availability of extended family caregivers, decisions of employers, government policies, and the way services are organized (Shonkoff & Phillips, 2000).

**Socioeconomics**

Families in general struggle to balance work and childcare and maintain adequate income against rising costs, but there is considerable evidence that families with children with disabilities and special health care needs struggle disproportionately compared to other families. Furthermore, families with children with disabilities struggle more if they are also members of a racial or ethnic minority group or have lower socioeconomic status.

The link between poverty, minority status, and presence of a disability is well established (Johnson, Guinan, Brown, & Shearer, 2005). According to a recent U.S. Census Bureau (2005) report on Disability and American Families, (1) families with children with disabilities are more likely to live in poverty, (2) racial minority families are more likely to include a member with a disability, and (3) racial minority families are more likely to live in poverty.

The U.S. Census report found that families raising children with disabilities have a lower median income than families raising children without disabilities (DHHS, 2002). Median annual income of parents of children with disabilities is nearly $12,000 per year lower compared to parents of other children and almost $17,000 lower for children with physical disabilities (DHHS, 2002). A study of out-of-pocket expenses for children with disabilities found average monthly expenses consumed 12.5% of average family income (Leonard, Brust, & Sapienza, 1992). Estimates of average out-of-pocket costs for families with members with disabilities added an additional $16,000 to the annual baseline costs of raising a child without disabilities (Lewis & Johnson, 2005).

Financial problems have been identified in the literature to be one of the most frequent concerns of families. Families raising children with disabilities report the triple effect of (1) extraordinary care needs, (2) decreased employment, and (3) financial hardship (Kruger, 2004). There is clear evidence of lower labor force participation and consequent lost income among mothers who care for children with disabilities (Lukemeyer, Meyers, & Smeeding, 2000). Unavailable or unreliable childcare for children with disabilities may prevent employment or reduce parents’ ability to maintain full time or steady employment. Childcare
costs are often higher for children with disabilities and beyond the reach of families with meager incomes (Shonkoff & Phillips, 2000), or the cost of higher quality childcare outweighs the economic gain of employment (Lewis & Johnson, 2005; Parish, Seltzer, Greenberg, & Floyd, 2004). In many ways, the predicament can be characterized as a “Catch-22.” Families of children with disabilities have disability-related expenses and therefore need more income, but they must manage with less income because those same needs reduce family member availability for employment.

Private costs have a disproportionate economic impact on families whose income is lower due to reduced employment. Even relatively small out-of-pocket expenses can create a significant burden when a family has little discretionary income or resources to spare (Lukemeyer et al., 2000). The costs of specialized transportation, travel expenses to frequent therapy and doctor appointments, specialized recreation, and hygiene supplies for children past early childhood can overwhelm the family budget (Leonard, Brust, & Sapienza, 1992).

Furthermore, the financial effect on families is cumulative over their life span. In a longitudinal study, Seltzer et al. (2001) followed individuals from age 18 into parenthood and middle age, some of whom subsequently became parents of children with developmental disabilities or mental health needs.

- Although parents of children with disabilities were similar to parents of children without disabilities in education, marital status, physical health, and psychological wellbeing, they had lower rates of employment.
- Parents of children with disabilities were more likely to report that caregiving responsibilities reduced their availability for full-time employment.
- By their mid-30s, when children were ten years old, parents of children with disabilities worked fewer weeks during the year.
- By their mid 50s, when children were 26, a higher proportion of mothers of children with disabilities remained full-time homemakers in contrast to the trend for mothers of non-disabled children to work outside the home.
- By their mid 50s, 57% of their children with disabilities were still living at home, while only 16% of children without disabilities were still living at home.

The cumulative impact of annual financial outlays over time swamps valued options to which families would otherwise direct discretionary dollars (e.g., housing or savings or investments). Foregone employment has implications for aging parents who also lose employer-provided retirement contributions and health care insurance (Parish et al., 2004).

In addition to being a source of income, parental employment is also the source of insurance coverage (Perrin, 2002). When ability to work is prohibited by care needs, insurance coverage is also forgone. However, even families with employer-provided insurance experience financial stress related to uncovered
health care costs. Lukemeyer and colleagues found that families with children with disabilities with forms of insurance other than Medicaid were significantly more likely to incur higher out-of-pocket expenses than families with Medicaid which provides more adequate coverage compared to most forms of private insurance (Lukemeyer et al., 2000).

Supplemental Security Income (SSI) is intended to provide financial assistance to low income families with members with disabilities. Lukemeyer et al. (2000) tracked disability related out-of-pocket expenses in a large study of 1764 families receiving public welfare assistance. Without SSI, 80% of the families with disability-related expenses were at or below the poverty line and 73% were in deep poverty. Even with SSI, 40% of the families with disability-related expenses lived at or below the poverty line, and 20% of families lived in deep poverty.

Families struggling to meet financial expenses face three difficult options: (1) become impoverished, (2) forgo or delay needed care, or (3) place the child out-of-home where care is paid with public dollars. Tragically, some families relinquish their children to child welfare systems in order to get the care their child needs (Bazelon, 1999).

Families struggle with whether to turn to formal services for assistance and with what happens when they do.

**Interaction with professionals**

Parents’ experiences, views, and decisions regarding their children with disabilities can be influenced by the professional and services personnel with whom they interact (Blacher, 1984). Interviews with families have found that a sense of control is a critical element in a satisfying life style. Integral to a sense of control are two elements: (1) positive prospects for the future, and (2) genuine partnerships with professionals and service providers (Knox, Paremeter, Atkinson, & Yazbeck, 2000). Lindblad, Rasmussen, and Sandman (2005) studied the experience of parents with children with extensive care needs requiring continuous, long-term support from professionals. Families’ struggles were described as arduous, time-consuming, draining, and fraught with uncertainty, frustration, exhaustion, and needing to always be on-guard.

In a review of research on interactions with services systems, families with children with disabilities generally report:

1. Dissatisfaction with information provided about available support
2. Dissatisfaction with emotional support relative to the gravity of the child’s needs
3. Lack of respect as partners having expertise or competence (Lindblad et al., 2005)
Support needed by families is more than availability of supplemental caregivers or assistance from professionals with particular expertise. In interviews with parents, Lindblad et al. (2005) found that parents were affected by the way in which they were engaged. Parents reported they were invigorated when they were helped to gain confidence and when they felt their child was valued, and that they were deflated and demoralized when their confidence was obstructed and when they felt their child was not valued.

Specifically, parents reported that they felt invigorated when professionals:

- Acknowledged them as a person
- Talked about things other than disability
- Cared about their state of being
- Acknowledged them as capable
- Were easily accessible, listened, and gave advice

Parents reported they felt their children were valued when professionals:

- Talked to the child, touched the child, and attended to the child’s appearance
- Expressed hope for the child’s future
- Understood the child’s future development rather than just focusing on the disability
- Maintained continuity over time
- Treated the child as worthy of help
- Attended to the child’s emotional as well as practical needs

Deflated and demoralized parents may be more likely to seek out-of-home placement.

**Out-of-home placement decisions**

Parents’ decisions about out-of-home placement have been found to be directly influenced by professionals. Bruns (2000) interviewed parents of children with complex medical needs who had placed their young children in facilities. Parents reported that a professional had been the catalyst for action and that it was a professional who had “planted the seed” that led them to place. Professional advice was found to be an essential ingredient for actively pursuing out-of-home placement.

A number of studies have looked at the relationship between parental decision-making regarding out-of-home placement and availability of support. Studies looking at the impact of external resources have had equivocal results. An often-cited example is a study by Cole and Meyer (1989) that surveyed 103 parents about their future plans for their children with severe mental retardation. A significant relationship was found between external support and planning for out-of-home placement. By contrast, in a longitudinal
study of 100 families with children with severe disabilities, Hanneman and Blacher (1998) found that
support resources had little effect on placement intentions. Interestingly, children’s characteristics failed to
predict placement intentions or actual placement with one exception, that the more normative the child’s
appearance, the less likely parents were to seriously consider placement or to place. The study also found
that mothers who had higher status occupations and levels of education were more likely to consider
placement.

Blacher and Baker (1994) interviewed 62 parents who had placed their children with mental retardation in
facilities in the previous two years. The children ranged in age from 2-18 and the facilities ranged in size
from small group homes to facilities larger than 50. Most parents felt their child received better services at
the facility than at home identifying availability of better therapies, medical care, and schooling. Despite
being highly satisfied with their child’s placement, however, 84% of parents were dissatisfied regarding
staff competence, staff-to-client ratios, or turnover.

Cultural influences

Factors that influence family decisions about raising children and using services are highly influenced by
cultural values. Two notes of caution are warranted before raising findings of cultural differences. First,
there is wide variation within groups so any broad group generalizations should not be assumed in individual
situations (Bailey et al., 1999). Second, socioeconomic factors and ethnic/racial groupings are commonly
confounded, leading to findings which are attributed to racial or ethnic minority status which may be more
appropriately related to socioeconomic status (Bailey et al., 1999; Heller, Markwardt, Rowitz,
& Farber, 1994).

With these cautions, research studies have identified cultural group differences on a variety of factors
including beliefs about disabilities or illness, the nature of family and community supports, use of
professional services, problem-solving strategies within family and social networks, decision-making, help-
seeking, access to public agency services, and utilization rates of formal services (Bailey et al., 1999;
Bornheim et al., 2006; Heller, et al., 1994; Krahn, 1993; Quirk et al., 1986; Rogers-Dulan & Blacher,
1995).

Explanations for differences include:

- Language or communication problems
- Lack of knowledge about systems
- Acceptability of external help seeking
- Discrimination by service systems
- Distrust of dominant group authority
Studies found higher use of extended family care for children with disabilities from ethnic minority groups. Minority group differences have also been found in the perceived level of burden of caring for a child with disabilities. White mothers who were older, healthier, wealthier, and more educated reported higher burden and lower caregiver satisfaction than African American and Hispanic mothers (Bailey et al., 1999; Heller et al., 1994; Lefley, 1997; Rogers-Dulan & Blacher, 1995). Some studies have found non-white families keep their children at home in greater numbers than Anglo parents who are more likely to place their children out-of-home (Borthwick-Duffy, Eyman, & White, 1987). Other investigations, however, which took socioeconomic status into account, found that minority group out-of-home placement rates were comparable to white families (Bailey et al., 1999; Heller et al., 1994).

Family decisions and service use are influenced by culture but are also influenced by the way services are organized, a topic to which we turn next.

**SUMMARY**

Families’ responses to having children with disabilities vary based on their culturally shaped values and beliefs, their personal and socioeconomic circumstances, and the service systems with which they interact. Families trying to raise children with disabilities face struggles related to their child’s needs. They are also more likely to face financial difficulties related to increased disability-related expenses and decreased labor force participation than other families. They can find invigoration but more often struggles related to getting support to enable them to meet their needs. Often families need assistance from beyond their personal network. Often they need financial assistance, emotional support, and utilitarian assistance including assistance from supplemental caregivers and expert professional advisors. Families’ beliefs, circumstances, and their experience of support or its lack, impact their decisions about out-of-home placement. They are affected by the kind of interactions they have with those from whom they seek help, and by the services offered by the systems from which they seek help. We turn now to those service systems.
WHAT DO WE KNOW ABOUT SYSTEMS OF SUPPORT?

How services are organized contributes to whether resources are directed to support families or whether they maintain congregate care that may not be beneficial to children and may not be what families need or want. To address inadequacies found in congregate care requires alternatives that can reduce the need for congregate care. Following a description of overall trends in organized services to support families, I will briefly review each of the four major child-serving systems: mental retardation and developmental disabilities, health, mental health, and child welfare. I will briefly review (1) how each system conceptualizes and organizes services for the subpopulation it serves, (2) concerns that are prevalent in the literature, and (3) promising approaches that are emerging in each system. Given the scope of the literature available, these summaries provide only a brief glimpse of these large and complex systems.

Overall trends in support of families

Family support has been characterized as a national “movement” (Kagan, 1996; Vandenberg, Bruns, & Burchard, 2003). The family support movement views the family unit as the recipient of services rather than its individual members and has brought a concomitant shift in service delivery (Kagan, 1996; Krahn, 1993). Family support is now acknowledged and defined in federal legislation.

- The Omnibus Budget Reconciliation Act of 1993 defines family support as:

  Community-based services that promote the well-being of children and families designed to increase the strength and stability of families, to increase parents’ confidence and competence in their parenting abilities, and to afford children stable and supportive family environments and otherwise enhance child development. (Kagan, 1996)

- The Family Support of Children with Disabilities Act of 2000 defines family support as:

  Supports, resources, services, and other assistance provided to families of children with disabilities pursuant to State policy that are designed to:
  a. support families in the efforts of such families to raise their children with disabilities in the home;
  b. strengthen the role of the family as the primary caregiver for such children;
  c. prevent involuntary out-of-home placement of such children and maintain the family unit; and
  d. reunite families with children with disabilities who have been placed out-of-home, whenever possible. (Bornheim et al., 2006).
Supports to families have become key components of both federal and state initiatives in developmental disabilities, special education, mental health, health care, and child welfare (Bornheim et al., 2006). A variety of programs introduced since the 1970s have contributed to decreases in residential care in every state (Lakin, Anderson, & Prouty, 1998):

- Supplemental Security Income (SSI) provides financial assistance to low-income families with children with disabilities (Lewis & Johnson, 2005; Silverstein, 2000)
- Education for All Handicapped Children legislation for the first time mandated that public education be available to children with disabilities (Lewis & Johnson, 2005; Silverstein, 2000)
- Medicaid waivers introduced in 1981 redirect funding from institutional settings to home and community-based services (Lakin, 2005/2006)

Numerous definitions and sets of principles have been offered as underpinning family support for children with disabilities. Common features of these expressions of family support include (Agosta & Melda, 1996):

- An explicit set of values or guiding principles
- Inclusive and collaborative practices
- Family oversight of design and implementation
- Family control of resources
- Multiple and flexible services
- Maximizing existing informal supports
- Localized decision-making

In general, family support seeks to allow families to design supports to suit their unique circumstances rather than choose from a predetermined list. Family support has been described as anything that a family says it needs for the development of its child and the functioning of the family (Bornheim et al., 2006). In a word, family support is “whatever works.”

The ubiquity of family support principles (at least in rhetoric) is evidenced in six core outcomes for children and youth with special health care needs (including children with chronic physical, developmental, behavioral, and emotional conditions) developed by the Maternal and Child Health Bureau, the Health Resources and Services Administration (HSRA), the U.S. Department of Health and Human Services (DHHS) and incorporated into the President’s New Freedom Initiative (Bornheim et al., 2006).

1. Families and youth with special health care needs will partner in decision-making and will be satisfied with the services they receive.
2. All children and youth with special health care needs will receive coordinated ongoing comprehensive care within a medical home.
3. All children and youth with special health care needs will have adequate public and/or private insurance to pay for the services they need.
4. Children will be screened early and continuously for special health care needs.
5. Community-based services for children and youth with special health care needs will be organized so families can use them easily.
6. Youth with special needs will receive services necessary to support transition to adulthood.

Whether these outcomes are met is most often a function of the specific service systems that families engage on behalf of their children. Families raising children with disabilities often come in contact with multiple services systems. In general, policy changes in all of the systems have contributed to an increased emphasis on family support in principle but have not (yet) realized adequate support for families in practice. While family support calls for holistic responses, services systems continue to be siloed and are often described as a fragmented maze (Hornberger, Martin, & Collilns, 2006).

Below we will look at family support from the perspective of each of four major categorical systems serving children with disabilities.

1. Developmental disabilities and mental retardation  
2. Health care  
3. Mental health  
4. Child welfare and protection

**Developmental disabilities and mental retardation**

A massive shift away from institutional care to community care has been underway in mental retardation and developmental disability services (MR/DD) over the past thirty years (Braddock et al., 2005; Parish et al., 2003). During the 1950s, public financial resources were directed almost exclusively to large residential settings (Parish et al., 2003). Until the 1970s families could either place their child in a state institution or keep them at home with little or no system support (Agosta & Melda, 1996). The services landscape changed dramatically in the 1970s (Seltzer & Heller, 1997). In the past decade, there has been a rapid rise in supports for individuals with intellectual or developmental disabilities living with family members, rising from 205,121 in 1993 to 500,004 in 2003 Coucouvanis, Prouty, and Lakin (2005). There is also evidence of increasing use of alternate family living arrangements. Host family placements increased by 73% from 1995 to 2004 to serve almost 40,000 of the 420,000 people receiving residential supports in MR/DD service systems (Coucouvanis, Prouty, and Lakin (2005).
Family support. Spending on residential care has decreased and spending on family support has increased. Between 1996 and 2000, family support spending grew 85% and reached 37% more families. By 2000, all fifty states had dedicated family support funding and total family support spending had reached $1 billion (Parish et al. (2003).

Overall, however, family support still represents a small proportion of total expenditures for MR/DD services nationally. Although 60% of individuals with intellectual or developmental disabilities live with their families compared with 15% who live in residential services, families receive a disproportionately small share of public MR/DD services spending. As of 2000, family support represented only 4% of overall MR/DD resource allocations (Parish et al., (2003). Furthermore, this 4% includes families with adult members with disabilities who live at home, so the proportion of family support for parents of minor children represents an even smaller proportion of overall resource allocations.

Patterns in state spending for family support vary widely (Parish et al., 2003). Some states have more aggressively redirected resources formerly used for residential facilities to family support. The impact of a major shift in spending can be seen in the experience of Minnesota where policies to promote family care instead of residential care gradually reshaped the state’s balance of spending. Over a ten-year period from 1980 to 1990, the number of children living in out-of-home settings was reduced from 830 to 291 while the number of families served was increased from 50 to 1827. Expenditures for family support rose from $20.4 million to $24.3 million. The net result of policy changes and redirection of resources was a 240% increase in the number of families served with only 20% increase in spending. Minnesota policy-makers projected that if changes had not been implemented and the same 830 children had remained in residential care, in 1990 the cost would have been $44.3 million rather than $20.4 (Agosta & Melda, 1996).

Waivers. One of the major funding mechanisms for financing long-term care for individuals with intellectual or developmental disabilities has been the federal Medicaid program. In the early 1980s, the Medicaid program established “waiver” programs as a mechanism to allow resources that had formerly been allocated to institutional services to be redirected to community-based supports. Parish et al. (2003) found a strong relationship between states’ family support efforts and their use of Home and Community-Based Services (HCBS) waivers. States with waivers showed a greater commitment of financial resources for family support than states that didn’t use waivers. Parish et al. (2003) strongly recommended that states pursue HCBS waivers:

The HCBS waiver provides an otherwise unequalled opportunity for states to leverage their resources and secure extensive federal matching funds. . . . Family support can be expanded well beyond the current level in most states if existing state family support allocations are deployed to aggressively leverage federal funds. (Parish et al., 2003, p. 186)
**Subsidies.** Some states provide funds directly to families through the use of cash subsidies. Cash or vouchers allow more flexible and individualized support because they are family controlled and can be attuned to the unique needs of their situations. By 2004, 22 states had instituted cash subsidies for 33,000 families with median per-family allocations of $2850 yearly at an overall cost of $95 million (Braddock et al., 2005).

Michigan was one of the first states to develop a cash subsidy program for children with significant disabilities. Initiated in 1984, cash subsidies of $222 per month are provided to families with taxable incomes of less than $60,000 and raising minor children. Eligibility is based on the educational categories of Severely Mentally Impaired, Severely Multiply Impaired, or Autism (Herman & Thompson, 1995). The cash can be used for any needs as determined by the family and does not require approval for purchases. An evaluation of the subsidy involving 405 family interviews concluded the cash subsidy was “highly flexible and responsive” (Herman & Thomson, 1995, p. 81). Families reported using the funding for ordinary expenses such as clothing, general household expenses, sitters, and educational toys and aids as well as specialized services such as respite and adaptive equipment (Herman & Thompson, 1995). Interestingly, families reported purchasing few formal external supports when free to determine how to use resources.

In addition to targeting the best fit between needs and resources, an appealing feature of putting resources in the hands of families is that they have been found to be very frugal managers. Systems’ reticence to provide discretionary funds directly to families is frequently based on concern about misuse or overuse. Kendrick (2001) provides an example of family frugality and responsible use in his evaluation of projects in Massachusetts that used families to govern and make decisions about distribution and use of family support funds. The analysis found:

1. With no upper limit on how money could be spent for individual families, the average expenditure was $1200 per year.
2. 25% of the families declined cash, preferring social support.
3. Families returned resources when they found they did not need what had been anticipated.

**Permanency planning.** Permanency planning seeks to assure a secure, safe, nurturing family home on a permanent basis. While federal legislation mandates permanency planning for children in the child welfare system, the mandate does not extend to children in the disability service system (Johnson & Kastner, 2005; Rosenau, 2000; Taylor, et al., 1989). In 1987, the Center for Human Policy convened a group of advocates from the disability community who developed a document called the Statement on Behalf of Children and Families which called for application of permanency principles to disability services systems (CHP, 1987).
Now almost twenty years later, the concept is still unfamiliar to most disability service systems. Exceptions are the states of Michigan and Texas.

Michigan has vigorously embraced permanency planning policies in its developmental disability service system since the mid 1980s (Taylor et al., 1989). Michigan’s permanency planning policies reached beyond the child welfare system to address the developmental disability system where attention to a child’s need for family life instead of residential placement coincided with Michigan’s progressive deinstitutionalization policies (Taylor et al., 1989). Systemic changes corresponding with permanency planning included (1) providing better in-home supports to families, (2) placement with an alternate family rather than in a residential facility when parents sought out-of-home placement, and (3) assertive recruitment of alternate families to make such alternatives available (Rosenau, 2005).

In addition to Michigan, Texas applies permanency planning in its developmental disability services system. Texas has the only known legislation in the country that requires permanency planning for all children served in its voluntary disability sector living in long-term residential settings including large congregate facilities, group homes, and nursing homes. The Texas permanency planning legislation focuses on family support and the importance of a parent-child relationship in a child’s living arrangement.

*Permanency planning means a philosophy and planning process that focuses on the outcome of family support by facilitating a permanent living arrangement with the primary feature of an enduring and nurturing parental relationship.* (Texas Acts, 2001)

In addition to developing better family support, to make permanency planning a reality requires development of family-based alternatives to congregate care.

**Family-based alternatives to congregate care.** Of the 4.6 million people with mental retardation, 2.8 million receive residential support from family caregivers (Braddock et al., 2005). Host family living arrangements have grown by 73% in the past decade (Braddock et al., 2005).

One of the rationales for continuation of congregate care is the belief that it serves a unique population of individuals whose disabilities are so severe that they cannot be served in family homes. An interesting 1992 study examined a nationally representative sample of 336 persons with mental retardation living in 181 specialized foster homes and small group homes (Hayden, Lakin, Hill, Bruininks, & Chen, 1992). The study found group homes had a higher proportion of individuals with mild mental retardation. Foster homes served primarily individuals with moderate to severe mental retardation. Foster care residents were more likely to require physical assistance in toileting and mobility than group home residents and 48% of the foster home residents in the study had behavioral problems. The average longevity in foster care was 9 years compared to 4-5 years in congregate settings with 30% of the residents of foster homes having lived
in the same home for at least 11 years. The results showed that alternate family home placements successfully serve a variety of people and that placements generally last for many years, contrary to common assumptions that foster care will only serve individuals with less challenging needs or will not last.

**Health care**

Increasing numbers of children with increasingly complex health care needs are surviving and being raised at home with technology and medical support. Thirteen percent of U.S. children have special health care needs (Allen, 2004).

Initial interest in home care of children with complex health care needs was sparked by positive outcomes of pilot projects in the early 1980s that transitioned technology-dependent children from hospitals to family homes. These early initiatives generated health benefits as well as cost benefits. An example is a 1984 study of the cost effectiveness of home care for 18 ventilator dependent children that found a reduction of health care costs of 70% or more with a child’s transfer home from a hospital setting and also found unanticipated improvement in the child’s medical condition and psychosocial development (Shelton et al., 1989).

**Waivers.** As with MR/DD services, a shift from institutional to home-based services for children with complex health care needs has been accompanied by redirection of Medicaid funding for community-based care through waivers which enable states to furnish services at home for individuals who would otherwise require continued hospitalization or nursing home care (Silverstein, 2000). Support under waivers can include case management, homemaker services, and home modifications, as well as health care and specialized therapies (Vessey, 2004).

**Medical home.** Increased use of home care has brought recognition of the need for coordination and continuity of care. A collaboration between the American Academy of Pediatrics and the Maternal and Child Health Bureau has developed the concept of a “medical home” (Kruger, 2004). A medical home involves organizing health care through an identified primary care physician who works to assure care that is accessible, continuous, comprehensive, family-centered, coordinated, collaborative, compassionate, and culturally sensitive (Allen, 2004; Vessey, 2004). Expectations of medical home physicians are that they know community resources, are anticipatory, holistic, and engage in partnership with parents (Allen, 2004).

**Family-centered care.** “Family-centered” is a term used to describe optimal partnering relationships with parents. Family-centered guidelines and practices developed by a collaboration of families and
professionals are outlined in a document entitled *Family-Centered Health Care For Children with Special Health Care Needs* published by the Association for the Care of Children’s Health with support from The Division of Maternal and Child Health (NCNCS, 1987). Following is a summary of elements of family-centered care:

1. Recognition that the family is the constant in the child’s life while the service systems and personnel within those systems fluctuate.
2. Facilitation of parent/professional collaboration at all levels of health care
   a. Care of an individual child;
   b. Program development, implementation, and evaluation; and
   c. Policy formation.
3. Sharing of unbiased and complete information with parents about their child’s care on an ongoing basis in an appropriate and supportive manner.
4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families.
5. Recognition of family strengths and individuality and respect for different methods of coping.
6. Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care delivery systems.
7. Encouragement and facilitation of parent-to-parent support.
8. Assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs.

**Care coordination.** The complexities of health care are daunting, not only at the aggregate level but at the individual family level (Knoll, 1989; Vessey, 2004). The National Council on Disability report on long-term services and supports for individuals with disabilities (both children and adults) describes a fragmented system of more than 20 federal agencies and almost 200 programs that provide a wide range of assistance and service with no single point of entry or access. It describes the system as complex, confusing, and resistant to change.

While many reforms motivated by cost containment are underway, cost is only one part of the complex puzzle (NCD, 2005). Potential cost savings and improved outcomes are being exploring in how services are delivered as well as how they are funded (Tschida, 2005). Care coordination has become recognized as a key feature in successful home care, necessitated in part because of individual children’s health care complexity, but necessitated in large part because of the health care system’s complexity (Mastal, 2005).

Increasingly a distinction is being drawn between case coordination and care coordination (Kruger, 2004). Case coordination employs a cost containment model with a focus on monitoring and directing individual service usage. Care coordination, by contrast, applies a social service model with the goal of facilitating access to quality support across a broad range of programs and community services, both formal and
informal. Care coordination is directed at the family as a unit rather than the individual patient/case. It is anticipatory and proactive, and takes the stance of “whatever it takes” as its guiding ethos (Knoll, 1989; Kruger, 2004).

Care coordination proponents suggest that better coordination can increase families’ access to needed services, maximize efficiency by better matching needs and services, and minimize duplication of services. Both, both families and payors benefit. At least ten states have piloted comprehensive service coordination programs of Medicaid benefits (Palsbo & Mastal, 2005).

**Family-directed services.** Of increasing interest in service delivery innovations are practices embraced under the term “self-directed,” or “family-directed” services in the case of children. In these approaches, the service user is directly involved in decisions about resource use (Tschida, 2005) and makes decisions from a position of self-interest in optimizing funds. The general idea is that the user has access to a capped amount of funds that they can choose how to use and can flexibly arrange to create individualized responses to their self-identified needs (Clark, 2005). While systems are motivated by cost containment, these arrangements usually offer the user greater freedom in purchasing decisions in trade for a discounted personal budget that costs less than the system would otherwise spend on traditional services (Tschida, 2005).

Proponents argue that family-directed services offer the flexibility and control families need and desire. For example, family-directed services can allow a family to select, hire, and schedule the staff that come into their home. The advantage of family management of staff is that the costs usually required for agency administration can be redirected into direct services, thus stretching service dollars to a family’s benefit. Despite this appealing feature, managing in-home nurses and home help aides is a struggle in logistics that can add another source of stress to an already burdened family (Clark, 2005). Continued exploration and creativity may offer future improvements in this yet emerging trend in service delivery.

**Mental Health**

According to the U.S. Surgeon General, as many as 11% of all U.S. children have a mental disorder that significantly impairs their day-to-day functioning and 5% of all U.S. children have a serious mental health disorder that has an extreme impact on daily functioning (Koyangi & Semansky (2003). From 4.5 to 6.3 million children with severe emotional disorders are reported to be unserved or served inappropriately (CMNS, 2001). According to the Bazelon Center for Mental Health Law, general hospital inpatient services and inpatient psychiatric care are the most common residential services for children with serious emotional
disturbances. Next most common are residential treatment centers and even less common are therapeutic group homes smaller than sixteen beds (Bazelon, 1999).

**Medicaid.** Medicaid is the backbone of funding strategies for children with mental health needs (Koyangi & Semensky, 2003). Medicaid-enrolled children are entitled to any medically necessary care to correct or ameliorate mental health needs discovered in screenings mandated through Early Periodic, Screening, Diagnosis, and Treatment (EPSDT) (Koyangi & Semensky, 2003). However, many children with serious mental health needs are not covered by Medicaid and even for those who are Medicaid eligible, the seeming promise of EPSDT assurances has not been fulfilled (Bazelon, 1999).

The Bazelon Center conducted focus groups of 86 parents of children with serious mental disorders in two states with relatively comprehensive Medicaid plans (Koyangi & Semensky, 2003). One state had a fee-for-service system and the other had a managed care system. Parents of children with severe emotional disorders across both states reported remarkably similar experiences describing the system’s response to them and their children. Parents reported that they seldom had access to intensive community supports, or when available, they were provided in insufficient amounts to be effective. Parents’ reports were consistent with literature about services for children with serious mental health needs. Specifically, parents reported:

- Systems are crisis oriented.
- Families’ early recognition of their child’s problems are routinely ignored.
- Families face long delays in getting services, ranging from 6-15 years from recognition of problems to formal assessment and acknowledgement.
- Families are offered little education or training.
- Families have almost no access to intensive community services.
- Children are sent out of the area or out-of-state to obtain services.
- Casemanagers are inexperienced, poorly trained, and burdened with high caseloads.
- Therapy is infrequent.
- Age-appropriate services are rarely available as most mental health services focus on adults.
- Crisis services are patched together and mobile crisis units are rare.
- Discharge planning after facility admission is poor.
- Schools fail to respond appropriately.
- Parents are often advised to seek services from the child welfare system where they face relinquishment to obtain services.

**Inpatient and residential care.** Research has consistently found that outcomes on a variety of dimensions are better in organized community-based systems of care than hospitals (Kiesler, 1994). Policy analysts seem to agree that there is a need to decrease inpatient psychiatric care for children and youth in favor of
community care, yet mental health funds remain biased toward inpatient care (Kiesler, 1994). Attempts to decrease public psychiatric beds in the 70s and 80s resulted in significant increases in residential treatment centers (Kiesler, 1994).

The general public and families expect specialized help when using highly specialized and expensive services. Specialized services usually refer to professional expertise. A study comparing psychiatric units in general hospitals, private psychiatric hospitals, and residential treatment centers found significant differences in the availability of professional expertise (Kiesler, 1994).

### Availability of Professional Expertise: Patients per full time staff in various settings

<table>
<thead>
<tr>
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<th>Psychiatric unit in general hospital</th>
<th>Private psychiatric hospital</th>
<th>Residential treatment center</th>
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<tbody>
<tr>
<td>Psychiatrist</td>
<td>5.1</td>
<td>15.1</td>
<td>64.8</td>
</tr>
<tr>
<td>Professional staff</td>
<td>0.56</td>
<td>0.66</td>
<td>0.91</td>
</tr>
</tbody>
</table>

Kiesler (1994) calculated that in a psychiatric unit where a psychiatrist provides six hours of client contact daily, each child would get on average one hour a day of the psychiatrist’s attention; in the private hospital each child would get 20 minutes; and in the residential treatment center treatment center, each child would get about six minutes a day.

**Family support.** Many states have policies that actually prevent children with serious emotional disorders from receiving services that would enable them to avoid residential or inpatient hospital placement (Bazelon, 1999). A disturbingly large number of parents give up custody of their children to child welfare systems in order to obtain access to Medicaid funded mental health care. A recent study identified this as a pervasive problem in half the states and that one quarter of parents had been told by a public official that they needed to relinquish custody to get needed services (Bazelon, 1999).

Barriers are especially high for intensive in-home family support. Insurance and Medicaid rules based on insurance principles, reflect a medical model which focuses on the child as “patient,” requires a diagnosis, and restricts services to the child-recipient. Early intervention and family support are thereby inhibited, if not prohibited (Bazelon, 1999). A proliferation of recent managed care arrangements has created confusion and resulted in families being unaware of available services, or when aware of services, facing time-consuming and costly battles to obtain them (Bazelon, 1999). Families report that the intensive community services which they find most helpful are the least available (Bazelon, 1999).
Wraparound. Despite the dismal picture of mental health services for children and youth and their families, a number of approaches have emerged as effective service delivery strategies and are underway nationally as part of efforts to reform children’s mental health services (Bazelon, 1999). Wraparound is one such approach. Wraparound is both a philosophical approach and a set of services for children who have serious mental or emotional disorders. Wraparound is an interagency, interdisciplinary, flexible, non-categorical approach with no preset list of services. Its elements are individualized plans, an array of home and community based services and supports, case management, and crisis response. Wraparound has been found to be effective for a diverse range of youth of different ages who are at risk of out-of-home placement (Bazelon, 1999). [Wraparound will be covered in more detail later in this report.]

Systems of care. Systems of care is another promising approach that seeks interagency cooperation and effective pooling of resources across agencies to deliver child-centered, family-focused, community-based services (CMHS, 2006; Stroul & Friedman, 1994). [Systems of care will be covered in more detail later in this report.]

Child welfare

There is considerable evidence that children with disabilities are over-represented in the child welfare systems (Bruhn, 2003; Rosenberg & Robinson, 2000; UCP/CR, 2006). At least one third of children in foster care have disabilities (UCP/CR, 2006). Half of children available for adoption have a disability (Hanley, 2002). Almost two-thirds of children in child welfare have mental health needs (Koyangi & Brodie, 1996). The disproportionate number of children with disabilities in child welfare is the result of several interrelated factors (Bruhn, 2003; Rosenberg & Robinson, 2000; Skolnick, 1998) including:

1. A well-established link between disability, race, and socioeconomic status.
   a. Poor and minority families are more likely to have children with disabilities.
   b. Poor and minority families are more vulnerable than other families to state intervention and removal of their children.
2. A link between disability and abuse or neglect.
   a. Disability can be caused by abuse or neglect.
   b. The presence of a disability increases the risk of abuse and neglect.
3. A link between entry and exit.
   a. Children with disabilities are more likely to enter the child welfare system.
   b. Children with disabilities are less likely to leave the child welfare system.

Once in care, children with disabilities face inadequacies within the child welfare system. A 1995 U.S. General Accounting Office report identified that a significant portion of children in foster care did not receive critical health care services or early intervention services (Bruhn, 2003). Untrained caseworkers
may not recognize disabilities or related service needs or may take inappropriate action (Bruhn, 2003; Rosenberg & Robinson, 2004; UCP/CR, 2006).

Once removed from their birth families, children with disabilities experience a different pattern of out-of-home placement than other children in care (Rosenberg & Robinson, 2004) including:

- Parents more likely to be judged as having coping problems
- More removals from parents
- Longer stays in care
- Lower rates of return to parents
- Greater instability of placements
- Placement in more settings
- Higher likelihood of being placed in an institutional setting than a family home

**Permanency planning.** Permanency is a policy framework that grew out of criticisms in the 1970s of unstable placements of children who had been removed from their families of origin due to abuse or neglect (Rosenau, 2000; Johnson & Kastner, 2005; Taylor et al., 1989). Permanency planning seeks to assure a secure, safe, nurturing family home on a permanent basis. Permanency takes as its premise:

1. The value of rearing children in families
2. The importance of the parent-child relationship
3. The role of attachment in child development
4. The significance of the biological family for a sense of identity, belonging, and connectedness
5. The importance of daily parent-child interaction in developing emotional bonds
6. The role that stability and continuity plays in child development
7. The deleterious impact on children of separation from parents

Taylor et al., (1989) traced the history of permanency planning in the child welfare sector and its implications for children in the disability services sector. In 1978, the Children’s Defense Fund (CDF) issued a report indicting federal and state governments for depriving some 400,000 children in child welfare custody of growing up in a stable family environment. The opening of the report captures the essence of permanency:

> *Children require, before all else, the sense that they belong to reliable and loving adults who will care for their needs, emotional as well as physical . . . children require stability, most particularly an inner assurance that caring adults will remain firmly in their lives.* (Knitzer, et. al., 1978 cited in Taylor et al., 1989).
Spurred by the CDF report, Congress enacted the Adoption Assistance and Child Welfare Act which sought to support stable, enduring family homes rather than temporary, revolving foster homes. The legislation required individual case plans and imposed mandatory administrative reviews on state child welfare systems to assure that plans either facilitated reunification with parents or led to an alternative permanent family placement (usually adoption) within specified time frames (Taylor et al., 1989). In subsequent legislation, the Child Abuse Prevention & Treatment Act (CAPTA) was passed and amended in 1995 to improve prevention by adding new family resources and supports, specifically including children with disabilities (Silverstein, 2000).

Permanency planning has had a profound effect on the expansion of models of family-based alternatives to congregate care for children with disabilities, including specialized foster care and subsidized adoption.

**Specialized/treatment foster family care.** Specialized family foster care emerged in the 1980s as an alternative to traditional foster care. Traditional foster care focused on short-term arrangements and served children with less intense needs (Bryant, 2004; Terpstra, 1996). Specialized family foster care arrangements are found in the literature under various terms which distinguish them from traditional foster care including: treatment foster care, medical foster care, therapeutic foster care, professional foster care and family-based treatment. Important features of specialized foster care are enhanced support, financial stipends, careful matching of children and families, and preparation of the foster family [Specialized foster care will be covered in more detail in a later section of this paper.]

**Adoption subsidies.** There is now ample evidence that families in the community will accept and raise children with disabilities on a long-term basis through adoption (Lightburn & Pine, 1996). Studies of families who have adopted children with developmental disabilities report high satisfaction and few disruptions five to ten years post adoption (Glidden, 2000; Groze, 1996).

Adoption subsidies are perhaps the single most powerful tool by which to encourage adoption and support adoptive families (Impact 2005/2006). Nearly all children who have been adopted from foster care in recent years have specialized needs and have received adoption subsidies. A feature of both adoption and specialized foster care is the financial assistance to a family. This assistance serves both as an inducement to consider caring for a child with challenges and as a source of flexible funding under parental control to use as needed for family needs once the child joins the family. Studies of adoptive parents have identified that their perception of adequate financial support is a predictor of their overall satisfaction (Lightburn & Pine, 1996).
**Family group decision making.** Family group decision making (also referred to as family group conferencing) is an emerging approach in child welfare that seeks to engage the extended family and social network of a child who comes to the attention of the child welfare system. This group participates in and contributes to solutions that will safeguard the child (Pennel & Anderson, 2005). Traditionally, child welfare systems have dealt primarily with the parent(s) of a child who comes into care. Family group conferencing is a mechanism to harness the potential of the larger family system and their chosen allies to maintain a child in his or her own social network, while also offering safeguards to ameliorate the problem that brought the child to the attention of the system. [Family group conferencing will be addressed in detail in a later section of this report.]

**SUMMARY**

A national family support movement is affecting all child-serving systems. The MR/DD, health care, mental health, and child welfare systems are all moving in the direction of better services to families of children with disabilities. All are also challenged to find more effective ways to support families and more effective ways to manage resources. Each of the service systems discussed is struggling with similar and different issues. Each is exploring and implementing reforms and new approaches to be more effective. Each system has examples of efforts to implement more family participation in planning and decision-making, more family-directed use of funds for family-identified needs, and redirection of policy and resources from facilities to families. Increased coordination, collaboration, and flexibility are common goals to improve family support in each system. We next take up some of the promising approaches that are contributing to the development of family-based alternatives to congregate care.
WHAT DO WE KNOW ABOUT FAMILY-BASED ALTERNATIVES TO CONGREGATE CARE?

EMERGING PROMISING APPROACHES

The premise of continued use of congregate care is that it fills a need that is otherwise unmet. We take up next some alternatives to congregate care that involve family-based arrangements capable of serving children with disabilities who would otherwise require congregate care.

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>FAMILY-BASED ALTERNATIVES</th>
<th>Non-related family</th>
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<tbody>
<tr>
<td>MH</td>
<td>Wraparound Systems of care</td>
<td>Treatment foster care</td>
</tr>
<tr>
<td>CHILD WELFARE</td>
<td>Family group conferencing Kinship care</td>
<td>Treatment foster care</td>
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<td>MR/DD</td>
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<td>Shared parenting</td>
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Each promising approach includes a brief description and history followed by relevant research evidence. I then discuss how the approach could contribute to reducing the need for congregate care and how the approach fits with other promising approaches and trends.

**Wraparound**

Families who are struggling to raise their children with significant disabilities face complex systems whose services are often inadequate in type or quantity to fit the child’s or family’s needs.

**Description**

Wraparound represents a relatively simple philosophy: that the community services and supports that a family needs should be identified and provided for as long as they are needed (Burchard, Bruns, & Burchard, 2002). Wraparound is a team-based approach and a planning process to create in a unique set of community services and supports that are individualized for a child and family to achieve a positive set of outcomes. The term has become shorthand for flexibility and comprehensiveness in service delivery approaches that try to keep children and youth in the community (Vandenberg et al., 2003). Wraparound has two main components:

- A family-centered decision-making process, and
- An actual array of services and supports (Burchard et. al., 2002).
Wraparound has become the most commonly implemented form of individual service planning within children’s mental health (Walker, u.d.). While many individual services planning processes are used across mental health and health care contexts, wraparound has more stringent requirements (Walker, u.d.). Individual services planning processes generally involve assessments, goals and objectives, progress monitoring, and participation of individuals and families. Wraparound adds:

- Active engagement of children and families as equal partners
- A single, comprehensive plan across agencies and settings
- Strength-based promotion of home and community life and roles
- Stimulation of flexible problem solving and creative strategies

The addition of more stringent requirements is associated with a shift from traditional service planning and delivery (Walker, Koroloff, & Schulte, 2003) including:

- A shift from professional domination of planning
- A shift from traditional service-driven approaches that fill program slots or beds
- A shift from a focus on deficits
- A shift from single agency procedures, policies, organizational cultures, and funding requirements

History

Wraparound has been evolving over the last twenty years (Burchard et al., 2002). It first emerged as a values-based planning process for children with serious emotional and behavioral disorders. The term “wraparound” was coined in the early 1980s in North Carolina where a law suit which sought alternatives to institutions led to development of an array of comprehensive, community-based services (Vandenberg et al., 2003). In 1985 it was used in Alaska to successfully return almost all youth with complex needs from out-of-state institutions. Initial evaluations and success stories promoted explosive growth in the use of wraparound (Vandenberg et al., 2003). It has since spread to all 50 states and other countries (Vandenberg et al., 2003).

Wraparound has received the support of the National Institute on Mental Health Child and Adolescent Services Programs (CASSP) and the Substance Abuse and Mental Health Services Administration (SAMHSA) (Vandenberg et al., 2003). The remarkable expansion of wraparound has been accompanied by the belief that it is more effective and less costly than traditional services (Burchard et al., 2002).
Research evidence

A significant amount of research has been undertaken about wraparound. Some studies suggest the wraparound process increases family empowerment and improves quality of life (Walker, Schulte, & Koren, 2006). Burchard et al. (2002) reviewed 15 studies that attempted to assess the effectiveness of the wraparound approach. Overall, they concluded that while the research base is undeveloped compared to many child and family interventions, there is nonetheless significant evidence of wraparound’s effectiveness.

In the late 1990s, concerns began to emerge about the lack of specificity of the approach. A significant amount of research has subsequently been done by the Research and Training Center on Family Support and Children’s Mental Health to further define the framework and practice model of wraparound (Walker et al., 2003). Their research suggests successful programs use a clearly defined practice model with clear guidelines for family engagement; preparation; reflective listening; true partnerships with families; and for the recruitment, welcoming, and appreciation of families’ self-selected support people. Walker et. al.’s research has also made it clear that high quality individualized services and planning cannot succeed without organizational, policy, and funding support as the context in which teams work. Their research has delineated the necessary conditions for high quality implementation of individual services/supports planning as including activities at three interrelated levels: the team, the organization, and the system.

Burchard et al. (2002) have further identified requirements for wraparound practices including:

1. A community collaborative structure with broad representation to manage the overall wraparound process and establishes the vision and mission.
2. A lead organization designated to function under the community collaborative structure and manage the implementation of the wraparound process.
3. A referral mechanism established to determine which children and families to be included in the wraparound process.
4. A resource coordinator who works with the child and family to form a child and family team.
5. Resource coordinators hired as specialists to facilitate the wraparound process, conduct strengths/needs assessments, facilitate the team planning process, and manage implementation of the services/support plan.
6. A child and family team that functions as a team and engages the child and family in an interactive process to develop a collective vision, related goals, and an individualized plan that is family centered.
7. A child and family team-developed crisis plan.
8. Each goal within the service/support plan has measurable outcomes and progress monitored on a regular basis.
9. A community collaborative structure for plan reviews.
With the rapid proliferation of wraparound, concerns have been raised about fidelity to essential elements and requirements for practice (Burchard et al., 2002). While many programs claim to use wraparound, many do not truly adhere to the essential elements of the model and practice principles (Burchard et al., 2002). A wide variety of programs using the name wraparound are inconsistent with the now-well developed approach. For example, wraparound was conceived and intended to be a community-based alternative to institutionalization, so fidelity to the model precludes its use to maintain long-term residence in treatment centers (Burchard et al., 2002).

In practice, it has proven quite difficult to realize the vision of wraparound teamwork (Walker, 2004). A study of observations and expert reviews of 72 actual wraparound meetings from around the country found that high quality appeared only rarely (Walker et al., 2006). Teams tended to be responsive to families’ wishes, but were not particularly successful in developing community or informal services and supports:

- A large majority of teams made only minor changes to formal services.
- Only half of teams discussed providing a regular community service.
- Fewer than one in six teams facilitated the use of a regular community service.
- Only one quarter of teams facilitated the use of a natural support.
- Less than 10% of teams facilitated access to tailored community support.
- Few teams engaged in activities that stimulated creativity.

While many practitioners endorse the values of wraparound planning, operationalization has proven problematic (Walker et al. (2006). A number of studies found that professionals consistently rate their collaborativeness with families higher than do families (Walker et al., 2006). Koroloff, Schulte, and Walker (2003) found that teams were rarely successful in building plans that are not primarily reliant on formal services. Their research indicates that this is in large part due to the lack of support at organizational and systems levels. Challenges remain in implementing the promise of wraparound including organizational cultures that are locked into traditional ways, interagency barriers and funding exigencies; and skepticism about the effectiveness of family-centered strength-based practices (Walker et al., 2003).

Walker et al. (2003) raised concern that unless practice guidelines are further developed and promoted, the wraparound approach may gradually be abandoned. They suggested the viability of teams and the sustainability of wraparound over time will be contingent on supportive systemic conditions including:

- Level of motivation
- Development of relationships between and across leaders and implementers
- Influential allies
- Legitimacy through use by well-established agencies
- Clarity of models of practice
Application to congregate care

Legislative, judicial, and economic factors are increasing pressure to find more creative ways to use resources and to find alternatives to congregate care. Thirty major state lawsuits have served to focus attention on the lack of creative services for families with children with complex needs as alternatives to institutions. The Olmstead Supreme Court decision requires states to develop plans to look at community-based services for institutional residents. Many state plans regarding compliance with Olmstead specifically call for use of wraparound (Vandenberg et al., 2003).

Convergence

While early work focused on children and youth with severe emotional and behavioral problems, wraparound has also proven useful for individuals with severe and/or chronic physical illnesses and developmental disabilities, and has been used effectively in education, child welfare, and juvenile justice systems (Burchard et al., 2002).

The wraparound process has been stimulated in part by the family support movement that has been emerging in mental health services (Vandenberg et al., 2003) and across all service systems. It has parallels in individualized planning efforts in other systems (Vandenberg et al., 2003) including:

- Person-centered planning in developmental disabilities
- Family group decision-making in child welfare
- Individual educational plans in education
- Restitution plans in juvenile justice

Systems of care

Systems of care is another approach that emerged from concerns about services for children with serious emotional disturbances.

Description

“System of care” involves the concept of providing individualized services, designed to surround a child and family with a full network of support (Stroul & Friedman, 1994). The target population for systems of care has been children whose emotional problems and behavioral challenges are long-term in nature. The systems of care approach recognizes that mental health services alone are insufficient to promote proper
growth and development and that often other agencies and services are involved including special education, child welfare, health, vocational, and juvenile justice (Stroul & Friedman, 1994).

A system of care approach is more than a network of services components; it represents a philosophy about the way in which services should be delivered to children and their families (Stroul & Friedman, 1994). It calls for a shift from more traditional services and requires systems to adapt to children and families rather than expect children and families to conform to preexisting service configurations. In addition, it requires a commitment to support families (in addition to treating the individual child with mental health needs) and to preserve family integrity to the greatest extent possible within their own unique and specific cultural context (Stroul & Friedman, 1994).

Distinguishing features of systems of care approaches (Stroul, & Friedman, 1994) include:

- Comprehensiveness
- Individualization
- Least restrictive setting
- Family orientation
- Services integration
- Casemanagement
- Early intervention
- Smooth transitions
- Rights protection and advocacy
- Non-discrimination

History

The growing family support movement that began to emerge in the late 1960s has contributed to a paradigm shift in services for children with serious emotional disturbances (CMHS, 2001). The 1969 Joint Commission on Mental Health of Children through the National Institute on Mental Health recognized serious limitations in services for children with serious mental health issues. By the mid 1980s increasing attention brought recognition that children with serious emotional disturbances were often unserved, underserved, or inappropriately served in excessively restrictive forms of care. By the mid 1980s, pilot projects had demonstrated that intensive services provided in homes and schools could reduce the need for residential care and that when residential care was needed, less restrictive community-based intense support could present an alternative to institutional placement (Stroul & Friedman, 1994).
While recognition grew that residential institutional services were overused when community-based services could be more effective, concerns were also raised about serious gaps and inadequacies in community services, including: lack of coordination of existing services; fragmentation of services; and lack of commitment to preserving families – all serving to promote removal of children from their families (Stroul & Friedman, 1994). These concerns led to establishing a national goal to develop a comprehensive, coordinated “system of care” (CMHS, 2001; Hornberger et al., 2006).

The Child and Adolescent Services System Program (CASSP) was launched by the National Institute of Mental Health in 1984 to promote development of a comprehensive, coordinated, community-based system of care for children and youth with serious emotional disturbances (Stroul & Friedman, 1994). It offered a funding mechanism to support creation of systems of care and the necessary infrastructure to implement the approach (CMHS, 2006; Stroul & Friedman, 1994).

By 1986, half of the states were involved in a CASSP initiative (Stroul & Friedman, 1994). In 1992, CASSP became part of the Center for Mental Health Services (CMHS) under the newly formed Substance Abuse and Mental Health Administration (SAMHSA). By 2003, CMHS had funded 92 programs in 47 states to implement systems of care (Mandell, Walbraith, Manteuffel, & Pinto-Martin, 2005).

**Research evidence.**

In addition to funding state initiatives, CMHS and the National Institute on Disability and Rehabilitation Research (NIDRR) funded two research and training centers to focus on children and youth with serious emotional disorders (Stroul & Friedman, 1994). Through the efforts of these two centers and an extensive consultative process with the field, a monograph was published in 1994 that provided a technical assistance tool describing the model of systems of care, a conceptual framework, guiding principles, and management approaches (Stroul & Friedman, 1994).

The monograph provided a definition of systems of care:

*A system of care is a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and adolescents with severe emotional disturbances and their families.*
In fleshing out the details of this new paradigm of services, the monograph identified three core values and ten principles of services (Sroul & Friedman, 1994).

VALUES AND PRINCIPLES FOR THE SYSTEM OF CARE

CORE VALUES

1. The system of care should be child centered and family focused, with the needs of the child and family dictating the types and mix of services provided.

2. The system of care should be community based, with the locus of services as well as management and decision making responsibility resting at the community level.

3. The system of care should be culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve.

GUIDING PRINCIPLES

1. Children with emotional disturbances should have access to a comprehensive array of services that address the child’s physical, emotional, social, and educational needs.

2. Children with emotional disturbances should receive individualized services in accordance with the unique needs and potentials of each child and guided by an individualized service plan.

3. Children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate.

4. The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services.

5. Children with emotional disturbances should receive services that are integrated, with linkages between child-serving agencies and programs and mechanisms for planning, developing, and coordinating services.

6. Children with emotional disturbances should be provided with casemanagement or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that they can move through the system of services in accordance with their changing needs.

7. Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes.

8. Children with emotional disturbances should be ensured smooth transitions to the adult service system as they reach maturity.

9. The rights of children with emotional disturbances should be protected, and effective advocacy efforts for children and youth with emotional disturbances should be promoted.

10. Children with emotional disturbances should receive services without regard to race, religion, national origin, sex, physical disability, or other characteristics, and services should be sensitive and responsive to cultural differences and special needs.
The monograph summarized the experience of states that had been funded since 1986 in transforming their systems (Stroul & Friedman, 1994). Experienced states identified major areas that they had to address:

- **Overall management.** The monograph identified three different approaches that have been used by different state initiatives:
  1. a consolidated agency
  2. a lead agency
  3. multiple agencies with formal agreements

- **System change strategies.** Activities were identified as most likely to have broad impact:
  1. planning and needs assessment
  2. modifying the mental health system
  3. interagency collaboration
  4. technical assistance and training
  5. constituency building
  6. local system development

- **Rebalancing.** Effective state initiatives found they needed to shift the balance from residential treatment toward more home and community-based services.

- **State/local relationships.** A major issue for system management was the relationship between state-level and community-level agencies in terms of:
  1. control of financial resources
  2. degree of flexibility
  3. locus of decision-making

Subsequent studies since 1994 have looked at these issues as states have continued to try to implement the philosophy of systems of care. A congressional mandate for CMHS to demonstrate the effectiveness of systems of care resulted in an evaluation that has been described as the most extensive study ever undertaken of a children’s mental health services initiative (CMSH, 2001). It involved assessments of child outcomes and family functioning for 950 children across the country.

Findings from the evaluation study described the children and families served by system of care initiatives:

- Average age of children served was 12.2.
- Ethnic/racial identity of children was 60% white, 23% African American, 12% American Indian, and 10% Hispanic.
- Majority of families were poor.
- Mother-maintained households had the highest poverty levels.
- 94% of children had been exposed to at least one risk factor (such as family substance abuse, domestic violence, parental mental health issues, parental felony convictions)
Findings described child participant outcomes:

- Improved stability of residence
- Fewer residential placements
- Greater rates of positive change in behavioral and emotional problems compared with a non systems of care group
- Casemanager satisfaction

The evaluation described successful systems of care approaches as marked by *three hallmark tenets* (CMHS, 2001):

1. Mental health systems are driven by needs and preferences of children and families.
2. Services are community-based with management built on multi-agency collaborations.
3. Services are offered based on need and are responsive to cultural context.

The evaluation described system of care activities as occurring on *two distinct levels*:

1. Infrastructure development to house, organize, and manage the integrated program elements.
2. Service delivery to provide services, treatments, and supports directly to families.

A 2006 joint effort of the Child Welfare League of America and the Robert Wood Johnson Foundation produced a report based on a series of summits and workshops involving 100 organizations and 200 individuals organized to describe current practice wisdom around systems of care involving integration of mental health, substance abuse, child welfare, and juvenile justice (Hornberger et al., 2006). The goal of the project was to find consensus regarding:

1. Ways to promote the organizational culture changes required to integrate systems of care
2. Strategies to advocate for change
3. Methods to increase the field’s knowledge of what works best to transform agency silos into integrated systems of care to benefit children, youth, families, and communities

Consensus emerged on the need to do business differently and described the kind of shift that was required to integrate systems of care as a “sea change” (Hornberger et al., 2006).

The attribution of a sea change in policy, practice, and administration has been picked up by others (e.g. Koyangi & Feres-Merchant, 2000). The level and kind of change required for success calls for reorienting, redesigning, and refinancing children’s mental health. In *Promising Practices*, Koyangi and Feres-Merchant (2000) describe the systems of care grants which have been most successful and found ways to be sustainable.
Successful sites:

- Were entrepreneurial
- Had good leadership
- Learned from business models
- Engaged in real collaboration
- Involved local parent support organizations
- Redirected resources
- Had a reinvestment strategy
- Provided good data to policy-makers
- Used sophisticated communication and media approaches to inform and mobilize the public

Application to congregate care

The goal of systems of care is to maintain as many children as possible in their own homes by providing a full range of family-focused and community-based services and supports. Out-of home placement too frequently has been used because intensive, community based alternatives have not been available. Accumulating evidence suggests many children with severe emotional disorders can be maintained within their own homes and communities and that intensive services can minimize the need for out-of-home placement. If placement becomes necessary, rapid reintegration to the family can be facilitated by systems of care planning.

Even when out-of-home placement is needed, it need not require congregate care placement. Innovative models of services and supports provide increasing evidence that systems of care can be employed with extended family and with surrogate or substitute families (Stroul & Friedman, 1994). The concepts of system of care can be effectively used with kinship care and treatment/therapeutic foster care [topics that will be further discussed below].

Convergence

Overall, a system of care approach is based on the premise that the mental health needs of children and youth and their families can be met within their homes, schools, and community environments (CMHS, 2006). Successful system change efforts through systems of care approaches have come about and been maintained through the development of broad-based constituencies of parents and professionals and providers in partnering on advocacy coalitions at the state and community levels. System of care proponents argue that the importance of a strong and vocal constituency cannot be underestimated (Stroul & Friedman, 1994). State initiatives have used various vehicles to build such constituencies including study groups, task forces, advisory bodies, and statewide coalitions. These kinds of constituency building activities have also been identified as key to other promising practices.
**Kinship care**

When parents cannot care for their children, a living arrangement that may serve as an alternative to congregate care is living with extended family.

**Description**

Nationally, over 72 million children under age 18 live with relatives other than their parents (Bornheim, et al., 2006). Children with disabilities are more likely than children in general to be living with grandparents and other relatives (Bornheim, et al., 2006). Over the last decade, child welfare agencies have increasingly relied on extended family members to act as foster parents for children who come to the attention of child protective services (DHHS, 2000). These extended family arrangements are referred to as kinship care.

Kinship care offers a number of advantages over non-kin foster care. It tends to support a child’s sense of family identity; maintains continuity of family relationships and community ties; involves caregivers who have knowledge of family history and dynamics, and sustains relationships that existed prior to entering care and are likely to be ongoing into adulthood (DHHS, 2000; Hornby, Zeller, & Karracker, 1996).

A 2002 national survey (Urban Institute, 2006) found the following figures regarding kinship care:

- 2.3 million children in kinship care
- 400,000 in kinship care with court involvement
- 140,000 in voluntary kinship care without court involvement
- 1,760,000 in private kinship without the involvement of social service agencies or the court
- 1,360,000 in kinship care live with grandparents

A Report to Congress on Kinship Foster Care (KFC) summarizes current knowledge about kinship care. The report identified the extent to which children are placed with relatives, cost and sources of funds, state policies, characteristics of kinship caregivers and their households, conditions by which children enter kinship care, services to kinship caregivers, and birth family involvement (DHHS, 2000). The remainder of this discussion of kinship care is based on that report unless otherwise indicated.

The KFC report defined kinship care broadly as any living arrangement in which a relative or someone else emotionally close takes primary responsibility for rearing a child. The report distinguishes between public and private kinship care based on whether the living arrangement was made with or without the child welfare system.
History

Kinship care increased substantially in the late 1980s and 1990s, however, since 1994, the number and proportion of children in kinship care has decreased (DHHS, 2000). The evolution of kinship care has been affected by two different federal policies: income assistance and child welfare.

*Income assistance policies.* Income assistance to kinship caregivers has been provided in two ways: (1) family assistance with eligibility based on family needs (as available to any other needy family), and (2) child-only assistance (not based on family need) for a relative not legally required to support a child.

Income assistance to dependent children has provided support to kin carers that has allowed children to be kept out of the child welfare system. Title IV of the *Social Security Act of 1935* sought to address the financial needs of dependent children. Later Title IV-B established Aid to Families of Dependent Children (AFDC) to help neglected and disabled children. Recent shifts in income assistance policy have placed work participation requirements on caregiver recipients impacting their ability to stay home to care for dependent children with disabilities.

*Child welfare policies.* Kinship care has also been affected by child welfare policies and legislation. In 1961, Congress required states to provide foster care as part of AFDC. The *Indian Child Welfare Assistance Act of 1978* acknowledged the role of extended kin for American Indian families. The *Adoption Assistance and Child Welfare Act of 1980* mandated that children be served in the least restrictive, most family-like setting available in close proximity to the parent’s home consistent with the best interests and special needs of the child. The AACWA has been interpreted to encourage kinship care.

The level of financial assistance to kinship caregivers has tended to be less than that provided to non-kin foster parents, although court cases have challenged that. In 1979, the Supreme Court ruled that kin are entitled to receive the same level of federal financial support as non-kin foster parents. In 1989, the ninth Circuit Court found that children have a constitutional right to associate with relatives and that states’ failure to use kin as foster parents denied them that right. Other court decisions found that states are not obligated to take children into foster care, but if they do then they must show parity for kin and non-kin care financial assistance.

Issues of race and socioeconomic status have been and continue to be intertwined with child welfare services and kinship care policies and practices. Child welfare systems have historically reflected Western, white middle class values and nuclear families. Care by extended family has been particularly important in ethnic minority communities. A majority of children in kinship care are children of color. In part, this reflects a cultural strength of minority communities, especially African American families. In part,
however, this reflects historical exclusion from public and private child welfare services based on discriminatory practices (Kang, 2003a).

Research evidence

A literature review of empirical studies of kinship care found mixed evidence of the well-being of children in kinship care (Kang, 2003b):

- Children and youth had substantial health care needs but received inadequate health services.
- Placements were more stable.
- No differences were found between adults who had been raised in kinship care and non-kin care.

Literature reviews also found evidence about the well-being of kin caregivers (Hornby et al., 1996; Kang, 2003a).

- Kinship caregivers are more likely to be receiving public benefits based on their own economic status.
- Of private kinship caregivers, 39% live in homes below the poverty level.
- Kinship caregivers are generally more likely to be older, single, African American, have less education, low income, and be in poor health.

The DHHS (2000) KFC report found that kinship caregivers are less likely than non-kin foster parents to receive services from child welfare agencies. A number of studies have revealed kinship caregivers’ frustration and mistrust of child welfare systems that have failed to respond to their needs and the needs of their children (Kang, 2003a, 2003b). Studies found that kinship carers tended to have less preparation and training prior to placement and less support after placement. Children adopted by non-kin foster parents were more likely to receive higher adoption subsidies than children adopted by relatives (Impact 2005/2006).

Child welfare caseworkers provided less supervision and monitoring to kinship caregivers than non-kin foster care, and were less familiar with children on their caseloads who were in kinship care (Hornby et al., 1996). One study found a quarter of kinship caregivers went a year or more without contact with a caseworker. In addition, kinship caregivers tended to request fewer services and receive fewer services when requested. Studies found that child welfare caseworkers provided less information to kinship caregivers than to non-kin foster parents and were less likely to respond to requests for information by kinship caregivers. Caseworkers were less likely to offer health screening, psychological assessments and educational services to children in kinship care. Children in kinship care were less likely to have seen a doctor, dentist, or mental health professional in the past year. A study of grandmothers providing foster
care for their grandchildren with disabilities reported they did not receive any services for disabilities and that they could not access community-based disability services because services were unavailable to kinship foster parents (Kang, 2003a).

Despite the findings of lower services, assistance and oversight, children in kinship care appear to experience benefits over children in non-kin foster care. Children in kinship care are less likely to experience multiple moves. They are more likely to be the only child in the household while non-kin foster homes are more likely to have 5 or more children in care. They have fewer health, mental health, or behavioral problems, however, due to methodological issues in the research, the extent to which these positive factors reflect characteristics that existed prior to care is unclear.

Kinship caregivers have been found to be more willing and committed to taking care of children despite lower financial resources and fewer supports and services than non-kin caregivers (Kang, 2003a). Positive attitudes and cultural role identity seem to play a role (Kang, 2003a). Kin carers in general, as compared to non-related caregivers, have been found to have more positive perceptions of their children and felt responsibility for children in their care (Kang, 2003a).

Better outcomes for children appear to come at a cost to kin carers. Kinship caregivers tend to experience lower well-being than non-kin foster parents in terms of economics and health. Studies of grandparent caregivers found that they experienced substantial physical and psychological costs as well as social and financial costs even though they felt satisfaction and gratification from child-rearing (Kang, 2003a).

While trends can be seen in the available data regarding kinship, the KFC report suggests that there is little information on how public kinship care affects the long term health and well-being of children. Recent demonstration projects are underway across the country to study issues more closely. One such study was the CREST program (Hawkins & Bland, 2002), a three year demonstration project in Texas which sought to support kinship caregivers. The project offered three primary services: (1) formal group training, (2) individualized casemanagement, and (3) limited financial assistance. The project involved 304 families caring for 579 children. An extensive evaluation using interviews, questionnaires, and focus groups of caregivers, caseworkers, and supervisors found caseworker contacts with families increased, caseworkers had greater knowledge about their homes, and caregiver ratings were overwhelmingly positive. Caregivers reported appreciating the emotional support as much as formal services.
Application to congregate care

Kinship care has advantages over congregate care, if kin carers are well-supported, prepared, assisted, and trained regarding the special needs of children with disabilities as well as how to advocate for health, mental health, education, and disability services (Berrick & Barth, 1994; Hornby et al., 1996).

If, however, we view kinship care as a cheap alternative to foster family care and provide little to bolster the significant work involved in caregiving, we will create a two-tiered system . . . this two-tiered system already appears to be in place. (Berrick & Barth, 1994)

The DHHS KFC report of 2002 seems to confirm the continuation of this two-tiered system. To be a viable alternative to congregate care, kinship families, like birth families, need to be better supported.

Convergence

Kinship care can address the attachment needs of children, especially if an emotional relationship existed prior to the need for placement. Like birth families, the extent to which kinship care succeeds is related to the extent of relevant support. Supporting kin caregivers has a significant relationship to the goals of permanency planning. To what extent the opportunity for well-supported kinship arrangements might present alternatives to congregate care is related to the extent and fit of support available.

Family group conferencing

Kin relations are part of a child’s personal network. One of the ways in which safe and nurturing family life can be fostered is through the effective planning and decision-making processes that include extended family members. An approach that is increasingly being used in child welfare systems with increasingly good outcomes, is a process called “family group conferencing” (FGC) (Pennell & Anderson, 2005). The premise of FGC is:

We cannot help children and young people without attending to their key relationships and surroundings. (Pennell & Anderson, 2005, p. 1)

Description

FGC is a means of involving extended family and close support people in making and carrying out plans to safeguard children. One of the express purposes of FGC is to identify and mobilize the extended family to bring together resources to assist at-risk family members (Anderson, 2005a; Merkel-Holguin & Wilmot, 2005). The shift to increased participation of extended family and significant others gives recognition to the
fact that child welfare systems alone cannot protect children. FGC is a strategy to mobilize a wider spectrum of community resources around a child and family (Pennell, 2005b).

The distinguishing features of FGC (Pennell & Anderson, 2005) are:

- Convening a conference that embraces the child’s extended family members and “like family” friends and close others in the community as decision-makers
- An independent coordinator to facilitate the conference
- Significant preparation in advance of the conference
- The use of family “private time” whereby families meet for a portion of the conference among themselves without the presence of professionals

FGC contrasts with typical child welfare case plans which have been criticized as ‘one-size-fits-all’ and so routinized that they do not reflect differences in families or their resources (Anderson, 2005b). FGC represents a dramatic transformation in traditional approaches to child welfare. Rather than a set of activities or techniques, it is a set of values and approaches (Anderson, 2005b). In FGC, the independent coordinator has no service delivery responsibilities and is able to focus total attention on helping the extended family network to assume responsibility and to offer their resources to find a solution to the problem that brought the child to the attention of the system. Involvement of the extended family network acknowledges to the family that services systems alone cannot solve family problems. Furthermore, providing an opportunity for private time signals that the extended family network is entrusted with the welfare of the child and family and that they are competent to define solutions that are unique to their own cultural views and individual circumstances.

FGC uses four capacity-building strategies (Pennell, 2005b):

1. Family leadership development
2. Organizational development
3. Community organizing
4. Interorganizational collaboration

History

The model was first developed in New Zealand in the late 1980s as a move away from expert-driven intervention toward promoting family group responsibility, children’s safety, cultural respect, and community-government partnerships (Pennell & Anderson, 2005). Its impetus was an economic crisis and resultant calls for greater government accountability, coupled with objections by indigenous Maori people about government treatment (Pennell & Anderson, 2005). While FGC is new to human services, it has
been part of the traditions of many cultural groups from many continents for many years (Pennell & Anderson, 2005). Its implementation in New Zealand was in part successful because it reflected already existing traditions.

FGC is consistent with family involvement themes that emerged in social work practices in child welfare in the 1980s. It marked a shift from professional-driven systems to family-driven systems; from viewing service recipients as clients to viewing them as partners; from focusing on pathology to focusing on strengths; and moving from a medical model to a family-centered model (Merkel-Holguin & Wilmot, 2005).

The growth of FGC in the U.S. followed reviews conducted by the U.S. Children’s Bureau in 2001/2002 which found that child welfare systems which involved parents in case planning were more likely to stabilize children’s living arrangements; heighten families’ ability to care for their children; and meet children’s educational, physical, and mental health needs (Pennel & Anderson, 2005). From the mid-1990s to 2005, FGC has moved from an innovation to an accepted services approach (Merkel-Holguin & Wilmot, 2005).

**Research evidence**

Multiple studies of FGC have found positive results of the FGC process (Anderson & Whalen, 2005; Merkel-Holguin & Wilmot, 2005; Pennell, & Anderson, 2005) including:

- Family groups and professionals overwhelmingly report that they like FGC.
- Child welfare workers authorize the vast majority of plans made during family private time.
- Family-generated solutions go beyond standard service plans and are more imaginative and wider ranging.
- Families are reasonable in what they ask for in their plans.
- Family-developed plans are accepted by responsible case-workers 90-95% of the time.
- Participation of fathers and paternal relatives increased.
- Re-referral rates for abuse and neglect are lower over time.
- Children are kept connected to families.
- Kinship care is promoted.
- Placements are stabilized.
- Child development improved.
- Rates of positive involvement of families and professional participants are higher.
- More children live with parents after conferences.
- Fewer children live with nonrelatives after conferences.
- Families, child welfare staff, and the public express satisfaction.
While there are significant positive research findings regarding FGC, it should be noted that research is limited by methodological problems such as the lack of experimental design, small sample sizes, and measurement instrumentation issues (Anderson & Whalen, 2005). In part this is because FGC is relatively new from a research perspective and does not yet have a large body of knowledge or established methods (Rowe, 2005). While a systematic study of the cost-benefits of FGC does not yet exist, since FGC programs have demonstrated that they are no more costly than traditional approaches and appear to achieve a high level of benefits for participants, there is preliminary evidence to conclude that FGC is an effective alternative to traditional approaches (Rowe, 2005).

FGC has been used internationally with varying degrees of acceptance. In New Zealand where it was first introduced, it is legislated as a right of children and families; in the U.K., it is considered good practice; in the U.S. it is still generally regarded as a tool or technique (Merkel-Holguin & Wilmot, 2005).

Studies of FGC suggest it cannot work in a vacuum, but requires a climate that supports it. Supportive environments include those that provide a responsive organizational culture, technical assistance, training, supervision, consultation, ongoing evaluation, and advisory boards with parent representatives (Pennell & Anderson, 2005). Full embrace of FGC requires accepting the values that (1) family groups can make well-informed decisions about keeping their children safe, (2) family groups are experts on themselves, and (3) all families have strengths (Merkel-Holguin & Wilmot, 2005).

**Application to congregate care issues**

One of the outcomes specifically sought by U.S. Department of Health and Human Services is reducing placements of young children in group homes and institutions (Anderson & Whalen, 2005). In focusing on supporting the family and extended family, FGC addresses both the policy and legal mandates of permanency planning in child welfare systems (Anderson, 2005b). FGC goals are consistent with the hierarchy of permanency goals which assert the first priority of permanency is to consider the safe preservation of the child’s family; and the second priority is relative caregivers if out-of-home placement becomes necessary, with reasonable efforts to reunify the child and family (Anderson, 2005b). Proponents argue that in increasingly resource-depleted environments, full community involvement as promoted by FGC is essential and can prevent costlier out-of-home placement (Merkel-Holguin & Wilmot, 2005). Also of note in the application of FGC in Pennsylvania, research has found that FGC has had a positive influence on staff retention, a critical problem in congregate care generally (Unger & Fatzinger, 2006).
Convergence

FGC has been implemented in Pennsylvania since 1999 where it has expanded from pilot projects in particular counties to system-wide application (Unger & Fatzinger, 2006). Interest in FGC has spread to juvenile justice, mental health, corrections, aging, faith-based communities, and among providers. Preliminary results of a statewide evaluation mirror those found in research elsewhere indicating (1) family and non-family satisfaction and, (2) plans that protect child and community safety (Unger & Fatzinger, 2006).

FGC is increasingly recognized as congruent with reforms that child-serving systems have been undergoing over the past twenty-five years. FGC addresses the basic elements of these reforms: (1) provision of customized responses to families, (2) development of community-based systems of child services, and (3) involvement of informal and natural helpers (Anderson, 2005b). Furthermore, FGC is congruent with the goals of the U.S. Department of Health and Human Services (DHHS) to strengthen families; prevent removal; promote reunification; and provide comprehensive, child-centered, family-focused, individualized, culturally competent, community-based services and supports reflective of community partnerships (Anderson, 2005c).

The experience of FGC has parallels in other services where individualized planning processes have been used. Variations of family group conferencing have been employed in wraparound in mental health (Merkel-Holguin & Wilmot, 2005). Developmental disability service systems use “circles of support” which seek to mobilize extended family, friends, and local community members around an individual in creating a unique, relationship-based plan (O’Brien & O’Brien, 1997, 1999).

Treatment foster care

When support cannot be effectively mobilized around a child and their extended family, and a child needs to be placed out of the family home, a promising model of practice that has been used for children with emotional disturbances is “treatment foster care” (TFC).

Description

Treatment foster care is a family-based service delivery approach providing individualized treatment for children, youth, and their families. Treatment is delivered through an integrated constellation of services with key interventions provided by treatment foster parents who are trained, supervised, and supported by qualified program staff (FFTA, 2004).
Treatment foster care combines the professional features of residential treatment with the family component of foster care (Redding, Fried, and Britner, 2000). The term the “treatment” refers to both intervention techniques and to the foster parent relationship as a therapeutic mechanism of change. A number of terms have been used in the literature to refer to the model, including specialized foster care, intensive foster care, or therapeutic foster care, although arguably not all situations using these labels apply all of the model’s distinguishing elements. For the purposes of this literature review, the term “treatment foster care” is used to refer to approaches which include all of the elements described below.

*Structural* features that distinguish treatment foster care (Bryant, 2006; Curtis et al., 2001; Meadowcroft et al., 1994; Redding et al., 2000; Terpstra, 1991; Twigg, 2006) are:

1. Limited number of children (one or two) placed in one home
2. Targeted recruitment for a specific population
3. Careful selection
4. Careful matching
5. Low caseloads for caseworkers (ten or less)
6. Intensive casemanagement
7. Frequent supervision
8. Availability of crisis intervention 24/7
9. Coordination of services
10. Intensive and specialized training of treatment foster families
11. Comprehensive array of flexible supports and services tailored to fit the child and treatment foster family
12. Residence is the foster parents’ own home
13. Compensation to foster parents greater than traditional foster care
14. Foster family access to professional teams and planning
15. Foster parents as team members
16. Focus on children with complex needs who would otherwise be in a congregate settings
17. Acknowledgement and involvement of the child’s family of origin

*Clinical* features that distinguish treatment foster care (Bryant, 2006; Meadowcroft et al., 1994; Redding et al., 2000; Terpstra, 1991; Twigg, 2006) are:

1. A safe and functional home
2. A nurturing family
3. Effective parenting
4. A clear treatment philosophy
5. Foster parents as paraprofessionals
6. Specialized services to the child for specialized needs
7. Intensive intervention from relationship-based caregivers
8. Professionalized treatment plans
9. Relationship-based therapy
10. Continuity with loved ones
11. A plan for involvement of the birth family and a permanency priority of reunification

History

TFC had its early roots in the 1950s but was abandoned until the 1960s and 1970s when it was revived in concert with critiques of institutional care, and preferences for community-based care (Meadowcroft et al., 1994). By the mid-1980s it was recognized as an important part of the system of care (Wells & D’Angelo, 1994). In 1988, providers of treatment foster family services organized the Foster Family-based Treatment Association (FFTA, 2004; Twigg, 2006). By the mid 1990s, there was a proliferation of TFC models across the U.S., Canada and Europe. In 1991, the FFTA providers established standards that have since become widely adopted (FFTA, 2004). By 1996, 23,000 children were served in TFC as compared to 68,000 in residential group care. (Curtis et al., 2001). There are now over 400 provider members in the association whose mission is to advocate, develop, and evaluate treatment foster care.

Research evidence

The TFC model has been the subject of a growing research base. In recognition of the need for evidence-based and best practice, the FFTA has devoted energy to outcome research (FFTA, 2004, 2006).

Summaries of the empirical literature as of 1994 suggested TFC was an effective alternative to residential treatment for seriously “troubled and troubling” children, was less expensive, and produced behavioral improvements in a population of children and adolescents with similar problems as those in residential group homes (Hudson, Nutter, & Galaway, 1994; Meadowcroft et al., 1994). Best practice wisdom until that time had assumed that residential group care was most appropriate for children with behavioral and emotional problems, for children who couldn’t tolerate the emotional intimacy of family life, and for children who were highly aggressive, hostile, or defiant (Curtis et al., 2001). Emerging research evidence suggested that child welfare agencies had underestimated the number and variety of troubled youth who could successfully be served in family placements (Curtis et al., 2001).
Later literature reviews continued to find that TFC served as an effective alternative to residential treatment and psychiatric hospitalization (Bryant, 2006; Twigg, 2006). Studies contrasting TFC programs with residential treatment programs found:

1. TFC serves similar children to those in group settings.
2. TFC children have better adjustment after discharge.
3. TFC is less costly.
4. TFC children had reduced incidents of serious behavior problems.
5. TFC children spent increased time with a supervising adult rather than peers with similar needs.
6. TFC demonstrated stability for children with histories of instability.

Studies consistently reported either positive outcomes or no difference in TFC outcomes compared to residential care but an advantage to TFC because similar outcomes are achieved at lower cost (Twigg, 2006).

Reviewers also note limitations in the research. Current studies tend to be small scale, vary widely in rigor, and suffer from methodological limitations including non-randomization; instruments of unproven reliability, validity, or norms; and challengeable evaluation methods (Redding et al., 2000; Twigg, 2006). However, despite methodological limitations, reviews of published outcome studies suggest treatment foster care is effective compared with traditional foster care or group homes:

*The research corpus is sufficient to provide useful guidance for policy makers and practitioners in development of effective TFC programs, particularly as relating to foster parent selection and training and models of service delivery.* (Redding et al., 2000, p. 444).

Redding et al. (2000) reviewed research predictors of positive outcomes of TFC. The features in the literature that correlate with successful TFC are:

1. Effective parenting style
2. Child-parent attachment
3. Social support
4. Therapeutic efficacy

Successful treatment foster parents are emotionally stable, realistic, hardy, sensitive and responsive, motivated, and authoritative (rather than authoritarian). Correlates of successful treatment foster care placements are related to characteristics and motivations of the foster parents (Redding et al., 2000):
1. Desire to parent
2. Personal experiences that identify with disadvantaged children
3. Higher quality home environment
4. Interactive parenting style
5. Consistency and structure
6. Availability of social supports

A feature of treatment foster care is the multiple relationships involved between foster parents, birth parents, caseworkers, and foster children (Wells & D’Angelo, 1994). Correlates of successful TFC placements identify professional relationships (Redding et al., 2000) including:

1. Caseworker contact, rapport building, and energy expended
2. Overall rapport between the families and the agency
3. Rapport between the child and the caseworker

Jivanjee (1999a, 1999b) conducted a series of qualitative studies involving interviews to try to understand the perspectives of providers, providers, birth parents and treatment foster parents experiences. Capturing the positive relationship from a birth parent’s perspective was this quote from a birth parent referring to her relationship with the foster parent:

“not only . . . on my side, but can understand my side.” Jivanjee, 1999a, p. 454)

Redding et al. (2000) reported that some of the anxiety and ambiguities between birth and foster parents can be reduced when foster families adopt the role of extended family members in which the child’s relationships with their biological family members are kept intact.

A question that is emerging in the research regarding TFC is clearer identification of the specific factors of the model that result in positive change. The majority of research on out-of-home care has emphasized characteristics of children or families over characteristics of treatment intervention (Curtis et al., 2001; Redding et al., 2000). Little research has been done comparing differences in treatment approach and intensity between group care and treatment foster care. The research agenda of FFTA is focusing on identifying the therapeutic mechanism of change and trying to better understand the contribution to positive change of the treatment intervention employed by foster parents and the parent-child relationship itself (Wells & D’Angelo, 1994).
Application to congregate care

TFC was initially designed for short-term intensive treatment as a transition between residential care and returning to the family. Now it is more frequently viewed as an alternative to residential care and can be longer term in nature (Redding et al., 2000).

TFC has proven more effective than regular foster care for children who cannot live with their birth families and at least as effective as congregate care with comparable children for comparable or better outcomes (Bryant, 2004). It has been particularly effective with children with emotional disturbances and behavior challenges. According to a report of the Surgeon General, in TFC there is less susceptibility to the “contagion effect” in congregate settings where negative behavior is modeled, reinforced, and passed among peers who are housed together (Bryant, 2004).

An oft-repeated concern about the potential of building a system of family foster care as an alternative to congregate care is finding a sufficient supply of families who are willing and capable. Redding et al., (2000) suggests that problems with finding families are related to failure to devote sufficient energy to recruitment, targeting appropriate populations, and/or providing sufficient pay to attract parents interested in the professional aspects of treatment foster parenting.

Convergence

The early history of TFC was influenced by deinstitutionalization in mental health and by permanency planning in child welfare. The vision of the FFTA organization is that all children and youth need and have a right to a permanent family and to that end, family reunification, adoption, kinship care or other long-term stable family living arrangements are crucial (FFTA, 2004).

TFC has expanded beyond its original application for children with severe emotional disturbances. It has since been used as an alternative to congregate care for children with all types of disabilities including children with complex medical conditions, children who have behavioral challenges and hyperactivity, developmental delays, mental retardation, psychiatric disorders, and head injuries (Meadowcroft et al., 1994; Terpstra, 1991; Twigg, 2006). It’s model of intensive support for family life provides an alternative to congregate care for children with significant needs.

TFC has embraced the concept of “wraparound” to surround the foster family with individualized, flexible supports and a “do-what-works” approach (Meadowcroft et al., 1994; Twigg, 2006). TFC draws much of its therapeutic effect from the relationships entailed in family life, especially from the parent-child
relationship. TFC is most successful when it carefully matches the caregiver’s capacities with the child’s needs, provides families with the necessary supports to fit their unique needs and circumstances, and when it nurtures the relationships between the family and the supporting staff (Bryant, 2006).

**Shared parenting**

The most familiar form of alternate family is foster care in the child welfare systems where parents’ rights have been abridged. Outside the child welfare system, much of the literature addressing out-of-home placement of children with disabilities assumes congregate residential placement is the only alternative when birth parents cannot continue to care for their children. Other family-based arrangements within disability services, however, are possible. A smaller literature describes voluntary family-based living arrangements including host family care, shared care, co-parenting, and mentoring families (Baxter, Cummins, & Volard, 1992; Coucovanis et al., 2005; Hayden et al., 1992; Johnson & Kastner, 2005; Lunken & Grant, 2002; Rosenau, 2005; Taylor et al., 1989; Terpstra, 1991). Each of these involves a shared parenting relationship between the birth family and the alternate family.

**Description**

Across cultures, informal shared caregiving arrangements for children are normative (Kilbride & Kilbride, 1994). Many cultures use informal fostering systems as a safety net for children and a resource for parents in need of help in meeting their parenting responsibilities. Variations include nurturant fostering when parental capacities are limited by health or adverse socioeconomic situations. In many cultures, fostering includes a community exchange system with “fictive kin,” that is, community members who are accepted “as if” they were kin. Such arrangements involve reciprocal assistance and companionship where families maintain a relationship with each other. Delegation of elements of parenting roles are accomplished without affecting the identity of the child or the child-birth parent relationship. Minority cultural groups have historically used a variety of child-rearing configurations involving networks of caregiving adults (Howes, 1999). In contemporary U.S. society, divorce and step-parenting often involve shared child-rearing arrangements across households with multiple sets of parents.

Such arrangements are most successful when there is mutual trust between the families, open communication, and where high value is placed on child-rearing and strong familial bonds (Kilbride & Kilbride, 1994). Motivations of successful alternate families are both utilitarian and an outgrowth of finding pleasure in caring for children. Arrangements are viewed as an extension of the family system, and as incorporation of additional caregivers into the system rather than as replacements for biological parents.
The key element of shared parenting is the relationship between the birth family and the alternate family. Some disability systems have implemented a voluntary shared parenting model to accommodate birth families whose circumstances prevent them from raising their children or caring for them full time. It provides for their ongoing and close relationship with their child and with an alternate family who assists them by providing a home for the child (Hayden et al., 1992; Rosenau, 2005). The model accommodates varying distributions of parenting activities across multiple parenting figures and also accommodates various patterns of time spent between families in arrangements tailored to fit the circumstances.

Research evidence

No research studies were found that examined shared parenting for children with disabilities. However, Rosenau (2005) presents a detailed description of a shared parenting model for children with developmental disabilities and provides examples of its application.

Studies in the child welfare system have found a consistent association between the frequency of parental visits and shorter stays in out-of-home care (Davis & Ellis-MacLeod, 1994). In a study of a demonstration project where family involvement was actively facilitated for children in a residential facility, the group with active facilitation showed significantly more family visits and reunifications than the comparison group (Landsman et al., 2001). The evaluation noted, however, that reunification was not always possible and suggested that long-term foster care coupled with active involvement of birth families was a more realistic way to assure family life as an alternative to congregate care (Landsman et al., 2001).

Application to congregate care

For children with disabilities, shared parenting has been employed on a limited basis but holds significant potential for children who would otherwise be placed in congregate care (Rosenau, 2005). The idea of shared parenting is more akin to kinship care and step families than traditional foster care because of its voluntary choice by the birth family and the expectation of continued involvement with the child. Like congregate care, its utilitarian benefit is an accommodation for birth families who are unable to care for their children. However, its advantage over congregate care is the relationship that it offers the child and the supportive parent-to-parent relationship it offers the birth parent. Families who have chosen this form of care speak of their parenting partner using terms like “friend” or “like a sister” (Rosenau, 2005).

Policy can support and facilitate (or thwart) creative use of shared caregiving arrangements for children with disabilities. Kilbride and Kilbride (1994) suggest that U.S. national policy has had a preoccupation with the nuclear family, arguably a white, Western cultural phenomenon (Howes, 1999), that interferes with the notion of shared parenting. Often it is the nature of adults’ difficulties rather than the children’s
needs that dictate out-of-home placement (Blacher, 1994b). If an alternate family is sought, it has often required relinquishment by the birth parent to the child welfare system. In disability services and mental health services where placement is voluntary, often the “choices” offered when out-of-home placement is sought have not included a shared parenting arrangement where the ongoing birth family relationship is maintained.

**Convergence**

Permanency planning is a vehicle for building alternatives to assure family life. The development of creative family-based care arrangements could be expanded to include shared parenting arrangements. The lack of visibility of shared parenting in the literature does not necessarily reflect its feasibility or benefit. Like other promising approaches, practice often precedes research literature.

**SUMMARY**

All child-serving systems have been challenged to shift from traditional ways of serving children and families. In particular each system is trying to find alternatives to congregate care for children. Wraparound is an approach that seeks more flexible and creative ways to surround families with support that fits their unique needs. The systems of care approach seeks more cross-system collaboration. Family group conferencing and kinship care seek more engagement of extended family members in organizing support to assure family life. Treatment foster care and shared parenting engage non-family members in creating family-based living arrangements which maintain birth family involvement. Each of the promising approaches discussed suggests ways to more effectively support family life, but practitioners trying to implement each approach are wrestling with the hard work required to translate promising ideas into practical realities. The research literature shows evidence of positive outcomes from various approaches, but also highlights the difficulty of specifying the particular factors that contribute to successful outcomes and the difficulty of maintaining fidelity to the practices that are identified as responsible for producing positive outcomes.

While different child-serving systems have developed their own approaches and terminology, there are commonalities across the approaches. All of the approaches described increase the voice and decision-making of families as active participants in finding solutions that work. All of the approaches described have some level of cross-system involvement or could benefit from increased cross-system collaboration. We turn now to a discussion of the converging momentum across approaches and systems toward creating alternatives to congregate care and the continuing challenges and emerging opportunities in evidence in the literature.
OVERALL CONVERGENCE OF LITERATURE FINDINGS
CHALLENGES AND OPPORTUNITIES

All child-serving systems are struggling. All are widely reported as complex, fragmented, over-burdened, inflexible, and under-serving or unserving (DHHS, 2000; Hornberger et al., 2006; Koyangi & Boudreaux, 2003; UCP/CR, 2006).

A sampling of family experiences from each system sound very similar:

“I was tired, not so much of caring for Jessie, but of fighting with the Regional Center, the nursing registry, Medical [the Medicaid system] and so on to get the services Jessie needed.” [parent of a child with mental retardation, Blacher & Baker, 1994, p. 12]

“There’s a constant battle to get the smallest things.” [parent of child with special health care needs, Knoll, 1989, p. 66]

“I was not prepared to spend 4-6 hours on a regular basis making phone calls and haggling over supplies and services.” [parent of child with complex health care needs, Knoll, 1989, p. 70]

“My dearest wish is for my son to be able to be maintained at home. He’s been at residential facilities and hospitals on and off since he was seven years old. I have asked for support from the county and have been denied any kind of financial support. I’ve been denied and told that there were no services available, period, to maintain him in the home. The county had the money to maintain him in a residential facility or hospital, but not maintain him at home.” [parent of child with serious mental health needs, Koyangi & Semansky, 2003, p. 5]

“I don’t feel like we need the government to pay us money to keep him, but why will they pay somebody else money to take care of him when we wanted to and couldn’t afford to?” [parent of child with complex medical needs, Bruns, 2000, p. 57]

While current service systems are organized in categorical silos, the realities of the children served do not fit neatly into categories (Koyangi & Boudreaux, 2003). In child welfare, an estimated 60% of children served have mental health care needs (Koyangi & Brodie, 1994). At least one third of children in foster care have disabilities (UCP/CR, 2006). An estimated 20-35% of children with mental retardation and developmental disabilities also have mental health needs (Kastner & Walsh, 2006; Pfeiffer & Baker, 1994). At least half of U.S states place children with mental health needs in child welfare or juvenile justice because mental health needs have been unmet (Koyangi & Semansky, 2003). The needs of children with multiple disabilities go beyond the focus of a categorical agency and are often poorly assessed, unmet, poorly met, or inappropriately met resulting in poorer outcomes (Pfeiffer & Baker, 1994; UCP/CR, 2006).
Despite the preponderance of frustration and consensus about inadequacy identified in the literature in all systems of care, a number of promising directions and common themes about major shifts also emerged in the literature. These are discussed below.

**Direction**

All systems have had a legacy of seeing the child as the case/patient/recipient of services, but all systems have been moving in the direction of recognition of families as an integral and the inescapable factor in children’s services. Where a child lives and with whom is increasingly recognized as having a bearing on their development, and the parent-child relationship is increasingly recognized as a critical feature of development (AAP, 1993). These acknowledgements demand a paradigm shift in child-serving systems (CMHS, 2001). The shift requires moving from trying to fit a child into a service, toward fitting services around the child’s family (Simpson et al., 2001). Whether in reference to the family of origin or to an alternate caregiving family, all interventions need to be in some way built around, or based on, the special relationship that develops between the child and the caregiving family (Johnson & Kastner, 2005; Redding et al, 2000; Sagi-Schwartz & Aviezar, 2005; Shonkoff & Phillips, 2000; Twigg, 2006).

Services are being called on to move away from the traditional “curing model” to address constructive adaptation and accommodation of family environments (AAP, 1993). Services to families of children with disabilities are being called on to see them less as dysfunctional causal agents, and more as social units in need of invigorating support (Lindblad et al., 2005; McWilliam, Tocci, & Harbin, 1998). Successful family support includes seeing children with disabilities as valued members of their families, rather than burdens in need of removal (Ferguson, 2002; Lindblad et al., 2005). Services are being called on to move from professionals as gatekeepers using complex rules and procedures to control service use, to partners in finding creative ways to assure that the rhetoric about the centrality of home and family life is supported by day-to-day practices (Knoll, 1989).

**Language**

The shift in direction is seen in language use. Terms like family-focused, family-centered, family-driven, and family-directed are increasingly part of the literature and service system vocabulary invoked to draw contrasts with previous approaches to service delivery that have been professional/expert directed and driven (O’Brien & O’Brien, 1999; Worthington, Hernandez, Friedman, & Uzzell 2001). In moving in the direction of family support, terms like partnership and collaboration are now ubiquitous. The more subtle language of relationships is also finding its way into services discourse (McWilliam et al., 1998). Interpersonal terms like trust, sensitivity, friendship, respect, and sense of humor are now becoming as legitimate as administrative terms like goals, objectives, and outcome measures (Lindblad et al., 2005;
Worthington et al., 2001). The term dependence is coming to mean confidence in the reliability of support, rather than dysfunctional neediness and pathological disempowerment (Lindblad et al., 2005).

**Principles of family support**

Movement toward family support is endorsed in federal policy (if not yet fully in practice) and shows a clear preference for in-home care and family preservation (DHHS, 2000). This philosophy was stated in the First White House Conference on the Care of Dependent Children in 1909 (DHHS, 2000) and is restated in the President’s New Freedom Initiative. It is repeated in numerous sets of principles (described earlier), such as the Statement on Behalf of Children and Families; Family-Centered Health Care for Children with Special Health Care Needs; and Values and Principles of the System of Care.

Despite these widely accepted sets of principles, child-serving systems lag behind the rhetoric. Each of the service systems has shown a bias toward out-of-home placement and congregate care arrangements over family support (Kastner & Walsh, 2006; Koyangi & Boudreaux, 2003; Parish et al., 2003). Programs across all agencies still tend to fund only the child and struggle to support collaboration. Families across systems complain that they are daily exposed to seemingly capricious decisions, accompanied by seemingly irrational regulation (Knoll, 1989). All of the systems face complaints about burdensome paperwork, eligibility overlaps or gaps, and repeated assessments to document conditions that are essentially unchanging (Knoll, 1989; Koyangi & Boudreaux, 2003). Federal, state, and local data collection systems regarding children with disabilities are inconsistent, lack common operational definitions, and fail to track the type of data needed; making internal and cross agency communication, assessment, planning, and cooperation difficult (DHHS, 2000; UCP/CR, 2006).

While there is wide agreement about family support principles and clearly growing momentum for family support and interagency collaboration, there is as yet no coherent cross agency policy regarding children and families (Koyangi & Boudreaux, 2003).

**Relationships as the mechanism for change**

Child development research has confirmed for decades that children need parental nurturance, continuity, and constancy (Shonkoff & Phillips, 2000). Studies of families of origin and treatment foster care arrangements have shown that the strength of the child-parent relationship is the greatest predictor of treatment success (Redding et al., 2000; Shonkoff & Phillips, 2000; Twigg, 2006). The interaction between the child and the parent on a daily basis is what makes the developmental environment and therapeutic environment effective (Twigg, 2006).
Congregate care as a “treatment milieu” unavoidably includes its multiple and interchangeable caregivers and its congregation of multiple children with similar needs, neither of which have been shown to produce positive change. Young children raised in congregate settings have typically encountered 50-80 caregivers before reaching school age (Sobsey, 1994). Careful deconstruction of the purported mechanism of positive change in congregate care must acknowledge that it is not the presence of other children or interchangeable caregivers. When positive outcome is found in congregate settings, and research is able to pinpoint its source, it often finds that the “active ingredient” to positive change is the relationship between a child and a specific individual with whom a bond formed, whether professional or paraprofessional (Redding et al, 2000; Shonkoff & Phillips, 2000). Clinically, psychotherapists recognize the power of such relationships. Anecdotally, direct services workers, families, and providers recognize the power of such relationships.

If such a relationship is at the heart of benefit to the child, then we need to figure out how to make such relationships the key feature of their living arrangements. At the end of the day, all congregate care is physical building with a workforce of caregiving employees. By prioritizing relationships as key to success, it is likely that we would organize our direct care workforce in different ways that are not contingent on having multiple children congregated together in buildings where the logistics make relationships less likely.

Relationships are also the key to the most promising system change strategies. A theme that dominates the literature of system change is partnerships and collaborations between parents and professions, providers, and policy-makers who have come together to form political constituencies which subsequently became most effective when relationships of trust develop (Koyangi & Semensky, 2003; NCD, 2005).

**Flexibility and funding options**

Family-based alternatives can embrace a much wider range of flexible alternatives than congregate care or traditional foster care. Better support to birth families and shared parenting arrangements represent promising approaches that can effectively offer children and their families alternatives to congregate care.

The terms “wraparound” and “systems of care” used widely in mental health, though less so in child welfare and developmental disabilities, refer to ways of working more flexibly and effectively across and within systems. They have demonstrated ways to increase flexibility in the use of funding that is currently tied up in categorical system silos (Hornberger et al, 2006).

One of the most frequent concerns of families of children with disabilities is the economic impact of disability-related expenses. Interviews with families participating in systems of care initiatives found that
flexible funding was one of the keys to success (Worthington et al., 2001). Putting funds directly in the hands of families is one way of increasing flexibility.

Many examples of family-controlled funds already exist. In developmental disability services, 22 states have implemented financial subsidies for birth families of children with developmental disabilities (Braddock et al, 2005). In health and developmental disabilities, family-directed personal care and nursing have allowed families to decide how to use a pool of funds (NCD, 2005). Financial subsidies in child welfare provides discretionary funds that enable families to adopt children with disabilities (Impact, 2005/2006). Treatment foster care provides enhanced stipends to families which they can use at their discretion for their self-defined needs. Studies have demonstrated the advantages in flexibility and tailoring that are enabled by discretionary use of subsidy funds (Herman & Thompson, 1995).

Alternate families

There will always be families who are unable to raise their children with significant disabilities (Blacher, 1994). Systems must find ways to assure family life for these children. The treatment foster care model has a long history of providing services to children with significant disabilities (FFTA, 2004). Michigan began using treatment foster care in 1984 with emotionally disturbed youth; Pennsylvania began using it in 1985 with children with aggressive behavior and hyperactivity; Florida and Illinois began using the model with children with complex health care needs in 1986 and 1988 respectively; Massachusetts began using it in 1986 with developmentally delayed infants (Terpstra, 1991).

A powerful feature of treatment foster care which contrasts with residential care is the amount of time a child spends with a parent figure as compared with the amount of time spent with other youth with similar needs (Meadowcroft et al, 1994). Key features of success in TFC are (1) the interpersonal fit between the family and the child, (2) the intensity of support available to the family, and (3) the therapeutic benefit of the relationship that is nurtured between the parent and child over time (Bryant, 2004; Hanley, 2002).

Children with the most complex needs in each system who are served successfully in families do not look essentially different from children in residential care (Avery, 2000; Meadowcroft et al., 1994). While many programs demonstrate that families are willing and able to provide homes for children with significant disabilities as alternatives to congregate care, little energy is actually devoted to specialized recruitment, preparation, and support of potentially available families for children with disabilities who are unable to live with their birth families (Avery, 2000; UCP/CR, 2006).

Recruitment of sufficient numbers of competent families is an ongoing concern in creating alternatives to congregate care. Studies have demonstrated that specialized recruitment strategies are more likely to attract
potential families, yet known specialized techniques are not widely employed (Avery, 2000). Successful recruitment strategies for children with disabilities have been found to differ from traditional foster care recruitment approaches (Holman, Charles, & Barner, 1991):

- Child-specific approaches work better than general appeals.
- Recruiters need to be thoroughly familiar with the child for whom they are recruiting.
- Foster parents are effective as recruiters.
- Simple word of mouth is an effective tool.
- Recruiting is more successful from the environment where the child is already known.
- Media campaigns are not as successful as assumed.
- Networking with a wide array of cooperating child serving agencies is required.

In addition to recruiting differently for children with disabilities, recruitment strategies will also differ for shared parenting arrangements (Rosenau, 2005).

Beyond expanded and targeted family recruitment, essential elements of successful and specialized support for family foster care and shared parenting arrangements targeting children with disabilities include:

1. Integration of developmental and child welfare concepts
2. Multidisciplinary planning and collaboration
3. Professional networking
4. Specialized training for families
5. Specialized training for all collaborating professionals
6. Ongoing services following placement

Not surprisingly, many of these essential elements of services to support alternate families are also strategies to support birth families of children with disabilities. Importantly, these successful supports are an outgrowth of efforts to promote the principles of family support whether applied to birth families or alternate families.

**Permanency planning**

Influential studies in the 1960s and 1970s showing that children in care in child welfare systems rarely returned home without a purposeful plan were the impetus for federally mandated permanency planning. Permanency seeks to assure a permanent family home where the nurturing parent-child relationship is the foundation and provides an inner assurance to children that caring adults will remain firmly in their lives. As permanency was taking hold, the application of permanency to children with disabilities was
investigated in the late 1980s in a comprehensive analysis of a statewide system of services in Colorado that looked at both the child welfare system and the developmental disability system (Ott & Langer, 1987). The analysis found that permanency principles were slow to be embraced by developmental disability professionals. Identified barriers were:

1. Beliefs that long term care was the intervention of choice
2. Assumptions that permanent families could not be found for children with developmental disabilities
3. Unwillingness to intervene if parental rights were intact, even if parents didn’t visit after placement in a facility

Factors projected in 1987 as potentially opening the disability services atmosphere to permanency principles included:

1. Deinstitutionalization
2. Cost effectiveness
3. Normalization
4. Expansion of family support
5. Recruitment of foster families
6. Successful adoption of children with developmental disabilities

The analysis compared the experience of Colorado with Michigan. In 1987, Michigan was the only widely known and well-developed statewide permanency planning initiative specifically targeting children with developmental disabilities. Ott and Langer (1987) attributed Michigan’s success to having “a unique and powerful policy” (p. 61) whereby parents were “simply” not offered congregate care but were instead offered either support for their own family or voluntary placement with an alternate family. This policy stance was possible and defensible only because of corresponding policies and practices of rich family support. The components of Michigan’s developmental disabilities system (Ott & Langer, 1987) included:

1. Family support
2. A public policy commitment to move all children out of congregate care
3. Permanency planning targeted at institutionalized children
4. Cessation of new institutional admissions
5. Adoption subsidies
6. Enhanced foster care stipends
7. Innovative family arrangements including open adoption and voluntary foster care
8. Aggressive recruitment of alternate families
9. Enhanced casework through reduced caseloads
10. Decisive casemanagement with a complete array of flexible supports
11. Regular casework supervision and administrative reviews
12. Complementary fiscal and state policy support
13. Permanency training for staff, parents, administrators, and clinical professionals
14. Parent agency agreements enacted before out-of-home placement, whereby the birth parent, the state agency, the provider agency, and an alternate parent entered a mutual plan setting out expectations, rationale for returning home or sharing care and maintaining contact

In contrast with Michigan, the study concluded that despite good intentions, the Colorado system failed to embrace permanency planning for children with disabilities. The system’s rhetoric was not matched by actions—no matter how much participants professed to believe in permanency planning, the principles were rarely influential in placement decisions. The dilemmas and barriers in Colorado were described as pervasive and formidable and included:

1. Philosophical tensions around family versus government responsibility and intervention
2. Fiscal limitations in making an array of family support available
3. Absence of leadership
4. Lack of clear responsibility
5. Resistance of institutional providers
6. Resistance of parents who over many years and many moves had became content or had little contact or emotional attachment to their children
7. Judicial reluctance to treat absence of parents as abandonment if they had planned and placed based on professional advice
8. Case workers’ lack of practice knowledge about the range of possible options

The dilemmas and subsequent recommendations suggested by Ott and Langer (1987) are arguably as relevant today as they were in 1987 and as relevant to other states as they were to Colorado:

1. Reduce ambiguous responsibility
   a. designate a lead agency
   b. consider a Children’s Bureau
2. Make a formal commitment to permanency policy for children with disabilities
   a. establish that long term congregate care is not acceptable
   b. commit to respectfully work with birth parents
3. Establish and fund essential components
   a. provide comprehensive, flexible family support
   b. aggressively recruit alternate families
   c. provide liberal adoption subsidies and enhanced alternate family stipends
4. Establish decision-making criteria
   a. conduct regular reviews
   b. conduct regular training for staff, families, and administrators
While the term “permanency planning” is not widely applied in mental health or MR/DD systems unless child welfare is involved, there are complementary activities which involve permanency principles, if not the term. The process of life planning and “circles of support” which centralizes the emotional relationships in a person’s life have been a focus of individualized planning in developmental disability services (O’Brien & O’Brien, 1997, 1999). Wraparound and systems of care principles are consistent with permanency planning principles. A pilot attempt to introduce permanency planning to mental health residential treatment centers increased permanency outcomes for children with serious emotional disturbances by facilitating parental involvement during placement so as to assure a family-based discharge plan (e.g., Landsman et al., 2001; Worthington et al., 2001).

A note of caution is in order about the use of the term permanency outside the child welfare system. Permanency focuses on a living arrangement where the interpersonal parent-child relationship is characterized as close, trusting, emotionally secure and enduring and is the central feature of the living arrangement. The term permanency, however, has been misunderstood and misused if it refers to the longevity of a living arrangement rather than the relational characteristics of the living arrangement. Implementing permanency planning will also be mistaken if it invokes relinquishment or adoption as the only choices for birth families who cannot provide fulltime care for their children or if they are given a higher priority than shared parenting.

Organization matters

Families matter, but organizations matter too. Organizational culture establishes the context for a family level response. A provocative study of a statewide attempt to improve coordination in the Tennessee child welfare system showed organizational culture as the primary predictor of positive child outcomes (Glisson & Hemmelgarn, 1998). Provider attitudes were found to be more important than service system configuration. Interorganizational coordination, paradoxically, had a negative effect of child outcomes. Attempts to increase coordination actually decreased positive outcomes. The research evidence suggested that coordination efforts diffused responsibility and that reduced personal involvement of caseworkers resulted in reduced benefit. The researchers suggested that service teams that do not work directly with children do not assume the same degree of responsibility for well-being as those with a personal relationship. While coordination may be effective in controlling services and costs, it cannot be expected to improve child outcomes because effective children’s services require nonroutinized, individualized service decisions tailored to each child—decisions that can only be accomplished with personal and intimate knowledge of the child and family.
Interviews with officials from states with a history of interagency collaboration across mental health, child welfare, education and Medicaid agencies have found that successful systems held a clear vision and had champions in leadership positions (Koyangi, Bourdreaux, & Lind, 2003). In addition, successful collaborators were able to build relationships based on trust. Characteristics of agencies that are most successful in supporting children with challenging needs in families are those who have a commitment at all levels of the organization from direct line staff to administration (Avery, 2000). In an era where organizations use outcome measures to focus their efforts, Koyangi & Boudreaux (2003) suggest establishing an outcome measure such as the percentage of children served who live with stable supported families to focus efforts.

If the needs of children and families were not sufficient motivation to shift away from congregate care, the crisis in direct care turnover and shortages demands finding different ways to organize resources and services (Braddock et al., 2005; Seavey, 2004). In times of shrinking resources and expanding needs, family support can generally avoid some of the costs of residential care. Well-supported families require a pool of well-supported staff to be available to provide assistance, so personnel costs are not necessarily reduced. However, some family support can be delivered episodically as needed, and can allow more efficient deployment of staff, in contrast to institutional staff who are present continuously despite empty beds or individual children’s episodic behavior or variable health status (Terpstra, 1991). In addition, costs such as building construction, facility maintenance, and food services are not necessary.

As we identify more clearly what functions congregate care currently fulfills, family-based alternatives that might fulfill those functions more effectively with better developmental outcomes for children with disabilities can be explored. We can find ways to move important functions into family homes and extended and shared family arrangements.

**CONCLUSION**

All child-serving systems are involved in a paradigm shift in reconceptualizing services from child-as-patient/case to child-in-the-context-of-family. This shift is evident in language and prolific expressions of family support principles. It is evident in increased challenges to the way funding is organized and whether it supports families or facilities. It is evident in questions raised about therapeutic assumptions of congregate care and alternative arrangements where a secure parental relationship anchors the living arrangement.
Little of the literature reviewed suggests positive outcomes for children placed in congregate care facilities. Congregate care offers too little benefit at too great a developmental cost to children when family-based alternatives are possible. The literature provides evidence that family-based alternatives to congregate care are feasible. The literature raises challenges about continuing to maintain settings which are inconsistent with the developmental needs of children and with positive public health policy and practice when alternatives are feasible (Healthy People 2010).

The most pressing need for systems is to forge a clear common mission that affirms that children need to grow up in families; but that also recognizes that family-functioning is key to child functioning; that support is key to family functioning; that support is furnished to the “child-and-family” as a unit; that families have considerable insight about what can work; and that collectively we can figure out how to do whatever it takes to assure children grow up in families.

A driving philosophy that underpins promising approaches to supporting families is (1) the belief that family life is essential for children and (2) the expectation that sufficient support should be provided to a family, whether the family of origin or another family. Such a two-pronged philosophy argues that policies need to be re-evaluated from the child’s point of view taking into perspective their relational needs and from the families’ point of view taking into perspective their support needs. Embracing both views, the emotional attachment between a child and parent becomes a central goal of organizing services for children. Such a goal would address both the support needs of parents and the developmental needs of children to support a parent-child relationship as the central feature of day-to-day living arrangements.

This review was not intended to debate the question of congregate versus family life, but rather to contribute to solving the problems that congregate care was intended to address, but which it does at too great a developmental cost to children. Much effort and interest is underway to explore effective alternatives. The challenge that the review poses is how to come together to use our collective knowledge and resources differently to solve the problems that inhibit nurturing and sustainable family life for children with disabilities and to redirect our efforts to support families to provide it.
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