

NEEDS ASSESSMENT OF INCLUSIVE CHILD CARE FOR SCHOOL AGE CHILDREN
WITH DISABILITIES: PARENTS' AND PROVIDERS' PERSPECTIVES

by

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(Under the Direction of Zolinda Stoneman)

ABSTRACT

Families having school age children with disabilities are increasingly relying on non-parental childcare for their children, like most other families in the U.S. In spite of these laws like the ADA and IDEA, parents still struggle with finding appropriate and accommodative out-of-school care for their school age children with disabilities. To explore this issue further, we conducted focus groups and phone interviews with 37 parents and 41 child care providers. Three related studies were conducted.

In study 1, we examine the process through which families of school age children with disabilities seek care and to identify the points in the process where the system fails families. Using a flowchart (which we refer to as the 'care cycle'), we outline a conceptual framework for understanding the extrinsic barriers with which families of school age children with disabilities are faced. We not only highlight the three main reasons why childcare becomes unavailable to families of these children but also provide some specific and practical solutions that have the potential to creatively address these barriers.

In study 2, we focus on highlighting parent's perspective on features that contribute to successful inclusion of school age children with disabilities in child care and other out-of-school settings. Parents identified a host of adaptations including adaptations of physical space and activities, adaptations focusing on peer socialization, supervision and safety, parent-provider communication, and those focusing on the attitude and skills of child care providers.

Study 3 focuses on the challenges that providers face related to inclusion and the supports and resources they need to better facilitate overall development of children having disabilities. The challenges expressed by providers in our focus groups can be put into three broad categories – issues related to staff, the lack of resources and issues related to communication and collaboration between the different people involved. The supports that child care providers need to make inclusion work revolve around needing more training on disability issues, more resources including additional staff, more funding, more information about available resources, and greater communication and collaboration with parents, school teachers and therapists.

INDEX WORDS: Child care, school age care, disabilities, focus groups, parents, providers, challenges, supports, training, resources, communication, collaboration.

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DEDICATION

This dissertation is dedicated to my parents - Mr. Amirali and Mrs. Karima Jinnah, and
my partner – Akeel Ghelani.

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CHAPTER 1

INTRODUCTION AND RATIONALE

During the year 2004, 73% of all women in the U.S. with children between ages 6 and 17 years were employed (U.S. Bureau of Labor Statistics, 2005). This statistic highlights the large proportion of women with school age children in the labor force. Also, the 2000 U.S. census reported that there are 2.6 million children between ages 5 and 15 years who have a disability (U.S. Census, 2003). There is evidence to suggest that labor force participation of mothers of children with disabilities is significantly lower than that of mothers having children without disabilities (Brandon, 2000; Glendinning, 1992; Lukemeyer, Meyers, & Smeeding, 2000; Shearn, 1998; Worshtil, 1990; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Beresford, 1995; Shearn & Todd, 2000; Olsson & Hwang, 2003; Freedman, Litchfield, & Warfield, 1995). A large proportion of these mothers remain full-time home makers through their midlife, when other mothers in their age group work outside of the home (Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996; Parish, Seltzer, Greenberg, & Floyd, 2004; Seltzer et al., 2001). Parents of children with disabilities in contrast to other caregivers are more likely to work part-time, earn less money, and take leaves to care for their children (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; LeRoy & Johnson, 2002; Shearn & Todd; Warfield, 2001). Among employed women, limited childcare options force mothers of children with disabilities into jobs that are less career-oriented and that under utilize their skills (Warfield, 2005; Shearn & Todd; Glendinning). Parish et al. concluded from an analysis

of Wisconsin Longitudinal Study data that reduced employment rates for mothers of children with disabilities place them at long-term economic disadvantage. They suggested that these families might experience increased economic vulnerability as they age. Lukemeyer et al. also found that children with severe disabilities placed increased financial strain on families who were already economically disadvantaged. They found that the more substantial the child's disability, the less likely the child's mother was to be employed. A significant proportion of mothers who do not work outside the home would like to join the labor force if appropriate childcare were available (Shearn & Todd; Worshtil).

Jobs outside home not only provide mothers with financial remuneration, but also provide health benefits including psychological fulfillment and a sense of control over their lives (Freedman, et al., 1995). Lack of employment can lead to psychological costs, such as feelings of isolation, lack of fulfillment, and low self-esteem (Shearn & Todd, 2000). Being involved in paid work as well as in parenting provides mothers the buffering effects of multiple roles (Barnett & Hyde, 2001), which may be associated with benefits, including decreased caregiver stress (Kagan, Lewis, Heaton, & Cranshaw, 1999; Shearn & Todd, 2000).

In addition to helping parents, inclusive childcare also benefits children. The presence of social role models to foster learning is important for children with disabilities (Martin, 2000). This is especially important for older children who increasingly look to their peers for support and approval (Abery & Simunds, 1997; Owens, 2002). Inclusion offers typically developing children opportunities to develop an appreciation for others

who are different from them, to develop social skills, and to learn altruistic behaviors (Staub, 1996; Terrell, 2001).

For the past 20 years, researchers have cited the inability of parents to find appropriate child care for school age children with disabilities as a major barrier keeping mothers from entering, or re-entering, the workforce (e.g. Fink, 1988; Scott, 1988; Seltzer et al., 2001). This problem continues to exist even though the Americans with Disabilities Act (ADA) passed in 1990 prohibits childcare centers, as places of business, from discriminating against children with disabilities. The Americans with Disabilities Act (ADA) requires childcare centers, as places of business, to include children with disabilities and make appropriate modifications that are needed for their full functioning. Title III of the ADA requires that center-based childcare and home care facilities examine their rooms and spaces, playgrounds, and activities to make them accessible to children with disabilities (Craig & Ann, 1994; Parette & Murdick, 1994). The Individuals with Disabilities Education Act (IDEA) reauthorized in 1997 requires children with disabilities to receive education and care in places where typically developing children spend their time. A key implication embedded in these laws is that children with disabilities should be able to fully participate in child care settings that serve typically developing children. With laws like ADA and IDEA, child care providers cannot discriminate against school age children with disabilities. However, parents still struggle to find child care centers that will accept and make appropriate accommodations needed for the successful inclusion of their children.

Researchers have examined reasons why care options are unavailable for many families of school age children with disabilities. Some challenges faced by these families

are similar to those faced by all families looking for out-of-school care, such as the lack of care options in rural areas (Kagan et al., 1999; Miller, O'Conner & Sirignano, 1995), during summer and holidays (Fink, 1988; Parish, 2006), and lack of transportation (Parish; Miller et al.). Certain problems, however, are more aggravated for children with disabilities, including children with behavioral problems (Fink; Freedman et al., 1995; Kagan et al., 1999) and those having severe or multiple disabilities (Worshtil, 1990; Brandon, 2000; Wagner, Cadwallader, Newman, Garza, & Blackorby, 2002; Palfrey, Walker, Butler, & Singer, 1989).

When children are young, they have increased needs for care and supervision. Child care settings providing for young children are therefore geared toward meeting these needs. As typically developing children grow older, they become more independent and autonomous and therefore they can spend increased amounts of time with minimal supervision and care. Unlike typically-developing children, some children with disabilities may require close supervision and care well into middle and high school years (Freedman et al., 1995). Many youth with significant disabilities require constant supervision, even after they reach an age in which other children can safely spend periods of time away from adults (Freedman et al.; Parish & Cloud, 2006). Parents of these youth often face major challenges in securing appropriate care (Kagan et al., 1999; Worshtil, 1990; Parish, 2006; Shearn & Todd, 2000). The current after-school care system is geared to meet the needs of typically developing children but families having school age children with disabilities struggle to find settings that would appropriately accommodate their children. In addition to challenges in finding formal childcare, parents of school age children with disabilities also report less access to informal care from relatives, friends,

and older siblings who are either unavailable or viewed as not competent or physically able to provide the required care (Kagan et al.; Shearn & Todd). For those that do have informal child care, this option decreases as children grow older. Whereas for most parents this waning corresponds with increased independence of the children, for those with children having disabilities, the care needs remain, so the loss of informal child care is problematic.

Devore & Bowers (2006) studied the processes through which families of young children with disabilities sought and successfully secured childcare, but similar process-oriented data do not exist for families of school age children. From existing research on school age care, it cannot be clearly determined at what point in the process that the system breaks down for families. Brandon (2000) noted that it is difficult to formulate coherent policy without further research elucidating the specific childcare barriers faced by families of school age children with disabilities. Therefore, the first part of this study tracks the pathways that families follow in their quest to secure care for their school age children with disabilities. The first research objective is to examine the process through which families of school age children with disabilities seek care and to identify the points in the process where the system fails families.

Being accepted into a child care or activity setting is only a first step. There are a host of problems that parents of children with disabilities face related to adaptations and accommodations even after the child has been accepted into a setting. Past studies on inclusive practices of young children with disabilities in child care settings have focused on provider's needs. Barriers that prevent young children from being included in child care settings include attitudes of providers (Dinnebeil, McInerney, Fox, Juchartz-Pendry,

1998; Buell, Gamel-McCormick, & Hallam, 1999; Buysse, Wesley, Keyes, & Bailey, 1996); and lack of provider knowledge and training (Fewell, 1993; Warfield, Hauser-Cram, 1996; Dinnebeil et al.). Researchers have also looked at program practices that can help full inclusion of children with disabilities (Newman & Tyler, 1991). Through direct observations and conversations, Brennan, Ama, & Gordon, 2002 investigated practices child care staff use to include young children with emotional and behavioral challenges into child care programs. Setting up physical and social environments to encourage cooperation and self-regulation, building strong relationships with individual children and anticipating social and emotional challenges, peer acceptance of children with disabilities and integrating mental health services into the scheduled center activities were some key practices used by staff to ensure inclusion. The specific types of modifications or adaptations needed to accommodate school age children with disabilities in child care settings need much more exposition and elaboration in the literature. Cross, Traub, Hutter-Pishgahi & Shelton (2004) suggested that there are identifiable elements and associated practices that contribute to successful inclusion of young children with disabilities in community settings. According to them, provider attitudes, parent-provider relationships, therapeutic interventions and adaptations are the four elements contributing to successful inclusion of young children with disabilities in childcare settings.

As children with disabilities grow older, their characteristics and needs keep changing and therefore the supports that they would need for their full functioning in inclusive settings would be qualitatively different from those needed by younger children. More has appeared in the literature on specific elements of inclusive care as it relates to child care for younger children with disabilities but there is scant information on these

elements for school age children with disabilities. Fink (1988) presented snapshots of the perspective of 66 parents of school age children between 5 and 16 years who had mild to severe disabilities. He explored parent's experiences in seeking and using child care for their child with disabilities. Based on parent's experiences, Fink suggested important adjustments to the physical environment, adaptations of activities, orienting families to the program and its services, involving family in child's program, maintaining open, honest communication with families and providing supports to the family. However, these findings are almost twenty years old; it is not clear whether these issues have changed or remained the same over this period of time. Further research is needed to understand and implement practices that permit school age children with disabilities to have a successful inclusion experience (Cross et al., 2004). Also, most studies to date have considered the perspective of experts and providers on how to make inclusion work. Parent's perspective on what supports and accommodations will be best for full inclusion of their children with disabilities in child care settings is underrepresented in the literature. The adoption of family centered practice in early intervention literature has led to numerous studies assessing parents' resources, priorities and satisfaction with services (e.g. Bailey & Simeonsson, 1988; Turbiville, Turnbull & Turnbull, 1995). The embracement of family-centered practices in school age child care requires that the needs and concerns of parents and their views on ideal school age care for their children with disabilities be considered. The second objective is to fulfill this gap in literature by focusing on parent's perspective on features that contribute to successful inclusion of school age children with disabilities in child care and other out-of-school settings.

From a systemic perspective, it is not only important to consider parent's perspective on the issue but is also important to identify the challenges and needs of child care providers. As federal and state mandates demand inclusive practices, school age child care providers are increasingly being asked to include children with disabilities in their settings (National Easter Seal Society, 1998). As more school age child care settings include children with disabilities in their setting, more focus on the challenges that providers face related to inclusion and the supports and resources they need to better facilitate overall development of children having disabilities is needed. Most of the literature on child care to date has focused on the needs and challenges of providers related to inclusion of young children with disabilities in child care settings. Studies focusing on the challenges that school age child care providers face related to the inclusion of children with disabilities are largely missing from the literature. As children with disabilities grow older, their characteristics and needs keep changing. Therefore, the challenges that providers face in making adaptations for older children with disabilities would be qualitatively different from those needed by younger children. The third study addresses this gap in literature by focusing on barriers that providers face related to inclusion and the supports they need to effectively promote inclusion in school age child care settings. The third research objective was to explore the joys and challenges of providers related to caring for school age children with disabilities in settings and the supports that they need to provide better care for these children. The three main research objectives that this study addresses are listed below:

Research Objectives

1. To examine the process through which families of school-age children with disabilities seek care and to identify the points in the process where the system fails families.
2. To explore parent's perspective on features that contribute to successful inclusion of school age children with disabilities in child care and activity settings.
3. To explore the challenges that providers face related to inclusion and the supports they need to successfully include school age children with disabilities in child care and activity settings.

CHAPTER 2

REVIEW OF LITERATURE

Access to Child Care for School Age Children with Disabilities

The most comprehensive study on the issues of school age children with disabilities related to out-of-school care options was done by Fink (1988). He presented snapshots of individual's views related to the issue. He surveyed 66 parents of children between 5 and 16 years who had mild to severe disabilities. Parents' experiences in seeking and using childcare were explored. He found that 25% of parents of five-to-seven year old children with disabilities had been denied admission or had been discouraged from applying to a child care program since their child entered school. Of children 12 to 16 years old, nearly half had been refused child care during their years in school. Children with disabilities having behavioral problems were more likely to be refused admission or be terminated from programs they previously attended. Also, older children with disabilities were substantially more likely to be refused admission to a child care program than younger children. Parents mentioned that lack of childcare had affected their employment choices and personal lives. Only 23% of the mothers of 6 to 21 year olds in sample had full-time jobs with another 27 percent holding part-time jobs. Fifteen percent reported they had given up a job and 27 % had passed up at least one opportunity because of the child's need for care. However, these findings are almost twenty years old; it is not clear whether these issues have changed or remained the same over this period of time.

Palfrey et al. (1989) interviewed a random sample of 1726 parents of students in special education across five large urban school systems. Problems in finding child care were reported by 22% of parents of children with mental retardation, 27% of parents of children with emotional disturbances, and 38% of parents of children with physical and/or multiple disabilities.

The acute need for greater childcare options for school-age children with disabilities is reflected in a needs assessment by Worshtil (1990). He found that more than half of the parents themselves cared for their children with disabilities after school as opposed to one-fifth parents of children without disabilities. Most of the children with moderate to severe disabilities were not receiving any form of care. He also found that many children with disabilities require care well past the usual age of 14 years. Parents of children with disabilities were found to be less likely than other parents to work outside home. Almost half of the single parents and three-fourth of the parents who were unemployed said they would pursue training and employment if appropriate childcare were available for their child with disability.

Freedman et al. (1995) conducted a series of focus groups with parents who indicated that locating and maintaining child care for children with behavioral problems is particularly difficult. They found that work plays a vital and positive role in the lives of families with children having developmental disabilities. Parents depend on their jobs not only for financial remuneration and health benefits, but also as a psychological source of fulfillment, respite, and control over their lives.

Miller et al. (1995) discuss the factors that are involved in parents' decisions about after-school care. Three important factors include income, geographical location

and transportation. The family's geographical area affects what choices are available to parents. Rural and low-income urban areas do not have the same variety of organized activities from which to choose. Fewer opportunities for enrichment are available, and parents of low income also have difficulty paying for the opportunities that do exist.

Kagan et al. (1999) conducted semi-structured interviews with forty working parents having at least one child with disabilities about their experiences with respect to formal and informal sources of child care. They found that from infancy through early adulthood, lack of availability of appropriate and flexible care and lack of information about options available are main barriers to center-based care for families of children with disabilities. They found that children living in rural areas and those having older children had more trouble finding appropriate child care. Disabling barriers include physical, attitudinal or material. When formal child care was available, appropriate and accommodating to the needs of both parents and the child with disabilities, parents reported being able to combine working and caring roles successfully. However, where formal supports were inadequate or non-existent, parents who could rely on the support of family and friends to supply emotional and instrumental assistance reported balance between work and caring roles. However, not all parents had this kind of help and for those that did, informal child care decreased as children grew older. Whereas for most parents this waning corresponds with increased independence of the children, for those with children having disabilities, the care needs remain, so the loss of informal child care is problematic. Whilst all parents need satisfactory child care in the early years, these parents' needs extend beyond the childhood years: the parents' accounts highlighted their complex and long-term child care needs.

Shearn & Todd (2000) conducted qualitative interviews with 18 mothers of children with disabilities between 5 and 15 years of age in United Kingdom. They concluded that these mothers encountered unusual time demands, and a lack of adequate and affordable child care. They therefore found employment difficult. Majority of non-working mothers of children with disabilities wanted to work. The lack of opportunities to engage in employment led, in varying degrees, to feelings of isolation, a lack of fulfillment and low self-esteem. The mothers felt they were on the periphery of society with little release from the pressures of caring. Mothers who had part-time jobs often did poorly paid work of low status, thereby encountering few opportunities to use their skills and abilities to the full potential. Those who attempted a full-time job experienced stress from the dual demands of home and work, and from a fear that they were failing as mothers.

LeRoy & Johnson (2002) conducted qualitative interviews with 39 urban and rural families who received welfare support and had school age children with disabilities. The mean age of the children was 8 years. One third of the mothers in this study were employed to some degree. However, their employment tended to be temporary in nature with no benefits and extremely low wages. Families of children having disabilities reported limited transportation and inadequate child care as barriers to attainment of self-sufficiency. Parents of children with disabilities reported difficulties in securing appropriate, safe and affordable child care.

In another similar study, Wagner et al. (2002) found that a large proportion of elementary and middle school children with disabilities went home from school and a very few (18%) participated in after-school activities. They found that students with more

severe disabilities like mental retardation, multiple disabilities, and deaf-blindness were much less likely to participate in extracurricular activities.

In a more recent study, Parish, Cloud, Huh, & Henning, (2005) conducted the first nationally representative probability sample study of child care for school age children. Low income children with disabilities who live with single parents are at greater risk for adverse outcomes than other children. They found that the cost of child care for children with disabilities in single-parent homes suggest the care that these children receive may be of questionable quality. However, majority of children were between 0 and 5 years of age (91%) with only 9% of the sample being school age children with disabilities.

Brennan & Brannan (2005) explored the relationship between school age children's emotional and behavioral symptoms and workforce participation of their family caregivers. The findings demonstrated that greater emotional and behavioral disorders are associated with caregivers reporting less adequate access to childcare and more role strain attributed to missing work or neglecting duties. These data further indicated that with greater strain from missing work, less adequate childcare, caregivers were less likely to participate in paid workforce.

Knoche, Peterson, Edwards, Joen (2006) studied parents of infants/toddlers, early childhood and school-age children with and without disabilities. Parents of children with disabilities reported greater difficulty in finding care and higher levels of stress related to their childcare services than those without, even after controlling for income and type of care. Parents of children with disabilities rated provider's willingness to accept subsidy and to enroll children with disabilities as important in choosing care for the child as other

parents. Children with disabilities experienced multiple types of care which is likely related to a lack of availability of appropriate child care arrangements.

Summing up, studies on school age child care have found that parents have trouble locating and maintaining appropriate child care for their school age children with disabilities (Fink, 1988; Palfrey et al., 1989; Worshtil, 1990; Freedman et al., 1995; Kagan et al., 1999; Shearn & Todd, 2000; LeRoy & Johnson, 2000; Wagner et al., Brennan & Brannan, 2005; Knoche et al., 2006). Researchers have examined reasons why care options are unavailable for many families of school age children with disabilities. Some challenges faced by these families are similar to those faced by all families looking for out-of-school care, such as the lack of care options in rural areas (Kagan et al., 1999; Miller et al., 1995), during summer and holidays (Fink, 1988; Parish, 2006), and transportation (Parish, 2006; Miller et al., 1995). Certain problems, however, are more aggravated especially for children with disabilities, including children with behavioral problems (Fink, 1988; Freedman et al., 1995; Kagan et al.) and those having severe or multiple disabilities (Worshtil, 1990; Brandon, 2000; Wagner et al., 2002; Palfrey et al., 1989). Although many studies have documented the problems parents face in accessing and maintaining childcare for their school age children with disabilities, few studies have focused on barriers faced and adaptations and accommodations needed in child care settings to effectively meet the needs of children with disabilities.

Accommodations for Inclusion in Child Care Settings

Zigler and Lang (1991), in their book on child care issues, have identified a host of barriers parents face in securing child care for their children with disabilities including inadequate numbers of trained caregivers who can effectively meet these children's

needs, prejudice and fear about disability, limited knowledge regarding nature of disabilities, physically accessibility barriers including lack of wide doorways or modern style bathrooms with support grips, and transportation barriers for children with mobility impairments.

Mulvihill, Cotton and Gyaben (2002) conducted a review of literature and based on that, suggested best practices for child and adolescent out-of-school care. These included a written program philosophy, a written plan for inclusive programs, strong leadership, disability awareness for staff and children, training and support for staff, sufficient staff to meet child and program needs, communication and collaboration, adapted setting, activities and time, collaboration with families and an evaluation plan.

Through direct observations and conversations, Brennan et al., 2002 investigated practices child care staff use to include young children with emotional and behavioral challenges into child care programs. Setting up physical and social environments to encourage cooperation and self-regulation, building strong relationships with individual children and anticipating social and emotional challenges, peer acceptance of children with disabilities and integrating mental health services into the scheduled center activities were some key practices used by staff to ensure inclusion.

Cross et al. (2004) suggested that there are identifiable elements and associated practices that contribute to successful inclusion of young children with disabilities in community settings. According to them, attitudes of providers, parent-provider relationships, therapeutic interventions and adaptations are the four elements contributing to successful inclusion of young children with disabilities in childcare settings.

Researchers have suggested program practices that can help in successful inclusion of children with disabilities (Newman & Tyler, 1991). The specific types of modifications or adaptations needed to accommodate children with disabilities in child care settings need much more exposition and elaboration in the literature.

Summing up, studies focusing on child care for school age children with disabilities are limited in number and scope. Majority of them have focused on lack of availability and access to child care for school age children with disabilities while some have focused on the adaptations that are needed for successful inclusion of school age children with disabilities in child care settings.

Studies on young children with disabilities

Past studies have shown that mothers of children with disabilities report greater difficulty in finding care than do mothers of typically-developing children (Brandon, 2000; Warfield & Hauser-Cram, 1996; Fink, 1991; Booth & Kelly, 1998). The severity of disability and behavior problems further aggravate the situation (Brandon, 2000; Warfield & Hauser-Cram). Numerous studies have focused on utilization of child care and barriers related to care for young children with disabilities including infants (Kelly & Booth, 1999; Sparling, Lewis, Ramsey, Wasik, & Bryant, 1991), toddlers (Booth & Kelly, 2002; Gil, 1984) and preschool children (Bailey, McWilliam, Buysse, & Wesley, 1998; Booth-LaForce & Kelly, 2004; Buysse, Wesley, Bryant, & Gardner, 1999; Buysse, Wesley, & Keyes, 1998; Guralnick, 2001; Odom & McEvoy, 1990; Parish et al., 2005; Smith & Rose, 1993; Warfield & Hauser-Cram, 1996; Wolery et al., 1993). Barriers in accessing childcare for young children with disabilities include high cost, lack of appropriate transportation, lack of trained personnel, negative attitudes, and an overall

lack of settings that accept and appropriately accommodate children with disabilities (Crowley, 1990; Dinnebeil et al., 1998; Fewell, 1993; Warfield & Hauser-Cram).

Warfield and Hauser-Cram (1996) surveyed mothers of 5-year-olds regarding their child care needs, arrangements and satisfaction with them. Mothers of children with developmental disabilities report higher levels of difficulty in finding care than do mothers of typically developing children. Brandon (2000) analyzed longitudinal national data on mothers' of preschool children's use of child care. Mothers having children with disabilities mentioned that they cannot work because they have more difficulty locating appropriate child care than mothers of typically developing children. Severity of child's impairment and whether or not they have a behavioral or emotional problem predicts their hours of child care use.

Buyse et al. (1998) examined the underlying factor structure of the barriers and supports to Early Childhood Inclusion Scale. Subjects were 287 parents (93% mothers) of children with disabilities ages less than or equal to 5 years. Factor structure analysis showed the 3 primary barriers to be: (1) early childhood program quality; (2) community resources; and (3) coordination and integration of services for children with disabilities and their families.

In a study conducted by Fink (1991), parents of children with disabilities under 6 years of age reported numerous problems in finding care. More than one-fifth of sample (22%) indicated that they were forced to take whatever they could find. About two-thirds reported having at least one type of problem in finding care including lack of information about options available (27%), high cost (27%), limited or inconvenient hours (20%), inconvenient location (16%) and lack of qualified caregivers (16%). Further, almost one-

fifth reported having been refused services because of their child's disability. Refusals appeared to be based either on the child's characteristics (e.g. poor communication skills, behavior problems, or lack of independent toileting) or on the center's characteristics (e.g. lack of staff experience with children who have disabilities and inadequate staff training).

Compared to mothers of typically developing children, mothers of young children with disabilities return to the work force later, choose relative care more often than center or family child care, use fewer hours of child care, and experience more problems finding quality care (Booth & Kelly, 1998).

Benefits of Inclusion

Inclusion of children having disabilities with typically developing children in child care settings has important benefits for both and their families (Odom & Diamond, 1998, Odom & McEvoy, 1988, Wolery & Wilbers, 1994). Including school-age children with disabilities in childcare settings is important not only to enable parents to work full-time, but also because these experiences are important for the social and emotional development of children. Inclusive care settings offer children and youth the ability to experience a new environment where the effects of segregation, such as labeling and negative attitudes are limited (Wolery & Wilbers). They also offer a greater variety of experiences than segregated settings, such as opportunities to go on field trips or to be exposed to different curricula (Thompson et al., 1993; Hobbs, Bruch, Sanko, Astolfi, 2001).

Socialization, including the presence of role models to foster learning of adaptive and social skills through imitation, is one of the most important benefits of inclusive

childcare (Worshtil, 2000; Wolery & Wilbers, 1994). This is especially important for older children who increasingly look to their peers for support and approval (Abery & Simunds, 1997; Owens, 2002). Children with disabilities in inclusive settings show developmental gains, especially in communication, social and motor skills, and the development of friendships (Brady, Martin, Williams & Burta, 1991; Burack & Volkmar, 1992; Odom & McEvoy, 1990). They gain practice in social interaction and develop friendships with typically developing peers that will help them prepare to live in the community (Wolery, & Wilbers; Thompson et al., 1993; Guralnick, 2001).

The benefits of inclusion are not restricted to children with disabilities but extend to typically developing children as well (Terrell, 2001). Inclusion offers typically developing children an opportunity to develop appreciation for those that are different from them and become more aware of other children's needs (Peck, Carlson, & Helmstetter, 1992). Inclusion offers typically developing children an opportunity to develop tolerance, appreciation for others who are different from them and to learn altruistic behaviors like patience, kindness and respect (Staub, 1996). Typically developing children in inclusive settings display improved social skills and fewer disruptive behaviors when compared with children in non-inclusive settings (Strain & Cordisco, 1994).

In one study, Peck et al. (1992) found that parents report typically-developing preschool children in inclusive settings to show less prejudice and have fewer stereotypes, to be more responsive and helpful to others than those in non-inclusive settings. In another study, Stahmer, Carter, & Baker (2003) established that majority of parents whose toddlers were enrolled in the inclusion program felt that their child gained

a greater acceptance and understanding for children with disabilities as a result of being in an inclusion program, as well as increased sharing and interaction skills. Some studies have shown that parents believe that inclusion programs taught their child compassion, acceptance of differences at an early age and understanding for children with disabilities (Stahmer et al., 2003; Cross et al., 2004).

Parents of children enrolled in inclusion programs did not report any increase in difficult behaviors such as biting and aggression and imitation of aberrant behavior (Stahmer et al., 2003). These results can help allay fears that children enrolled in inclusion programs will “pick up” bad habits from their classmates with disabilities. Literature shows that this concern is often expressed by parents of typically developing school age children who have not had the opportunity to experience integrated settings (e.g. Green & Stoneman, 1989; Guralnick, 1994). These results suggest that once families participate in inclusion programming, this fear will probably be reduced.

Research has suggested that typically developing children, who have been in inclusive settings, and who interact with children who have disabilities hold a more positive attitude toward people with disabilities than their peers who lack this experience (Favazza & Odom, 1997; Stoneman, 1993). Diamond (2001) and Stoneman suggested that those positive experiences enhance the development of positive attitudes both during the early years and later.

Families of both typically-developing children as well as those having disabilities learn a lot about each other by being in inclusive settings. Families with typically-developing children learn that families having children with disabilities face some of the

same joys and challenges of parenting including taking pride in their children's achievements and dreams about child's success in future (Guralnick, 1994).

Maternal Employment and Child Care

A pool of research studies suggest that labor force participation of mothers of children with disabilities is significantly lower than that of mothers having children without disabilities (Brandon, 2000; Glendinning, 1992; Lukemeyer et al., 2000; Shearn, 1998; Worshtil, 1990; Seltzer et al., 2001; Beresford, 1995; Shearn & Todd, 2000; Olsson & Hwang, 2003; Freedman et al., 1995). Researchers have found that caring for a child with disability lowered the probability of maternal employment and the number of hours of employment (Baldwin & Glendinning, 1983; Breslau, Salkever, & Staruch, 1982). A significant proportion of married mothers having children with disabilities remain out of the full-time labor force even when their children reach high school (Porterfield, 2002). A large proportion of these mothers remain full-time home makers through their midlife, when other mothers in their age group work outside of the home (Gallimore et al., 1996; Parish et al., 2004; Seltzer et al., 2001). In contrast to other caregivers, these mothers are more likely to work part-time, earn less money, and take leaves to care for their children (Gallimore et al., 1993; LeRoy & Johnson, 2002; Shearn & Todd, 2000; Warfield, 2001).

Mothers of children with disabilities have been found to miss more days of work in comparison to mothers of children without disabilities (Neal, Chapman, Ingersoll-Dayton, Emlen, 1993). A national survey of parents of children with special health care needs revealed that they had cut down the hours they worked to care for their child (Leiter, Krauss, Anderson, & Wells, 2004). More than half the mothers who were not working reported that they had stopped working because of their child's health. Thyen,

Terres, Yazdgerdi, & Perrin (1998) found that almost one-half of the mothers of children who were technology dependent quit their job to care for their child. Barnett and Boyce (1995) also found that mothers of children with Down syndrome decreased their time in paid work.

Analysis of the Wisconsin Longitudinal study, which collected data on respondents at ages 18, 36, and 53 or 54, found that although the employment rates of all respondents looked similar at age 18, those who later became parents of a child with a disability had lower rates of employment and social participation than those who became parents of children without disabilities (Seltzer et al., 2001).

Booth and Kelly (1998) examined the influence of different child characteristics on maternal employment decisions within a sample of mothers of infants with disabilities. The impact on work was greatest for mothers of infants with lower mental, motor and adaptive functioning as well as mothers of infants with chronic health problems and those who require adaptive equipment.

Brandon (2000) used data from the 1986-1988 panels of the survey of income and program participation (SIPP) and found that the labor force participation rate among mothers raising a child with a disability (56.2%) was six percentage points lower than that of mothers who did not have a child with a disability (62.2%), a modestly significant difference. Breslau et al., (1982) found that child disability exerts a greater negative impact on labor force participation of black and low-income families, as compared to white and high-income families.

A major reason why mothers of children with disabilities cannot maintain employment is due to lack of appropriate child care arrangements (Fink, 1988; Scott,

1988; Brandon, 2000; Cuskelly, Pulman, & Haynes, 1998; Shean & Todd, 2000; Freedman et al., 1995; Kagan et al., 1999). The difficulty associated with finding appropriate child care services for children with disabilities may help explain these reductions in work hours and poorer attendance records. Among employed women, limited childcare options force mothers of children with disabilities into jobs that are less career-oriented and that under utilize their skills (Warfield, 2005; Shearn & Todd, 2000; Glendinning, 1992).

Mothers of children with disabilities have fewer sources of reliable child care than do mothers of typically developing children (Fink, 1988; Warfield and Hauser-Cram, 1996; Scott, 1988). Parents of children with disabilities report higher levels of stress related to their child care services (Knoche et al., 2006).

Warfield and Hauser-Cram (1996) studied the child care arrangements used by mothers of 5-year-old children with disabilities. Mothers who worked full-time reported more difficulty locating childcare overall and had a greater number of problems related to care than did mothers who were not working full-time.

Parents of older school age children with disabilities particularly reported problems maintaining or re-joining employment. Freedman et al. (1995) conducted a series of focus groups with parents who indicated that locating and maintaining child care for children with behavioral problems is particularly difficult. When children reach school age, parents often plan to work during their child's school hours. However, if schools do not offer full-day programs or parents are unable to arrange care or supervision in the after-school hours, they may be limited to part-time positions. Also, unlike their typically developing peers, some children with disabilities may not be able to

stay at home alone even when they grow older. In such cases, parents may need to continue providing care for the children, thus negatively impacting their labor force participation (Freedman et al., 1995). In cases where parents do enter the workforce, maintaining a balance between work and caring responsibilities poses a big challenge. A focus group study was recently conducted by Parish (2006) to develop an understanding of the experiences of mothers who are trying to balance employment with caring for an adolescent with developmental disabilities. Mothers reported facing considerable difficulties balancing work and care giving responsibilities because support services rapidly declined when their child reached adolescence. Service cuts were related to the fact that adolescents are expected to be able to care for themselves, despite the fact that for many adolescents with disabilities, this is not possible. The mothers also reported that the preponderance of the responsibility for arranging care for their children was theirs and was not shouldered by their partners.

Nationally representative findings suggest that the impact of a child with a disability on parental employment varies with marital status. Married mothers of school age children with disabilities are less likely to be employed than other married mothers of school age children, while single parents of school age children with disabilities are employed at rates similar to those of single parents of non-disabled children (Porterfield, 2002). In a parallel finding, Parish & Cloud (2006) found minimal differences between low-income families of school age children with and without disabilities in their overall use of childcare. The authors suggest that economic hardship may force low-income parents, including many single parents, to enter the workforce and find some type of care for their children regardless of barriers encountered. However, they also found that

children with disabilities paid very low hourly cost suggesting that the care that they receive may be of questionable quality.

In another study, Wall, Kisker, Peterson, Carta, & Jeon (2006) reported that children with disabilities received care of lower quality than their typically developing peers, and their parents were less satisfied with the care arrangements. Cuskelly et al. (1998) found that 100% of mothers of children with disabilities indicated that they were employed because their “wage is needed”. In such cases, families may have fewer options or control over the type and quality of care arrangement. Thus, even if single parents having children with disabilities report using child care at the same rate as parents with typically developing children, the decision may be driven more by the economic need rather than choice, and the care that their children receive may be of questionable quality.

Parish et al. (2004) concluded from an analysis of Wisconsin Longitudinal Study data that reduced employment rates for mothers of children with disabilities place them at long-term economic disadvantage. They suggested that these families might experience increased economic vulnerability as they age. Families having children with disabilities have lower household incomes than the population in general with single parents being the poorest of all (Beresford, 1995). Lukemeyer et al. (2000) also found that children with severe disabilities placed increased financial strain on families who were already economically disadvantaged. They also found that the more substantial the child’s disability, the less likely the child’s mother was to be employed.

Fink (1988) suggested that parents whose children are physically, emotionally or mentally challenged have many reasons for working. They must often pay for costly

medical care or expensive equipment. They frequently pay extra for baby sitters, recreational and leisure activities. Some studies reveal a higher number of divorces in families with special needs children, adding pressure to the remaining wage earner. Finally, there is the psychological need to get outside the home and invest one's energy into something other than the care and rearing of a child with extraordinary needs. Ironically, in spite of all these reasons that indicate a greater need to work among parents of children with disabilities than among the population as a whole, the reality is that fewer of them are working. Survey results show that most mothers do stay at home when the school is out. So, it may seem that after school care for school age children with disabilities is not a big issue because these mothers do not work and feel they have to be home when school is out, given the tremendous needs of their children. But only rarely is this their first choice. More often, it is a choice born of bitter frustration after numerous failed attempts to find competent, reliable and appropriately designed child care or recreational environments. A significant proportion of mothers who do not work outside the home would like to join the labor force if appropriate childcare were available (Shearn & Todd, 2000; Worshtil, 1990; Glendinning, 1992).

Maternal Role Strain

Role strain refers to tension that result from trying to fulfill two or more culturally defined set of expectations (Morris & Coley, 2004). Having a child with disabilities is related to higher maternal role strain among working mothers (Morris & Coley). The degree to which women feel they have a choice in adopting the multiple roles of worker and parent is also related to role strain, as research suggests that maternal employment

benefits women and children when mothers choose to work but may cause strain when they feel that they need to work (Alvarez, 1985).

Brennan & Brannan (2005) explored the relationship between school age children's emotional and behavioral symptoms and workforce participation of their family caregivers. The findings demonstrated that greater emotional and behavioral disorders are associated with caregivers reporting less adequate access to childcare and more role strain attributed to missing work or neglecting duties. These data further indicated that with greater strain from missing work, less adequate childcare, caregivers were less likely to participate in paid workforce. Among mothers who had greater work interest, those with more behavioral problems reported greater parenting role stress than mothers of children with fewer behavioral problems (Warfield, 2005). A major source of parental stress comes from inadequate access to childcare, which has been reported by working parents as problematic for families caring for children with disabilities (Heymann, 2000; Warfield & Hauser-Cram, 1996); including those having emotional or behavioral challenges (Rosenweig, Brennan, Huffstutter, & Bradley, 2005; Rosenweig, Brennan, & Ogilvie, 2002).

Swain, Finkelstein, French, & Olivers' (1993) notion of disabling barriers is a useful way of conceptualizing mechanisms by which people are excluded from full participation in all aspects of civic life, including for example, family, work and leisure. While this concern was for people with disabilities, the framework equally applies to parents. Parents of children with disabilities encounter a series of societal barriers to the effective and fulfilling management of work and parenting roles.

Benefits of Maternal Employment

Freedman et al. (1995) found that work plays a vital and positive role in the lives of families with children with developmental disabilities. Parents depend on their jobs not only for financial remuneration and health benefits, but also as a psychological source of fulfillment, respite, and control over their lives. Many mothers describe work as a 'respite', a welcome distraction and 'a salvation' (Freedman et al.) while others note 'it saves my sanity' (Lewis, Kagan, Heaton, & Cranshaw, 1999). According to Glendinning (1992), employment can provide some break from the tensions of caring, playing 'a vital and positive role in the lives of working mothers.

Lack of employment can lead to psychological costs, such as feelings of isolation, lack of fulfillment, and low self-esteem (Shearn & Todd, 2000). Mothers who are not involved in paid work cannot profit from the possible buffering effects of multiple roles (being involved in both paid work and child care) such as feeling involved and successful at work, and may therefore run a greater risk of experiencing negative stress reactions (Barnett & Hyde, 2001). Mothers of children with disabilities who are employed have been shown to experience fewer of the negative effects associated with caring for a child with disabilities (Kagan et al., 1999; Shearn & Todd). Olsson & Hwang (2006) found that mothers and fathers of children with intellectual disabilities who are less involved in paid work also have lower levels of well-being. The results indicate a positive relation between involvement in paid work and well-being for both mothers and fathers. In order for mothers of children with disabilities to hold jobs and continue to be economically productive members of the society, especially after their children enter school, they need

community supports like child care and other out-of-school settings that will accept and appropriately accommodate their children with disabilities.

Provider's Perspective on Child Care Inclusion

Most of the literature on child care to date has focused on the needs and challenges of providers related to inclusion of young children with disabilities in child care settings. Researchers have identified barriers that prevent young children from being included in child care settings, including attitudes of providers (Dinnebeil et al., 1998; Buell et al., 1999; Buysse et al., 1996); and lack of provider knowledge and training (Fewell, 1993; Warfield & Hauser-Cram, 1996; Dinnebeil et al.). Cross et al. (2004) suggested that there are identifiable elements and associated practices that contribute to successful inclusion of young children with disabilities in community settings. According to them, attitude of providers, parent-provider relationships, therapeutic interventions, and adaptations are the four elements contributing to successful inclusion of young children with disabilities in child care settings. In a national survey of administrators, service providers, and parents, Smith and Rose (1993) found that issues related to personnel training as well as attitudes and values were described as disincentives to early childhood inclusion by a majority of the respondents.

DeVore & Hanley-Maxwell (2000) focused on childcare provider's ability to provide child care for young children with disabilities. The main contributing factors include provider's commitment, finding balance between resources and needs, problem-solving with parents, access to emotional support and technical assistance and access to other supports.

Numerous studies have focused on the challenges and needs of family child care providers related to inclusion. Buell et al. (1999) found that family childcare providers who were unwilling to care for children with disabilities indicated three primary barriers: lack of knowledge about disabilities, limitation that caring for a child with disabilities would impose on caring for other children and the need to purchase special equipment. Past studies have also found that the concerns that family childcare providers have regarding serving children with disabilities include liability, lack of training and inability to meet the needs of these children (Deiner & Whitehead, 1988; Fewell & Neisworth, 1987; Salkever & Connolly, 1988). Family childcare providers mention that they need training in behavior management, planning curriculum and activities, social skills development and working with children having disabilities (Rusby, 2002). Supports indicated specifically by family child care providers include increased information, the need for knowledge about teaching strategies and funds for special equipment (Buell et al., 1999; Deiner & Whitehead; Kontos, 1988).

Buysse et al. (1998) developed a rating scale to assess the perceived barriers and supports associated with early childhood education. The three factor structure for barriers that emerged included barriers related to early childhood program quality, community resources and coordinating and integrating services for children with disabilities. They found that the barriers factor structure for parents was similar to that obtained for providers.

Bricker (1995) believes successful inclusion of children with disabilities is influenced by three factors: attitude, resources, and curricula. According to him, teachers with a positive attitude also need resources to implement an inclusive, rather than an add-

on program. An inclusive curriculum would include activities that promote interaction between children and naturalistic approaches that encourage participation in activities in which the children are interested.

Providers experience many challenges related to inclusion. The inability of settings to maintain a high staff-child ratio needed to care for children having disabilities is due to the lack of funding and high staff turnover rate (Gable & Halliburton, 2003). The high staff turnover is perhaps because child care employment offers low wages, few job benefits, and limited opportunities for professional advancement (Whitebook, 1999).

The manner in which inclusive approaches involving children with disabilities are put into practice, is determined to a large extent by the attitude of providers (Smith & Rose, 1993, Stoiber, Gettinger, & Goetz, 1998). Social psychological literature regarding the role of attitudes in behavior suggests that the attitudes of child care providers may be related to their willingness to include children with disabilities in their programs designed for typically developing children. Numerous research studies have shown that positive attitudes and perceptions of providers are crucial determiners of the acceptance of inclusive practices regardless of the type of program (Mulvihill, Shearer & Van Horn, 2002; Procter & Niemeyer, 2001). On the other hand, negative attitudes held by providers may be a significant barrier to the successful inclusion of young children in early education and child care environments (Eiserman, Shisler, & Healey, 1995; Klein & Sheehan, 1987; Odom & McEvoy, 1990; Recchia, 1995; Rose & Smith, 1993; Tari, Hancock, & Brophy, 1987).

Just as attitudes influence behaviors, behaviors and experiences may in fact lead to the development of certain attitudes (Avramidis, Bayliss, & Burden, 2000; Cooper &

Fazio, 1984; Eagly & Chaiken, 1993; Festinger, 1957; 1964a; 1964b; Festinger & Carlsmith, 1959). When providers have successful experiences with children having disabilities, they become more open and willing to subsequently include other children with disabilities in the future (Buell et al., 1999; Cross et al., 2004). Family child care providers who had experience caring for children with disabilities were more likely to report a willingness to care for them in future (Buell et al.). Early Childhood Education teachers also expressed interest in including other children with disabilities in the future because of the success they had had with “the more challenging child (Cross et al., 2004). Although community-based providers are often concerned about being prepared to serve children with disabilities (Strain, Smith, & McWilliam, 1996), research has indicated that the more positive experiences childcare providers have with children with special needs, the more they enjoy their jobs and the more positive their attitude toward inclusion is likely to be (Soodak & Erwin, 2000; Strain et al., 1996). Therefore, with respect to inclusion, the premise is that changing provider attitudes or behaviors in a positive fashion will present more opportunities for children with disabilities to be included in all types of programs (Jackson, Ryndak, & Billingsley, 2000; Jordan & Stanovich, 2001).

Providers sometimes are hesitant to include children with disabilities in their setting because they are frightened. A common reason for this fear is they feel inadequate to meet the child’s needs (Kliwer, & Macfarlane, 1999). Apprehension often comes from a lack of knowledge or self-confidence (Rose & Smith, 1992). Lack of knowledge regarding care requirements of children with disabilities was cited most often as a barrier to inclusive childcare (Dinnebeil et al., 1998). Inadequate program resources and lack of adequate training opportunities have often been cited as a barrier to successful inclusion

(Bailey & Winton, 1987; Guralnick, 1994; Peck, Hayden, Wandschneider, Peterson, & Richarz, 1989; Wesley, Buysse, Tyndall, 1997). Provider training has been suggested as a strategy to counteract barriers to inclusion (Smith & Rose, 1994), including negative attitudes of care providers (Avramidis et al., 2000; Bailey & Winton, 1987; Gallagher, 1992; Kuester, 2000). While many authors believe that well-trained and dedicated child care providers should be able to easily adapt their skills to accommodate children with special needs (Hanson & Hanline, 1989; Klein & Sheehan, 1987; Ross, 1992), others stress the importance of staff training for successful inclusion (Appl, 1995; Marchant, 1995; Rose & Smith, 1993; Wesley, 1994). Researchers have argued that positive staff attitudes are critical for successful inclusion and that on-going in-service training may be an effective strategy for promoting these attitudes (Kuester; Odom & McEvoy, 1990). Most agree that the nature of this training must be dynamic, ongoing, and responsive to particular program needs (Hanson & Hanline; Klein & Sheehan; Wesley). Disability-specific training increases the teachers' comfort level with serving children having disabilities (Buysse et al., 1996). Caregivers with more training perceived fewer needs and barriers related to inclusion (Giangreco, Dennis, Cloninger, Edelman, & Schattman, 1993).

Childcare providers are interested in a wide variety of training opportunities. Training in behavior management was reported as having the highest priority (Rusby, 2002; Mueller & Orimoto, 1995; Bailey & Osborne, 1994). When frequent behavior problems occur, caregivers are likely to spend more time attending to the problems and less time in positive interactions and learning activities with children. Gaining skills in behavior management would likely increase the quality of care and level of safety in the

child care environment, and increase the time in which caregivers are able to engage in activities to promote child development (Rusby). Other areas in which providers, especially family child care providers need training include curriculum and activities, stress management, social skills development, disability-specific training, learning environments, business management, language development, working with families, assessment, recognizing child abuse, and safety (Rusby). Participants described a need for low-cost training in the evening or on weekends that is relevant to family child care settings with one caregiver serving children of varying ages (Rusby).

Providers also need training in promoting interactions between children with and without disabilities in the setting. In a study of interactions between children with and without disabilities in an integrated preschool, Beckman (1983) found that there were fewer interactions between children with and without disabilities when caregivers had not directly promoted interaction. Potential benefits of mainstreaming are most likely to occur when positive interactions between children with disabilities, their caregivers, and their peers are actively promoted by knowledgeable child care providers (Beckman; Jenkins, Odom & Speltz, 1989; Odom & McEvoy, 1990). Some researchers are of the view that successful integration of children with and without disabilities requires intensive staff development including carefully planned procedures to facilitate the development of social and language behavior (Klein & Sheehan, 1987; Kontos & File, 1993).

Underlying the parent–provider relationship is the ongoing communication that keeps families informed and involved in the decision-making process about their child (Fialka, 2001). Professionals and families agree that without regular communication and

collaboration, there is duplication, fragmentation, and ineffective service provision (Scott, McWilliam & Mayhew, 1999). Cooperation, collaboration and mutual respect between professionals working with children having disabilities are important components of successful inclusive programs (Kontos & File, 1993; Peck, Odom, & Bricker, 1993). Limited time and limited opportunities for collaboration received the highest ratings as barriers to inclusion (Stoiber et al., 1998). In another study, Buysse et al. (1998) found that the complexities of coordinating services for children with disabilities and their families often serve as a barrier to inclusion from the perspective of practitioners and administrators.

Family Child Care Provider and Inclusion

Buell et al. (1999) found that family childcare providers who were unwilling to care for children with disabilities indicated three primary barriers: lack of knowledge about disabilities, limitation that caring for a child with disabilities would impose on caring for other children and the need to purchase special equipment. Past studies have also found that the concerns that family childcare providers have regarding serving children with disabilities include liability, lack of training and inability to meet the needs of these children (Deiner & Whitehead, 1988; Fewell & Neisworth, 1987; Salkever & Connolly, 1988). Family childcare providers mention that they need training in behavior management, planning curriculum and activities, social skills development and working with children having disabilities (Rusby, 2002). Supports indicated specifically by family child care providers include increased information, the need for knowledge about teaching strategies and funds for special equipment (Buell et al.; Deiner & Whitehead; Kontos, 1988).

Theoretical Framework

A comprehensive model of human development that facilitates analysis of how broad social changes impact upon individual development can help us understand the school age child care phenomenon for children with disabilities better. Bronfenbrenner's (Bronfenbrenner, 1979) ecological model is therefore valuable in studying the child care phenomenon. According to Bronfenbrenner (1979), developmental contexts are conceptualized as nested, hierarchical structures existing at four levels. A range of ecological variables is identified, from those directly affecting the individual to those that operate more indirectly through the functions of social institutions and through cultural values and beliefs. The microsystem refers to the structures and processes that occur in the immediate setting containing the developing person (such as the home or childcare setting of the school age child with disabilities). The mesosystem refers to the interrelations of two or more microsystems in which the school age child with disabilities actively participates, such as the relationship between parents and childcare providers, and the relationship between children with disabilities and typically developing children. The exosystem refers to settings in which the developing person does not actively participate, but which affect the person in important ways, such as the parent's, especially mother's workplace or IEP meetings in school. The macrosystem refers to the overarching social, political, and cultural structures of society that define the character and structure of the more proximal systems (e.g. policies on child care access, child care subsidies or incentives to childcare settings for including children with disabilities).

This model suggests that individual development can be fully understood only by considering the impact of each of these systems on the developing person. Further, the

model is congruent with the life span developmental perspective, which holds that development is a lifelong process, with multiple determinants that are multidirectional in nature. This model provides a useful framework for approaching the issue of child care for school age children with disabilities pointing to the importance of reviewing research that bears on each of these developmental contexts.

Changes in the macrosystem, such as social policies and legislation (e.g. policy on child care access, child care subsidy, incentives to childcare settings for including children with disabilities, better leave policies for parents, especially mothers of children with disabilities), may affect more proximal developmental contexts, such as womens' experience in the workplace, or families' economic condition or availability and access to school age child care or children's experience in child care settings, which in turn affect the overall development of children with disabilities.

Thus, it is important to consider not only the direct effects of childcare availability on the development of children with disabilities (microsystem) but also the effects on womens' employment (microsystem and exosystem), the intersection between home and work contexts (mesosystem), home and childcare setting (mesosystem) and the broader social policy initiatives that are relevant to these issues (macrosystem).

One of the central assumptions of Bronfenbrenner's (1979) conceptualization of the ecology of human development is that he characterizes the relationships between individuals and their environments as transactional. A transactional perspective highlights the reciprocal and co-evolutionary qualities of change occurring in both individuals and their environments over time (Peck, 1989). This assumption suggests that we should look carefully at both the effects of integrated environment on the child, and how the inclusion

of children with disabilities affects the environment itself, including possible changes in instructional practices, teacher behavior and social relationships among children (Guralnick, 1981, 1990). Concerns about how inclusion may affect the programmatic environment have often focused on the possibility of negative impacts such as reduction in teacher attention to non-disabled children or deceleration of curriculum coverage (Peck et al., 1989). Some studies on older children (e.g. Biklen, Corrigan, & Quick, 1989; Murray-Seegert, 1989) also suggest that including children with disabilities may actually affect mainstream programs positively.

CHAPTER 3

PARENTS' EXPERIENCES IN SEEKING CHILD CARE FOR SCHOOL AGE
CHILDREN WITH DISABILITIES—WHERE DOES THE SYSTEM BREAK
DOWN?¹

¹ Jinnah, H.A., & Stoneman, Z. (2008). Accepted by *Children and Youth Services Review*. Reprinted here with permission of publisher.

Abstract

The purpose of this study was to examine the process through which families of school age children with disabilities seek care and to identify the points in the process where the system fails families. Using a qualitative approach, we track the pathways that families follow in their quest to secure care. Focus groups and phone interviews were conducted with 37 parents. Data were analyzed qualitatively using a grounded theory approach with the help of Nudist (N6) software. Clear patterns emerged regarding why care options were perceived to be unavailable. We use a flowchart, which we call the 'care cycle' to identify pathways representing the sequence of activities followed by families in their search for child care. We also discuss possible solutions that can help address barriers that occur at each phase of the care cycle.

Keywords: Child care, school age care, disabilities, focus groups, parents, access, challenges, care cycle.

Introduction

During the year 2004, 73% of all women in the U.S. with children between ages 6 and 17 years were employed (U.S. Bureau of Labor Statistics, 2005). This statistic highlights the large proportion of women with school age children in the labor force. Also, the 2000 U.S. census reported that there are 2.6 million children between ages 5 and 15 years who have a disability (U.S. Census Bureau, 2003). There is evidence to suggest that labor force participation of mothers of children with disabilities is significantly lower than that of mothers having children without disabilities (Brandon, 2000; Glendinning, 1992; Lukemeyer et al., 2000; Shearn, 1998; Worshtil, 1990; Seltzer et al., 2001; Beresford, 1995; Shearn & Todd, 2000; Olsson & Hwang, 2003). Parents of children with disabilities in contrast to other caregivers are more likely to work part-time, earn less money, and take leaves to care for their children (Gallimore et al., 1993; LeRoy & Johnson, 2002; Shearn & Todd, 2000; Warfield, 2001). A large proportion of these mothers remain full-time home makers through their midlife, when other mothers in their age group work outside of the home (Gallimore et al.; Parish et al., 2004; Seltzer et al.). Parish et al. concluded from an analysis of Wisconsin Longitudinal Study data that reduced employment rates for mothers of children with disabilities place them at long-term economic disadvantage. They suggested that these families might experience increased economic vulnerability as they age. Lukemeyer et al. found that children with severe disabilities placed increased financial strain on families who were already

economically disadvantaged. The more substantial the child's disability, the less likely the child's mother was to be employed.

Nationally representative findings suggest that the impact of a child with a disability on parental employment varies with marital status. Married mothers of school age children with disabilities are less likely to be employed than other married mothers of school age children, while single parents of school age children with disabilities are employed at rates similar to those of single parents of non-disabled children (Porterfield, 2002). In a parallel finding, Parish and Cloud (2006) found minimal differences between low-income families of school age children with and without disabilities in their overall use of childcare. The authors suggest that economic hardship may force low-income parents, including many single parents, to enter the workforce and find some type of care for their children regardless of barriers encountered. However, they also found that children with disabilities paid very low hourly cost suggesting that the care that they receive may be of questionable quality.

In another study, Wall et al. (2006) reported that children with disabilities received care of lower quality than their typically developing peers, and their parents were less satisfied with the care arrangements. Cuskelly et al. (1998) found that 100% of Australian mothers of children with disabilities indicated that they were employed because their "wage is needed". In such cases, families may have fewer options or control over the type and quality of care arrangement. Thus, even if single parents having children with disabilities report using child care at the same rate as parents with typically developing children, the decision may be driven more by the economic need rather than choice, and the care that their children receive may be of questionable quality.

Jobs outside the home not only provide mothers with financial remuneration and health benefits, but also provide psychological fulfillment and a sense of control over their lives (Freedman et al., 1995). Lack of employment can lead to psychological costs, such as feelings of isolation, lack of fulfillment, and low self-esteem (Shearn & Todd, 2000). Being involved in paid work as well as in parenting provides mothers the buffering effects of multiple roles (Barnett & Hyde, 2001), which may be associated with benefits, including decreased caregiver stress (Kagan et al., 1999; Shearn & Todd).

For the past 20 years, researchers have cited the inability of parents to find appropriate childcare for school age children with disabilities as a major barrier keeping mothers from entering, or re-entering, the workforce (e.g. Fink, 1988; Scott, 1988; Seltzer et al., 2001). This problem continues to exist even though the Americans with Disabilities Act (ADA) passed in 1990 prohibits childcare centers, as places of business, from discriminating against children with disabilities and requires them to make appropriate modifications needed for the full participation of these children. In addition to challenges in finding formal childcare, parents of school age children with disabilities also report less access to informal care from relatives, friends, and older siblings who are either unavailable or viewed as not competent or physically able to provide the required care (Kagan et al., 1999; Shearn & Todd, 2000). A significant proportion of mothers who do not work outside the home would like to join the labor force if appropriate childcare were available (Shearn & Todd; Worshtil, 1990). Among employed women, limited childcare options force mothers of children with disabilities into jobs that are less career-oriented and that under utilize their skills (Warfield, 2005; Shearn & Todd; Glendinning, 1992).

In addition to benefiting parents, inclusive childcare also benefits children. The presence of social role models to foster learning is important for children with disabilities (Martin, 2000). This is especially important for older children who increasingly look to their peers for support and approval (Abery & Simunds, 1997; Owens, 2002). Inclusion offers typically developing children opportunities to develop an appreciation for others who are different from them, to develop social skills, and to learn altruistic behaviors (Staub, 1996; Terrell, 2001).

Researchers have examined reasons why care options are unavailable for many families of school age children with disabilities. Some challenges faced by these families are similar to those faced by all families looking for out-of-school care, such as the lack of care options in rural areas (Kagan et al., 1999; Miller et al., 1995), during summer and holidays (Fink, 1988; Parish, 2006), and lack of transportation (Parish, 2006; Miller et al., 1995). Certain problems, however, are more aggravated for children with disabilities, including children with behavioral problems (Fink, 1988; Freedman et al., 1995; Kagan et al., 1999) and those having severe or multiple disabilities (Worshtil, 1990; Brandon, 2000; Wagner et al., 2002; Palfrey et al., 1989).

When children are young, they have increased needs for care and supervision. Child care settings providing for young children are therefore geared toward meeting these needs. As typically developing children grow older, they become more independent and autonomous and therefore they can spend increased amounts of time with minimal supervision and care. Unlike typically-developing children, some children with disabilities may require close supervision and care well into middle and high school years (Freedman et al., 1995). Many youth with significant disabilities require constant

supervision, even after they reach an age in which other children can safely spend periods of time away from adults (Freedman et al., 1995; Parish & Cloud, 2006). Parents of these youth often face major challenges in securing appropriate care (Kagan et al., 1999; Worshtil, 1990; Parish, 2006; Shearn & Todd, 2000). The current after school care system is geared to meet the needs of typically developing children but families having school age children with disabilities struggle to find settings that would appropriately accommodate children with disabilities.

DeVore and Bowers (2006) studied the processes through which families of young children with disabilities sought and successfully secured childcare, but similar process-oriented data do not exist for families of school age children. From existing research on school age care, it cannot be clearly determined at what point in the process that the system breaks down for families. Brandon (2000) noted that it is difficult to formulate coherent policy without further research elucidating the specific childcare barriers faced by families of school age children with disabilities. In this study, we used qualitative focus group methods to track the pathways that families follow in their quest to secure care. The purpose of the current study was to examine the process through which families of school age children with disabilities seek care and to identify the points in the process where the system fails families.

Method

Focus Groups

Because focus groups allow participants to share or discuss their responses in a group, often a broad range of issues and diverse opinions are gathered (Carney et al., 1998; Krueger & Casey, 2000). Also, because of the structured, yet open nature of focus

groups, facilitators have the flexibility to explore unanticipated issues that may emerge (Krueger & Casey). These strengths led us to adopt focus group methods for this study. Five communities, representing urban, rural, and semi-urban areas, were targeted. Local coordinators (i.e., childcare inclusion coordinators, family support personnel, and childcare resource and referral employees) assisted with recruitment for the focus groups and provided logistical support. These local coordinators made the initial contacts with potential participants. Coordinators used purposive sampling to recruit families having children with a wide range of disabilities. The coordinators targeted parent groups, parents in their databases, and parents the coordinators knew personally.

Five focus groups were held at community locations based on the convenience of the participants. Sessions lasted approximately 2 h and were audio taped. Two researchers facilitated each group; one served as moderator and the second as scribe, taking notes. A semi-structured interview guide, which provided direction for the discussion, included questions about the out-of-school care parents used for their children with disabilities and their experiences in finding and maintaining that care. Discussion ended with the moderator summarizing the themes and issues that emerged, verifying information with participants, and thanking the parents.

Individual parent interviews

Eight phone interviews were held with parents, many of whom lived in rural areas, who wanted to participate but could not attend the focus groups. The phone interviews, conducted by the researchers who facilitated the focus groups, followed a similar process in that they were audio taped and similar questions were asked.

Participants

A total of 37 caregivers (34 mothers, 2 fathers, 1 grandmother) participated in the focus groups (n=29) and phone interviews (n=8). Eighty-one percent were white/non-Hispanic; 16% were African American; 3% were Asian. Seventy-six percent were two-parent families. Respondent ages ranged from 25 to 64 years; 46% were between the ages of 35 and 44. Families had an average of two children (ranging from 1 to 4). Eight percent of the respondents had a high school degree or GED; 3% attended technical school; 27% had some college; 11% had an associate degree; 30% had a college degree; 14% had some graduate work; and 5% had a graduate degree. One participant did not provide this information.

Among the 28 two-parent families, 23% had both parents employed full-time, 36% had one parent employed part-time, and 41% had both parents not employed. Of the 9 single parents, 33% were employed full-time, 11% were employed part-time and 56% were not employed. Nineteen percent of the families earned less than \$30,000 per year; 46% earned between \$30,000 and \$59,999; and 35% earned over \$60,000. Most of the families (65%) did not use formal center- or family-based care at the time of the focus groups. Eleven percent used after school care at a childcare center; 11% used after school care at school; 5% used after school care at a community location; 5% used family-based childcare; and 5% had children participating in recreational activities or clubs.

The children with disabilities ranged in age from 6 to 22 years (mean=11 years). Most of the children were male (26 or 70%). All children were reported to be of the same racial group as their parents. Sixteen of the children had autism or pervasive developmental disorder (PDD), 6 had Down syndrome, 7 had other intellectual

disabilities, 4 had cerebral palsy, 2 had spina bifida, 1 had Aspergers' syndrome, and 1 had ADHD. Three of the children with cerebral palsy also had intellectual disabilities; one of these children also had cystic fibrosis. Another child with cerebral palsy and an intellectual disability also had autism. One child with PDD had an additional diagnosis of schizophrenia.

Data Analysis

The focus group and phone interview audiotapes were transcribed verbatim. Data analysis took place simultaneously as data were being collected. Following each focus group, the moderator and the scribe debriefed the session summarizing the main themes. After the second focus group and the groups thereafter, the moderator and scribe also discussed repetition of themes that had emerged. Identification of recurring themes helped researchers gain a sense of issues to be further explored for greater understanding. This is consistent with the recursive process approach to focus groups, which involves constant reflection to refine research design, procedures, and questions based on emerging themes (Brotherson, 1994).

Data were analyzed using the constant comparative method described by Glaser and Strauss (1967) which is an iterative process of collecting and analyzing data with the ultimate aim of generating a theory that is 'grounded' in the natural context in which the inquiry takes place. Information was collected until it reached a point of saturation. Data collection was stopped when most of the issues brought up by the parents were being repeated. Elements of frequency, extensiveness and intensity of the comments expressed by participants were taken into consideration. Initial ideas or themes were first identified into discrete categories (open coding), then fractured and recoded using axial coding to

make connections between categories and sub-categories that reflected more generalized, emerging themes (Vaugh, Schumm, & Sinagub, 1996). Finally categories were integrated to form a grounded theory (selective coding) that clarified concepts and allowed for interpretations and conclusions (Gilgun, Daly, & Handel, 1992). The qualitative software program, Nudist 6.0 (N6) was used for analysis.

Trustworthiness was established by the discovery that findings were generally consistent across the five focus groups. Multiple researchers checked and read the transcripts and analyzed the data. Threats to analytic validity were addressed through member checks. Member checks were conducted by mailing written summaries of conclusions drawn by the researchers to a random sample of participants and followed up with phone interviews to make sure the participants identified with the themes that had emerged. This process allowed participants to evaluate the fairness and validity of the interpretations and conclusions of the research team. Although transferability is not a critical issue in qualitative analysis (Maxwell, 1996), we had a diverse sample in terms of the breadth of disabilities and geographic location to enhance transferability.

Results and Discussion

During focus group discussions, parents identified numerous problems in their search to find childcare for their school age children with disabilities. A parent of a 6-year-old with autism described her situation in these words, “The childcare options that I currently have for my child is zero. How's that for an answer? Zero. There is absolutely none anywhere.” Based on analysis of the focus group comments, we teased out the reasons why care options were often perceived to be unavailable. Clear patterns emerged from the data. We use a flow chart, which we call the care cycle (see Fig. 1), to identify

pathways representing the sequence of activities followed by families in their search for childcare. At every phase of cycle, families experienced success or failure. Families take different pathways in the care cycle based on their unique characteristics and life situations. The same family may repeat steps in the cycle, as care solutions are found and then lost. The following sections describe each phase of the care cycle.

Phase 1: Absence or Presence of Out-of-School Care Settings

To start with, at the very top of the care cycle, is the presence or absence of care settings for school age children in a given geographical area. A parent of an 8 year old with cystic fibrosis and cerebral palsy described, “There is nothing, as far as I know, in several of the surrounding counties where I am at.” Options were more limited in rural areas. A parent of an 8 year old with multiple disabilities commented:

I think my county is more rural and so, there is nothing. I mean for the most part the parents either have grandparents or whatever that watch their children. I don't have that option available to me. It basically ties my hands behind my back...

If there are no care settings available in the community, then all families of school aged children, including children with disabilities, will fail in their attempts to acquire formal care.

When care is not available close to home, parents may have to travel long distances. The parent of a 16-year-old with PDD said, “I've contacted respite type facilities and they are all far away. You really have to travel to be able to access a lot of the activities.” Traveling can present barriers that are disability-related, as described by a parent of a 7-year-old with autism.

They are all, like, in the north part of the town, at least an hour to hour and a half away, and the time it would take to drive there in traffic, it would be horrendous for him. He is not a very patient person. It would be horrible for me in the car...

Another parent of a 16 year old with PDD commented:

...most of the things are more in downtown type area and that is in after school traffic that would take an hour to get there and for a lot of our kids riding in the car is not a great experience. So by the time you get there they are a little stressed out...

Transporting children with physical disabilities also poses challenges, as described by a parent of an 8-year-old, “Picking up and putting a wheelchair in the van, three or four times a day and driving over here. Then you can't work a full-time job because you don't have any care for them. Then to pay for the gas, you know? It gets complicated. It's just ridiculous.”

Regardless of the disability status of the child, care options often become unavailable during certain times of the year (Fink, 1988; Parish, 2006). A mother of a 13-year-old with autism and cerebral palsy explained: “It's just that there is no alternative option. It's closed on school, federal holidays”. Summers are a problem, as described by a parent of a 15-year-old with spina bifida, “I went so far as to ask the school system to put him in summer school, just so he would have something to do all summer and there's nothing. So when school gets out, he'll sit at home all summer.” Although all families can experience challenges in developing opportunities for their children during summer vacation from school, summers are more likely to mean isolation and loneliness for some

children with disabilities. Even visiting friends can be challenging as described by this parent of a 17-year-old with spina bifida:

The biggest downside is once you're off from school or in the summertime, there's no socialization. She runs the risk of a great deal of loneliness. I try to get people to come once in a while, friends of ours, but again we're dealing with mostly older people. The problem we ran into as she was growing up is the regular education kids were okay to play with her until they got to be about 8 years old. 8, 9, 10, in that range, then they left her in the dust. They went upstairs to play; she can't get upstairs. Friends would invite us to their house. Well they have a drive under garage with a large number of steps to get up into the house and so the accessibility just wasn't there.

Unlike typically developing children, children with disabilities may need care well into middle and high school years (Freedman et al., 1995). The childcare system is geared to meet the needs of younger children. A mother of a 20-year-old with Down syndrome explained, “Well, I think it's because most children, after they get thirteen, fourteen and fifteen, they can stay home for a couple of hours by themselves, but our kids can't do that, they have to have constant supervision.” A parent of a 13-year-old with autism shared a similar concern:

Below 12 years old there is childcare in the after-school programs, you just have to make the school system do it (6th grade or below). But after 6th grade, there's absolutely nothing. Childcare centers only take children up through 12-years-old, for insurance purposes. There's nothing that says they have to take your child if he is over 12-years-old. I see that as the number one thing. Typical children can

be latchkey kids, our kids can't. I'd end up in jail if I said; he's got the key to the house, just drop him off there!

A parent of an 11-year-old with autism commented, “I would like to see the older children thought about more. It seems once they reach a certain age they're left to their own, especially middle and high school.”

Thus, for some families, a major challenge occurs early in their search for care, namely the total lack of after school, summer, or holiday care settings for all children, regardless of their disability status. Additional issues can affect families of children with disabilities, including transportation challenges and the lack of care options for older youth with disabilities.

Phase 2: Providers Accept or Refuse Care for Children with Disabilities

When care options are present, the next phase in the care cycle occurs when a parent of a child with a disability applies for program access. In spite of the Americans with Disabilities Act that prohibits discrimination against children with disabilities, some providers refuse parents outright. A parent of a 6 year old with autism had the following experience: “They gave me all the information that I needed. I walked in and found out all the information, the rates, teachers names. They gave me a tour of the facility, but then when they heard autism they had no availability.” A parent whose child has cerebral palsy and cystic fibrosis noted the reality that many parents experience, “There are not many options. Childcare centers find all kind of legal loopholes that naturally are going to apply to a child with disabilities...It gets very frustrating.” In addition to their own experiences, parents described situations faced by other families of children with disabilities. A parent of a 13 year old with autism mentioned, “...I know of one parent

right now who is actually paying her son's para-professional to do after school care for him in her home because her school refused to allow her son in their after school program.” A parent of a 17-year-old with an intellectual disability noted, “Just if someone is having lots of behavior issues they probably don't let them come...I know a lot of them with the behavior issues. I guess they don't go any where for after school care.”

Children's inability to perform self-care tasks such as toileting or eating sometimes causes providers to deny acceptance. A parent of an 8-year-old with cerebral palsy explained:

First of all, you can't find settings.... To have someone at the after-school program that will be there for him to be able to attend to his toiletry needs. He's potty trained, but he walks on crutches and it's not as easy for him just to go to the bathroom. He can't get his pants down by himself. The extra help that he needs for his self-care is something that we hit roadblocks with constantly.

Many typically developing children spend out-of-school hours in organized activities, such as sports, rather than in formal group after school care. A parent of a 6 year old with autism noted that personnel responsible for these activities frequently deny access to children with disabilities, “I find it very hard to get into childcare centers, sports activities and clubs etc. because they don't have the training to deal with the autism, they are scared of it. They don't want to deal with it because they don't want to be held legally liable for anything that may go wrong.” A parent of a 12-year-old with an intellectual disability commented: “The department of recreation offers things like t-ball, softball for

typically developing children, but there is nothing offered for children with special needs.”

Phase 3: Providers Terminate or Continue Care

Parents stressed that even if they were successful in enrolling their children in out-of-school programs, they could not be confident that the placement would last. Providers may accept children with disabilities, but when difficulties arise, care is often terminated. A mother of a 12-year-old with autism explained:

There are a lot of people that say they will take kids with disabilities, but they put in a little disclaimer that if their behaviors are safety issues then they're out, which rules out just about every autistic child I've ever known. I'm fortunate enough that I don't have to work so I can be at home when he gets off the bus. But if I had to work, I have no idea what I would do.

For many parents, loss of care happened again and again. A parent of a 13-year-old with autism and cerebral palsy commented, “She was expelled four times in 4 months.” Other parents recounted similar experiences.

We got kicked out of the first daycare. We went to one setting, he was there for 2 months, and we've literally been kicked out by everybody. I went on family medical leave with my job and after my 15th phone call, I found this new setting and we lasted 2 months there, also. So there's just nobody there to keep our kids and I can't even work. There's nobody (Parent of a 6-year-old with autism).

My son, this year, was kicked out of the after-school program on day four. He was thrown out because of behavior issues, because they couldn't handle those. Last year he made it 4 1/2 weeks and he was kicked out, never to return. They do give

you 3 strikes and you're out. Last year he was kicked out, once he was hospitalized, they didn't even want to deal with him (Parent of a 9-year-old with PDD and schizophrenia).

Phase 4: Parents continue Care or remove their Child from the Care Setting

Even when providers continue to serve a child, parents sometimes terminate care. If parents are satisfied, then the care option is successful and care continues. However, if the parents are not comfortable, they may withdraw the child. Safety is sometimes a concern. A parent of an 8 year old with autism commented: “They told me they had a problem but they would try to work through it. Yet I decided to take him out because he kept running away and I didn't want him to get hit by a car.” The parent of a 9 year old with autism elucidated:

It's not only that centers won't take your children, it's that I don't want to leave my son somewhere where he's going to get hurt or he's going to hurt somebody else. Even though they say we'll take him, you know, if somebody makes him mad he'll smack them in the head with something.

A parent of a 9 year old with schizophrenia made a poignant comment:

In day care centers, if they have one child in a wheelchair, they've got access. The sad thing is, some days I truly wish my child was in a wheelchair. If they have a disability of the mind, the brain, it should be treated the same. Yet, it's still not that way. I'm so frustrated every day. If they have one kid in a wheelchair they have to have a ramp, bars around the toilets. If they have one kid with a mental disability, they won't.

Among the focus group parents, only one parent, the mother of an 8-year-old girl with Down syndrome, described being satisfied and happy with the care arrangement for their child, “I would like to say that I've done after school care for my child and she goes and fits in just fine. They're very willing and accepting of her.” Unfortunately, most of the parents who successfully found out-of-school care were not positive about the quality of their children's experiences in the setting. A parent of a 16-year-old with PDD summarized, “I haven't talked to a parent yet who has found something they are happy with.” Even when parents maintained their children in the settings because they needed the care, many were anxious and concerned about their choice.

Repetitions of the Care Cycle

Care options for school age children with disabilities tend to be unstable. Families make their way through the care cycle again and again. At any phase in the cycle, if the care situation ends, the family either starts from the top of the care cycle, searching for another care option, or they may give up and decide to care for the child themselves. A family may fall into different phases of the care cycle at different times in their child's development. Care options may be identified for a younger child, but then lost as the child “ages out” of the setting or activity.

Implications

The first step in solving a problem is to clearly identify and understand the nature of the problem. Understanding why childcare is unavailable to many families of school age children with disabilities is important in order to find enduring solutions. The care cycle that emerged from study data provides a framework for understanding the sequence of activities followed by families in their search for childcare and the points in the

sequence in which care becomes unavailable. In this section we discuss possible solutions that can help address barriers that occur at each phase of the care cycle.

For parents at Phase 1, local out-of-school care options may not be available for children regardless of whether or not they have disabilities. For example, summers and holidays create care problems for most families. Economic development in rural areas is hindered by lack of childcare options. These shared issues create opportunities for families of children with and without disabilities to band together to create change. For example, parents could establish a community task force to explore how inclusive out-of-school programs could be developed and funded. This taskforce would have broad membership, including parents of children with and without disabilities, care providers, educators, and economic development representatives.

Older youth with disabilities present different challenges. Formal childcare is less normative for older children (Shearn & Todd, 2000). Since typically developing youth required less supervision as they age, older youth often spend out-of-school time in recreational and sports activities that are staffed with only a small number of adults. Adding youth with more intense supervision needs to these settings without additional modifications frequently would not result in a positive outcome. In states with family support programs (Parish, Pomeranz-Essey, & Braddock, 2003), families can use this flexible funding to hire a companion who could transport the youth to desired activities and provide individualized on-site support and supervision. By considering the full resources available in the community, the availability of quality, age-appropriate inclusive out-of-school programs and activities for older children can be increased.

For families in Phase 2, care options exist but children with disabilities are denied acceptance. The solution to this problem involves training and information. Providers and parents need to be made aware of the American's with Disabilities Act (ADA). Title III of the ADA requires that center-based childcare and home care facilities, as places of business, examine their rooms and spaces, playgrounds, and activities to make themselves accessible to children with disabilities (Craig & Ann, 1994; Parette & Murdick, 1994). Providers sometimes are hesitant to include children with disabilities in their setting because they are afraid and feel inadequate to meet the child's needs. Lack of knowledge regarding care requirements of children with disabilities has been cited as a major barrier to inclusive childcare (Dinnebeil et al., 1998). Provider training has been suggested as a strategy to counteract barriers to inclusion (Smith & Rose, 1994), including negative attitudes of care providers (Avramidis et al., 2000; Kuester, 2000; Buell et al., 1999; Buysse et al., 1996; Giangreco et al., 1993). When both providers and parents are aware of the legal requirements for access contained in the ADA and when providers have the training to feel confident in supporting children with disabilities, fewer children will be turned away from care.

For parents in Phase 3 of the care cycle who are confronted with termination of services, the solution also rests on increased provider training, as well as on resources for ongoing technical assistance and programmatic support for providers. Training opportunities need to be made available to providers so that they know how to make appropriate adaptations and modifications to meet the needs of children with disabilities while maintaining the challenge and fun for other children in the setting. Specifically,

providers need training in strategies to address challenging behaviors; the major issue cited by many of the focus group parents as being responsible for program termination.

In addition to training, on-site technical assistance needs to be available to providers in order to help them address challenges presented by specific children. Childcare resource specialists, school personnel, or other community providers could provide this support. Disability service providers could also be called upon for assistance. These professionals are often unaware of the childcare barriers faced by parents (Parish, 2006; Shearn & Todd, 2000), but could provide important expertise if asked. Often the child's parents are the most important resource to assist in problem solving around individual children. Parents know their children and know the strategies they use to teach and manage their children. Several parents mentioned that they either were never asked by providers to assist in problem-solving, or their suggestions were not followed. Quality communication between parents and providers could help solve these problems.

In order to address the lack of parent comfort and satisfaction with care arrangements creating barriers at Phase 4 in the care cycle, several previously identified solutions come into play. Parents feel comfortable with care when they believe their children are safe, there is adequate supervision, and activities and settings are age-appropriate and are modified to involve their children. These outcomes occur when providers are adequately trained and philosophically committed to inclusion, providers and parents have trusting open communication, and providers engage in creative problem solving with parents and outside consultants when problems arise. Unfortunately, low-income women, including many single parents, must access care for their children with disabilities due to economic necessity and in order to stay employed. These women do

not have the luxury of terminating care with which they are dissatisfied. Parish and Cloud (2006) caution that the children of these women, especially those with complex care needs may be at particular risk for negative developmental outcomes. The care needs of these children require special attention. The dire choices faced by economically stressed families remind us that just because families have secured out-of-school care for their children with disabilities does not mean that the care is of high (or even adequate) quality.

The care cycle identified in this paper focuses attention on one set of solutions to the out-of-school care barriers faced by parents. Other solutions proposed in the literature supplement the issues that arise from the phases of the care cycle. For example, Brandon (2000) suggested supply-side interventions, such as providing financial incentives to providers to provide care for children with disabilities. Other solutions, such as increased employer flexibility and job sharing (Shearn & Todd, 2000) originate in the workplace. Demand-side interventions, such as providing childcare vouchers (Brandon; Freedman et al., 1995), have also been proposed. The care cycle does not provide a comprehensive examination of the overall system of childcare availability, but does provide important insights about parents' experiences in seeking childcare and about workable solutions that address specific situations faced by families as they search for care.

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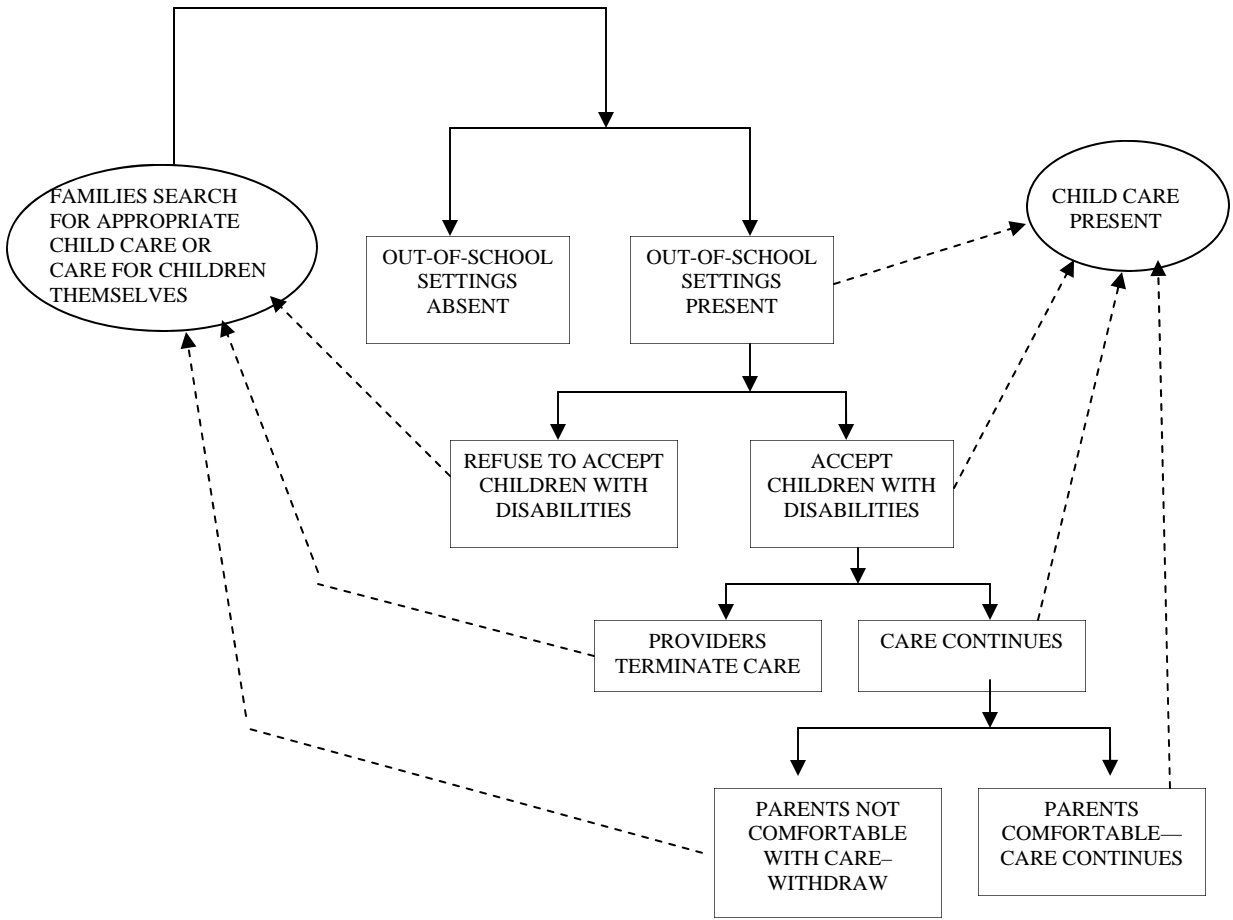


Figure 1. Care cycle for families of school age children with disabilities.

CHAPTER 4

ELEMENTS OF SUCCESSFUL INCLUSION FOR SCHOOL AGE CHILDREN WITH
DISABILITIES IN CHILD CARE SETTINGS²

² Jinnah, H.A., & Stoneman, Z. (2008). Submitted to *Child Care in Practice*.

Abstract

When a school age child with disabilities is accepted into a child care setting, it is only the first step. The sustenance of the care option depends on whether the setting makes appropriate adaptations to accommodate the child with disability in the setting. Parents face a host of challenges related to adaptations and accommodations. This study focuses on parents' perspectives related to features needed to appropriately accommodate school age children with disabilities in child care and other out-of-school settings. Focus groups and phone interviews were conducted with 37 parents. Data were analyzed qualitatively using a grounded theory approach with the help of Nudist (N6) software. Parents identified a host of adaptations including adaptations of physical space and activities, adaptations focusing on peer socialization, supervision and safety, parent-provider communication, and those focusing on the attitude and skills of child care providers.

Keywords: Child care, school age care, disabilities, focus groups, parents, adaptations, accommodations, challenges, supports, resources, communication.

Introduction

Labor force participation of mothers of children with disabilities in United States is significantly lower than that of mothers having children without disabilities (Brandon, 2000). A large proportion of these mothers remain full-time home makers through their midlife, when other mothers in their age group work outside of the home (Gallimore et al., 1996). The inability of parents to find appropriate child care for school age children with disabilities has been cited as a barrier keeping parents from entering, or re-entering, the workforce (Fink, 1988; Scott, 1988; Seltzer et al., 2001). This study focuses on parent's perception of the specific elements and associated practices that facilitate successful inclusion of school age children with disabilities in child care settings.

Including school age children with disabilities in child care settings is important not only to enable their parents to work full-time, but also because these experiences are important for the social and emotional development of these children. Inclusive child care settings provide children having disabilities with role models to foster their learning of adaptive and social skills through imitation (Wolery & Wilbers, 1994). Children with disabilities in inclusive settings show developmental gains, especially in areas of communication, social and motor skills (Brady et al., 1991; Odom & McEvoy, 1990; Burack & Volkmar, 1992). The benefits of inclusion are not restricted to children with disabilities but extend to typically developing children as well (Terrell, 2001). Inclusion offers typically-developing children the opportunity to develop tolerance and an

appreciation for others who are different from them and to learn altruistic behaviors like patience, kindness and respect (Peck et al., 1992; Staub, 1996).

In the past two decades, laws that have implications for inclusion of children with disabilities in child care settings have been passed and reauthorized. The Americans with Disabilities Act (ADA) passed in 1990 requires child care centers, as places of business, to include children with disabilities and make appropriate modifications that are needed for their full functioning. Title III of the ADA requires that center-based child care and home care facilities examine their rooms and spaces, playgrounds, and activities to make themselves accessible to children with disabilities (Craig & Ann, 1994; Parette & Murdick, 1994). The Individuals with Disabilities Education Act (IDEA) reauthorized in 1997 requires children with disabilities to receive education and care in places where typically developing children spend their time. A key implication embedded in these laws is that children with disabilities should be able to fully participate in child care settings that serve typically developing children. With laws like ADA and IDEA, child care providers cannot discriminate against school age children with disabilities. However, parents still struggle to find child care centers that will accept and make appropriate accommodations needed for the successful inclusion of their children.

Past studies on inclusion of children with disabilities in child care settings have focused almost exclusively on young children and have examined the needs of child care providers, rather than the perspectives of parents. This research has identified barriers that prevent young children from being included in child care settings, including attitudes of providers (Dinnebeil et al., 1998; Buell et al., 1999; Buysse et al., 1996); and lack of provider knowledge and training (Fewell, 1993; Warfield & Hauser-Cram, 1996;

Dinnebeil et al., 1998). Researchers have also looked at program practices that can help full inclusion of young children with disabilities (Newman & Tyler, 1991). Through direct observations and conversations, Brennan et al., 2002 investigated practices child care staff used to include young children with emotional and behavioral challenges into child care programs. Setting up physical and social environments to encourage cooperation and self-regulation, building strong relationships with individual children, anticipating social and emotional challenges, peer acceptance of children with disabilities, and integrating mental health services into the scheduled center activities were some of the key practices used by staff to ensure inclusion. Cross et al. (2004) suggested that there are identifiable elements and associated practices that contribute to successful inclusion of young children with disabilities in community settings. According to them, provider attitudes, parent-provider relationships, therapeutic interventions, and adaptations are the four elements contributing to successful inclusion of young children with disabilities in child care settings.

There is scant information on the elements needed to successfully support the inclusion of school age children with disabilities in child care settings. As children with disabilities grow older, their characteristics and needs keep changing. Therefore, the supports that they would need for their full functioning in inclusive settings would be qualitatively different from those needed by younger children. Fink (1988) explored parent's experiences in seeking and using child care for their school age child with disabilities. He presented snapshots of the perspectives of 66 parents of children between 5 and 16 years who had mild to severe disabilities. Based on parent's experiences, Fink suggested important adjustments to the physical environment, adaptations of activities,

orienting families to the program and its services, involving family in child's program, maintaining open, honest communication with families and providing supports to the family. However, these findings are twenty years old; it is not clear whether these issues have changed or remained the same over this period of time.

Further research is needed to understand and implement practices that permit school age children with disabilities to have a successful inclusion experience (Cross et al., 2004). Parents' perspectives on the supports and accommodations that will be best for full inclusion of their children in child care settings is underrepresented in the literature. Most studies to date have considered the perspectives of experts and providers on how to make inclusion work. The adoption of family centered practices in early intervention has led to numerous studies assessing parents' resources, priorities and satisfaction with services (e.g. Bailey & Simeonsson, 1988; Turnbull & Turbiville, 1995). The embracement of family-centered practices in school age child care requires that the needs and concerns of parents and their views on ideal school age care for their children with disabilities be considered. This study seeks to fulfill this gap in the literature by focusing on parents' perspectives related to features needed to accommodate school age children with disabilities in child care and other out-of-school settings.

Method

Focus Groups

Five focus groups were held at community locations in the Southern United States based on the convenience of the participants. Five communities, representing urban, rural, and semi-urban areas, were targeted. Local coordinators (i.e. child care inclusion coordinators, family support personnel, and child care resource and referral employees)

assisted with recruitment for the focus groups and provided logistical support. These local coordinators made the initial contacts with potential participants. Coordinators used purposive sampling to recruit families of children with a wide range of disabilities. The coordinators targeted parent groups, parents in their databases, and parents the coordinators knew personally. Two researchers facilitated each group; one served as moderator and the second as scribe, taking notes. A semi-structured interview guide, which provided direction for the discussion, included questions about the out-of-school care parents used for their children and their experiences related to adaptations and accommodations needed by their children in those settings. Discussion ended with the moderator summarizing the themes and issues that emerged, verifying information with participants, and thanking the parents. Sessions lasted approximately two hours and were audio taped.

Individual Parent Interviews

Phone interviews were held with parents, many of whom lived in rural areas, who wanted to participate but could not be included in focus groups. The phone interviews, conducted by the researchers who facilitated the focus groups, followed a similar process in that they were audio taped and similar questions were asked.

Participants

A total of 37 family caregivers (34 mothers, 2 fathers, 1 grandmother) participated in the focus groups ($n = 29$) and phone interviews ($n = 8$). Respondent ages ranged from 25 to 64 years; 46% were between the ages of 35 and 44. Families had an average of two children (ranging from 1 to 4). Eighty-one percent were white/non-Hispanic; 16% were African American; 3% were Asian. Seventy-six percent were two-parent families. Eight

percent of the respondents had a high school degree or GED; 3% attended technical school; 27% had some college; 11% had an associate degree; 30% had a college degree; 14% had some graduate work; and 5% had a graduate degree. One participant did not provide this information.

Among the 28 two-parent families, 23% had both parents employed full-time, 36% had one parent employed part-time, and 41% had both parents not employed. Of the 9 single parents, 33% were employed full time, 11% were employed part-time and 56% were not employed. Nineteen percent of the families earned less than \$30,000 per year; 46% earned between \$30,000 and \$59,999; and 35% earned over \$60,000. Most of the families (65%) did not use formal center- or family- based care at the time of the focus groups. Eleven percent of the families used after school care at a child care center; 11 % used after school care at school; 5% used after school care at a community location; 5% used family-based child care; and 5% had children participating in recreational activities or clubs.

The children with disabilities ranged in age from 6 to 22 years (mean = 11 years). Most of the children were male (26 or 70%). All children were reported to be of the same racial group as their parents. Sixteen of the children had autism or Pervasive Developmental Delay (PDD), 6 had Down syndrome, 7 had other intellectual disabilities, 4 had cerebral palsy, 2 had spina bifida, 1 had Aspergers syndrome, and 1 had ADHD (Attention Deficit Hyperactive Disorder) with an accompanying cognitive delay. Three of the children with cerebral palsy also had intellectual disabilities; one of these children also had cystic fibrosis. Another child with cerebral palsy and an intellectual disability also had autism. One child with PDD had an additional diagnosis of schizophrenia.

Data Analysis

Data analysis took place simultaneously as data were being collected. Following each focus group, the moderator and the scribe debriefed the session summarizing the main themes. After the second focus group and the groups thereafter, the moderator and scribe also discussed repetition of themes that had emerged. Identification of recurring themes helped researchers gain a sense of issues to be further explored for greater understanding. This is consistent with the recursive process approach to focus groups, which involves constant reflection to refine research design, procedures, and questions based on emerging themes (Brotherson, 1994). The focus group and phone interview audiotapes were transcribed verbatim.

Data were analyzed using the constant comparative method described by Glaser and Strauss (1967) which is an iterative process of collecting and analyzing data with the ultimate aim of generating a theory that is 'grounded' in the natural context in which the inquiry takes place. Information was collected until it reached a point of saturation. Data collection was stopped when most of the issues brought up by the parents were being repeated. Elements of frequency, extensiveness and intensity of the comments expressed by participants were taken into consideration. Initial ideas or themes were first identified into discrete categories (open coding), then fractured and recoded using axial coding to make connections between categories and sub-categories that reflected more generalized, emerging themes (Vaughn et al., 1996). Finally categories were integrated to form a grounded theory (selective coding) that clarified concepts and allowed for interpretations and conclusions (Gilgun et al., 1992). The qualitative software program, Nudist 6.0 (N6) was used for analysis.

Trustworthiness was established by the discovery that findings were generally consistent across the five focus groups. Multiple researchers checked and read the transcripts and analyzed the data. Another way in which the trustworthiness of data was ensured was by doing a member check. This process allowed participants to evaluate the fairness and validity of the interpretations and conclusions of the research team. Although transferability is not a critical issue in qualitative analysis (Maxwell, 1996), we had a diverse sample in terms of the breadth of disabilities and geographic location to enhance transferability.

Results

Parents acknowledged that it is not enough to accept children with disabilities in out-of-school settings. Acceptance is only the first step. Parents stressed that even after their children are accepted in out-of-school programs, the sustenance of the care option depends on whether the setting makes appropriate adaptations to the setting. Adaptation refers to a change made to support a specific child's ability to be functional and to support the child to play, learn and socialize. Adaptations include both modifications and accommodations to an object, environment, instruction, communication, process or product (Horn, Lieber, Sandall, Schwartz, & Wolery, 2002). Parents in our focus groups would like to see a variety of adaptations that would ensure full participation of their school age child(ren) with disabilities in out-of-school settings. Parents however add that all children will not need all adaptations. The level and type of adaptation needed depends to a large extent on the nature and severity of the child's disability. Therefore, adaptations need to be individualized for each child based on his or her unique needs.

Six themes emerged from the parents' discussions, namely, adaptations related to: 1) the physical setting, 2) activities, 3) peer socialization, 4) supervision and safety, 5) parent-provider communication, and 6) the attitudes and skills of child care providers.

Theme One: Adaptation of the Physical Setting

Parents emphasized that physical accessibility is an important first step in making settings available to children with physical disabilities. Features like ramps, railings, wider doors, and accessible rest rooms would be required. Title III of the Americans with Disabilities Act (ADA prohibits child care centers from discriminating against children with disabilities and requires them to make appropriate physical modifications. Parents acknowledged that sometimes programs are willing to accept children with disabilities, but logistical constraints like lack of funding and resources prevent providers from making needed architectural accommodations. Smaller, low-budget programs and family care settings find it difficult to make accommodations like building ramps or railings. As in the words of a parent of an 11-year-old child with Aspergers' syndrome:

When you start with handicapped accessibility and these issues, even if you found somebody willing, the child is in a motorized wheelchair, and they've only got a door this wide and a bathroom that the chair can't go in, you wind up with a center that's willing but with logistical constraints there that are a real problem.

Physical adaptations become even more important for children as they grow older. It is relatively easy to physically lift or move a younger child. As children grow older, it becomes more difficult, perhaps even socially inappropriate, for an adult to physically lift or move the child, and may also cause embarrassment to the child.

In addition to wheelchair accessibility, other aspects of the physical setting were also noted as being important. For example, parents commented that being in a small room or even a large room with many children causes some children with autism to feel overwhelmed:

It depends on the structure of the building; whether it's a real open space with a lot of children and not enough workers—that could be a big barrier for an autistic kid. I think it's a lot of input...a lot of stuff. I guess it probably makes him uneasy, being in a place with a whole lot of children (Parent of an 8 year old with autism)

Theme Two: Adaptation of Activities

Provision of age-appropriate activities. Parents of older children emphasized the importance of having programs, settings, materials and activities that are appropriate for a child's age. A parent of a 17-year-old with autism explained:

Accept the fact that our children, even though they have cognitive or behavioral disabilities, they age just like everybody else. They may mature at a different level and a different rate, but they are maturing... Rather than pushing them into a program that's really for young children and is totally inappropriate, they should have age-appropriate things, have toys that are age-appropriate. Activities that will keep them interested and will help them develop and grow.

Problems related to age-inappropriate activities are of greatest concern for older children with disabilities. As children mature, the disparity between children with disabilities and their typically-developing peers tends to increase. Parents commented that providers sometimes fail to or are unable to make the needed accommodations for

older children to be served in settings with their same-age peers. These providers sometimes inappropriately place older children in settings designed for children who are much younger. A parent of a 6-year-old with autism explained, “They said they put him in the 2-year-old room. He wasn't two years old. They said that's where he'll fit in”. In addition to the lack of same-age peers in this setting, activities and materials in a class designed for 2-year-olds were not age appropriate for a child who is 6 years of age.

Involvement in activities. Full inclusion of children with disabilities involves more than just physical presence in the setting. Parents suggested that activities often need modification in order to ensure full participation of their children. The mother of a 6-year-old with autism stressed, “... if they had made the right accommodations they wouldn't have dis-enrolled my child.” Although children with disabilities may mature at a different rate than their typically developing peers, they still need stimulation by being involved and engaged in meaningful activities. This point was made by a parent of a 13-year-old with autism and cerebral palsy, “In 98% of the places I've found, even in the after-school program, it was a babysitting program, it was not an after-school program for her. The programs should focus on quality life skills that our kids need to learn.” A parent of a 16-year-old with PDD made a similar comment about her child's after-school program, “The people there are not engaged, if they will sit and do nothing, they will let them sit and do nothing.” Parents wanted providers in inclusive settings to adapt materials, games, and activities, as needed, to include children with disabilities while maintaining the challenge and fun for other children in the setting.

Structure and routines. As children grow older, they tend to need less structure in activities and are more comfortable with flexible schedules. However, as children with

some disabilities like autism grow older, they may still have the need for structured activities and planned routines. Parents noted that ambiguity and lack of structure tend to make older children with autism uncomfortable and can result in undesired behaviors. A parent of a 16-year-old with autism commented:

Once they do their activity, then down time is either playing basketball out in the gym, or sitting and watching a video for a couple hours. Or, you know, they sit and color. There aren't really planned activities for the down time. There are planned activities to go [to] but the down time is not planned. It's very unstructured. And being autistic, my child needs structure.

Access to outdoor activities and field trips. Parents expressed concern that children with disabilities are sometimes excluded from outdoor activities. Parents commented that lack of adaptive equipment, lack of adequate staff for individualized supervision, or simply lack of willingness to include all children in outdoor activities, are the things that prevent children's full participation. The mother of a 6-year-old with autism commented:

He did not have the same opportunity to go outside on the playground as other kids in his age group would have gotten. When his class would go out to the playground, he would just stand at the fence instead of playing and look at the other kids that were older, like his age. It was like he was longing to be with them.

Children with physical disabilities are sometimes excluded from activities such as field trips that require transportation. A wheelchair-accessible van may be necessary to provide appropriate accommodation. The parent of a 15-year-old with spina bifida explained, "My son was not allowed to go to the recreation department. They told me that

they couldn't take him because they didn't have a wheelchair van. So he couldn't go on field trips with them."

Theme Three: Adaptations focusing on Peer Socialization

Although opportunities for out-of-school activities were quite limited for the children of parents in the study, parents held strong beliefs about their importance for their children. Parents emphasized the need to have inclusive after-school settings rather than segregated environments. They believed that children with disabilities need opportunities to interact with typically-developing children in order to develop friendships and gain social skills. They also communicated that children with disabilities need role models for learning positive social behavior. A father of an 11 year old with Asperger's syndrome explained:

So many children with disabilities suffer from socialization skill deficits anyway, how does any child learn social skills? ... From being around other children; and if your child is not going to be around, for lack of a better term, typically behaving children, how will he learn those skills? ... If somebody would open tomorrow, the disability after-school, not really what anybody wants, they just want an inclusive setting.

As children approach the teenage years, their identity development takes place. Social interactions with peers, is an important factor that helps in this process. Therefore, interaction and approval from peers becomes more important to them than ever before and helps them in development of identity and intimacy (Owens, 2002). Another mother endorsed this need for greater social interaction for her 16-year-old daughter with autism:

We had a meeting and I told them what I thought she really needed. It was more social interaction because she's usually in a classroom of three or four kids. She's usually the only girl, and they are not very verbal, and I really wanted her to have social environment because that's where she is more challenged, and she likes to be social even if she is autistic. She likes attention. And so I wanted her to be able to interact socially.

Thus, irrespective of the nature of their disability, parents asserted that all children need opportunities for social interaction. Parents wanted program staff to make special efforts to promote interaction between children with disabilities and typically-developing children.

That's where the inclusion would come in. I think it would take extra effort on the part of the facility to find typically-developing kids who are almost drawn to our special needs kids, who just have extra patience and extra love. If it would be possible for the facility to make extra effort to put our special needs kids with those typically-developing kids, who have an extra caring for our kids. That would be great! (Parent of a 6-year-old with autism).

Theme Four: Adaptations for Supervision and Safety

Supervision. As children grow older, they become increasingly independent and autonomous and therefore, the adult to child ratio needed to care for them in child care settings is lowered. However, some children with disabilities may need increased supervision even as they age, to ensure their safety and to promote positive development. Parents in our study believed that the number of adults per children in settings, especially formal child care centers, often is not sufficient to ensure adequate supervision and care

of children with disabilities. As a parent of an 8-year-old with autism commented, “The setting that my child was in had many children and not enough workers. Not enough teachers watching him and giving him attention like he should get.” A parent of a 13-year-old with cerebral palsy voiced her concerns:

Things I would like to see for our daughter... after-school care with smaller groups, in classrooms with one instructor and one paraprofessional with say, six or four children, so that if someone has to take someone to the restroom, someone would be still be there. My daughter doesn't do too well under too much stimulation. She gets overloaded and has her meltdowns. Small groups of children would be beneficial.

When children needed one-on-one supervision, parents wanted to be able to fund a person who could accompany their child. This would allow the child to take advantage of multiple out-of-school programs and opportunities. The child would experience increased independence and the parent would be relieved of constant supervision.

That they are able to participate in summer reading club, just like Boy Scouts, have somebody there with them constantly, instead of having me hover over him. He gets tired of me doing that. If there was somebody else that was trained and could be in those positions that would be great. (Parent of an 8-year-old with cystic fibrosis).

Safety. Parents expressed numerous safety concerns about having their children with disabilities in out-of-school programs. Parents talked about fears that their children might fall, get hurt, run away from the setting or get hit by a car. The parent of a 17-year-old with an intellectual disability explained, “Because my child is having ambulation

problems and I don't want him to fall. It's kind of uneven terrain. So if I have someone to watch him, then he can still have fun. But just have more supervision for safety."

A mother of an 11-year-old with Asperger's syndrome reflected the comments of numerous parents when she stated:

Parents of typical children leave their child at day care and they don't think about it.

Whereas, parents with special needs' children think, oh my Gosh, when is the phone going to ring? It's that constant fear of, is whoever I've left my child with, going to be able to handle a meltdown? We shouldn't have to be afraid to leave our children.

Thus, even when parents are successful in finding out-of-school programs, many parents are worried about the safety of their children. Parents commented that they feel more secure about their children's safety when their children are around familiar adults, especially those who have specialized training and are responsible for fewer children, which allows the providers to give more individualized care.

Protection from abuse. National data show that adolescents continue to have the highest rates of rape and other sexual assaults of any age group (American Academy of Pediatrics, 2001). Statistics also show that children with disabilities are 4 to 10 times more vulnerable to sexual abuse than their non-disabled peers (National Resource Center on Child Sexual Abuse, 1992). Although none of the study questions focused on abuse, parents in two different focus groups and one of the individual interviews expressed concern that their children might be abused while attending a care setting. Parents of children who were non-verbal were worried that their children could not tell them about abuse if it were to happen. The parent of a 9-year-old with autism remarked, "My son is non-verbal. So if he's abused in any way or handcuffed or thrown in a closet, 10 minutes

before I get there he could get let out and I would never know.” Another parent of a 10-year-old with autism attested to this fear by adding, “Exactly, my son's non-verbal too. I worry about that all the time. I'm terrified of that. Terrified!”

Some parents had direct experience with abusive situations. A parent of a 20-year-old with autism commented, “I have used daycares in the past. There was a daycare we used before, and the director was arrested for child molestation. So that right away was a big issue.” A parent of a 13-year-old with autism illustrated the fear by narrating an incident that happened with her child:

My child is non-verbal. There were instances, in the after-school program, the principal and director accused his teacher several years ago of abusing him, took her out of the classroom, forced her to sign a letter of resignation in effect at the end of the year. They never bothered to tell me. I found out five months later from that teacher. The same people had determined the teacher they hired was not qualified. You're talking about fear.

Providers can help alleviate parental fears regarding their child being abused by providing reassurance and having increased communication with parents about their child.

Theme Five: Adaptations focused on Parent-Provider Communication

Parents participating in the study described communication as being crucial in promoting a positive inclusion experience for all involved. As children grow older and more communicative, they take some of the responsibilities of sharing information between home and school or child care setting. However, for some older children with disabilities who may not be as communicative, child care staff members need to make

special efforts to maintain communication with the child's family. Parents would like providers to communicate with them regarding the child's progress. If there were behavioral issues with the child, parents would like providers to inform and consult them so that they can work on solutions together. Some parents complemented providers for informing parents about problems, consulting and working with them to find solutions. A parent of an 8-year-old with autism narrated: "They're real good, I mean they love working with him. The center is like, 'we have problems but we'll try to work with him', but then they still feel like they've got a lot of problems and they don't know what to do or how to work with him. But the other one, they're like 'he's a joy to work with'. So, it's like a contrast".

Other parents were less satisfied and expressed a desire for more communication from providers. The parent of a 6-year-old with Down syndrome explained, "There have been some situations where I wish that they would have talked to me about certain things and I could have given them some input as to better ways to handle behavior issues and so forth." Parents also commented that they want to feel welcome when they visit the child's care setting. These issues were captured in the following quote from a mother of a 6-year-old with autism:

If the staff could give me a weekly update of the activities that my child did today, just to let me know if he cooperated or not. Ask my feedback. Ask me to come in and watch him. Most of the places made me feel very, very uncomfortable if I went and visited because they said he would not perform the way he typically would if I was not there. ...I just got a lot of complaints from them. I couldn't

give them feedback unless I saw what was going on. I would like it if they would be more flexible and open to input from parents.

Several parents complained that providers dismissed their children from programs without sufficient communication or problem-solving efforts. For example, a parent of an 8-year-old with early childhood onset schizophrenia commented, “I want to add that they all kick them out without a conference or anything, because of bad behavior.” A parent of a 6-year-old with autism described a similar concern:

They didn't tell me there was a problem. They just kicked him out. ...They let him turn on the water and play with the sand at the table because that calmed him.

They said we don't have a problem with that. He's the only one that was allowed to do that. That's why they kicked him out.

Parents also stressed that they would like providers to value their input in caring for the children. Parents believe that they can help providers understand their child better by sharing their insights and wisdom about the caring of their child.

Theme Six: Adaptations focused on the Attitudes and Skills of Providers

Attitudes. One of the most important pre-requisites for the above mentioned adaptations to occur is a positive attitude on the part of providers related to inclusion of children with disabilities in child care settings. Parents expressed concern that certain child care providers have a generalized stereotype that including a child with a disability in the setting would inevitably disrupt the setting, placing a heavy demand on time and other resources of staff members. However, parents believe that this is usually not true. A parent of an 11-year-old with Asperger’s syndrome explained, “It’s a struggle and I think

it's a slow process...to convince people that a child with disabilities will not disrupt a daycare setting, and I think there's a fear factor, and you have to overcome that."

When asked to describe the type of attitude that parents would like child care providers to have, one mother commented:

I would like it if the teachers could have a non-judgmental attitude, a more loving, accepting and non-judgmental attitude. I would like them to understand that when my child does these things like flipping the light switches, its not to be bad, its not to irritate them, it's a way that he is soothing himself... So if the teachers could just be non-judgmental and remember that our special needs kids are trying, they are trying in the best way that they know how to take care of themselves. And if the teachers could instead of stopping our kids, support and guide them and that's a way they could build a bridge to the child. (Parent of a 6-year-old with autism)

Skills. Parents believed that providing program staff with appropriate training is one of the best ways to cultivate a positive attitude toward children with disabilities. A parent of a 20-year-old with autism and cognitive delay emphasized the importance of training, "I think training is important so that they don't have a fear. People are afraid of what they don't know. Give them some training so they can lose their fear and can accept the child with disabilities." Other parents added:

The bad thing is most teachers are not taught how to deal with learning disabled children or children with any kind of disability. They have one class that they take for the special education and that's it. It's just one quarter and it's not really enough attention that's being given to disability issues. (Parent of a 12-year-old with ADHD and cognitive delay)

Parents suggested that in addition to the training on general disability issues, providers need to know more about specific disabilities so that they can understand and provide for the needs of children with different disabilities. A parent of a 6-year-old with autism made a similar comment:

I find it very hard to get into child care centers, sports activities and clubs etc. because they don't have the training to deal with the autism, they are scared of it. They don't want to deal with it because they don't want to be held legally liable for anything that may go wrong.

Parents also would like the providers to be trained in administering medications.

As this mother of a 16-year-old with cerebral palsy commented:

That's one of my biggest fears. It's that somebody is not going to give him his medicines reliably because... (Especially with seizures and stuff), it's very important that it's timely and he takes it all. So, they need to have medical training.

Parents who have children with disabilities having behavioral issues would like to see providers receive training in behavioral management. As in the words of this mother of a 16-year-old with PDD:

"...just basic (training in) behavior management. You know I think a lot of time when people who don't know, are dealing with children with special needs, they tend to cuddle them and try to baby them and have less expectations for them and sort of let things slide that you would not let a typical child slide with and when you have a child that has behaviors they take that door and run with it. Or (at least) my child does".

Another parent of a 13-year old with autism:

... (providers) need to have behavior modification training. They... have the training for the medical issues because it's a life and death issue. They don't provide the severe behavior training issues. And without the severe behavior training issues, then you're looking at a much lower quality of life for your child".

Conclusion and Implications

Results of the focus groups and phone interviews provide insight into the challenges that parents experience in finding and maintaining appropriate out-of-school care for their school age children. Almost 20 years after Fink's (1988) landmark study on school age child care and in spite of having laws like the ADA and IDEA in place, comments of parents still reflected the same struggles and frustrations with finding appropriate and accommodative out-of-school care for their children with disabilities. Parents unanimously agreed that they would like to have more school and community-based after-school care settings that are inclusive.

By being inclusive, parents do not only refer to school age children being accepted in programs, but their complete involvement in them. Ideal school age care programs would have features like ramps, railings, wider doors and accessible rest rooms to make them accessible to all children, including those with physical disabilities. Providers would make special efforts to provide age appropriate activities that meet children's developmental needs. Parents would like providers in inclusive settings to adapt materials, games, and activities, as needed, to involve children with disabilities, while maintaining the challenge and fun for other children in the setting. All children

would be included in outdoor activities and field trips. Programs would have a sufficiently high adult-child ratio to ensure adequate supervision. Increased supervision would help in addressing the safety concerns of parents. Providers would make special efforts and design activities to promote interaction and friendships between children with and without disabilities. Providers would have open and frequent communication with parents about their child's progress and the challenges that they face in working with the child. Providers would have a non-judgmental, loving and accepting attitude toward all children. Above all, staff would be competent and well trained.

These results need to be interpreted bearing in mind certain limitations of this study. Although transferability is not claimed in qualitative research, an attempt was made to make the sample as representative as possible. Parents from a wide range of geographical areas (rural, urban and semi-urban) and families whose children had a wide range of types and intensities of disabilities were included. The sample was highly educated and more representative of two-parent than single-parent households. Further research is needed to better understand the perspective of low-income families and single parents. Future research also should be conducted with larger and more diverse samples to test the hypotheses generated through this study and to verify if study findings hold true for diverse sub-groups of families. Future research could specifically examine if these concerns, needs and desires hold true for families from specific ethnic and racial groups, focusing on identifying supports that would be needed to balance work and child care demands. Future research also needs to focus on the specific needs of children with different types of disabilities.

This study provides rich information about the perspective of parents related to out-of-school care for their school age children with disabilities. The information can be a valuable resource for planning and adapting out-of-school care settings to appropriately accommodate school age children with disabilities. This information can be useful for child care administrators, staff, policy makers and other professionals. In addition, findings from this study can be useful in developing training modules for child care providers.

Finally, although past research has focused on the perceptions of providers, almost all of these studies have addressed issues related to child care for young children. It will be important in the future to obtain the perceptions of providers of school-age care. Just as parents perceive that providers do not fully understand their needs, it is possible that parents do not fully understand the perspective of providers and the school age contexts in which they work. The voices of school age children themselves are also needed. By understanding the unique and common perspectives of all parties involved, particularly the parents, children and providers, it is more likely that lasting changes related to inclusion in the school age care system will occur.

CHAPTER 5

INCLUDING SCHOOL AGE CHILDREN WITH DISABILITIES IN CHILD CARE
SETTINGS: PROVIDERS' PERSPECTIVE ³

³ Jinnah, H.A., & Stoneman, Z. (2008). To be submitted to *Child and Youth Care Forum*.

Abstract

Because of laws like ADA and IDEA, school age child care providers are increasingly being expected to include children with disabilities in their settings. As child care providers include school age children with disabilities in their setting(s), they face certain challenges. This study focuses on the challenges that providers face related to inclusion and the supports and resources they need to better facilitate overall development of school age children having disabilities. Focus groups and phone interviews were conducted with 41 child care providers. Data were analyzed qualitatively using a grounded theory approach with the help of Nudist (N6) software. Providers mention experiencing both joys as well as challenges related to inclusion of school age children with disabilities in their settings. The challenges expressed by providers can be put into three broad categories – issues related to staff, the lack of resources and issues related to communication and collaboration between the different people involved. The supports that child care providers need to make inclusion work revolve around needing more training on disability issues, more resources including additional staff, more funding, and more information about available resources. Additional supports needed by providers are also discussed.

Keywords: Child care, school age care, disabilities, focus groups, providers, challenges, supports, staff, resources, training, communication, collaboration.

Literature Review

Families having children with disabilities are increasingly relying on non-parental childcare for their children, like most other families in the U.S. A set of legal, moral, rational and empirical arguments form a basis for inclusive practices (Bailey et al., 1998). In the past ten years, numerous laws have been passed and amended to ensure equal rights of children with disabilities in child care settings. The Americans with Disabilities Act (ADA) passed in 1990 requires childcare centers, as places of business, to include children with disabilities and make appropriate modifications that are needed for their full functioning. Title III of the ADA requires that center-based childcare and home care facilities examine their rooms and spaces, playgrounds, and activities to make themselves accessible to children with disabilities (Craig & Ann, 1994; Parette & Murdick, 1994). The Individuals with Disabilities Education Act (IDEA), reauthorized in 2004, requires that children with disabilities receive education and care in places where typically developing children spend their time. A key implication embedded in these laws is that children with disabilities should be able to fully participate in childcare settings that serve typically developing children. With laws like ADA and IDEA, childcare providers cannot discriminate against school age children with disabilities. As federal and state mandates demand inclusive practices, school age child care providers are increasingly being asked to include children with disabilities in their settings (National Easter Seal Society, 1998). As more child care settings include children with disabilities, research on the challenges

and barriers that providers face while doing so, and the supports they need to ensure full inclusion of children with disabilities is needed.

Most of the literature on child care to date has focused on the needs and challenges of providers related to inclusion of young children with disabilities in child care settings. Researchers have identified barriers that prevent young children from being included in child care settings, including attitudes of providers (Dinnebeil et al., 1998; Buell et al., 1999; Buysse et al., 1996); and lack of provider knowledge and training (Fewell, 1993; Warfield & Hauser-Cram, 1996; Dinnebeil et al.). Cross et al. (2004) suggested that there are identifiable elements and associated practices that contribute to successful inclusion of young children with disabilities in community settings. According to them, attitude of providers, parent-provider relationships, therapeutic interventions, and adaptations are the four elements contributing to successful inclusion of young children with disabilities in child care settings.

In a national survey of administrators, service providers, and parents, Smith and Rose (1993) found that issues related to personnel training as well as attitudes and values were described as disincentives to early childhood inclusion by a majority of the respondents. DeVore & Hanley-Maxwell (2000) focused on childcare provider's ability to provide child care for young children with disabilities. The main contributing factors include provider's commitment, finding balance between resources and needs, problem-solving with parents, access to emotional support and technical assistance and access to other supports.

Numerous studies have focused on the challenges and needs of family child care providers related to inclusion. Buell et al. (1999) found that family childcare providers

who were unwilling to care for children with disabilities indicated three primary barriers: lack of knowledge about disabilities, limitation that caring for a child with disabilities would impose on caring for other children and the need to purchase special equipment. Past studies have also found that the concerns that family childcare providers have regarding serving children with disabilities include liability, lack of training and inability to meet the needs of these children (Deiner & Whitehead, 1988; Fewell & Neisworth, 1987; Salkever & Connolly, 1988). Family childcare providers mention that they need training in behavior management, planning curriculum and activities, social skills development and working with children having disabilities (Rusby, 2002). Supports indicated specifically by family child care providers include increased information, the need for knowledge about teaching strategies and funds for special equipment (Buell et al., 1999; Deiner & Whitehead, 1988; Kontos, 1988).

Whereas a lot of research has focused on the perceived barriers and supports needed by providers of young children and family child care providers, studies focusing on the challenges of school age care providers related to the inclusion of children with disabilities are largely missing from the literature. As children with disabilities grow older, their characteristics and needs keep changing. Therefore, the challenges that providers face in making adaptations for older children with disabilities would be qualitatively different from those needed by younger children. Buysse et al. (1998) developed a rating scale to assess the perceived barriers and supports needed by child care providers related to early childhood education. However, similar scales for school age care providers are missing. More research is needed to elucidate the perceived barriers and supports of school age care providers and to explore if they are different

from those experienced by early childhood providers. The previous paper focused on the parents' perceived needs related to accommodations and adaptations in child care settings for school age children with disabilities. From a systemic perspective, it is also important to consider the perspective of child care providers related to inclusion. This study addresses this gap in literature by focusing on barriers that providers experience related to inclusion and the supports they need to effectively include school age children with disabilities in child care settings.

Method

Focus Groups

Several reasons directed our choice of focus groups as the primary data source for this study. Because focus groups allow participants to share or discuss their responses in a group, often a broad range of issues and diverse opinions are gathered (Carney et al, 1998; Krueger & Casey, 2000). Also, because of the structured, yet open nature of focus groups; facilitators have the flexibility to explore further any unanticipated issues that may emerge during the discussion (Krueger, 1998).

The purpose of the provider focus groups was to discuss the rewards and challenges experienced by providers in caring for school-age children with disabilities and to obtain information about how to best support providers in serving this group of children. Community members (i.e. childcare inclusion coordinators, family support personnel, and child care resource and referral employees) were identified to assist with recruitment for the focus groups and to provide logistical support. These local community coordinators made the initial contacts with potential participants. Organizing provider focus groups was challenging due to time constraints experienced by childcare providers.

A total of 33 providers participated in 6 focus groups. Providers from a variety of settings including home-based settings, private child care centers, after school programs, and recreational programs participated. An attempt was made to include people from all levels of hierarchy including child care administrators (directors or supervisors), those who work directly with children (head teachers and field staff) and professionals who support or advocate for youth with disabilities. The average size of the provider focus group was 6 participants. The focus group protocols were explained verbally and given to each participant in the form of an informed consent sheet before each focus group began. A demographic questionnaire and an informational packet were given to each participant.

Focus groups were conducted at community locations based on the convenience of the participants, lasted approximately two hours, and were audio taped. Refreshments were provided. A semi-structured interview guide provided direction for the focus group discussion. Two researchers facilitated each group with one member serving as the group moderator and the second serving as the scribe, taking notes and summarizing the key points at the end of the session to verify the information with participants. The focus group started with researchers introducing themselves and reminding participants of the meeting's purpose. Next, the moderator raised a series of discussion questions.

Study Questions

Providers were asked about their experiences in including children with disabilities in their care settings, as well as the benefits and challenges associated with including these children. Providers were also asked about the joys and challenges they experience in including school age children with disabilities in their setting(s) and the supports that would help them in doing this. The questions were neutral in tone, as we

were interested in knowing both the positive as well as not so positive experiences of providers. The discussion ended with the moderator summarizing the main themes and issues that emerged and thanking the providers for their time.

Individual Provider Interviews

Because of the difficulty in arranging times when providers could meet together for focus groups, individual phone interviews were conducted with providers who were unable to attend. Purposive sampling was primarily used to recruit provider phone interview participants. Private day care providers were targeted because they were typically the most difficult to recruit for focus groups. Time constraints were a factor for many of the provider phone interviews, most of which were conducted during the work day. Often the phone interviews had to be rescheduled several times. There were a total of 8 provider phone interviews. Provider phone interviews used the protocols that included informed consent forms that had to be received before the interview was conducted and telling participants that the phone interviews would be audio taped.

Some providers felt more comfortable sharing personal experiences on the phone than in focus groups. Also, it is possible that in focus groups, since there are other providers present, providers would tend to give socially desirable responses and do less self-disclosure. This could have led to a potential bias in the data if we just had focus groups. An implicit benefit of having phone interviews was these providers got their chance to share their thoughts over the phone.

Participants

All 41 of the participants were female (41 or 100%). Two thirds (27 or 66%) were Caucasian, 32% were African American, and 2% were Asian. The age of the providers

varied from early adulthood through retirement age, with most of the providers (63%) ranging between 35 and 54 years of age. Most of the providers (61%) were married and 76% had children of their own, ranging in age from less than one year to 41 years. Two thirds of the focus group participants (27 or 66%) worked full-time. Almost half (19 or 46%) of the professionals attending the focus groups had a four year degree or more. Thirty-four percent or 14 providers had completed some college or had an associate degree. Another 12% or 5 providers had done some technical school or had completed technical school. The remaining 7 % or 3 providers had a high school or GED degree.

Twenty four percent (10) of the providers worked in an afterschool program in a school, thirty four percent in a child care center (14) and two percent in a community-based setting such as a YMCA (1). Almost one-fourth of the providers (9 or 22%) cared for or provided services to children in their own homes or the child's home. Other providers worked in settings offering short-term enrichment classes and summer camps (15%). Only one provider worked in an advocacy agency. Ages of the children served by these settings ranged from 0 through 21 years. Majority (93% or 38) of the settings currently include or had in the past included children with disabilities. Using Bachtel's² county classification system, we had 19 (46%) participants from urban counties, 5 (12%) from suburban counties, and 17 (42%) from rural growth counties.

The group included administrators (directors, assistant directors) of after-school and youth programs (27%), lead and assistant staff members (34%), group home and family child care providers (20%), program volunteers (5%), and program support staff such as family support specialists and therapists (12%). About two-fifth (37% or 15) providers had more than 10 years of experience in the child care field and about 29% or

12 providers had more than 10 years of experience in their current position. About two third (67% or 29) of the providers worked full-time and one third (14 or 33%) worked part-time. The sample was diverse in terms of the number of years of experience providers had in the child care field. Over 61% or 25 providers have been working in the child care field for 6 to 10 years or more with 7% or 3 providers who have been working for less than two years in the field. Twenty nine percent or 12 providers have had between 2 to 5 years of experience in the childcare field.

In summary, the provider focus groups included professionals from a wide variety of school-age care and activity settings. The groups included administrators, those who work directly with children, and professionals who support or advocate for youth with disabilities. They work in home-based, facility-based, and drop-in settings, some of which offer year-round care, others of which are only short-term enrichment, recreation or respite care. The only sub-group of providers we were unable to attract to the focus groups/interviews were informal caregivers—the family, friends, and neighbors who care for children.

Data Analysis

Two transcribers transcribed audiotapes of the focus groups and phone interviews verbatim. The researchers were able to fill in gaps in the transcripts that were difficult to hear on tape. Data analysis took place simultaneously as data were being collected. Following each focus group, the moderator and the scribe debriefed the session summarizing the main themes and impressions about the session. After the second focus group and the groups thereafter, the moderator and scribe also discussed repetition of themes that had emerged. Identification of recurring themes in previous focus groups

helped researchers gain a better sense of issues and needs to be further explored for greater understanding. This is consistent with the recursive process approach to focus groups, which involves constant reflection to refine research design, procedures, and questions based on emerging themes (Brotherson, 1994). Additionally, the transcripts were reviewed many times by the researchers.

Data were analyzed using the constant comparative method described by Glaser and Strauss (1967) which is an iterative process of collecting and analyzing data with the ultimate aim of generating a theory that is ‘grounded’ in the natural context in which the inquiry takes place. Information was collected until it reached a point of saturation. Data collection was stopped when many of the issues brought up by the providers were being repeated. Elements of frequency, extensiveness and intensity of the comments expressed by participants were taken into consideration. Initial ideas or themes were first identified into discrete categories (open coding), then fractured and recoded using axial coding to make connections between categories and sub-categories that reflected more generalized, emerging themes (Vaughn et al., 1996). Finally categories were integrated to form a grounded theory (selective coding) that clarified concepts and allowed for interpretations and conclusions (Gilgun et al., 1992). The goal of analysis was to identify patterns, make comparisons and contrast one set of data with another. The qualitative software program, Nudist 6.0 (N6) was used for analysis.

Trustworthiness of the findings was established by the fact that our findings were generally consistent across the five focus groups. Multiple researchers checked and read the verbatim transcripts and coded as well as analyzed the data. We collected data from multiple geographical areas (i.e. rural, urban, and semi-urban) and included families

having children with a wide range and intensity of disabilities. Another way in which the trustworthiness of data was ensured was by doing a member check. This process allowed participants to evaluate the fairness and validity of the interpretations and conclusions of the research team. Although transferability is not a critical issue in qualitative analysis (Maxwell, 1996), we tried to have a diverse and representative sample to enhance transferability.

Results

School age care providers shared with us both the joys and challenges of working with children having disabilities in after school care and activity settings.

Joys of Working with School-age Children

Providers mentioned that working with children who have disabilities can be deeply rewarding for all involved. Providers mentioned that they cherish the unconditional, open and honest love that they receive from these children. Several providers also mentioned that they believe that children with disabilities appreciate them more than typically developing children. A therapeutic recreation provider from a suburban county put it this way, “We do the work and we’re supposed to give to them. But they give us so much more than what we give them”. A child care center staff member from the same county added, “It doesn’t matter if it’s a bad hair day. You could be having the worst day and it doesn’t matter. They are waiting on you, every one of them, for you to get there. They’re happy to see you. It’s just rewarding”.

Another source of gratification for many providers is seeing improvements in school age children with disabilities. As one provider commented, “You just want some kind of response. Once they make that connection, you feel you’ve opened up the world”.

Events like saying their first words, making eye contact, or drawing a picture, which might be commonplace for typically-developing children, can be extremely satisfying for providers who have helped children with disabilities develop even in small ways. A family child care provider in a rural county explained:

When I started out, that's what I wanted to do was special needs children. The first child I had, he came to me when he was 8 years old and he had water on the brain. He was considered non-trainable. They'd just sit him in the chair and keep him dry and feed him his bottle and not worry about him. Now I really wanted to do more than that and I said "Don't tell me what his limits are. I don't want to put a top on it. I want to open the door wide and see what he can do." By the end of summer he had been upgraded three years when he went back to school. He was walking with assistance. He was eating hamburgers and milk shakes at McDonalds.

Children with disabilities can have a profound effect on typically-developing children by bringing out their compassion, understanding and leadership. A provider working in an inclusive setting in an urban county explained:

The true beauty of the whole program is what it does for the typical child...We'll get one of the typical children to push the wheel chair. We'll get them to hold the hand, you know...and it's amazing to see the compassion and leadership skills the typical children develop by having early exposure to that. Also the acceptance.

When other children and parents are able to see beyond the child's disability and recognize the person, it brings true joy to many providers.

Summing up, providers value the opportunity to involve children with disabilities in their program. They enjoy seeing the children progress in their abilities and they are constantly rewarded by the love and affection children with disabilities give to them. Many providers also believe that including children with disabilities in their settings enriches the lives of typically-developing children, helping them to develop compassion and to gain new ways of interacting with others. However, along with the joys that providers' experience, working with school age children having disabilities also brings with it some challenges. The challenges expressed by providers in our focus groups can be put into three broad categories – issues related to staff, the lack of resources and issues related to communication and collaboration between the different people involved.

Theme one: Issues related to Staff

A. Staff-child ratio. One of the greatest barriers in accommodating children with disabilities as perceived by providers is related to the number and quality of staff. Providers believe that given their specialized needs, sometimes children with disabilities—especially children having behavioral and emotional issues—may require more attention and supervision than other children. Many school age care providers believed they did not have enough staff to effectively care for children with disabilities. Providers added that it is not only a matter of having sufficient staff, but also an issue of staff quality, training and attitudes. A director of a child care center explained: “Just more people wouldn't help. But more people that are trained to understand these children—in what to do in situations—would be better”.

A large percentage of positions in child care centers, recreation programs and summer camps are entry-level. This, combined with the low pay, high staff turnover, less

educated and trained personnel, and the occasional staff member who is just ‘in it for the paycheck’ were all described as making it difficult for child care settings to provide care for children with disabilities. Providers mentioned that they need more resources to be able to better serve all children with disabilities. More staff was definitely seen as a need. But as mentioned earlier, simply having more bodies is not the solution. They need qualified staff with the training needed to work effectively with all children and especially with children having disabilities.

B. Attitude of staff. The attitude of staff towards inclusion plays an important role in how inclusive practices are implemented in childcare settings (Smith & Rose, 1993; Stoiber et al., 1998). Providers mentioned that they were afraid to include children with disabilities in settings because they do not have enough knowledge about how to manage the child. They were sometimes worried about the safety of the child and other children in the setting. They were also worried about the possibility of the child hurting other children. They feared being held liable if something happens to the child while he or she is with them.

It's the fear of not understanding the disability the child has. They're afraid they'll be liable if something happens to the child. I don't think it's really that they don't care. It's fear from lack of training and not knowing what to do.

[Director of an urban childcare center]

They were afraid of him, of his disability and his problems, because if he climbed up on the equipment or whatever, you know, that he could fall off and that would be a liability to them.

[Family child care provider in a suburban county]

In addition to the fear factor, the extra work involved in caring for children with disabilities was mentioned as dampening the motivation of providers. An assistant teacher in a community-based child care center explained: “To be truthful, some days I just don’t want to go to work, especially in the summer because it is just exhausting”. Providers also believe that caring for children with disabilities is very time consuming. They worry that it will result in taking time away from other children in the setting. These worries are evident in this statement by a provider:

“We don’t have the manpower. I’m taking another teacher away from all the other children, and that’s very costly....When that child decides that he doesn’t like what’s going on, I have to end up sending a third person in there. That’s taking away from the other part of the center”

Even if the director is positive and encouraging of including children with disabilities, providers noted that it could be a struggle to motivate the staff members who interact with the child on a daily basis. An urban childcare center staff member discussed the case of a child with disabilities that she knows of:

Now he has started the running bit. And I think the director at the childcare is very open and accepting to having him there. But the hands-on persons are the ones that are saying, “Oh no. He’ll run out in the street, get hit by a car.” Of course, they’re in the day to day, one-on-one, and they said we can’t do this any more. That mindset, that block there, is because we aren’t trained and we don’t know how.

Even when providers are able to make appropriate accommodations, the slow progress of some children with disabilities can attenuate their spirits. It can take a long

time before noticeable change occurs in some children. A center-based staff member expresses her frustration by saying:

You want to see all those warm fuzzes. But sometimes it feels like my efforts are just futile because you do not see immediately what you have done, the results of those efforts. So that would be a frustrating part. And hoping that you have made a difference and not realizing whether you have or not.

C. Staff Training. One of the most important barriers to inclusive childcare emerging from the results is the lack of knowledge among providers about the care needs of children with disabilities. Fear or apprehension towards inclusion was described as often stemming from lack of knowledge or confidence in one's ability to take care of the child. As one provider explains, "They're just afraid because they haven't been trained."

A recurring issue related to inclusion that was mentioned by virtually all providers was the lack of training in caring for children with disabilities. Although providers are required to attend a certain number of training hours per year, there is almost no training focusing on working with children having disabilities. An assistant teacher in an urban childcare center who works exclusively with children having disabilities explained: "The trainings I have been to have focused on the general population. They might touch bases on a child with Attention Deficit Hyperactive Disorder (ADHD) or a wheelchair, but to focus on children with disabilities – that is almost non-existent". The director of a childcare center in a suburban county confirmed the need for training: "Training is such a big deal. I mean our teachers are not necessarily trained and don't have a lot of access to training for working with disabilities and there are so many disorders". Providing

caregivers with the required knowledge and information is one of the easiest ways to cultivate a positive attitude towards inclusion.

Theme Two: Lack of Resources

A. Information. In addition to lack of training, another frustration expressed by providers was the lack of a centralized source where they can get information on school age children with disabilities. Many providers cited the Babies Can't Wait program as a great resource for younger children. However, when children reach the school age years, providers complained about losing this valuable resource because there was no comparable level of support. As this director of a child care center explained:

When I'm thinking of Babies Can't Wait, I'm thinking about when they come out to the center and they talk to the teachers, they talk to the children to see what the children think. They come...I've had some come out and tell us what we can do. I would love to see that in the school age program.

Although inclusion coordinators associated with Child Care Resource and Referral agencies are available to provide some support to school age providers, they are stretched very thin and providers often did not know about the assistance that these agents can provide.

Both child care center staff and family childcare providers hit roadblocks when they try to get adaptive equipment for the children with disabilities in their setting. Firstly, the equipment is very expensive. Often providers do not have any information about funds or grants available for making adaptations for children with disabilities in child care settings. In cases where providers do manage to gather funds, they often do not know

where to get the needed equipment from. A family childcare provider from a rural county explained:

I had to figure everything out for myself. I had no support from anybody to encourage me, to help me to get the equipment. It can feel kind of cumbersome and frustrating when you're trying to figure out things for a child and you don't have equipment and you don't have any place to get it from and you've got nobody to talk to about it. You really have to have a lot of commitment.

Summing up, providers wanted greater access to information about resources available to them to care for children with disabilities. The focus groups often became platforms for providers to share information about services that were offered and different resources that were available to them in their communities.

B. Funding. Providers believed that financial constraints limit the resources available to them, affecting their ability to care for children with disabilities. They commented that paying for the extra staff needed to effectively incorporate children with disabilities in their setting is prohibitive for many school-age care programs. At school, some children with disabilities have paraprofessionals or “shadows” to help them in the classroom. The providers noted that this same level of one-on-one care cannot be made available in most school-age settings because of limited funding. A family child care provider explained:

Children, especially with autism, or children with disabilities, the schools have individual people—care providers—that follow the child in regular classroom all day. They have the resources; the funds for that. We don't have those resources

available, so that we could have that extra hand to give. We can't hire a special teacher just for one child. It's just not feasible, or even for two children.

In other cases, providers explained that the cost of adaptations was prohibitive - especially when the equipment would typically be used for very few children. A family child care provider put it this way: "Any piece of equipment is expensive even for typically developing children. But those for children with disabilities are even more expensive. Also, even if you don't have that many children with disabilities, you have to have those equipments for the few of them".

An even greater expense cited by some providers is the cost of adding ramps, lifts or other adaptations to vans and buses to make them accessible. The same family child care provider quoted earlier went on to say, "If I had to build something - a ramp of some kind - to accommodate that child, it would have been a real drain on my finances. And it's not that we don't want to do it. It's that we don't have the resources for it". Moreover, short-term enrichment and recreation activities are housed in a wider variety of community settings, many of which may not be adapted to the needs of children with more severe disabilities.

Thus, providers believed that the high cost of adaptive equipment and modifications make it difficult to accommodate children with disabilities, especially in small centers and family child care homes.

Theme Three: Issues related to Communication and Collaboration

A. Between parents and childcare providers. Communication between parents and providers can play a pivotal role in affecting provider's ability to effectively care for a school age child with disabilities in child care and activity settings. Providers expressed

frustration with parents of children with disabilities who try to do everything for their child and have the same expectation of providers. These expectations were described as being a source of tension between providers and parents, particularly when providers try to encourage more independence in the child.

What is frustrating for us is that we have children that can actually do things for themselves and the parents want you to do things for them that they can do for themselves.

[Suburban family childcare provider]

I have this one; he's a Down's syndrome. I have always treated him normally. His mom used to try to use it as a handicap and I told her, "Don't do that. Treat him as a normal child. That's the way he wants to be treated; he wants to fit in."

[Suburban family child care provider]

Providers believe that by being over-protective of their child, parents may unknowingly be hurting the child and abating the child's progress. As this therapeutic recreation provider, who is also the parent of a child with an intellectual disability, narrates, "I was once 'just a parent.' When I came to work here, my son and I have grown so much. I wanted to do all these things for my son, because I felt sorry for him. Because he was my son, I loved him and I helped him. Now, looking back, I can see that I hurt him...I was making him so dependent that when I wasn't here, he wouldn't be able to live either. That's what a lot of parents do".

Conversely, providers are equally frustrated when parents are not involved enough in their child's life. "Challenges definitely can come from parents especially if the parents are not tuned into putting the child's needs first," states a formal day provider.

Another provider adds, “If the parents are not involved in the right way or in the way you want them to, then it can make your job a hundred times harder”. When parents do not communicate information about situations going on at home, a child’s favorite toy or activity, or techniques for managing the child’s behavior, it makes it far more difficult for providers to care for children. The director of a childcare center shared this example:

I’ve had a couple of children that I tried to do my very best with. But finally I had to give the parents a notice that I wouldn’t be able to keep them here. The parents would not communicate to me what was going on. I hate that, because I don’t want to turn anybody away. But the parents were too involved in their own personal life to give me information about the child that I really needed.

Deception by parents desperate for care is another challenge that some providers face. Providers have to grapple with a multitude of issues when parents do not disclose their child’s disability causing a threat to the safety of the child having disabilities and other children in the setting. This situation is illustrated in a story told about one urban provider’s experience in a summer recreation program:

One of the biggest problems I have is parents bringing children and not telling the truth when they have a disability. It’s very dangerous. For example, if they not only have special needs, but need a special diet, a child will snatch their buddy’s peanut butter sandwich or the candy with the peanuts in it and the child gets ill...Parents with these children literally have to lie--because they have to go to work—out of desperation. They’re willing to pay for the camp, but they don’t have any other place to put these children.

Another challenge providers reported was related to parents of other children (who do not have disabilities) in the setting. Parents of other children often raise questions about why special accommodations are being made for the child with disabilities. Like this provider from a larger setting commented, “Parents of other children in the setting put pressure on us. They say that you hold the same standards of behavior for all children, so why is that child able to do that or why doesn’t that child do this?” Parents of typically-developing children also worry about the safety of their children and whether their child will get enough attention in the setting given that there is a special needs child. As one provider explains, “There is a fear amongst parents that by having a special needs child in their child’s classroom, their child will not receive as much (attention) as they would in a typical classroom”.

B. School and childcare providers. Lack of communication between the school and after school care providers can hinder the provider’s ability to provide appropriate care to school age children. A potentially confusing situation for the child exists when providers are unaware of what the child is focusing on in school or the behavior management techniques that are being used by the school teacher to discipline the child. A family child care provider expressed this concern:

I guess my biggest obstacle is that I worry that I could do such a better job of providing care for him after school if I knew what they were doing at his school. And this is to me the broken bridge...There’s a blank there. There’s an unwritten page I don’t have access to. I’ve made contact, sent letters, but can’t get a positive response from the school teacher.

As typically developing children grow older, they become more communicative and therefore play an important role in communicating information across settings. However, some children with disabilities may not be as communicative. It would be best if school teachers take steps to make sure that information about child is communicated to other people working with the child – including child care providers, therapist and parents. This issue was of concern to providers in several other settings:

We have no assistance from the school. I have no clue what my children do in school. I've called the school and asked them to meet and they go, oh, they don't have time. So we work with them the best we can.

[Community-based after-school program staff]

That's one of the reasons I don't have any [children with disabilities] is because I feel like I can't give the kind of care that the children need, because I don't have that continuity there. You know, we don't get anything from the school system to help us in the business.

[Family child care provider]

The broken bridge of communication between school and after school settings can result not only from lack of communication, but also from not understanding the technical terminology used in forms, such as Individualized Education Plans (IEPs), pertaining to children with disabilities. The family childcare provider quoted above went on to say: “I do get copies of his IEP, but, I'm not a doctor. I don't specialize in special needs and sometimes you need a doctor to go through those forms and explain what it all means”. Providers who have not worked extensively with children having disabilities may be more likely to have problems deciphering the forms used by school and other professionals.

C. Therapists and child care providers. Children with disabilities are often supported by a variety of professionals including teachers, speech, physical and occupational therapists; medical professionals, and school-age care providers. Ensuring continuity of care across settings for children with disabilities was noted as a challenge for many providers. Providers would like to learn more about what therapists are doing in order to apply some of the strategies and techniques that could help them better serve children with disabilities. However, it is important that providers be willing to take the time needed to use these resources if they are made available. A family childcare provider shares her experience in working with a therapist about a child with Down syndrome:

I would sit there and I would learn what he had to learn. It's just going through it with them and that helps. They were always giving me a list of what he needed to know and just continuing to work with him.

But not all providers take the time to learn from therapists. Sometimes providers view professionals coming into the setting as a time for them to accomplish other goals. A therapist who works in an after-school program in an urban child care center explained, "It's the same thing when we go into the day cares and they think, 'That's her job, she'll take them off for an hour. We have a break'".

Provider's Conception of an Ideal World

So - what do providers want in an ideal world? Providers would like to have more training, more resources including additional staff, more funding, and more information about available resources. They would like to see greater collaboration and networking among different individuals working with school age children having disabilities.

Training

Providers expressed a strong need for more training on disability issues to be able to work effectively with children having disabilities in inclusive settings. The most important area in which providers perceived the need for training was related to behavior management of children having disabilities. An assistant teacher in an urban childcare center explained: “We would need more training especially with behavior problems. We have a lot of children with behavioral problems and we don’t have any clue what to do with them when they start acting out”. An assistant director of a suburban after school program explained, “What to do with the child that doesn’t want to interact with other children. What to do when the child gets in a rage because things don’t go his way...What to do when the child seems intimidated by other children. I would love to see that. I would jump on a class like that in a heartbeat”. Another provider added:

I mean even to keep the children from hurting themselves, we need that kind of training. That would be a specific kind of training—is how to contain a child that’s out of control so that we’re doing it with love and not as a punishment but to help that child to gain control.

[Family child care provider from a suburban county]

All the other children were picking up his habits and his language and his anger..., I think sometimes it’s hard on us, because we don’t want to have to give up on them...But we don’t know what else to do.

[Family child care provider from a suburban county]

Along with the strategies to manage difficult behaviors, providers wanted more ideas on how to make adaptations to accommodate children with disabilities in childcare

settings. As the following examples show, focus group participants had identified many practical, hands-on, low-cost modifications and adaptations for promoting inclusion of children with disabilities in their settings.

Those kinds of things have been very helpful—room arrangement, noise level in the classroom. For instance, if music would be more soothing, so that they have a corner they can go to and put on music.

[Center-based after-school program staff member]

It may be just trying to put paint on their hands. And the other child might be holding a small paint brush and painting within lines. So it's the same activity but the expectations are all different. So we use the environment to help us include the children in all activities.

[School-based staff member]

Space—they need space to move around in. They can't get in between tight spaces. If you expand your room, even though it might be further to run, it's better for them.

[Family child care provider]

Providers would like more training in developing individualized care plans, modifying activities to include all children and arranging the physical environment to support children with disabilities. Some providers would like to know more about modifications that they could make (even simple ones) that would enable the child with disabilities to participate in activities. Consequently, some children with disabilities can be easily included in certain activities by simply modifying the goals and expectations of the activity. A childcare center director explained:

They might just like the sunshine, they like to be outside and breathe fresh air, somebody just to talk to them... You could have a teacher that could help fill sand and water tables, or to hold a ball in their hand and maybe throw it. Some may not be able to do that. There are some things, I am sure they would be able to do.

Another issue is that, like all children, children with disabilities have unique needs. It requires more ingenuity, time and experimentation on the part of providers to find ways of modifying activities and the setting for the child based on his or her needs. An after-school staff member in a childcare center explained: “Every single child with a disability has very individual needs. And they have such individual learning styles and it’s about trying to figure it out”.

Balancing the right amount of assistance and the need to promote independence in children is also a skill that providers would like to learn. Providers commented that they sometimes may be tempted to do more for children with disabilities than what the child needs. Providers wanted to learn ways to appropriately challenge the child and adapt activities to include children with disabilities in them.

We have levels of expectations for typical children, but in our own mind we sometimes alter those for children with disabilities when we sometimes don’t need to.

[Child care center after-school staff member]

So, it’s really hard to step back and let them do those extra things and you’re thinking in the back of your mind, “Boy, I sure hope he’s going to be okay.” But, you know, they want to play and run and be with everybody else and everybody

else wants to be with them. You know, it's hard sometimes not to be overly protective. To give them that little bit of space.

[After-school program staff member from a rural county]

Providers requested training on how to promote positive interactions between typically-developing children and children with disabilities. This might include training on how to promote friendships between children who vary greatly in chronological age. Training on how to help typically-developing children interact successfully with a child who has challenging behaviors would be helpful. A childcare center director gave this example:

I think the biggest thing is explaining what's going on in a way a child can understand. For example, my grandson gets a lot of attention when he's here because he's in a wheelchair. I explain to them first that they have to be real careful—if he drops a toy, they want to pick it up. But he could hurt them without meaning to. They are very attentive to this and at first they're kind of scared and skittish that they want to pick up the toy. But they don't want him to kick them. They learn how to get over there to get the toys, how to put their hands up to guard in case he kicks without meaning to. Now they are playing constantly around him without being scared.

One of the greatest needs of providers in all settings - family child care homes, after-school programs in schools and other community settings, as well as recreation, enrichment and respite programs - is practical, hands-on training on how to work with children who have specific disabilities. A center director offered this suggestion:

When you do the training it might be giving a general brief overall—here’s an explanation of, you know, autism spectrum disorder. Here’s kind of what you might see in a child that has been either diagnosed or has symptoms of it. Now let me teach you how to work in the classroom with this child. Here are practical, hands-on things. More than just the theory of what is autism, more of the practical ‘how to deal with it’ type of things would be appreciated.

Being able to apply what was learned in trainings in their own setting is extremely important for many of the providers. As one provider from a center-based after-school program said: “I’m looking for a flyer that says how to run an effective school-age program involving children with disabilities. I would love to see a class like that”.

Providers requested workshops that focused specifically on children with disabilities. The training topics that were most requested by providers include: behavior management, modifying activities and setting to integrate children with disabilities in child care settings, using specialized equipment such as nebulizers, fostering independence in children having disabilities, promoting positive interactions between children with and without disabilities, administering medications and balancing the needs of children with and without disabilities.

A possible source of individualized training for providers is parents of children with disabilities. As one inclusion coordinator with a child care resource and referral agency commented, “The best hands-on trainers are the parents because they know the personality, the sign language, the body language...Maybe parents that have kids that are already in child care could say, ‘This is what we did.’”

In addition to learning from the child's parents, providers expressed a need for a resource person who could come on-site and guide them on the adaptations and modifications that may be needed for specific children with disabilities. As in the words of one provider, "...for us to have the opportunity to have someone in there that can help us to help a child...bringing somebody in to explain to us what we can do, how we can adapt our situation here to a child's needs. Many providers found the early intervention (Babies Can't Wait) staff serving children from birth through two years of age to be a wonderful resource for younger children and wanted a similar resource for school-age children with disabilities. Another family child care provider explained:

It's very difficult to have a workshop that would cater to everybody's needs. It would be a lot easier to have a person available, you know, a resource available that you could pull in and you could say—"Ok, I have this situation, this is what I feel like the need is"—or come in and tell me, this is what the child's needs are. You know, specifically to that child's needs. Babies Can't Wait, they're great. We don't have the resource for school age children. They just come right in and do just what we need. To have that resource to pull in for after-school children would be nice.

Currently, the major support that providers receive is from the inclusion coordinator(s) in their specific areas. This level of support depends on how involved the inclusion coordinator in that area is with school age child care and activity settings. Sometimes these inclusion coordinators are stretched very thin and in other cases, providers do not know about the assistance that these agents can provide.

Providers also feel training is needed for the general public to increase their awareness about children with disabilities. One provider described children with disabilities very beautifully, “Actually, in reality, we all have disabilities. So we try to tell the children that. You know, some people’s disabilities are more severe than others. But we all have disabilities”. This training would increase the understanding and exposure of people to children with disabilities and reduce some of the pressures placed on providers by parents of typically-developing children.

Greater resources

Staff, funding and information. To better serve children with disabilities, providers need greater access to resources. Having more qualified staff to work with children having disabilities is a much needed resource cited by many providers. Providers need cost effective ways to have the higher teacher to student ratios necessary to better accommodate children with disabilities.

Another resource that impacts provider’s ability to care for children with disabilities is their access to adaptive equipment. The high cost of equipment for children with disabilities makes it difficult for many settings to accommodate these children, particularly small private and family day care settings. Grants and other funding opportunities could help make the adaptive equipment more affordable for providers. However, information about these funding sources and the grant writing processes needs to be more accessible to providers. As one provider explains, “I mean its just money, its all about just having grants and things like that to be able to take care of a child with special needs, to be able to provide certain things.” Providers would like to see more avenues from where they could get information about grants and funding sources.

Integrated Team Approach

There needs to be greater collaboration between the providers, parents, teachers, therapists, and other professionals who work with a child with disabilities in order to have a more integrated, team-based approach. Parents are perhaps the most essential players on this team. Providers emphasized the need for stronger parent-provider relationships. Providers and parents of children with disabilities must develop trust, open communication and joint problem-solving approaches. Providers would like suggestions on how to better communicate with parents who have children with disabilities and to be a resource to them. A family child care provider explained:

How can we help the parents at home? You know, send something--because we do this with the normal children. If they have a problem we send a little note saying if you do this at home, it will help the child to better adapt to our situation. So that's what I would like to see more of in a perfect world.

Positive parent involvement enables providers to better support children with disabilities. In some cases, providers need more interaction with families. They need to know more about the home situation, the child's preferences, and the guidance techniques that work well with that child.

With other families, however, the main challenge is helping parents develop reasonable expectations for what is possible in the school-age care or activity setting and to recognize that over-protecting children can be damaging to the children's long-term development. Providers believe that parents also need training to help them work more effectively with school-age caregivers. For example, parents need to understand the importance of being up front about a child's disability, sharing information about things

going on at home, and the benefits of relaying information about effective behavior management techniques.

The hands-on, practical training that providers say they need could be provided in part by parents. Communication between parents and providers is crucial, yet many providers do not know the best way to create this dialogue between different types of parents. Having a systematic tool for communication, like a journal, encourages greater collaboration between the different people working with a children having disabilities.

Children with disabilities spend the majority of their day in the school. School teachers or para-professionals who work closely with children having disabilities could provide useful insight into learning and behavior management strategies they use and how they incorporate the child into the setting. When there is lack of communication and coordination between the school and the after-school setting, it becomes more difficult for providers to support the developmental and learning goals that they have established for these children. Providers would like a resource within the school that they can contact to learn more about how to best support a child. Providers would like information in the IEP to be in layman's terms so that they can easily utilize the information. Given the specificity of each disability and the uniqueness of each child, many providers feel that having a resource person who can come to the setting to provide hands-on training would be ideal.

Being able to integrate techniques used by therapists into a child's routine in the after-school setting benefits both the child and the provider. By continuing some of the work of the therapist, the provider is armed with hands-on, practical techniques that could help the provider better support and understand the child with disabilities. If providers

cannot participate in the therapy session with the child, having a quick reference list of key things to work on with the child would be a useful resource for providers that would allow for more continuity in care.

Providers would like tips on how to effectively manage communication across multiple individuals. School-age programs have higher child/staff ratios than preschool programs and that means that they have to communicate with more families compared to providers who care for preschool children. Even home-based providers said they find it very challenging to manage all of the interactions required to keep communication going. Some providers had developed easy but effective ways to manage this communication. For example, a family childcare provider in a rural area shared this example:

...what we've started doing at the end is getting a notebook and having the therapist write down in the notebook anything they wanted to tell the parents. Because there's so many kids and so many therapists, I was afraid I wouldn't get all the information to the right one. But we started providing the notebook and saying "you write down—this is this child's number—everything you want to tell your parent to do to work on at home."

Maintaining journals can also be an effective way of promoting interaction between the after-school program and the school. The director of a child care center explained:

We used to have a journal that the therapists would write in and communicate with the teachers and say, 'Okay, this is what we did today and this is what you need to focus on.' And you know, it would also communicate to the mother or father. It would stay in the child's cubby.

Thus, providers stressed on the need for greater collaboration between the providers, parents, teachers, therapists, and other professionals who work with the child in order to have a more integrated, team approach.

More Networking

Providers would like to interact with model inclusive programs from settings like their own - family child care homes; school, center, or community-based after-school programs; recreation and enrichment programs; and respite programs. Being able to observe and talk to others who do the same work they do - especially those who have found effective ways to meet the needs of children with disabilities - would be most welcome.

Limitations and Future Directions

These results need to be interpreted bearing in mind certain limitations of this study. Although transferability is not claimed in qualitative research, an attempt was made to make the sample as representative as possible. Providers from a variety of settings including home-based settings, private child care centers, after school programs, and recreational programs were included. An attempt was made to include professionals from all levels of hierarchy including child care administrators (directors or supervisors), those who work directly with children (head teachers and field staff) and professionals who support or advocate for youth with disabilities. Providers worked in home-based, facility-based, and drop-in settings, some of which offered year-round care, others of which were only short-term enrichment, recreation or respite care. The only sub-group of providers we were unable to attract to the focus groups/interviews were informal caregivers—the family, friends, and neighbors who care for children. Further research is

needed to better understand the perspective of informal caregivers. As purposive sampling was used for this study, there may be an inherent bias in sample such that providers who have a more positive attitude toward inclusion and were more open to including children with disabilities in their setting, were more likely to participate in this study.

This study provides rich information about the perspective of child care providers related to out-of-school care for school age children with disabilities. The information can be useful for child care administrators and policy makers to address the challenges and implement creative solutions to make the school age child care system work. Findings from this study can be useful in developing training modules for child care providers. This information can also be insightful for parents, school teachers and therapists to help them better understand the perspective of providers and the school age contexts in which they work. The information from this qualitative study can also be used to develop rating scales related to assessing barriers and supports of child care providers related to school age children with disabilities.

This exploratory study provided valuable insights about the challenges and needs of providers related to school age children with disabilities. Future research should be conducted with larger, more representative and diverse samples to test the hypotheses generated through this study and to verify if study findings hold true for different types of care providers. The previous paper focuses on the perspective of parents and this paper focuses on the perspective of providers related to child care for school age children with disabilities. The voices of school age children themselves also need to be considered. By understanding the unique and common perspectives of all parties involved, particularly

the parents, providers, therapists, school teachers and the children themselves, it is more likely that lasting changes related to inclusion in the school age care system will occur.

CHAPTER 6

CONCLUSION

Families having children with disabilities are increasingly relying on non-parental childcare for their children, like most other families in the U.S. A set of legal, moral, rational and empirical arguments form a basis for inclusive practices (Bailey et al., 1998). In the past ten years, numerous laws have been passed and amended to ensure equal rights of children with disabilities in child care settings. In spite of the laws like ADA and IDEA, parents still struggle with finding appropriate and accommodative out-of-school care for their school age children with disabilities.

We believe that the first step in solving a problem is to clearly identify and understand the nature of the problem. It would be difficult to formulate coherent policies for helping families without elucidating the specific child care barriers faced by these families. In Chapter 3, we examine the process through which families of school age children with disabilities seek care and to identify the points in the process where the system fails families. In that chapter, for the first time, we outline a conceptual framework for understanding the extrinsic barriers that families of school age children with disabilities are faced with, as they cycle through the child care seeking process. Clear patterns emerged regarding why care options were perceived to be unavailable by families. We use a flowchart, which we call the 'care cycle' to identify pathways representing the sequence of activities followed by families in their search for child care.

As a first step, care options are unavailable in rural areas, during summer time and more so for older children with disabilities. In phase 2, even if care options are present in the area, providers refuse to include school age children with disabilities in their setting, especially those who also have behavioral issues and toileting needs. In phase 3, even if a child is included in a setting, care is terminated shortly without enough problem-solving efforts. Phase 4 represents the situation where even if providers include the child with disabilities, parents are sometimes uncomfortable due to fear of abuse and safety related issues. In this chapter, we not only highlight the main reasons why childcare becomes unavailable to families, but also provide some specific and practical solutions that have the potential to creatively address these barriers. By applying these solutions to address the barriers, more options that are appropriate and accessible will become available to families having children with disabilities.

Being accepted into a child care or activity setting is only a first step. Even after the child is accepted in an out-of-school program, the sustenance of the care option depends on whether the setting makes appropriate adaptations to accommodate the child with disability in the setting. There are a host of problems that parents of children with disabilities face related to adaptations and accommodations. In Chapter 4, we highlight parent's perspective on features that contribute to successful inclusion of school age children with disabilities in child care and other out-of-school settings. Parents identified a host of adaptations including adaptations of physical space and activities, adaptations focusing on peer socialization, supervision and safety, parent-provider communication, and those focusing on the attitude and skills of child care providers.

From a systemic perspective, it is not only important to consider parent's perspective on the issue but is also important to identify the challenges and support needs of child care providers. Because of the federal and state laws, school age child care providers are increasingly being expected to include children with disabilities in their settings. As child care providers include school age children with disabilities in their settings, research related to the obstacles they face and supports they require, is needed. Chapter 5 focuses on the challenges that providers face related to inclusion and the supports and resources they need to better facilitate overall development of children having disabilities. Providers highlight the joys they experience as a result of including school age children with disabilities in their settings. However, providers mentioned that working with school age children having disabilities brings with it some challenges. The challenges expressed by providers in our focus groups can be put into three broad categories – issues related to staff, the lack of resources and issues related to communication and collaboration between the different people involved. The supports that child care providers need to make inclusion work revolve around needing more training on disability issues, more resources including additional staff, more funding, and more information about available resources. Providers would like greater communication with parents, school teachers and therapists related to the needs and progress of the school age child with disabilities. Providers would also like to see greater collaboration and networking among different individuals working with school age children having disabilities.

There were several points of intersection as well as differences in the perspectives of parents and child care providers related to inclusion of school age children with

disabilities. These similarities and differences have been highlighted in the subsequent paragraphs.

More staff. Both parents and child care providers emphasized the need for more staff in child care settings to ensure adequate supervision and safety of children with disabilities.

Staff attitude. Both parents and providers believed that staff attitude plays an important role in how inclusive approaches are implemented in child care settings. Parents expressed concern that certain child care providers have a generalized stereotype that including a child with disabilities in the setting would inevitably disrupt the setting, placing a heavy demand on time and other resources of staff members. However, parents believe that this is usually not true. On the other hand, providers mentioned that they were afraid to include children with disabilities in settings because they do not have enough knowledge about how to manage the child. They were sometimes worried about the safety of the child and other children in the setting. They were also worried about the possibility of the child hurting other children. They feared being held liable if something happens to the child while he or she is with them. Even when providers are able to make appropriate accommodations, the slow progress of some children with disabilities can attenuate their spirits. It can take a long time before noticeable change occurs in some children.

Staff training. Both parents and providers agreed that the staff need more training in working with children having disabilities. Both parents and providers mentioned that in addition to the training on general disability issues, providers need to know more about specific disabilities so that they can understand and provide for the needs of

children with different disabilities. Training in administering medications and working with children having behavioral issues was also mentioned by both parents as well as providers.

Adaptations for peer socialization. Parents believed that children with disabilities need role models for learning positive social behavior. They need opportunities to interact with typically-developing children in order to develop friendships and gain social skills. Child care providers mentioned that they need more training in how to promote positive interactions between children with and without disabilities.

Adaptations related to parent-provider communication. Both parents and providers would like the other to communicate more with them about the child. Parents would like providers to communicate with them regarding the child's progress. If there were behavioral issues with the child, parents would like providers to inform and consult them so that they can work on solutions together. On the other hand, providers mentioned that they get frustrated when parents are not involved enough in their child's life. When parents do not communicate information about situations going on at home, a child's favorite toy or activity, or techniques for managing the child's behavior, it makes it far more difficult for providers to care for children.

Providers expressed frustration with parents of children with disabilities who try to do everything for their child and have the same expectation of providers. Providers believe that by being over-protective of their child, parents may unknowingly be hurting the child and abating the child's progress. Deception by parents desperate for care is another challenge that some providers face. Providers have to grapple with a multitude of

issues when parents do not disclose their child's disability causing a threat to the safety of the child having disabilities and other children in the setting.

Parents, on the other hand, believe it is necessary for their children with disabilities to be accepted in care settings. Parents mentioned that they would like to feel welcome when they visit the child's care setting. Parents believe that they can help providers understand their child better by sharing their insights and wisdom about the caring of their child. Parents also stressed that they would like providers to value their input in caring for the children.

This research highlights the perspectives of both parents and child care providers related to inclusion of school age children with disabilities. It is important for both, parents and child care providers, to acknowledge and understand the others' point of view. By understanding the unique and common perspectives of all parties involved, it is more likely that lasting changes related to inclusion in school age child care system will occur.

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APPENDICES

APPENDIX A

FOCUS GROUP AND PHONE INTERVIEW QUESTIONS FOR PARENTS

Procedure:

- As you can see, we each have name tags. These tags help me remember names, but they can also help you. If you want to follow up on something that someone has said—if you want to agree or disagree—feel free to do that. You do not have to respond to me all the time. I want to encourage you to have a conversation with one another about these questions. In order to help us understand what each of you said at different points in time during the discussion, it will be great if you say your name each time before you start making a comment. For e.g. “This is Mary. I think my child needs this”.
- I am here to ask questions, to listen, and to ensure that everyone has a chance to share. Each of us has a different story about what happened and when. And that’s what might happen here tonight. Hamida and I, want to make sure that everyone has a chance to share their version of the story. So if you’re sharing a lot, I may ask you to give others a chance to share. And, if you aren’t saying much, I may call on you. We want to hear from all of you.

Introductions

- First, let’s go around the room and have everyone tell the group their first name, the ages of your children/grandchildren and whether your child has a disability and if so what type.

Definition of School-age care

- Now that we know who we all are, let’s get into our discussion about school age care for children with disabilities. Before we start, I want to re-emphasize what we mean by school age care.

All of the places that K-12th graders go when they are not in school and not with a parent.***Questions:***

1. Where do children with disabilities in your community spend their time when they’re not in school and not with a parent.
(*Probes: home, the library, friends and relatives, family child care homes, before and after-school programs, child care centers, sports activities, clubs, on the streets*).
2. Now, we would like you to think about the school-age care arrangements you currently use for your child. From now on, all the discussion that we have will be in relation to your school age child with a disability.
 - What type of school age care do you currently use for this child?
 - What type of activities do they do while they are in this setting? What kind of activities would you ideally like your child to be involved in?

- a) What do you like about your current school-age care arrangements? What you don't like?
- Overall, Are you satisfied with the current school-age care arrangement(s) for your child?
 - What accommodations would help you to feel more satisfied with you level of service? (*Probe: Do they work with other professionals... talk with you...*)
 - What type of training would be most valuable for the child care providers working with your child?
 - (*Probes: accommodations that they make for children with disabilities, training that they have in working with children having disabilities, support that is available for you as a parent, physical accessibility to the site, meet the needs of older as well as younger children*).
- b) Tell us more about the other children in the school-age care setting that your child currently attends.
- Do the other children in the setting have disabilities?
 - Are the other children in the setting of the same age as your child or is there a significant age difference (for e.g. are they a lot older or younger?)
 - Do you think your child is developing friendships in that setting? What makes you say that?
- c) How easy was it to find school-age care and activities for your child?
- *Did you have many options? (Probe)*
 - How did you learn about different school-age care programs?
 - Was it affordable?
3. In your experience, what are the barriers to including children with disabilities into school age care activity settings?
4. Now let's talk about the types of school-age care and activity settings you would like to have for your child.
- d) Ideally what types of school-age care and activities would you like to have for your child? (*Probe: quality indicators*)
- e) Is your child participating in these currently? If no, why isn't that happening?
5. **Final Question for all:**
 What could be done to improve the school-age care options in your community?
 (*Probes: For children in elementary school? Middle school? High school?*)
6. Is there anything else you would like to share?

APPENDIX B

FOCUS GROUP AND PHONE INTERVIEW QUESTIONS FOR PROVIDERS

Procedure:

- As you can see, we each have name tags. These tags help me remember names, but they can also help you. If you want to follow up on something that someone has said—if you want to agree or disagree—feel free to do that. You do not have to respond to me all the time. I want to encourage you to have a conversation with one another about these questions. In order to help us understand what each of you said at different points in time during the discussion, it will be great if you say your name each time before you start making a comment. For e.g. “I think my child care center needs this”.
- I am here to ask questions, to listen, and to ensure that everyone has a chance to share. Each of us has a different story about what happened and when. And that’s what might happen here tonight. I want to make sure that everyone has a chance to share their version of the story. So if you’re sharing a lot, I may ask you to give others a chance to share. And, if you aren’t saying much, I may call on you. We want to hear from all of you.

Introductions

- First, let’s go around the room and have everyone tell the group their first name, the type of setting you work in including the kinds of services and activities you provide, and ages of the children you work with.

Definition of School-age care

- Now that we know who we all are, let’s get into our discussion about school age care for children with disabilities. Before we start, I want to re-emphasize what we mean by school age care.

All of the places that K-12th graders go when they are not in school and not with a parent.*Questions:*

1. When you think about children with disabilities and special needs, who are the kids that you think about?
(What are they like, what are some of the disabilities or some of the things going on with the kids, to sort of make sure that we’re all kind of on the same page.)
 - ◆ What children do you view as having disabilities. Please give examples, so we have an idea of who we are talking about (Probes: behavioral problems, health problems, autism or physical disability).

2. As you think about the children with disabilities that you've talked about here in this area, when they are not in school and not with a parent, where are they?
 - ◆ Obviously your programs serve some youngsters, what else is available for children? What is available during the non-school hours, with working parents?
 - ◆ (Probes: home, the library, friends and relatives, family child care homes, before and after school programs, child care centers, sports activities, clubs, on the streets; adolescents and older children).

3. Do you include children with disabilities in your program?
 - f) **If not**, what stops you from including them in your setting?
 1. Are there children with certain types of disabilities whom you, up until now have not been able to include in your program? If yes, what are they?
 2. Is there any kind of support that could help you include them in your program?

 - g) **If you do** include children with disabilities, what types of disabilities do they have?
 1. Do you have any children who require special apparatus or medications? If so, how do you handle these situations?

4. Every job brings joys and challenges.
 - a) What are some of the joys of working with children having disabilities? (**Probes**: children that have been particularly enjoyable to work with, watching children develop and learn, working with the families of these children).

 - b) What are some of the challenges of working with children having disabilities? : **Probes**: accommodations that you need to make for children with disabilities, physical accessibility to the site,
 - a. balancing the needs of children with disabilities with that of other children,
 - b. striking a balance between supporting them and fostering independence in them,
 - c. promoting friendships between them and other children,
 - d. meeting the needs of older as well as younger children, meeting the needs of families).

5. Children with disabilities often need support from other professionals. Does your setting collaborate with other professionals/agencies (like therapists, medical assistants etc.) to provide services that children with disabilities need?
 - a) If so, describe the relationships between your setting and professionals from the medical, social services or special education fields?
 - b) How is information shared between these settings?

6. What could be done to improve school-age care activity settings for children with disabilities in your community?
(Probes: For children in elementary school? Middle school? High school?)
7. Now let's talk about your needs as school-age care providers when it comes to working with children with disabilities.
 - a) Do you feel like you have access to the resources needed to effectively support families of children with disabilities? If no, what more do you need?
 - b) Do you have the training to work with children having disabilities? If no, what type of training do you need?
8. Besides hiring more staff and more money, are there any types of support that would help you as providers of school-age care to better support children with disabilities?
9. The American Disabilities Act (ADA) has some provisions that relate to school age care for children with disabilities. Are you aware of these provisions? If so, how have they affected your program?
10. Is there anything else you would like to share?

11) What kind of school age care setting(s) and activities do you currently use to care for your child with a disability? (check all that apply).

At home with:

- parent(s)
- adult relative
- adult non-relative
- teenage sitter

At an after-school program

- at a child care center
- at a school
- at a community location (e.g, YMCA, church)

At home without an adult:

- with brothers & sisters, friends or alone

Child is somewhere else

- at a meeting, lesson, class, team practice, youth club, or recreation activity
- cared for by parent at the parent's worksite
- child is at a work or volunteer experience
- with friends (no adult present)

At someone else's house with:

- adult relative
- adult friend or neighbor
- adult child care provider
- teenage sitter

12) Do you have other children who also use school age care? Yes No

At home with:

- parent(s)
- adult relative
- adult non-relative
- teenage sitter

At an after-school program

- at a child care center
- at a school
- at a community location (e.g, YMCA, church)

At home without an adult:

- with brothers & sisters, friends or alone

Child is somewhere else

- at a meeting, lesson, class, team practice, youth club, or recreation activity
- cared for by parent at the parent's worksite
- child is at a work or volunteer experience
- with friends (no adult present)

At someone else's house with:

- adult relative
- adult friend or neighbor
- adult child care provider
- teenage sitter

13) What is your gender? Male Female

14) What is your marital status? (check ONE) Single/Never Married
 Married
 Divorced or Separated
 Widowed

- 15) What is your highest level of education? (check ONE)
- Eighth grade or less
 - Some high school
 - High school or GED
 - Some technical school
 - Technical school diploma or degree.
 - Some college
 - AA degree
 - BS/BA degree
 - Some graduate work
 - Graduate degree
- 16) What age range are you in? (Check ONE)
- 18 – 24 years
 - 25 – 34 years
 - 35 - 44 years
 - 45 – 54 years
 - 55-64 years
 - 65-74 years
 - 75 years and above
- 17) What do you consider to be your race/ethnicity? (check ONE)
- White, non-Hispanic, non-Latino(a)
 - Black/ African American
 - American Indian or Alaska Native
 - Native Hawaiian or Other Pacific Islander
 - Hispanic or Latino(a)
 - Asian
 - Multiracial
 - Other (please specify: _____)
- 18) What is your family's total yearly income? (check ONE)
- Less than \$15,000
 - \$15,000-\$29,999
 - \$30,000-\$44,999
 - \$45,000-\$59,999
 - \$60,000-\$74,999
 - \$75,000+

Thank you !

SCHOOL-AGE PROVIDER INFORMATION SHEET

We'd like to ask you some general information about you and your work situation. We will use this information to better understand your unique situation and to learn more about the conditions under which you work. You do not have to answer any questions you do not want to.

1) What is your current position in the school-age field? (Check ONE)

- Youth Program Director/Coordinator
- Child Care or School-Age Care Program Director/Administrator
- Part-Time Director/Part-Time Lead Staff
- Lead Staff or Head Teacher
- Assistant Staff or Assistant Teacher
- Group Home Provider
- Family Child Care Provider
- Informal Caregiver (e.g., family, friend, neighbor)
- Volunteer
- Other (Specify: _____)

2) Are you a part-time or full-time employee in this job?

- Part-time
- Full time

3) What is the primary setting in which you care for or provide programming to school age child? (Check ONE)

- In my home or someone else's home
- After school program in a school
- After school program in a child care center
- After school program in a community organization
(such as YMCA, Boys & Girls Club, etc).
- Short-term educational or recreational activities for school-age children before or after school
(e.g., soccer, crafts, hobbies, music lessons, art lessons)
- Youth development/leadership program
(e.g., 4H, Scouts, Girls, Inc, Campfire, etc.)
- A youth prevention/intervention program
- Other: _____

4) What ages of children do you/your program serve ? _____

Please tell us about yourself:

5) How many years of paid experience do you have in the school-age care field? (Check ONE)

- Less than 2 years
- 2 - 5 years
- 6 - 10 years
- Over 10 years

6) How many years of experience do you have in your current position? (Check ONE)

- Less than 2 years
- 2 - 5 years
- 6 - 10 years
- Over 10 years

7) Do you include children with disabilities in your program/setting? Yes No

8) Have you ever included children with the following disabilities in your program/setting?
(check whichever that apply)

- | | |
|---|---|
| <input type="radio"/> Down Syndrome | <input type="radio"/> Language/Speech delay |
| <input type="radio"/> Fragile X | <input type="radio"/> Cerebral Palsy |
| <input type="radio"/> Hearing impairment | <input type="radio"/> Physical Disability |
| <input type="radio"/> Cognitive/Mental delay | <input type="radio"/> Muscular Dystrophy |
| <input type="radio"/> Pervasive Developmental Delay (PDD) | <input type="radio"/> Autism |
| <input type="radio"/> Spina Bifida | <input type="radio"/> Visual Impairment |
| <input type="radio"/> Behavioral problems | <input type="radio"/> ADHD (Attention Deficit Hyperactivity Disorder) |
| <input type="radio"/> Other: (Please describe) _____ | |

9) What is your gender? Male Female

10) What is your marital status?(Check ONE) Single/Never Married
 Married
 Divorced or Separated
 Widowed

11) What is your highest level of education? (Check ONE) Eighth grade or less
 Some high school
 High school or GED
 Some technical school
 Technical school: diploma degree.
 Some college
 AA degree
 BS/BA degree
 Some graduate work
 Graduate degree

12) What age range are you in? (Check ONE) 18 – 24 years 55-64 years
 25 – 34 years 65-74 years
 35 - 44 years 75 years and above
 45 – 54 years

13) What do you consider to be your race/ethnicity? (check ONE)

- White, non-Hispanic, non-Latino(a)
- Black/ African American
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander
- Hispanic or Latino(a)
- Asian
- Multiracial
- Other (please specify: _____)

Do you have children of your own? Yes No

If yes, what are their ages? _____

14) How many children do you have? _____

15) Do you have a child or a close relative with a disability? Yes No

If yes, specify: Relationship to you: _____ What type of disability: _____

Thanks !