**Precarious Pathways: Use of Residential Congregate Care
by Children with Developmental Disabilities**

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Introduction

Commission from DSHS

The Texas Department of State Health Services (DSHS) contracted with EveryChild, Inc. to conduct a study to better understand the use of congregate care for children with disabilities in Texas. The DHSH is interested in this issue in part because of its responsibility to report on a state performance measure related to one of the public health indicators developed in a document called Healthy People 2010 regarding reducing the use of congregate care for children and young adults with disabilities. This literature review is one element of the study. Its intent is (1) to provide background information from existing research relevant to children with disabilities living in congregate care, and (2) to contribute to the second element of the study which involves analyzing existing records of Texas children to identify factors contributing to and sustaining placement of children with developmental disabilities in congregate care.

Statement of problem to guide the literature review

Raising children is never easy, but families raising children with disabilities face additional challenges. While most children with disabilities live with families, a subgroup lives in congregate care settings. To what extent and for what reasons is potentially informed by a wide-ranging set of research endeavors about children with disabilities, families, and service systems. The research questions which guided this literature review are:

(1) What does research literature have to tell us about the use of congregate care by children with disabilities?
(2) What does research literature have to tell us about families of children with disabilities and what leads to out-of-home placement in congregate care?
(3) What does research literature have to tell us about children with disabilities who live in congregate care settings compared to children who live with families?
(4) What does research literature have to tell us about alternatives to congregate care?

Author disclosure

The author is the Executive Director of EveryChild, Inc., a non-profit organization whose mission is to create a system that ensures children with disabilities grow up in families instead of institutions. EveryChild, Inc. receives funds from the Texas Health and Human Services Commission to assist in the development of family-based alternatives to congregate care for children and young adults with developmental disabilities currently living in Texas facilities.

Preliminary comments about literature review

Given the volume and range of literature on topics related to families and their children with disabilities, this review will necessarily be broad though not exhaustive, instead focusing on selected issues with particular relevance and studies that are particularly informative. The intent of this literature review is to identify the best research evidence available to inform practice and service development for children with disabilities and families caring for them. As there are serious limitations in the available research evidence, the review also includes literature that may not have an empirical research base or is not specific to children with disabilities, but offers important insights or perspectives.

A literature search using the term "disability" is problematic as there is no commonly accepted definition. For the purposes of this review, literature was included for the following subgroups: intellectual disability, developmental disability, and children with special health care needs (which include chronic physical, developmental, behavior, and emotional conditions. However, much of the literature cited comes from literature related to intellectual and developmental disabilities, in part because this disability is of specific interest to the DSHS study, and in part because this literature is well-developed and more familiar to the author.

The definition of "child" can also be problematic as various upper age limits are embraced in literature about children. For brevity, the term children as used in this review includes children, adolescents, and young adults under age 22, however, the primary interest is minor children under the age of 18.

Research evidence and review limitations

Issues related to the use of congregate care are complex, as is the literature that might inform them. The literature identified as relevant to the research questions is both substantial and unsatisfying. Despite diligent effort prior to and during the course of this review by the author and others with similar interests, the search uncovered no definitive, comprehensive, current, empirical research that specifically addresses the outcomes of congregate care compared to family-based alternatives for children with developmental disabilities, that is not confounded by methodological limitations. Research evidence around outcomes of congregate care placement is complex, contradictory, and fraught with methodological dilemmas and consequent interpretation. Limitations in research design, sampling procedures, randomization and control group strategies, and measurement instruments can be identified in most studies. Methodological conundrums make it difficult to sort out the contribution of disability from other factors, and the contribution of factors that preceded placement, from those attributable to the placement experience, from those attributable to factors after discharge.

In addition, the search/selection strategy itself was fraught with dilemmas. In part the task is complex because of the wide range of potentially relevant material, and in part because of the way services have been organized and subsequently studied.

- Literature about congregate care may not distinguish between children and adults.

- Literature about congregate care of children may represent international conditions that are not comparable to U.S. conditions.

- Literature about congregate care of children may not distinguish between children with and without disabilities.

- Literature about congregate care in the U.S. is often compartmentalized according to service systems.

    o Literature about congregate care in **developmental disabilities** services systems is not necessarily specific to children.

    o Literature about congregate care of children in **child welfare** services systems is not necessarily specific to children with disabilities.

    o Literature about congregate care in **mental health** services systems does not necessarily distinguish short-term treatment settings from long-term living arrangements.

Despite these limitations, there is a great deal of research evidence that has a bearing on factors that contribute to or detract from the well-being of children with disabilities and families whose circumstances may lead them to use congregate care.

LITERATURE FINDINGS

Research Question #1

<u>**What does research literature have to tell us about the use of congregate care by children with disabilities?**</u>

No sources were found that reliably and fully account for the current number of children with disabilities growing up in congregate care. Where data is available, it reflects a subset of children with specific disabilities in a subset of types of congregate care and is likely an underestimate of all congregate care settings.

Evidence

A large but unconfirmed number of children with disabilities are growing up in congregate care. For this literature review, the operating definition of congregate care is a living arrangement shared by multiple unrelated individuals with disabilities, where care is provided by multiple individuals not including a parent, and is intended to provide a residence of more than short-term duration. Multiple terms used in the literature to refer to congregate care including institution, facility care, or residential placement are subsumed under the term "congregate care" in this review.

The great majority of children with disabilities in the U.S. who are under the age of eighteen live at home (Agosta & Melda, 1996; Rizzollo, Hemp, & Braddock, 2006). Even when institutions for individuals with developmental disabilities were at their historical peak census, they housed fewer than 92,000 children and young adults (Breedlove, Decker, Lakin, Prouty, & Coucouvanis, 2005).

Statistics about current congregate care use by children with disabilities are difficult to tease out because this population is served through various service systems including developmental disabilities, child welfare, and health care systems, each overseeing their own versions of public and private congregate care. The Center for Disease Control reported 24,300 children and young adults under age 22 living in congregate care settings in 1997 (Health People 2010) but this report is primarily based on data from the developmental disabilities system.

Current data regarding congregate care use by children with disabilities

Current data is piecemeal within and between service systems.   Documented data from each system is presented below.

        <u>Developmental disabilities services system</u>

Data regarding the number of individuals living in congregate care settings administered under developmental disability service systems has been well-tracked for over twenty years in the <u>State of the States in Developmental Disabilities</u> reports by the Coleman Institute at the University of Colorado and the <u>Residential Services for Persons with Developmental Disabilities: Status and Trends</u> reports of the Research and Training Center on Community Living, Institute on Community Integration at the University of Minnesota.

Between 1965 and 2008, the number of children and youth under age 21 in out-of-home placements through the intellectual or developmental disability (ID/DD) service systems decreased from 91,000 in large institutions to 1600 (Lakin, Larson, Salmi, & Scott, 2009).

- 1611 children and youth under age 22 lived in large state ID/DD facilities as of June 30, 2008 (Lakin et al., 2009).

- 6966 children and youth under age 22 lived in an Intermediate Care Facility for Persons with Mental Retardation and Developmental Disabilities (ICF/MR) as of October 2009 (American Health Care Association [AHCA], 2009).

This data tracks only certain kinds of congregate facilities and is an underrepresentation of the total number of children with developmental disabilities living in all types of congregate care. For example, the data reflects large public facilities and facilities funded by one type of Medicaid, but does not reflect community group homes funded in other ways.

Health care services system

The total number of children with complex health care needs growing up in nursing homes and other congregate care settings is difficult to track. The American Medical Directors Association reports at least 100 pediatric facilities in the U.S. and Canada including dedicated pediatric facilities and pediatric units in facilities serving other populations (American Medical Directors Association, 2004). Children also live in non-pediatric nursing facilities.

- 6520 children and youth under age 22 lived in nursing homes as of 2009 (Nursing Home Compendium, 2009).

Child welfare/protective services system

The use of congregate care by children with disabilities has not been well tracked in child welfare/protective services systems. On any given day, about 500,000 children are in placements under child protective service systems (CPS) nationally, with roughly half in non-relative foster family care, one quarter with relatives, and one fifth in group homes or institutions (United Cerebral Palsy & Children's Rights [UCP/CR], 2006). Although most children in CPS custody live in family settings, 27% of children ages 8-17 live in congregate care and a majority of them have disabilities (North American, Council on Adoptable Children [NACAC], 2005).

- 50,349 children (with and without disabilities) in out-of-home care in child welfare services lived in institutions and 31,542 lived in group homes as of September 2006. (Child Welfare League of American [CWLA] National Data Analysis System, 2009).

Mental health services system

No current data on congregate care use in mental health was located.

- 66,000 children under age 18 who received mental health services in 1997 lived in residential care programs (Warned & Pottick, 2003).
    - 42,000 lived in residential treatment centers
    - 24,000 in other residential programs

Texas use of congregate care for children with developmental disabilities

Texas better accounts for congregate care of children with developmental disabilities in various kinds of congregate care settings across disability and child welfare state agencies. Texas legislation requires tracking of children and young adults under age 22 with developmental disabilities who live in facilities of various size and type including public and private facilities, nursing homes, and community group homes (Texas Acts, 2001).

- 1613 children with developmental disabilities under 22 lived in congregate facilities as of July 2009 (Permanency Planning & Family-Based Alternatives Report, 2009).
    - 683 in ICF/MR facilities of six or more beds under developmental disabilities services
        - 328 in large state ICF/MR facilities

- 47 in ICF/MR facilities of 14 or more beds
- 45 in ICF/MR facilities of 9-13 beds
- 263 in ICF/MR facilities of 8 or fewer beds
  - o 225 in group facilities including residential treatment centers under child protective services
  - o 98 in nursing facilities
  - o 607 in community group homes of four or fewer beds

Trends away from congregate care

Over the past forty years each system likely to serve children with disabilities has embraced disinclination toward large, long-term congregate care motivated by legal and funding issues, as well as philosophical and clinical perspectives.

1. Developmental disabilities and mental health have shared a movement toward **deinsitutionalization** which seeks to move individuals from large institutions to smaller community-based housing. (Braddock et al., 2005; Prouty, Smith, & Lakin, 2005; Shoultz, Walker, Taylor, & Larson, 2005)

2. Developmental disabilities, health, and child welfare have been guided by philosophy, legislation, and judicial mandates for **least restrictive settings** which give preference to community-based services over institutional settings (Braddock et al., 2005; Lerman, Apgar, & Jordan, 2005; National Council on Disabilities [NCD], 2005; Taylor, Lakin, & Hill, 1989).

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

4. Child welfare, developmental disabilities, health, and mental health have been moving to a preference for **family-based care** and **family support** rather than facility care (Bryant-Comstock, Huff, & Vandenberg, 1996; Johnson & Kastner, 2005; Rizzolo, Hemp, Braddock, & Schindler, 2009; Stroul & Goldman, 1996; Taylor et al., 1989).

Trends maintaining congregate care

How far these shifts away from congregate care will go, can go, or should go is a matter of considerable debate. Some countervailing national trends suggest maintenance or even growth in the use of congregate care.

- While out-of-home placements of children and youth aged 0-14 with intellectual or developmental disabilities have slowed substantially, if not ended, there has been an increase in the number of youth aged 15-21 in congregate settings of four or more people (Prouty, Lakin, Coucouvanis, & Anderson, 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 (Lerman et al., 2005).

- The number pediatric nursing facilities is growing (AMDA, 2004).

- 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).

- More than 50% of Medicaid resources support congregate care facilities (NCD, 2005).

- Family support constitutes only 5% of total spending by service systems for individuals with developmental disabilities (Rizzolo, Hemp, Braddock, & Schindler, 2009).

- A national organization of families advocates for institutions to remain an option in a continuum of services for individuals with severe and profound intellectual disabilities and complex medical or behavioral needs (McTernan & Ward, 2005).

Summary

In summary, the extent of use of congregate care for children with disabilities nationally is not clearly known but includes a significant number.

Research Question #2

What does research have to tell us about families of children with disabilities and what leads to out-of-home placement in congregate care?

> Research evidence describes families' daily life experience with a child with disabilities as variously shaped by multiple, interrelated factors including (1) <u>circumstances</u> such as the child's care needs, the families' socioeconomic position, and other family members' needs; (2) <u>interpersonal influences</u> such as culturally-shaped and professionally influenced parental beliefs and appraisals of their child's disability and their situation; and (3) <u>services and supports</u> of varying availability and adequacy.
>
> Research describes wide variability among families, from parents who report positive benefits in raising a child with disabilities, to parents who experience great distress. Evidence describes some families as overwhelmed or exhausted or restricted by their child's extraordinary care needs and the extended duration of childhood dependency; stressed by financial burdens of increased expenses and/or forgone employment; frustrated by inadequate, complex, fragmented services systems; and anxious about the uncertainties of their family's and child's future.
>
> Research evidence suggests families operate in a variety of psychosocial and socioeconomic contexts that contribute to resilience and vulnerability. Family resilience and vulnerability factors interact to affect decisions about placement. Multiple and cumulative vulnerabilities present risks for out-of-home placement which some families will act on but most do not. How systems have been organized and operate affects whether pathways lead to congregate care. While some out-of-home placement occurs by parental decision, the literature documents that a disproportionate number of children with disabilities are removed from their families through child protective services intervention.

Evidence

The vast majority of children with disabilities live with their families. Data from the most recent U.S. census indicates 2.8 million families, or 9.2% of all families raising children in 2000, were raising children with disabilities between the ages of 5 and 17 (U.S. Census Bureau, 2005).

Family adaptation

How well families adapt to raising children with significant disabilities has been the subject of a long line of research. Research approaches to studying parental adaptation to a child with a disability are shaped by socio/historical contexts that affect how investigators define, conceptualize, and design studies (Knafl & Deatrick, 1987). A review of research over the last century on parental reactions to having a child with a disability identified changes in researcher's

conceptualizations and interpretations (Ferguson; 2002). The 1960s saw a flood of research around parental adjustment marked by findings of pathology, dysfunction, and chronic sorrow. By the mid 1980s uniformly negative findings began to be challenged and research methodologies critiqued (Glidden, 1993; Knafl & Deatrick, 1987; Krahn, 1993; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Seltzer & Heller, 1997). Methodological problems were identified in sampling, comparison groups, and instrumentation. Critics noted that samples of parents of children with disabilities were drawn from families who had sought assistance because they were struggling, thereby virtually assuring findings of struggles. Measures were often taken after the child with a disability had entered the family, and parent/family characteristics prior to the child's diagnosis were not known or taken into account. Instrumentation failed to disentangle demands, stresses, and strains or recognize that greater demands do not necessarily translate into greater stress or strain, or that some stress can be manageable, even positive.

These issues contributed to the perception of universal maladjustment of families raising children with disabilities and masked positive adaptation (Ferguson, 2002; Seltzer & Heller, 1997). Early findings of negative responses 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 family support services (Seltzer et al. (2001). A more questioning view began to focus on understanding the environments in which families lived their lives. A more complex, dynamic, and contextual view emerged taking into account internal and external resources as wells as how families perceive and manage their situations (Knafl and Deatrick, 1987). This more nuanced research suggested a family's response to having a child with disabilities reflects an interacting mixture of factors, and an increased focus on context began to account for variation in families' adaptation (Seltzer & Heller, 1997).

A large body of literature has now identified numerous positive impacts of family life with a member with disabilities (e.g., Ferguson, 2002; Hastings & Taunt, 2000; Poehlmann, Clements, Abbeduto & Farsad, 2005; Scorgie & Sobsey, 2000; Trute & Hauch, 1988) including:

1. Pride in meeting challenges
2. Increased sense of self-worth
3. Experiencing comfort and pleasure in caregiving
4. New approach to life
5. Accelerated maturity of siblings
6. Enhanced relationships within the family
7. Increased appreciation of life
8. Greater sensitivity and tolerance toward individual differences
9. Increased coping skills
10. Increased adaptability
11. Increased family harmony and cohesiveness
12. Personal growth
13. Spiritual growth

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 co-occuring, interacting positive and negative elements of family characteristics and the contexts in which they live their lives. (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Krahn, 1993; Poehlmann, et. al., 2005; Trute & Hiebert-Murphy, 2002).

Family experiences

A wide range of studies have depicted family experiences in raising a child with disabilities. A sample of such studies is summarized in the following chart. While recognizing the co-occurrence of positive aspects, this summary identifies problematic areas that may place families at greater risk of out-of-home placement. Studies selected involved interviews with families of children with

varied kinds of disabilities, some of whom were placed while others lived at home. The method of in-depth interviews in the studies allows a particularly descriptive view of the multiple and interacting factors the affect families.

Family descriptions of struggles	References
Family circumstances	
Child's care requirements: 24 hour care, problem behavior, size, night-time needs, time, constant attention, dependency, medical needs	1,3,4,6,7,8,9
Workforce participation: reduced, restricted, foregone	4,5,6,7
Financial: costs, burden	1,6,7,
Housing: accessibility, space, location, instability, neighborhood	1,6,7
Household composition: other family member needs, parental illness or disability, lack of back-up	1,3
Coordination tasks: managing appointments, equipment, paperwork, insurance, service eligibility determinations	6
Family interpersonal dynamics	
Social: isolation, restricted contacts, negative contacts, marital problems, negative societal attitudes, lack of privacy, negative effect on siblings	1,2,3,4,5,6,7,8
Physical: exhaustion, lack of sleep, depleted energy	1,2,6
Emotional: chronic stress, anxiety about the future, hopelessness, permanency of condition, worry, depression, uncertainty	1,2,3,4,5,8,9
Competence: inability to manage behavior or medical interventions, lack of expertise	2,8
Beliefs: expectation of improvement in facility, normative launch	1,3,7,9
Services and supports	
Service adequacy: deficits, inadequacy, access difficulties, unreliability, unsuitability, exclusion from services	1,2,3,5,6,7,8
Coordination adequacy: lack of coordination, bureaucratic mix-ups	3,4,6
Quality: having to fight for services, unsupportive, unhelpful, turnover	6,9
Competence: uninformed coordinators, poor professional advice or expertise	3,6,8

References		Year	# families interviewed	Congregate care	ID/DD	Medical	Autism	Challenging behavior	Physical
1	Alborz	2003	18	Yes	X			X	
2	Bendrix et al.	2007	5	Yes	X		X		
3	Bruns	2000	5	Yes		X			
4	Case-Smith	2004	8	No		X			
5	Gray	2002	26	No			X		
6	Knoll	1989	48	No		X		X	X
7	Llewellyn et al.	2005	81	No	X		X		X
8	McGill, Tennyson et al.	2006	14	Yes	X			X	
9	Poehlman et al.	2005	21	No	X				
			226						

<u>Family experiences with services and supports</u>

A number of studies provide a closer view of families' experience of trying to get support.

A study by Knoll (1989) examined the daily life experience of 48 families whose children had chronic medical conditions, physical disabilities, or behavioral challenges.

- 83% had made a major change in the family lifestyle
- 73% had had increase in household expenses
- 73% reported the child's disability affected where they lived
- 54% had given up a job
- 41% of children did not sleep through the night
- 32% had experienced a life threatening crisis within the past month
- 27% had at least considered out of home placement

Families reported that most stress and dissatisfaction came from outside sources. Parents indicated that they did not consider the care of their child as not a burden, but identified the burden as the continual struggle to get the support they needed. They reported spending several hours a week on a regular basis making phone calls, haggling over supplies and services, and doing paperwork. The families felt exposed to arbitrary, capricious decisions and seemingly irrational regulation. They reported that casemanagers and benefits coordinators were uniformed or misinformed about necessary coverage and basic procedures. They found professionals with whom they interacted were focused on resource constraint or potential for fraud while failing to provide basic information and assistance.

In a more recent small, but similarly revealing study, Bruns (2000) interviewed five families of children with complex medical needs under the age of 5 who had placed their children in skilled nursing facilities. Parents attributed their decision about placement to a variety of factors including the 24-hour nature of care, their not-always successful struggle to soothe and comfort their children, a sense of isolation from extended family and friends, lack of services especially preschool and respite, discomfort with strangers in the home providing necessary nursing services, high turnover in nurses, uncovered medical costs, and bureaucratic mix-ups. Parents remarked on the cumulative and relentless nature of these factors. Significantly, each parent reported that a medical professional's advice *"planted the seed"* (p. 54) to consider out-of-home placement and was an essential factor in actively pursuing out-of-home placement. Parents reported that their decision was also related to financial burdens. Families reported that insurance and government funds did not cover all disability-related expenses, especially "hidden expenses" like travel to specialists. Parents stressed that they wanted their child to remain at home, but that costs associated with the child's care were beyond their means.

In a study of 66 families caring for children ages 3-19 with developmental disabilities and challenging behavior, families described a variety of interacting factors (McGill, Papachristoforou, & Cooper, 2006). Families described their daily lives as restricted by their child's behavior problems. Many families reported either not receiving services or receiving services or supports they did not find helpful. A quarter of families reported that the advice they received from professionals about treatment for their child's behavior was not helpful. Many felt professionals lacked understanding of their child's behavior. Families described their search for information and services as a constant battle.

A study using focus groups of 86 parents of children with serious mental disorders in two states, found parents across both states reported remarkably similar experiences describing service system responses to them and their children (Koyangi & Semansky, 2003). Parents reported that they seldom had access to intensive community supports, or when available, were provided in insufficient amounts to be effective. Parents reported that systems were crisis oriented and offered little education or training; that children were sent out of the area to obtain services; that

casemanagers were inexperienced, poorly trained, and burdened with high caseloads; that age-appropriate services were rarely available as most mental health services focus on adults; that crisis services were patched together; that schools failed to respond appropriately; and that they were often advised to seek services from the child welfare system where they faced relinquishment to obtain services.

Studies that have looked at the impact of external resources on families trying to raise children with disabilities and chronic health care needs have had equivocal results. Some studies have found a significant relationship between external support and planning for out-of-home placement (e.g., Cole and Meyer, 1989; Hatton & Emerson, 2003). These studies found that families who had access to resources were more apt to be planning to keep their children at home. By contrast, a longitudinal study of 100 families with children with severe disabilities found that support resources had little effect on placement intentions (Hanneman & Blacher, 1998). Over the course of ten years, some of the participating families had placed their children. Researchers reported that support resources had little effect on placement intentions or placement. Interestingly, child 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 found that families where mothers had higher status occupations and levels of education were more likely to consider placement.

Complexity and ecological contexts

The presence of a child with disabilities is often assumed to be the key stressor in families, but more methodologically diverse and theoretically sophisticated research reveals a more nuanced understanding that recognizes broader aspects of the social context in which families operate (Emerson et al., 2010; Hatton & Emerson, 2003).

Gallimore and colleagues (Gallimore et al., 1989; Gallimore et al.,1993) proposed an ecological view of the multiple and interacting factors which make up the daily life of a family caring for a child with disabilities. This contextual view is based on Bronfenbrenner's seminal model of circles of social-ecological influences ranging from those closest to the family and child at the household level to those most distant such as national economic policies and bureaucratic regulation, and cultural attitudes toward disability.

Gallimore and colleagues suggest families live their lives in an ecocultural context of constraints and resources and values. From domains common to all families, the unique "eco niche" of a given family is a mixture of interconnected material circumstances and social features including beliefs and culturally-shaped values. They emphasized that any one feature must be interpreted in terms of its connections to features all around it and attempts to address features as discrete variables will not be likely to detect the complexity of family accommodations (Gallimore et. al., 1989).

Domains identified include:

1. Family subsistence and financial base
2. Accessibility of health and educational services
3. Home and neighborhood safety and convenience
4. Domestic task and chore workload for the family (excluding child care)
5. Child care tasks
6. Children's play groups and peers
7. Marital roles and relationships
8. Social support
9. Sources of parental information and goals

Distress in these areas has been linked to seeking out-of-home placement. Recent research is trying to untangle the relationships between disability-related needs, parenting, and

socioeconomic position comparing families with and without children with disabilities (Emerson, Hatton, Llewellyn, Blacher, & Graham, 2006). In addition to finding wide variability among families with children with disabilities, a number of studies have also found less variability in comparison with families raising children without disabilities after controlling for socioeconomic circumstances. Studies have found lower levels of happiness, higher levels of psychological distress, and higher levels of economic disadvantage among families with children with disabilities, but after controlling for socioeconomic circumstances, the differences between groups were removed or markedly attenuated. These studies suggest the risk of poorer well-being of families of children with disabilities may be attributed to their increased risk for socioeconomic disadvantage (Emerson et al., 2006; Emerson et al., 2010; Hatton & Emerson, 2003).

Socioeconomic circumstances and psychosocial influences highlighted by this line of research are addressed in further detail below.

Socioeconomic circumstances

Financial problems have been identified in the literature as one of the most frequent concerns of families. 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. The problems faced by families of children with disabilities or complex health care needs are similar to other families (e.g., childcare costs and reduced income during years of dependence) but they are magnified and extend over more years as dependency stretches over a longer period. Financial issues involved a number of interrelated factors such as income, employment, housing, debt/savings, education, occupation, and disability-related expenses.

National surveys have captured an aggregate picture of the economic implications for families raising children with special health care needs and disabilities.

A National Survey of Children with Special Health Care Needs [CSHCN] 2005/2006 (U.S. Department of Health and Human Services [DHHS], 2008) found:

- 18% of CSHCNs have conditions that create financial burdens for families
- 10% of families spend more than 11 hours per week arranging or coordinating care
- 24% of parents cut back or gave up paid employment

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 (U.S. Department of Health and Human Services [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 (U.S. 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).

Related to financial costs are time costs to parents associated with increased caregiving time for children with severe disabilities. Time costs were not just in-home caregiving, but the disability-related miscellaneous time costs such as arranging and escorting to medical and therapy appointments, and managing finances including service eligibility and insurance paperwork (Leonard et al., 1992). Time demands and the lack of services outside normal working hours have an impact on parents' availability and reliability to hold employment (Lewis & Johnson, 2005; Sloper, 1999).

Families raising children with disabilities report the triple effect of (1) extraordinary care needs, (2) decreased employment, and (3) financial hardship. 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; U.S. Census Bureau, 2005). 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, or the cost of higher quality childcare outweighs the economic gain of employment (Lewis & Johnson, 2005; Parish, Seltzer, Greenberg, & Floyd, 2004). The predicament can be characterized as a "catch-22." Families of children with disabilities have disability-related expenses requiring more income, but must manage with less income because those same needs reduce parental 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 et al., 1992). The cumulative impact of annual financial outlays over time removes options to which families would otherwise direct discretionary dollars (e.g., housing or savings or investments). Foregone employment during childhood years has later implications for aging parents who also forgo employer-provided retirement contributions and health care insurance (Parish et al., 2004).

Even families with employer-provided insurance experience financial stress related to uncovered health care costs. 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). Some families with children with disabilities are eligible for public insurance through Medicaid by virtue of low income or specific state rules that exempt parental income or allow parents to "buy-in" to Medicaid. In general, compared to most private health insurance plans, Medicaid offers relatively generous benefits for eligible families. While the Medicaid package of benefits is generous, significant barriers exist in obtaining quality services due to limitations in providers willing to participate because of low reimbursement rates (Kastner & Walsh, 2006). In addition, coverage often ends when children age out in adulthood where no comparable package exists.

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. 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.

Psychosocial influences

<u>Cultural influences</u>

Factors that influence family decisions about raising children and using services are highly influenced by cultural values and beliefs about family responsibility and kinship obligations and the appropriateness of seeking support outside the family network. Research studies have found cultural group differences on a variety of factors including beliefs about disabilities, the use of family and community supports and professional services, and problem-solving strategies within the family and personal network (Howes, 1999; Krahn, 1993; Rogers-Dulan & Blacher, 1995; Magana, 1999; Quirk et al., 1986).

A common limitation in the research on families with children with disabilities has been findings that are based only on white, middle class samples (Mary, 1990). Two notes of caution are warranted before raising the findings from the growing body of literature around cultural differences regarding children with disabilities and family life. First, there is wide variation within groups so broad group generalizations should not be assumed in individual situations. Second, socioeconomic and ethnicity/race factors are commonly confounded, leading to findings attributed to racial or ethnic minority status which may be more appropriately related to socioeconomic status.

With these cautions, however, there is evidence that cultural differences play a role in families with children with disabilities. Lower utilization rates of formal services have been found for Latino/Hispanics (Bailey et al., 1999; Bruns, 2000; Heller, Markwardt, Rowitz, & Farber, 1994; Magana, 1999) and African Americans (Quirk et al., 1986; Rogers-Dulan & Blacher, 1995). Explanations for this include:

- Language or communication problems
- Acceptability of external help seeking
- Discrimination by service systems
- Distrust of majority group authority

Whites have been found to have higher levels of perceived burden of care for family members with disabilities than African-Americans (Rogers-Dulan & Blacher, 1995) and Hispanics (Bailey et al., 1999; Heller et al., 1994). White mothers who were older, healthier, wealthier, and more educated reported higher burden and lower caregiver satisfaction than African American mothers (Lefley, 1997). Some studies found non-white families to be less likely to place their children out-of-home than Anglo parents (Borthwick-Duffy, Eyman, & White, 1987; Bruns, 2000; Krahn, 1993). Other investigations, however, which took socioeconomic status into account, found that lower minority group out-of-home placement rates were explained by socioeconomics rather than racial identity (Bailey et al., 1999; Heller et al., 1994).

Professional interaction and influence

Parents' views of their children with disabilities and chronic health care conditions can also be influenced by the professional and services personnel with whom they interact (Bruns, 2000; Lindblad, Rasmussen, & Sandman, 2005). Some families report the direct influence of professional advice on placement decisions (Bruns, 2000). Interviews with families raising children with disabilities have found indirect influences also affect them. A sense of control has been found to be a critical element in a satisfying life style. Integral to the sense of control were two elements influenced by interactions with professionals: (1) positive prospects for the future, and (2) genuine partnerships with professionals and service providers (Knox, Parmeter, Atkinson, & Yazbeck, 2000; King et al., 2006; Lindblad et al., 2005). Professional interactions found to help parents feel invigorated in parenthood were those that (1) increased their confidence as a parent and (2) conveyed that their child was seen as valuable. By contrast, professional interactions that were undermining were those that deflated hope, focused only the child's disability; were narrow-minded or irrelevant; and reflected inability, unwillingness, or disinterest in helping (Lindblad et al., 2005).

Parental appraisal

Researchers have found a wide range of emotional reactions and perceptions of caregiving (Poehlmann, el. al., 2005; Trute & Hiebert-Murphy, 2002). Research evidence suggests similar disabilities may be experienced differently by different families (Sloper, 1999). Belief systems, world views, and values affecting how family members perceive and interpret their child's diagnosis, their experience, and/or the stress they experience are a fundamental component of how they appraise their situation and adapt or cope (King et al., 2006; Sloper, 1999; Woolfson, 2004). Research reviews have found that family variation is not explained by the severity of the

disability alone. Severity of the child's impairment did not correlate with increased levels of stress (Howe 2006a, 2006b) or maternal adjustment (Woolfson, 2004) and level of stress was similar for families who placed and those who did not (Alborz, 2003; McIntyre, Blacher, & Baker, 2002).

Appraisals of situations and options for action are affected by resources available and whether a family interprets something as a resource, or a constraint, or as irrelevant (Glidden, 1993). How services are perceived can be as much a factor as what assistance is offer. Unmet need, constant battles, and fragmentation of the service system may erode a parent's sense of control or hope (Knox et al., 2000; Sloper, 1999) which in turn can affect their appraisal of their ability to maintain their child at home.

The research evidence suggests wide variability in families' adjustment to life with a child with disabilities. Family resilience and vulnerability factors interact to affect which children with disabilities might be at risk for out-of-home placement. Disability, per se, does not predict placement, nor does parental stress, or resource access. Some families manage well with adequate supports, some manage with few resources, some seek out-of-home placement when resources are inadequate, and some seek out-of-home placement even when resources are available. A more nuanced understanding suggests that a mix of resilience and vulnerabilities reflecting material circumstances, the mind of the parent, their interpersonal influences, and their experience with service systems can affect placement decisions.

Vulnerability and resilience factors

Contexts	socioeconomic	psychosocial
Family	Socioeconomic position (income, household composition, employment, debt/savings, housing, disability-related expenses)	Appraisals and cultural influences
Service system	Funding and resource allocation policies and practices	Professional interactions and influences

Out-of-home placement through parental decisions

The research evidence of family vulnerabilities presents risk for out-of-home placement which some families will act on but most do not. In considering out-of-home placement decisions, the literature addresses families who seek voluntarily placement and families where child protective service intervention played a role. The voluntary group is considered first and the child protective group is covered in a subsequent section.

The reason for leaving the family home is often summarized in statements like "the parents feel they can no longer care for the child" (e.g., Burns, 2009. p. 1). Embedded in such phrases are the host of interacting factors discussed above.

Three placement profiles have been identified in the literature: (1) normative launching into adulthood, (2) stress process, or (3) anticipatory planning (Alborz, 2003; Blacher, Baker, & Feinfield, 1999). The stress profile figures prominently in studies of families who placed. Within the stress profile were various transition routes: (1) specific episodes or critical incidents (e.g, court contact, parental death), (2) ongoing family problems involving family issues (directly attributed to the child with a disability or not), and (3) failure of adequate resources and service deficits (Alborz, 2003). Where an episode or incident led to placement, in many studies parents reported a gradual accumulation of stressors with a "last straw" or "triggering" event that precipitated placement but was not its cause (Alborz, 2003; Blacher & Baker, 1994b; Bruns, 2000; Ratliffe, Harrigan, Haley, Tse, & Olson, 2002). Studies of parents' rationale for placement suggest the contributing factors were complex and the relative contribution of one factor over another was difficult to determine (Alborz, 2003; Ratliffe et al., 2002; McGill, Tennyson, and Cooper, 2006). Placement appears to occur through the amalgamation and cumulative effect of multiple risk factors rather than the individual effect of any one.

A number of studies have followed up with families after placement of their children in congregate care. Most parents have felt their child received better services at the facility than at home identifying availability of better therapies, medical care, and training or treatment (Blacher & Baker, 1994b; Bendrix, Nordstrom, & Sivberg, 2007; McGill, Tennyson, et al., 2006). However, studies have also found families have ambivalent feelings after placement in congregate care. A number of studies found family satisfaction with placement, but simultaneously found dissatisfaction with staffing including concerns about competence, quality, experience; staff-to-client ratios, or turnover (Benderix, Nordstrom, & Sivberg, 2007; Blacher 1994; McGill, Tennyson et al., 2006). The high level of family satisfaction despite concerns is likely related to the reports that parents believed that family life was better after placement and that having the child at home would make family life worse (Blacher, Baker, & Feinfield, 1994; McGill, Tennyson, & Cooper, 2006).

Out-of-home placement through child protective services

The literature also addresses the subset of children with disabilities whose placement out-of-home involves child protective services (CPS) systems where placement occurs as a result of abuse, neglect, or relinquishment. As a group, families of children entering care through CPS have complex multiple risk factors including poverty, unemployment, low parental education, housing overcrowding, single parent households, absent fathers, and high rates of mental illness, substance abuse, and criminal involvement (Bruhn, 2003; Szilagyi, 2009; Vig, Chinitz, & Schulman, 2005).

There is considerable evidence that children with disabilities are over-represented in the child welfare systems (Bruhn, 2003; Rosenberg & Robinson, 2000; Szilagyi, 2009; UCP/CR, 2006) but exactly how many children in CPS care have disabilities is unclear. A national study of child welfare agency policies in 36 states found that 40% of the sample had no policy to identify children with developmental problems (cited in Vig et al., 2005) A national data system for children in CPS care, known as AFCARS (Adoption and Foster Care Analysis and Reporting System), is required by all states, but it does not reliably report on children with disabilities (Bruhn, 2003). Despite problems in tracking, there is evidence of a large proportion of children with disabilities in CPS care. At least one third of children in foster care have disabilities, 35-60% have chronic medical needs, and 60-80% have mental health needs (Bruhn, 2003; Szilagyi, 2009; UCP/CR, 2006). Half of children available for adoption have a disability (Hanley, 2002).

The disproportionate number of children with disabilities in child welfare is the result of several well-established, interrelated factors (Bruhn, 2003; Rosenberg & Robinson, 2000; Szilagyi, 2009):

1. A 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.

Children with disabilities who come into CPS care experience a different pattern of out-of-home placement than other children in care (Bruhn, 2003; Rosenberg & Robinson, 2004; UCP/CR, 2006) 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
- More likely to experience maltreatment after entering care

There is some evidence of differential outcomes for subgroups of disabilities. Children with significant behavior challenges and developmental disabilities are apt to have more frequent foster home moves, while children with complex medical conditions tend to have more stable foster care and adoptive placements (Szilagyi, 2009).

Once in care, children with disabilities face inadequacies within the child welfare system. A significant portion of children with disabilities in CPS care do not receive adequate health care, specialty care, early intervention or adequate educational services (Bruhn, 2003; Szilagyi, 2009; UCP/CR, 2006). Untrained or inexperienced caseworkers may not recognize disabilities or related service needs or may take inappropriate action, such as underreporting abuse or neglect, making inappropriate placement decisions, or not arranging adequate services (Bruhn, 2003; Rosenberg & Robinson, 2004; UCP/CR, 2006).

A study of children considered hardest to place in family homes revealed the role of staff attitudes in placement of children (Avery, 2000). In case reviews of 80 children who had been waiting longest for permanent family placement, 88% had one or more disabilities. The reviews found that staff skepticism about the likely success of family placement led to significantly reduced efforts by caseworkers, supervisors and managers. Interestingly, the study group of children did not look significantly different from the other children of the agency. The researchers identified a contributing factor in reduced efforts was the lack of knowledge of disabilities, service needs, and availability of services which were left unexplored due to assumptions about probable success.

Summary

In summary, a variety of factors contribute to placement of children with disabilities in congregate care. Vulnerabilities and resilience factors at the family level and service delivery level intersect over time. Research evidence suggests congregate care has served parents and families for whom circumstances, interpersonal influences, and access to services and supports contribute to their ability or willingness to care for their children at home. How systems have been organized and operate affects whether pathways lead to congregate care.

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Research Question #3

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What does research literature have to tell us about children with disabilities who live in congregate care settings compared to children living with families?

> Research evidence from studies of early childhood development and attachment, and comparisons of outcomes of various caregiving arrangements suggest that a parental relationship characterized as readily available, responsive, nurturing, reliable, and consistent over time provides developmental advantage for children. There is little research evidence that congregate care benefits children, however, there is evidence to suggest risk of negative developmental consequences in the absence of a primary parental relationship, limitations in caregiving arrangements inherent in congregate care, and increased potential for maltreatment in congregate settings. Research evidence currently available suggests congregate care for children presents developmental risk without evidence of offsetting benefits.

Evidence

Early childhood research

An explosion of child development research in the past decade was reviewed by nationally recognized child development experts in a two and a half year project of the Board on Children, Youth, and Families of the National Research Council and the Institute of Medicine (Shonkoff & Phillips, 2000). The Committee's report identified the role of parenting in a child's early life as a critical feature in development. In the report "parenting" was operationalized as the focused and differentiated relationship that a young child has with the adult (or adults) who is (are) most emotionally invested and consistently available to him or her. The report identified recent neurological research that provides evidence of the growth-fostering importance of a nurturing parental relationship and how early childhood experience of caregiving shapes brain structure, chemistry, and neurological functions that affect developing cognition, emotion and behavior. To be optimally beneficial, this relationship requires stability, consistency, sensitivity, love, physical and emotional availability, and unflagging commitment to the child's well-being. The parenting figure needs to be attuned to and responsive to the child. Early development is, therefore, inextricably tied to the interpersonal context of the growing child, that is, to his or her caregivers and home.

Attachment research

A broad literature about the parent-child relationship has developed under the construct of "attachment." Spanning four decades and multiple countries and cultures, this body of research has examined the effects of separation and residential care through careful observation of children and longitudinal studies (Kobak, 1999; van Ijzendoorn & Sagi, 1999).

Attachment is a psychobiological theory about the primacy of the parent-child relationship for optimal development that posits two interrelated premises (Carlson, Sampson, & Sroufe, 2003):

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

Initially derived from observations of children separated from their parents in residential nurseries due to the large-scale disruption of World War, a resurgence of interest in attachment research was stimulated by institutional practices in Eastern Europe exposed in the early 1990s. Studies using recent technological advances in brain imagery have shown deficits in the areas of the brain associated with cognitive and emotional regulation of children reared in these institutions compared to family-reared children (Zeanah et al., 2003).

Research with non-disabled children suggests the developmental advantages of sensitive care, where sensitivity is related to timeliness and responsiveness. Research suggests a lawful relationship between sensitive parenting and significant aspects of family ecology (Belsky & Fearon, 2002). Studies with families of typical children have identified the role of contextual factors in parental sensitivity in findings that greater life-stress, financial difficulties, lower social support, and higher depression can undermine parental sensitivity (Belsky & Fearon, 2002).

   Attachment and disability

Attachment 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, but manifest somewhat differently (Carlson et al., 2003). Studies of children with Down syndrome, autism, cystic fibrosis, and congenital health defects found 50% were classified as securely attached compared to 65% of non-disabled children (Howe, 2006b). A review of attachment research evidence regarding

children with disabilities found an interaction between a child's characteristics and the caregiver's responsiveness (Howe, 2006b). Parental sensitivity can be affected by a child's temperament, innate reactivity, arousablity, and ability to self-regulate which may be affected by their disability (Howe, 2006b). For example, motor, perceptual, communication, or cognitive difficulties may make it difficult for parents to read a child's cues. Neurological impairments or physical conditions may increase a child's irritability, consolability, or predictability and can affect a parent's subsequent responsiveness (Carlson et al., 2003; Howe, 2006a, 2006b). Extensive or protracted care needs of children can present demands on parental time and energy resulting in parenting stress and fatigue that can reduce their responsiveness. Other parental circumstances (e.g., single parenthood or financial difficulties) or personal characteristics (e.g., emotional health or physical health) can affect their availability to their children (Maclean, 2003; Shonkoff & Phillips, 2000).

There is evidence for the role of parental appraisal in attachment (Howe, 2006b). Evidence of parental resolution or non-resolution regarding a child's diagnosis is strongly associated with secure or insecure child-parent attachment. Attachment patterns of children of parents who were unresolved regarding acceptance of their child's disability were nearly three times more likely to be insecure (Howe, 2006b). Some of the highest rates of attachment security in children with cerebral palsy were found in children with the most severe impairments (Howe, 2006b).

Attachment in the context of multiple caregivers

How well families function can be affected by how well parents are supported to provide a nurturing environment. For many children with disabilities, the extensiveness of a child's needs increase the likelihood of multiple caregivers (e.g., nurses, personal assistants, home help aides, and respite providers). Evidence about the implications of multiple caregiver arrangements is emerging from extensive research findings regarding out-of-home day care of non-disabled children (Shonkoff & Phillips, 2000). Generally, research findings suggest the influence of day care on a child is not as large as the influence of the family environment (Howes, 1999; Shonkoff & Phillips, 2000). 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 risk of negative results when poor quality day care is combined with poor quality care in the home (Carlson et al., 2003). Despite an increasing influx of children with disabilities into day care, little is known about patterns of childcare usage or quality for children with disabilities (Shonkoff & Phillips, 2000).

In seeking quality caregiver assistance, parental selection can be constrained by external factors such as availability of extended family, income, employer or government policies, and the way services are organized (Howes, 1999; Shonkoff & Phillips, 2000).

Out-of-home placement outcome research

A significant body of literature has compared outcomes for children raised in congregate care with outcomes for family-reared children, but studies in this literature are fraught with problems. Methodological limitations common in institutional outcome studies include problems with sample size, timing of assessment (e.g., pre/during/post residence), assessment measures, lack of randomization, cross sectional designs that cannot determine effects over time, and inadequate attention to details of the conditions of the institution (e.g., level of nutrition, cognitive stimulation, and caregiver relationships) (Maclean, 2003). These same matters apply to studies of home environments used in comparisons.

As a result, studies have been methodologically unable to attribute positive change for a child to specific features of congregate care (Little, Kohm, & Thompson, 2005). On the other hand, studies purported to show poor outcomes are outdated or are not generalizable to U.S. children with disabilities because they did not involve children with disabilities or involved international orphanages with more impoverished care than would be found in U.S. facilities. In either case,

neither of the two key aspects of residential care, separation from family and care in a group, has been shown to be beneficial in their own right.

Although the literature is complex and filled with methodological challenges affecting interpretation, with caution, many studies can be informative. There is some evidence that the quality of the institution makes a difference in outcomes, just as it does in a family home environment.

       <u>International studies</u>

Recent studies from Eastern Europe found better outcomes for children raised in a continuous family home by responsive parents compared to children raised in congregate care by rotating staff (Smyke, Dumitrescu, & Zeanah, 2002; Zeanah, Smykes, & Settles, undated). However, these institutional arrangements were significantly impoverished.

A recent international study of orphanages comparing 1357 children in institutions with 1480 community children in five countries found institution-dwelling children had better outcomes (Whetten et al. 2009). Of note, the study involved poor countries with poor community support and poor institutional support. The researchers emphasized that the variation in caregiving conditions explained more variation in child outcomes than the simple the designation of institution versus community. For example, institutional caregivers were more highly educated (10th grade) compared to community caregivers (5th grade) and spent more continuous time with children (100 or more hours per week for institution caregivers compared to part-time for community caregivers).

A series of longitudinal studies that followed children in Israeli kibbutz caregiving arrangements for two decades provides a unique comparison of home and institutional rearing not confounded by parental absence or socioeconomic status. These studies followed children placed by middle-class families in congregate settings where they were cared for in safe, well-run, well-supplied facilities by multiple rotating caregivers committed to the education and well-being of the children. Parents remained actively involved, visiting for several hours every afternoon. Despite these beneficial conditions, children raised in these settings had higher rates of attachment insecurity with corresponding detrimental effects that remained in young adulthood (Sagi-Schwartz & Aveizer, 2005).

In one study of kibbutz care where children spent several hours a day with their parents but spent most of the day and nights away from their parents in congregate care, attachment was found to be secure for the majority of children, but the proportion of securely attached children was found to be less than that found in children in day care who returned to their family home to sleep (Harden, 2002). In children who returned to sleep in their family home, levels of secure attachment were found to be similar to Israeli children being raised full-time in family homes (Harden, 2002). This series of Kibbutz studies is informative but is not specific to children with disabilities.

       <u>Congregate care for non-disabled children</u>

Systematic study has cataloged many negative consequences of congregate care in young children (Frank, Klaus, Earls, & Eisenberg, 1999; Harden, 2002; Zeanah et al., undated):

- Poorer rates of growth
- Higher rates of infection
- Delays in cognitive development
- Delays in language development
- Abnormal social and emotional development
    i. Indiscriminate friendliness
    ii. Aggression

          iii.   Impulsiveness
- Motor delays and abnormal motor patterns
- Stereotypical behaviors
- Self-abusive behaviors
- Atypical sensory stimulation
- Eating and sleeping disturbances
- Withdrawal
- Hyperactivity and attention problems

Despite lack of experimental design studies, both historical and contemporary investigations have noted a set of interrelated features *inherent* in congregate care that present risk for optimal development (Frank et al., 1999; Harden, 2002; Paul & Cawson, 2002; Sobsey, 1994):

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

Of importance to child development, 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 (Zeanah, Smykes, & Settles, undated). The logistics of caregiver assignments in congregate settings prevent timely and spontaneous reactions to children's subtle and unique signals and expressions, the hallmarks of caregiving qualities required for optimal growth and development.

Congregate care for individuals with disabilities

A significant body of literature specific to congregate care of individuals with disabilities exists however primarily includes adults. A number of studies have compared different kinds and sizes of institutional settings for individuals who moved from institutions to community settings matched with individuals who remained in the institutional settings. Lerman et al. (2005) conducted a large systematic review of research about deinstitutionalization. In twelve of the eight 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 in 1994, found significant decreases six years later in the scores of stayers in social and emotional skills and increases in the scores of movers in community and household skills.

In another large scale review of research, of 68 studies published between 1997 and 2007 comparing institutional and community living, the majority found community settings to be superior in 7 out of 10 domains (Kozma, Mansell, & Beadle-Brown, 2009). Individuals with high or complex needs including challenging behavior were found to be at risk of poorer outcomes in community services. The authors note wide variability in individual outcomes with inadequate means to determine the relative contribution that different factors contributed to outcomes.   For example, studies did not provide details about the specific characteristics of the living environment, except that problem behavior was associated with lack of staff attention or type of staff attention. Parents and families in the reviewed studies were generally found to be positive about their family members move from an institution to the community despite being critical initially. The researchers suggest research needs to better address the characteristics that lead to quality outcomes beyond the designation of community versus institution.

In one of the few methodologically rigorous studies involving children with disabilities, 219 children with chronic health conditions were randomly assigned to a home care program or a traditional hospital-based program. Home care was found to be more effective in improving the child's psychological adjustment as well as the family's satisfaction (Shelton, Jeppson, & Johnson, 1989).

No studies using rigorous experimental design were found addressing outcomes of congregate care specifically for children with developmental disabilities or comparing children with developmental disabilities living at home and with children in congregate settings.

Staffing issues

Serious workforce issues face congregate care providers including shortages and turnover (Braddock et al., 2008; Seavey, 2004). A study 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). 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). 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 (U.S. DHHS, 2006).

For the recipient of care, staff turnover means disrupted continuity of care and a continual adjustment to new caregivers who don't know preferred routines and with whom recipients lack relationships, situations that are also risk factors for abuse and neglect (Sobsey, 1994; White, Holland, Marsland, & Oakes, 2003).

Risk of 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). Once in out-of-home care, children with disabilities are at risk of subsequent maltreatment (Bruhn, 2003; Sobsey, 1994). Although there is disagreement about the precise figures, 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%

The National Clearinghouse on Child Abuse and Neglect Information (NCCANI, 2001) suggests the following risk factors in congregate care of children with disabilities:

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 promote learned compliance with authorities
6. Organizational cultures characterized by dehumanized care and abusive subcultures

There is a significant body of literature that suggests the nature of congregate care unintentionally but unavoidably includes factors that increase the risk of maltreatment (Paul & Cawson, 2002; NCCANI, 2001; Sobsey, 1994; White et al., 2003). Children with disabilities experience increased risk in congregate care settings both from caregivers and from other individuals with disabilities. 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 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 may be fostered in group care. Remote locations; locked doors; procedures for behavioral control that require physical management; staff deployment problems that include frequent turnover, fatigue, and inexperience; distant administrators and managers; and infrequent contact with the general public all contribute to increased risk.

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 facilitate family involvement add a preventive element as does community involvement (American Academy of Pediatrics [AAP], 2001). Factors such as distance and discouraged visits reduce this protective feature.

Family involvement post-placement

Little current research could be located regarding family involvement for children after placement. Although dated, research found considerable variation in family involvement after placement. In one study, of 266 children living in a residential treatment setting, one-third had no family visits (Pfeiffer & Baker, 1994). In another study of 55 families, 80% had contact with their children at least monthly while 18 % had contact six times a year or less (Blacher & Baker, 194a). Visitation patterns were not found to be related to parental feelings of attachment (Blacher and Baker, 1994a). In a study of young adults who were placed directly from home as normative launching, parent contact remained high after placement (Shwartz, 2005). Another study of launching stage placements found family involvement after placement was continuing and stable after three years (Blacher, Baker, and Feinfield, 1999). In a more recent study of adults who moved from long-term institutional placements to community placements, family involvement was more frequent

than involvement for residents who did not move (Stancliffe & Lakin, 2006).   Parental involvement after placement has been shown to be influenced by facility practices and distance from the facility. An evaluation of a project where staff facilitated family involvement found distance was less predictive of decreased involvement (Landsman et al., 2001).

> ### Children and youth voice

Of particular note in the literature was the absence of the viewpoint of children and youth about their experience of congregate care. Notable exceptions were found in studies from the U.K. where recent policies and legislation requires seeking the views of children and youth receiving services (Mitchell & Sloper, 2001). A U.K. study which interviewed youth and their families found that the youth valued different aspects of service quality than their parents. Four themes emerged for youth including staff attitudes, relationships, personal development, and community links. Parent themes included staff attitudes, information, and service organization attributes (Mitchell & Sloper, 2001).

Summary

In summary, there is little evidence to suggest benefit to children of congregate care and much to suggest risk.

Research Question #4

What does research literature have to tell us about alternatives to congregate care?

> Review of the research literature regarding alternatives to congregate care revealed much work underway within and across child serving systems to better support family life. Evidence, although tentative, identified potentially successful approaches in five areas: alternative funding strategies, alternative planning strategies, alternate family living arrangements, alternative practice approaches, and alternative frameworks guiding services. Common elements of the identified promising or emerging alternatives were centralizing the importance of family life for children, shifting from the child as recipient to the family as a unit, shifting radically from traditional services paradigms to fitting supports to individual family situations, addressing organizational culture and relationships, and reconceptualizing the underpinning framework that guides services.

Evidence

Congregate care has served as a way to solve problems experienced by families struggling to raise children with disabilities, but research suggests it comes at a developmental risk to children without evidence of a counterbalancing benefit. Of interest is whether there is research evidence of alternatives for families which offer less risk for children.

Studies summarized earlier of parents' experiences raising children with disabilities showed recurrent themes reflecting the inadequacy of services and support. Parents report fragmentation of services, problems getting information; lack of adequacy, timeliness, and/or flexibility of support; and lack of financial assistance despite extraordinary expenses. Before placing out-of-home, families raising children with disabilities often come in contact with multiple service systems including developmental disabilities, health care, education, child welfare, mental health, or income support systems. Pathways to congregate care invariably involve at least one of these systems. How systems have been organized and operate affects whether pathways lead to congregate care or alternatives which are family-based.

Addressed next is research evidence about alternatives to congregate care that involve family-based arrangements capable of serving children with disabilities who would otherwise require congregate care. Of note, the alternatives identified and the literature reviewed is not exhaustive but describes approaches found in the practice literature, some of which have more fully developed research evidence than others.

FUNDING STRATEGIES

Funding Shifts to Community Services

A massive shift away from institutional care to community care has been underway in intellectual and developmental disability (ID/DD) services over the past thirty years (Braddock et al., 2008, Lakin et al., 2009). Public financial resources during the 1950s were directed almost exclusively to large residential settings (Parish et al., 2003). A variety of programs were introduced in the 1970s including Supplemental Security Income (SSI) which provides financial assistance to low-income families with children with disabilities and Education for All Handicapped Children legislation that for the first time made public education available to children with disabilities (Johnson & Kastner, 2005; Lewis & Johnson, 2005; Silverstein, 2000). These programs contributed to decreases in residential care in every state (Lakin, Anderson, & Prouty, 1998) and fundamentally changed the age profile of persons with ID/DD in state institutions from 36% under age 21 in 1977 to 5% in 2006 (Braddock, Hemp, & Rizzolo, 2008).

Family Support Funding

As residential care decreased, spending on family support increased. Between 1996 and 2000, family support spending for ID/DD services grew 85% and reached 37% more families. By 2000, all fifty states had family support funding and total spending had reached $1 billion (Parish, Pomeranz-Essley & Braddock, 2003). As of 2006, average annual per family spending for family support was $5376 (Braddock, et al., 2008). Overall, however, family support still represents a small proportion of expenditures for developmental disability services nationally. Of an estimated 4.6 million Americans with ID/DD, 61% live with families. Family support spending for individuals with intellectual and developmental disabilities served 428,803 families in 2006 (including children and adults) (Braddock et al., 2008). As of 2006, family support represented only 5% of overall developmental disability resource allocations (Braddock et al., 2008; Rizzolo et al, 2009). In 2004, of 34 reporting states, 59% of families receiving family support services were providing care to children. Patterns in state spending for family support vary widely as some states have more aggressively redirected resources formerly used for residential facilities to family support (Braddock et al., 2008; Parish et al., 2003).

Waivers

One of the major funding mechanisms for financing long-term care for individuals with intellectual and 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 directed to community-based supports (Braddock et al., 2008). Waivers have been the principle Medicaid funding for ID/DD services since 2001 (Braddock et al., 2008). States with waivers show a greater commitment of financial resources for family support than states not using waivers (Parish et al., 2003). Waivers fund 70% of all family support services (Braddock et al., 2008). Of individuals using waivers (including children and adults), 45% live with their families (Braddock et al., 2008).   In a random sample of 1421 Medicaid recipients of waivers and ICF/MR services, individuals with waivers (of all ages) living in family homes, including birth families, host families, foster families, and shared living arrangements, had the lowest Medicaid expenditures (Lakin et al., 2008).

Despite the appeal of waivers, their use is not without controversy. Critics suggest the multiplicity of waivers targeted to subgroups of individuals with particular disabilities makes for a fragmented and confusing system, and waivers have become as over-regulated and over-professionalized as the residential services systems they were intended to replace.

Family-directed funding

Of increasing demand in service delivery is an approach called "self-directed," "consumer-directed," or "family-directed" (Braddock et al., 2008). Some consumer-directed programs have specifically targeted families (Caldwell, 2006). In these approaches, the service user is directly involved in decisions about resource use 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 use flexibly to create individualized responses to their needs (Caldwell, 2006). Motivated by cost containment, these arrangements usually offer the user greater freedom in purchasing decisions in trade for a discounted personal budget, that is, a budget that costs less than the system would otherwise spend in 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 support staff who come into their home (Caldwell, 2006). 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 services is a struggle in logistics that can add another source of stress to an already burdened family (Clark, 2005).

Research on family-directed supports for children indicates that the experience of increased control over services afforded by this arrangement can result in benefits including reduced stress, reduced caregiving burden, improved family life, eased financial burden, and decreased need for out-of-home placement (Braddock et al., 2008; Caldwell, 2006; Herman 1991).

One of the most common issues identified by families as necessary to improve support is increased flexibility. Cash subsidies have been used by some states to allow more flexible and individualized support. By 2006, twenty-four states had instituted cash subsidies for 40,866 families with median per-family allocations of $3046 yearly at an overall cost of $124 million (Braddock et al., 2008). However, only 5% of family support funding is used for cash subsidies (from an already small 5% of all disability funding dedicated to family support) (Rizzolo et al, 2009).

Family-directed funding in foster care and adoption has been found to have a positive effect on recruitment, satisfaction and retention (Glidden, 2000; Groze, 1996; Lightburn & Pine, 1996; Piescher, Schmidt, & LaLiberte, 2008). A feature of both adoption and specialized foster care is financial assistance to a family that serves both as an inducement to consider caring for a child with challenges and as a source of flexible funding to support extraordinary and unique expenses related to the child.   Studies of adoptive parents have identified that their perception of adequate financial support is a predictor of their overall satisfaction (Lightburn & Pine, 1996).

PLANNING STRATEGIES

Families with members with disabilities who have complex needs often require complex orchestration of supports and services. Assistance navigating complex systems is necessary in part because of the complex needs of children and families and in part because of the complex nature of service systems. A report by the National Council on Disability described the system of long-term services and supports for individuals with disabilities (both children and adults) as complex, confusing, resistant to change, and fragmented across 20 federal agencies and almost 200 programs with no single point of entry and uneven access (NCD, 2005).

Distinctions have been drawn about the functions served by coordination (Kruger, 2004; Thompson et al., 2009). Some coordination approaches focus on cost containment through monitoring and directing individual service usage. Some coordination approaches are directed at the child while others are directed at the family as a unit. Some coordination approaches are reactive, based only on expressed requests of families. By contrast, some coordination approaches focus on facilitating access to support and services in ways that are anticipatory and proactive (Thompson et al., 2009).

Distinctions have been drawn between approaches to planning for "supports" and planning for "services" (Thompson et al., 2009). Supports are resources and strategies that aim to promote development and well-being, while services are organized means of delivering supports, therapies, and other forms of assistance. Individualized, person-centered planning focusing on positive desired outcomes involves processes quite different from service coordination.

Research regarding three planning strategies that have been used to better support family life as an alternative to congregate care are reviewed next: **wraparound**, **systems of care**, and **family group conferencing**.

Wraparound

Description

Wraparound is a collaborative team-based approach and a planning process for developing and implementing individualized plans to create a unique set of community services and supports for a child and family to achieve a positive set of measureable outcomes (Burchard, Bruns, & Burchard, 2002). The term has become shorthand for flexibility, creativity, and comprehensiveness in surrounding a family with support to keep children and youth in the community (Vandenberg, Bruns, & Buyrchard, 2003). Families, providers, and key members of the families' social network collaborate to build the plan. Wraparound plans incorporate a combination of traditional and non-traditional services including community and informal supports. While many planning processes involve assessments, goals and objectives, progress monitoring, and participation of individuals and families; wraparound adds the following features (Walker, undated):

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

Wraparound is associated with shifts away from traditional service planning and delivery, professional domination of planning, a focus on deficits, service-driven approaches that fill program slots or beds, and single agency procedures, policies, and organizational cultures (Walker, Koroloff, & Schulte, 2003).

History

Wraparound first emerged early 1980s as a values-based planning process for children with serious emotional and behavioral disorders which sought community-based alternatives to institutions (Vandenberg et al., 2003; Walker & Bruns, 2006). In 1985 it was used in Alaska to successfully return almost all youth with complex needs from out-of-state institutions. Following initial evaluations and success, wraparound has since spread to all 50 states (Vandenberg et al., 2003). By 1999, an estimate 200,000 wraparound teams were at work across the country (Walker & Bruns, 2006). Wraparound has received the support of the National Institute on Mental Health Child and Adolescent Services System Programs (CASSP) and the Substance Abuse and

Mental Health Services Administration (SAMHSA) (Vandenberg et al., 2003). Many state plans specifically call for use of wraparound to comply with the Olmstead Supreme Court decision which requires states to develop community-based services for institutional residents (Vandenberg et al., 2003). While early use focused on children and youth with severe emotional and behavioral problems, wraparound has also been used for individuals with severe or chronic physical illnesses and developmental disabilities, and has been used in education, child welfare, and juvenile justice systems (Burchard et al., 2002).

Research evidence

Research has described wraparound as "promising" or "emerging" (Walker & Koroloff, 2007). A review of 15 studies designed to assess the effectiveness of the wraparound approach concluded that the research base is undeveloped compared to many child and family interventions, but suggested there is nonetheless significant evidence of wraparound's effectiveness (Burchard et al. (2002). Reviews suggest the wraparound process increases family empowerment and improves quality of life (Walker, Schulte, & Koren, 2006). Significant research has been underway by the Research and Training Center on Family Support and Children's Mental Health to study implementation of wraparound (Walker et al., 2003). While a wide variety of programs use the name wraparound and many practitioners endorse the values of wraparound planning, research suggests operationalization has proven problematic (Burchard et al., 2002; Walker et al. (2006). A study of observations and expert reviews of 72 actual wraparound meetings 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. Another study also found teams were rarely successful in building plans that were not primarily reliant on formal services (Koroloff, Schulte, & Walker, 2003). Several studies found that professionals consistently rate their collaborativeness with families higher than do families (Walker et al., 2006).

Challenges affecting implementation of wraparound include organizational cultures that are resistant to changing traditional ways, interagency barriers and funding exigencies; and skepticism about the effectiveness of family-centered practices (Walker et al., 2003). Research as well as operationalization has struggled due to the lack of consensus about the specific features that distinguish wraparound (Walker & Bruns, 2006). A recent study utilized a broad-based consultation effort by wraparound experts across the country to identify the contexts necessary for successful implementation of wraparound (Walker & Koroloff, 2007). Consensus was reached that successful contexts address three levels and five cross-cutting activities. The three levels identified were the team, organization and policy/funding. The five activities identified as required across all levels were a clear practice model, collaborative partnerships, capacity building and staffing, acquiring services and supports, and accountability. This research suggested high quality individualized services and planning cannot succeed without organizational, policy, and funding support as the context in which teams work (Walker & Koroloff, 2007).

Systems of care

Description

"Systems of care" is another approach that emerged from concerns about services for children with serious emotional emotional problems and behavioral challenges. Systems of care refers to a comprehensive spectrum of services which are organized to surround a child and family with a full network of support to meet their multiple and changing needs. Systems of care approaches are child-centered, family-focused, and culturally competent with an emphasis on individualized and least restrictive services (Famer, Mustillo, Burns, & Holder, 2008). The systems of care approach engages the multiple agencies and services that may be involved for a child with complex needs including special education, child welfare, health, vocational, and juvenile justice (Stroul & Friedman, 1994). The approach represents a philosophy about the *way* services should

be delivered to children and their families as much as *what* services should be delivered. It calls for a shift from more traditional services that expect families to conform to pre-existing service configurations, to a system that adapts to children and families. It requires a commitment to support families in addition to treating the individual child with mental health needs (Stroul & Friedman, 1994).

History

A 1969 investigation by the Joint Commission on Mental Health of Children through the National Institute on Mental Health found serious limitations in services for children with serious mental health issues including lack of coordination, fragmentation of services, and lack of commitment to preserving families that led to development of the approach known as system of care (Center for Mental Health Services [CMHS], 2001; Hornberger, Martin, & Collins, 2006). 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. In addition, pilot projects had begun to demonstrate that intensive community-based services provided in homes and schools could reduce the need for residential care (Stroul & Friedman, 1994). 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). During the 80s and 90s, federal and private foundations committed extensive resources to developing systems of care (Farmer et al., 2008). Nationwide capacity building undertaken by the Center for Mental Health Services (CMHS) has supported 126 demonstration grant sites involving over 70,000 youth (Farmer et al., 2008).

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. 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, and its conceptual framework, guiding principles, and management approaches (Stroul & Friedman, 1994). The monograph identified core values and principles of services. It enumerated the following distinguishing features:

1. a comprehensive array of services

2. individualized services

3. least restrictive, most normative clinically appropriate environment

4. families and surrogate families as full participants

5. integrated, linkages between child-serving agencies and programs

6. casemanagement

7. early identification and intervention

8. transitions to the adult service system

9. rights of children protection and advocacy

10. non-discrimination and responsiveness to cultural differences and special needs.

The monograph identified major areas that had to be addressed based on the experience of states trying to implement a systems of care approach: (1) overall management, (2) system change strategies, (3) rebalancing from residential treatment toward more home and community-based services, and (4) state/local relationships.

Research evidence

A congressional mandate for CMHS to demonstrate the effectiveness of systems of care resulted in an extensive evaluation involving assessments of child outcomes and family functioning for 950 children across the country (CMSH, 2001). Findings described the majority of children and families served by system of care initiatives as poor, mother-maintained households that were disproportionately ethnic minorities and had at least one risk factor (e.g., family substance abuse, domestic violence, parental mental health issues, parental felony convictions). The evaluation found participants in systems of care had improved stability of residence, fewer residential placements, greater rates of positive change in behavioral and emotional problems, and casemanager satisfaction in comparison to a group not using a systems of care approach.

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

1. Driven by needs and preferences of children and families.

2. Community-based with management built on multi-agency collaborations.

3. Based on need and responsiveness to cultural context.

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 practice wisdom around systems of care involving integration of mental health, substance abuse, child welfare, and juvenile justice (Hornberger et al., 2006). Consensus emerged that the kind of shift required to implement systems of care represented a "sea change" from traditional services (Hornberger et al., 2006).

Research on systems of care has been described as "promising but equivocal" (Farmer et al., 2008). Evaluations have shown increased access to services, more interagency collaboration, and decreased costs but have not yet clearly demonstrated outcomes at the child and family level (Farmer et al., 2008). Out-of-home placement is still common. A study of 3000 youth involved with systems of care found 32% were placed out-of-home during the two year period of the study with the majority going to restrictive settings such as residential treatment centers, group homes, and psychiatric hospitalizations while 12% were placed in traditional foster care and 6.5% in therapeutic foster care. In addition, 73% of youth who were placed experienced more than one placement in the two year period of the study. Interestingly, no differences were found between youth placed in foster family arrangements and youth placed in more restrictive settings. Of note, the family homes from which the youth were placed included half with incomes less than $20,000 and an average of 3 out of 6 risk factors including parental mental illness, psychiatric hospitalization, treatment for substance use, substance abuse, criminality, and domestic violence (Farmer et al., 2008).

Family group conferencing

Description

An approach increasingly being used in child welfare systems for planning and decision-making is a process called "family group conferencing" (FGC). FGC is a strategy to mobilize a wider spectrum of community resources around a child and family by involving extended family and family-selected close support people in making and carrying out plans to safeguard children (Pennell & Anderson, 2005). FGC is a set of values and approaches rather than a set of activities or techniques.

Distinguishing features of FGC (Pennel & Anderson, 2005) are:

- Convening a conference that embraces the child's extended family members and close others 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 uses four capacity-building strategies:

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

FGC represents a shift from traditional professional-driven systems to family-driven systems; from viewing service recipients as clients to viewing them as partners; from focusing on deficits to focusing on strengths; and from a medical model to a family-centered model (Pennell & Anderson, 2005). 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 own resources and ideas to find solutions to the problem that brought the child to the attention of the system.

History

The FGC 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. Its impetus was an economic crisis, calls for greater government accountability, and concern about culturally competent treatment (Pennell & Anderson, 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 that 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. From the mid-1990s to 2005, FGC has grown from an innovation to an accepted services approach (Pennel & Anderson, 2005).

Research evidence

Multiple studies of FGC have found positive results (Pennell, & Anderson, 2005; Unger & Fatzinger, 2006) including:

- 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.
- Child welfare workers authorize the vast majority of plans developed during family private time.
- Participation of fathers and paternal relatives increase.
- 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.
- Ratings of positive involvement of families and professional participants are higher.
- More children live with parents and fewer live with nonrelatives after conferences.

- FGC has a positive influence on staff retention.

Studies of FGC suggest successful implementation requires a responsive organizational culture, technical assistance, training, supervision, consultation, ongoing evaluation, and advisory boards with parent representatives (Pennell & Anderson, 2005). While a systematic study of the cost-benefits of FGC does not yet exist, FGC programs have been found to be no more costly than traditional approaches while appearing to achieve a high level of benefits for participants.

While there are significant positive research findings regarding FGC, the research is limited by methodological problems such as the lack of experimental design, small sample sizes, and measurement instrumentation issues (Pennell & Anderson, 2005).

FAMILY-BASED LIVING ARRANGEMENTS

Family Support

Family support for children with disabilities is part of a larger trend characterized as a national movement that views the family as a unit as distinct from its individual members (Kagan, 1996; Krahn, 1993). The family support movement reflects a shift from conventional service delivery by applying creativity, inventiveness, and collaborative problem-solving that transcends bureaucratic boundaries.

Since the 1970s, numerous definitions and sets of principles have shared common features as underpinning family support for children with disabilities (Agosta & Melda, 1996):

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

Family support of children with disabilities consists of a range of services and supports including in-home personal assistants, nursing, respite, home modifications, training and education, counseling, and specialized equipment. No predetermined list, however, captures the range of possibilities. Family support endeavors are often targeted to preventing out-of-home residential placement and have been shown to increase families' willingness and ability to keep their children at home (Braddock et al., 2008; Rizzolo et al., 2006).

Alternate family care alternatives to congregate care

Much of the literature addressing out-of-home placement of children with disabilities assumes congregate residential placement is the only alternative when out-of-home placement is needed. Other family-based arrangements, however, are possible. Most familiar are traditional foster care, specialized foster care, kinship care, and adoption. However, other voluntary alternate family living arrangements have been identified in the literature including host family care, shared care, co-parenting, and mentoring families (Baxter, Cummins, & Volard, 1992; Hayden, Lakin, Hill, Bruininks, & Chen, 1992; Johnson & Kastner, 2005; Taylor et al., 1989; Terpstra, 1991). Host family placements in developmental disability services increased by 73% from 1995 to 2004, however the extent to which host families have been used for children is not identified (Coucouvanis, Prouty, & Lakin, 2005).

While much of the literature about alternate families addresses foster care in the child welfare system, there is some limited research of voluntary alternate family care for children with

disabilities. A study of a program in the Netherlands examined the factors contributing to successful alternate family arrangements with longevity for children with intellectual disabilities and challenging behavior, of whom three-quarters had moved from residential care. Success was found to be related to extensive matching and preparation of both the child and the prospective family prior to any decision-making about long-term placement, taking ample time for matching and preparation activities, and providing emotional as well as practical support to alternate families (Laan, Loots, Jannssen, & Stolk, 2001). Of note, the researchers identified the role of choice on the part of the alternate family and fit with their family as factors in success. A Finnish program of specialized foster care for children with disabilities found that substantial financial support for alternate families contributed to having no shortage of potential families (Laan et al., 2001).

Research regarding three types of alternate family living arrangements is reviewed below: **kinship care**, **treatment foster care**, and **shared parenting**.

Kinship care

Description

Kinship care is broadly defined as a living arrangement in which a relative or someone else emotionally close takes primary responsibility for rearing a child. Kinship care proponents identify its advantages over non-kin foster care as supporting a child's sense of family identity, maintaining continuity of family relationships and community ties, involving caregivers who have knowledge of family history and dynamics, and sustaining relationships that existed prior to entering care and are likely to be ongoing into adulthood (U.S. Department of Health and Human Services [DHHS], 2000; Hornby, Zeller, & Karracker, 1996). Several kinds of kinship arrangements can be distinguished including formal (children in child protective custody), informal (arranged by child protective services but without CPS custody), and private (arranged between families without CPS involvement) (Winokur, Crawford, Longobardi, & Valentine, 2008). As of 2005, of more than 513,000 children in child protective custody (with and without disabilities), 124,153 were living with kin (Winokur et al., 2008).

History

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 (U.S. DHHS, 2000). Kinship care increased substantially in the late 1980s and 1990s (U.S. DHHS, 2000). A 2002 national survey (Urban Institute, 2000) found:

- 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

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 has been attributed to a cultural strength of minority communities and in part may reflect discriminatory practices (Kang, 2003a; Winokur et al., 2008).

Research evidence

The Report to Congress on Kinship Foster Care (KFC) summarized knowledge about kinship care (U.S. DHHS, 2000). While the report does not separately discuss children with disabilities, it

includes children with disabilities. Literature reviews of empirical studies of kinship care have found mixed evidence of the well-being of children in kinship care and kin caregivers (U.S. DHHS, 2000; Hornby et al., 1996; Kang, 2003 a, 2003b; Szilagiyi, 2009; Winokur et al., 2008):

Children in kinship care
- Had substantial health care needs but received inadequate health services.
- Had more stable placements.
- Were more likely to be the only child in the household while non-kin foster homes were more likely to have 5 or more children in care.

Kinship caregivers
- Were more likely to be older, single, African American, less educated, unemployed, poor, and be in poor health.
- Were less likely than non-kin foster parents to have preparation and training prior to placement or receive services after placement.
- Tended to request fewer services and receive fewer services when requested.
- Reported they did not receive any services for children with disabilities and could not access community-based disability services because services were unavailable to kinship foster parents.
- Were found to have more positive perceptions of their children compared to non-related caregivers.

Child welfare caseworkers
- Provided less supervision and monitoring of kinship caregivers than non-kin foster care.
- Were less familiar with children on their caseloads who were in kinship care.
- 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.
- Were less likely to offer health screening, psychological assessments and educational services to children in kinship care.

Overall, better outcomes for children in kinship care appear to come at a cost to kin carers who experienced substantial physical and psychological costs as well as social and financial costs even though they felt satisfaction and gratification from their child-rearing.

Caution is required in interpreting the findings reported due to methodological issues in the research. The extent to which positive child outcomes reflect characteristics that existed prior to care is unclear. The extent to which kinship would have better outcomes with better supports is also unclear. In addition, there is little information on how kinship care affects the long-term health and well-being of children (Winokur et al., 2008).

Treatment foster care

Description

Treatment foster care (TFC) is a family-based service delivery approach that has been used in child welfare and mental health for children with emotional disturbances. 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 (Foster Family-based Treatment Association [FFTA], 2004). TFC reflects an intersection of the benefits of professionalized intensive interventions and parenting in a home environment (Piescher, Schmidt, & LaLiberte, 2008; Redding, Fried, and Britner, 2000). The term the "treatment" refers to both intervention techniques and to the foster parent relationship itself 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 terms apply all of the model's distinguishing elements (Bryant, 2006; Curtis et al., 2001; Meadowcroft, Thomlinson, & Chamberlain, 1994; Redding et al., 2000; Terpstra, 1991; Twigg, 2006) which include:

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 in 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

History

TFC emerged in the 1960s and 1970s in concert with critiques of institutional care and preferences for community-based care (Meadowcroft et al., 1994). In 1988, providers of treatment foster family services organized the Foster Family-based Treatment Association (FFTA) (FFTA, 2004; Twigg, 2006). 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 but emerging success with TFC suggested that child welfare agencies had underestimated the number and variety of needs of youth who could successfully be served in family placements (Curtis et al., 2001). In 1991, the FFTA providers established standards that have since become widely adopted (FFTA, 2004). By the mid 1990s, 23,000 children were being served in TFC compared to 68,000 in residential group care (Curtis et al., 2001). TFC was initially designed for short-term intensive treatment as a transition between residential care and return to the family. TFC is now viewed as an alternative to residential care and can be longer term in nature (Redding et al., 2000). TFC has also expanded beyond its original application for children with severe emotional disturbances. It has been used as an alternative to congregate care for children with complex medical conditions, behavioral challenges, hyperactivity, developmental delays, intellectual disabilities, psychiatric disorders, and head injuries (Meadowcroft et al., 1994; Terpstra, 1991; Twigg, 2006). Of 510,000 youth in out-of-home care, 11% are served by TFC (Piescher, Schmidt, et al., 2008).

Research evidence

The TFC model has been the subject of a growing research base (FFTA, 2006). Summaries of the empirical literature have suggested TFC is an effective alternative to residential treatment for children with severe emotional disorders and behavioral needs which has produced behavioral improvements compared to children and adolescents with similar problems in residential group homes (Bryant, 2006; Hudson, Nutter, & Galaway, 1994; Meadowcroft et al., 1994; Piescher, Armendariz, & LaLiberte, 2008; Twigg, 2006). Studies consistently reported either positive outcomes or no difference in outcomes compared to residential care but a TFC advantage because similar outcomes are achieved at lower cost (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.

Correlates of successful TFC placements and characteristics and motivations of the foster parents (Redding et al., 2000) were found to include:

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

Correlates of successful TFC placements and professional relationships (Redding et al., 2000) were found to include:

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

Of note, reviewers identify limitations in the research. Existing studies tend to be small scale, vary widely in rigor, and suffer from methodological limitations in design;, non-randomization, instrument reliability, validity, or norms; and challengeable evaluation methods (Curtis et al., 2001; Redding et al., 2000; Twigg, 2006). The majority of research on out-of-home care has emphasized characteristics of children or families over characteristics of treatment intervention with little research distinguishing differences in treatment approach and intensity between group care and treatment foster care (Curtis et al., 2001; Redding et al., 2000). Despite methodological limitations, reviews of published outcome studies suggest the research body is sufficient to provide useful guidance for policy makers and practitioners in development of effective TFC programs (Redding et al., 2000, p. 444).

Shared parenting

Description

Across cultures, informal shared caregiving arrangements for children are normative (Kilbride & Kilbride, 1994). Minority cultural groups have historically used a variety of child-rearing configurations involving networks of caregiving adults including kin and unrelated community

members who are accepted "as if" they were kin, as a safety net for children and a resource for parents in need of help in meeting their parenting responsibilities (Howes, 1999). In contemporary U.S. society, divorce and step-parenting often involve shared child-rearing arrangements across households with multiple sets of parents. Shared parenting can take a variety of forms ranging from collaboration, to mentoring, to foster families caring for an entire family group (Piescher, Schmidt et al., 2008). A number of terms are used to refer to arrangements with some degree of collaboration between two families such as co-parenting, shared family care, and shared family foster care (Piescher, Schmidt, et al., 2008).

History

Child welfare systems are increasingly exploring ways to encourage relationships between birth families and foster families as a pathway to reunification (Piescher, Schmidt, et al., 2008; Tilbury & Osmond, 2006; Vig et al., 2005). Involving foster parents in permanency planning is a new trend in the child welfare system (Piescher, Armendariz, et al., 2008).

Some disability systems have implemented voluntary shared parenting models to accommodate birth families whose circumstances prevent them from raising their children or caring for them full time. Models described in the practice literature provide for an alternate family to assist the birth family by providing a home for the child where arrangements are viewed as an extension of the family system incorporating additional caregivers into the extended family system rather than as replacements for biological parents (Baxter et al., 1992; Rosenau, 2005). Descriptions of shared parenting suggest potential for accommodating varying distributions of parenting activities across multiple households with various patterns of time spent between families in arrangements tailored to fit individual circumstances. Rosenau (2005) presents a detailed description of a shared parenting model for children with developmental disabilities and provides anecdotal evidence of families who have successfully used such arrangements.

Research evidence

Research in child protection literature has found that birth and foster families working collaboratively leads to positive outcomes and that ongoing quality contact with birth families improves placement stability (Tilbury & Osmod, 2006). Research studies of training programs addressing co-parenting and shared parenting have been found to be "promising" or "emerging" (Piescher, Schmidt, et al., 2008). A study involving child welfare families with lower risk factors found significant gains in collaboration following a twelve-week joint training program involving opportunities for birth and foster family pairs to get to know each other better, and learn proactive communication and how to negotiate conflict (Linares, Monalto, Li, & Oza, 2006).

An informative study of an attempt to develop shared parenting comes from the child welfare literature. The study evaluated a program with the goal of reunifying children who had been removed from their families using a shared parenting arrangement where foster parents embraced the role of extended family rather than a substitute family and assisted in a gradual increase in the time the child spent with their birth family (Landy & Munro, 1998). Participants were families with multiple risk factors including substance abuse, physical and mental health issues, histories of abuse in their own families, and patterns of frequent moves. The program had little success. The researchers suggested that the model offered preventative potential for families with fewer risk factors but was not likely to be successful for families with chronic and extremely negative life situations.

No research studies were found that examined shared parenting for children with disabilities.

PRACTICE APPROACHES

Challenging behavior of children with disabilities is frequently identified as a contributing factor to family stress and risk of out-of-home placement (Alborz, 2003; Farmer, et al., 200; McGill,

Tennyson et al., 2006; McIntyre et al., 2002). Children with intellectual disabilities are at higher risk of developing problem behaviors (Hatton & Emerson, 2003; Kastner & Walsh, 2006; McIntyre et al., 2002). An estimated 10-15% of children with intellectual disabilities develop challenging behavior (Alborz, 2003). A retrospective study in Washington state looked at children ages 13-17 who had been placed in facilities over a two year period and compared them to other children (Lucenko, Manusco, & Janssen-Timmen, 2008). Investigators found the factors most predictive of placement were severely assaultive behavior, injurious behavior, need for close protective supervision, caregiver risk, and no availability of a back-up caregiver. Guidance to families on how to manage challenging behavior has been found to be an effective intervention (Laan et al., 2001; Vig et al., 2005). A literature review of studies published between 1997 and 2007 which found individuals with challenging behavior to be at risk of poorer outcomes in community services than institutional settings, raised questions about the characteristics of interventions in each setting (Kozma et al., 2009).

Positive Behavior Support

   Description

Positive Behavior Support (PBS) is a multifaceted evidenced-based intervention for addressing problem behaviors of children with disabilities (Kincaid, Knoster, Harrower, Shannon, & Bustamante, 2002; Sailor, Dunlap, Sugai, & Horner, 2009). PBS is a broad approach for organizing the physical, social, educational, biomedical, and logistical supports needed to achieve desired lifestyle goals while reducing problem behaviors that pose barriers to these goals (Sailor et al., 2009). PBS is characterized by four defining features:

   1. Application of research-validated behavioral science
   2. Integration of multiple intervention elements to provide ecologically valid, practical support
   3. Commitment to substantive, durable lifestyle outcomes
   4. Implementation of support within organizational systems that facilitate sustained effects

PBS involves development of a person-centered plan based on a functional behavioral assessment which identifies non-aversive interventions and techniques to alter the environment and teach appropriate behaviors to create lasting changes and increased quality of life for both the individual and those with whom they live (Carr et al., 1999; Kincaid et al., 2002). A key concept that defines PBS is that remediation of problem behavior requires remediation of deficient contexts of two kinds: environmental conditions and behavior repertoires (e.g., communication, self-management, and constructive behaviors).

   History

PBS emerged in the mid-1980s in the aftermath of deinstitutionalization and increased community and educational inclusion for people with disabilities. Applied Behavior Analysis (ABA) became a popular and well-researched intervention that offered 'behavior modification' as a means of supporting people with disabilities with challenging behavioral needs in the community. PBS is an extension of ABA with an added emphasis and understanding of the ecological context of behavior and lifestyle outcomes (Kincaid et al., 2002; Sailor et al., 2009).

Since its emergence in the mid 1980's, PBS has been used in a variety of school and community contexts with a diverse range of children including children with intellectual and developmental disabilities, autism, severe emotional disorders, and behavioral disorders served in education, child welfare, mental health, and juvenile justice systems (Sailor et al., 2009). With established effectiveness in reducing problem behavior, PBS efforts turned to improving quality of life, in particular, improving family outcomes in family contexts in addition to individual outcomes for children with challenging behavior (Smith-Bird & Turnbull, 2005).

Research Evidence

An extensive literature synthesis reviewed 109 studies which used rigorous methodologies published between 1985 and 1996 to evaluate interventions using PBS with individuals with intellectual disabilities, autism, pervasive developmental disorders, or problem behavior (Carr et al., 1999). The results concluded that PBS (1) is widely applicable for people with severe disabilities and serious problem behavior, (2) can be applied by typical intervention agents in typical settings (i.e. not restricted to experts operating in specialized circumstances), (3) results in a decrease in problem behavior from baseline for one-half (at 90% criterion) to two-thirds (at 80% critierion) of participants, and (4) success rates are greater when intervention involves system changes (i.e.,the individual's network).

The Handbook of Positive Behavior Support summarizes the rigorous research efforts and extensive clinical practice evidence for PBS (Sailor et al., 2009).   PBS is regarded as an evidence-based approach based on a body of rigorous research. In addition to decreasing problem behaviors, it has served as a preventative strategy. PBS has been shown to increase both individual and family ratings of overall quality-of-life outcomes (Kincaid et al., 2002; Smith-Bird & Turnbull, 2005).

FRAMEWORKS FOR SERVICES

There is no coherent national family policy that crosses all child-serving organizations (Davenport & Eidelman, 2008).

Permanency Planning

Description

Permanency planning is a policy framework that has been a guiding principle in child welfare services since the 1970s. It grew out of criticisms of services and practices for children who had been removed from their families by child protection intervention who subsequently experienced lack of stability in foster care (Rosenau, 2000; Taylor et al., 1989; Tilbury & Osmod, 2006). Permanency planning is theoretically informed by attachment theory and understandings of child development (Tilbury & Osmond, 2006). It 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 to 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 play in child development
7. The deleterious impact on children of separation from parents

Permanency planning addresses three aspects of a child's situation:

1. physical (a safe, stable living environment)
2. relational (stable emotional lifetime connections and a sense of belonging)
3. legal (a competent legally authorized decision-maker)

History

Spurred by concerns about out-of-home instability of children in protective custody, Congress enacted the Adoption Assistance and Child Welfare Act of 1980 and later the Adoption and Safe Families Act of 1997 which sought to support stable, enduring family homes rather than

temporary, revolving foster homes. Legislation requires individual case plans and imposes mandatory administrative reviews on state child welfare systems to assure that plans either facilitate reunification with parents or lead to an alternative permanent family living arrangement within specified time frames. The Child Abuse Prevention & Treatment Act (CAPTA) as amended in 1995 sought to improve prevention by adding new family resources and supports, and specifically includes children with disabilities (Siverstein, 2000).

Permanency has not been required for children placed out-of-home voluntarily by parents in disability services, but is federally mandated for children with disabilities cared for in child welfare systems (Taylor et al., 1989). Unlike other states, Michigan vigorously embraced permanency planning policies in its developmental disability service system in the mid 1980s (Taylor et al., 1989). Implementation in Michigan's disability services sector included (1) providing better in-home supports to families, (2) placement with an alternate family rather than a residential facility when parents sought out-of-home placement, and (3) assertive recruitment of alternate families to make family-based alternatives available (Rosenau, 2000, 2005).

Texas has the only statewide legislation identified in the literature that requires permanency planning for all children served in its voluntary disability services sector in residential settings including large congregate settings, group homes, and nursing homes. The Texas legislation establishes the permanency planning policy framework.

> "*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)

> *Research evidence*

The research basis for permanency is grounded in evidence from child development that children benefit from consistent and uninterrupted parenting and suffer from the reverse (Tilbury & Osmond, 2006). In practice, the research evidence regarding permanency planning in child welfare (as described earlier) has identified poor permanency planning outcomes for children with disabilities (Bruhn, 2003; Rosenberg & Robinson, 2004; UCP/CR, 2006).

No current research on permanency planning for children with disabilities in voluntary services was identified. However, an informative older study contrasted Colorado's attempt to introduce permanency planning to the developmental disability system similar to Michigan's approach. The findings described dilemmas and barriers as "pervasive and formidable" (Ott and Langer, 1987, p. 67) including:

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 with residential care 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 researchers attributed Michigan's success to having "a unique and powerful policy" 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 (p. 61). The researchers argued that this policy stance was possible and defensible only because of corresponding policies and practices of rich family support.

Summary

In summary, the research evidence for family-based alternatives to congregate care is equivocal but promising or emerging in many areas. In considering the equivocal findings of research regarding alternative approaches to congregate care, it is of note that practice often precedes research. Some of the alternatives reviewed are relatively new from a research perspective and do not yet have a large body of knowledge based on rigorous research methods. Nevertheless, commonalities of successful attempts to implement alternative approaches were identified in the existing research. Commonalities crossed child-serving systems and included alternatives to congregate care in the areas of funding, planning, family living arrangements, practice approaches, and guiding frameworks.

OVERALL CONVERGENCE OF LITERATURE FINDINGS:
RETHINKING AND REDESIGNING

The evidence reviewed to answer the four research questions of interest suggests (1) the true extent of use of congregate care by children with disabilities is unknown and likely underestimated, (2) some families face multiple, complex, and cumulative vulnerabilities, (3) some children face risk related to their families' vulnerabilities and the use of congregate care, and (4) many family-based alternatives to congregate care are being explored with various levels of outcome evidence.

RETHINKING

Over the past 25 years, ideas and models that inform policy, research, and services have undergone a number of changes (Sloper, 1999). The seeming illusiveness of solutions to the urgent unmet needs of children with disabilities and their families has led to a variety of challenges to the assumptions on which systems of services are built.

Some critics object to conceptualizing ordinary daily care of children who have atypical characteristics as "health care" with its grounding in a medical model that turns ordinary needs into treatment interventions that are supervised and regulated by medical bureaucracies (e.g., Krause, 1993). Other critics take issue with the current zeitgeist of "consumerism", suggesting it is an individualistic notion that does not adequately fit the interpersonal context of family life (e.g., Knox et al., 2000). Others argue that policies need to be re-evaluated from the child's point of view through the prism of their relational needs (e.g., Shonkoff & Phillips, 2000; Skolnick, 1998). Taking the view that the emotional attachment between a child and parent should be defined as the central goal supported by service design, suggests the rights and interests of parents should be seriously considered, but separately and apart from a child's interests which should be judged on the quality of intimate relational associations and day-to-day interactions (e.g., Skolnick, 1998; Tilsbury & Osmond, 2006).

Some critics suggest that the dominant paradigm affecting the way formal services are currently organized is based on assumptions that distribution of limited resources is best managed by applying standards of fairness and impartiality which are best achieved by rules and regulation. An alternative view contrasts a top-down hierarchical, expert-drive, control and compliance-oriented paradigm with a bottom-up, individualized, individual/family-driven paradigm (e.g., Walker & Koroloff, 2007; Thompson et al., 2009). The latter paradigm suggests that judgments are always situated and contextual, are necessarily subjective, and are best negotiated in interpersonal interaction through dialogue based on reciprocal partnerships. Permanency planning is an example of a framework that has been used on a large scale not guided by rules of

fairness, but guided by principles and case-by-case considerations of family situations with parent-child relationships as the basis for decision-making. This individualized process of planning, decision-making, resource use, and oversight offers a model that is based on the primacy of the child's needs, and involves negotiation with parents rather than application of rules of eligibility.

The contextual view increasingly taken in the reviewed research literature recognizes both individual family level factors and social and economic disadvantages faced by families with children with disabilities in general. Program and fiscal policies and intervention efforts to promote resilience and reduce vulnerabilities of families have been suggested as taking two forms: "changing the odds" of exposure to disadvantages and "beating the odds" when exposure cannot be prevented (Emerson et al., 2010).

REDESIGNING

All child-serving systems are widely reported as complex, fragmented, over-burdened, inflexible, and under-serving or unserving of identified needs of children and families (Koyangi & Boudreaux, 2003; NCD, 2005; UCP/CR, 2006; U.S. DHHS, 2002). Common themes about alternatives emerged in the literature across systems.

Paradigm shifts

Efforts to design more effective family support generally have been associated with radical and transforming paradigm shifts in child-serving systems (1) from trying to fit a child into a service to fitting services around the child's family, (2) from seeing the child as the recipient of services to seeing the child-in-family as a social unit in need of invigorating support, and (3) from professionals as gatekeepers who control service use through complex rules and procedures to partners in finding creative ways to assure nurturing family life is supported by day-to-day practices. Despite the ubiquity of rhetoric about supporting families, however, there is as yet no coherent national cross agency policy regarding children and families.

Organizational cultures

Research evidence regarding conditions for successful implementation of innovation frequently suggested organizational climate as a target for change. While current service systems are organized in categorical silos, the families with whom children live do not fit neatly into categories. A number of system change efforts identified the need for cross agency involvement and coordination. A provocative study examined the effects of organizational climate and interorganizational coordination over a three year period in a statewide attempt to improve services for children (Glisson & Hemmelgarn, 1998). Attempts to improve interorganizational coordination had no effect on child outcomes. The research evidence suggested that coordination efforts had diffused responsibility, and that reduced personal involvement of caseworkers resulted in reduced benefit to children. 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, and that better child outcomes were achieved through intimate knowledge of the child and family and personal ownership for the outcomes. The researchers concluded that organizational climate was the primary predictor of positive outcomes.

Relationships as the mechanism for change

Themes from the literature identified the importance of relationships at two levels: The parent-child level and the family-system level. At the parent-child level, child development research has identified the importance of a parent-child relationship where the nature of the relationship itself is the growth-promoting feature. Congregate care as a "treatment milieu" inherently includes multiple and interchangeable caregivers and congregation of multiple children with similar needs, neither of which have been shown to be factors that produce positive change. At the family-

system level, a prominent theme in the research evidence of successful system change is partnerships built on collaborative relationships between parents and professionals, providers, and policy-makers.

Flexibility and funding options

The literature identified a variety of efforts to achieve more effective use of funding which used similar strategies, although different terminology, to find ways to work more flexibly and creatively across and within systems. Common to efforts to increase flexibility was redirecting funding that is currently organized in categorical system silos and related provider organizations to be used more effectively and creatively through management at the child-family level with more family-directed mechanisms to enable tailoring to unique situations.

Alternate families

For family life to be achieved for some children will require that alternate families assume care when families are unable or unwilling to raise children born to them despite support available. Common features in the literature regarding successful alternate family living arrangements were (1) the interpersonal fit between the family and the child, (2) the intensity and fit of support available to the family, and (3) the adequacy of preparation of the family, and (4) the therapeutic benefit of the relationship nurtured between the parent and child over time. The literature suggests alternate families, whether kin or non-kin, as a group face a similar range of support needs as birth families though, like birth families, vary in the uniqueness of needs relative to supports and sources of vulnerabilities relative to resilience.

Guiding principles

The research reviewed regarding alternatives to congregate care for children emphasized the need for a guiding framework to underpin successful approaches--the belief that family life is essential for children and the expectation that sufficient support should be provided to a family, whether kin or non-kin, so they can offer children the nurturing and enduring relationships that are the essential features of family life and its developmental benefits. A parent-child relationship characterized as close, trusting, emotionally secure and enduring was seen in the research evidence as the central feature of a growth-promoting living arrangement and the foundation around which support is built. Whether applying the term "permanency planning" or not, the common thread in the literature reviewed is the need for guiding principles that centralize the role of supporting the parent-child relationship.

CONCLUSION

All child-serving systems are involved in efforts to reconceptualize and reconfigure services in the face of complex challenges. The literature reviewed raises questions about assumed but undemonstrated benefits of congregate care. With little research evidence of positive outcomes, congregate care offers too little benefit at too great a developmental risk to children when family-based alternatives are possible. The literature provides emerging evidence that family-based alternatives to congregate care are feasible. In rethinking what functions congregate care currently fulfills in meeting the needs of families with complex vulnerabilities, the literature suggests family-based alternatives that might be explored and developed to fulfill those functions more effectively with better developmental outcomes for children.

> Congregate care offers too little benefit at too great a developmental risk to children when family-based alternatives are possible.

The literature identified that multiple, cumulative family vulnerabilities and the way services have been organized serve as pathways to congregate care. Emerging attempts to redesign systems call for linking (1) an affirmation that children need to grow up in families, (2) that family-functioning is key to child functioning, (3) that support is key to family functioning, and (4) that support is furnished to the "child-and-family" as a unit. A guiding framework that underpins family-based alternatives to congregate care, whether the family of origin or another family, would address both the support needs of parents and the developmental needs of children by supporting a parent-child relationship as the central feature of day-to-day living arrangements. The literature identified ways to rethink and redesign support to families to provide the home life that children with developmental disabilities need.

> Organizing services for children to support the parent-child relationship would address both the support needs of parents and the developmental needs of children.

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