Out-of-School Settings for Georgia Youth with Disabilities

Hamida Jinnah & Dr. Christine M. Todd
Department of Child and Family Development

Anika Francis
Department of Educational Psychology
and Instructional Technology

Dr. Zolinda Stoneman
Institute on Human Development and Disability

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For more information contact:

Dr. Zolinda Stoneman, Professor & Director
Institute for Human Development and Disability
Rivers Crossing
University of Georgia
Athens, Georgia 30602
(706) 542-4837
zo@ihdd-uga.edu

Dr. Christine M. Todd, Professor
Child and Family Development
114 Dawson Hall
University of Georgia
Athens, GA 30602
(706) 542-4830
ctodd@fcs.uga.edu

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Executive Summary

To better understand the needs of Georgia families who have school-age children with disabilities and the providers who care for these children, we examined the results from 2,193 parent surveys across four Georgia counties and conducted focus groups and interviews with 37 parents and 43 providers. The results indicated that school-age children with disabilities are in the same types of settings as typically-developing children although there was some evidence that children with more severe disabilities are more likely than typically-developing children to be home with siblings and to attend after-school programs.

Although school-age youth with disabilities are in settings similar to those used by typically-developing children, families of youth with disabilities are less satisfied and reported more problems with these arrangements. The top problems experienced—affordability, finding care when school is not in session, and not knowing what options are available in the community—are the same for families of typically-developing children and children with disabilities, although the prevalence of these problems is higher for families who have children with disabilities.

Access to inclusive settings for youth with disabilities was especially limited in rural areas and for older youth, who may need supervision longer than typically-developing children. Families who have children with disabilities are no more likely than families with typically-developing children to worry about their safety, although they have a broader range of concerns, including fear that their child may run away from the setting or be hurt trying to get on and off buses, may hurt other children, and may not be able to tell adults about problems due to an inability to communicate.

Executive Summary

Providers who offer care and activities to school-age youth with disabilities value the opportunity to involve the children in their programs. Providers enjoy watching the children develop and are rewarded by the love and affection they receive from the children. They also report that typically-developing children benefit from inclusion of children with disabilities in the program.

Providers also experience some problems, however. They are frustrated by not having enough staff with training in disabilities and the equipment needed to fully include children with certain disabilities. Providers also need help learning how to adapt their curriculum and activities to meet the needs of children with specific disabilities and funding to cover the cost of accommodations to vans, buildings, and equipment.

Parents and providers agree that parents of typically-developing children are not always supportive of including children with disabilities in the program. Providers also wanted to strengthen relationships with the parents of children with disabilities. In some cases, providers need more information from parents to know how best to meet the needs of children. In other cases, they feel that parents need to have more reasonable expectations for what is possible in an after-school setting and to recognize that over-protecting children can be damaging to the child.

Parents who have children with disabilities want the same types of programs and supports for their children as parents of typically-developing children, but they want them to a somewhat greater degree. Providers want enough staff with specialized training and the materials and equipment needed to fully accommodate children with disabilities into their settings. Both parents and providers want more interaction between all individuals who support these children—parents, school personnel, and therapists—and a greater understanding of and sensitivity to diversity issues on the part of the larger community.

Fully supporting school-age youth with disabilities, as well as the school-age providers who care for and educate them, will require:

- Making families and providers more aware of existing resources;

- Increasing access through improved accommodations;

- Improving collaboration at the state, community, and program levels to address the issues identified by parents and providers;

- Increasing provider training opportunities by:

  o Adding workshops on working with children having specific disabilities;

  o Developing video-based training on specific disabilities for use in workshops or as self-studies;

  o Engaging parents who have children with disabilities as trainers; and

  o Expanding access to training scholarships to the full range of school-age providers, including providers of short-term recreation and enrichment activities, youth club leaders, and informal caregivers who receive subsidies to care for low-income children;

- Increasing the availability of school-age options, especially for times when school is not in session (e.g., summer, holidays), in rural communities, and for older youth who have disabilities; and

- Providing diversity training to the larger population via mass media and workshops to support full inclusion of school-age children with disabilities in out-of-school settings.

Out-of-School Settings for
Georgia Youth with Disabilities

How youth spend their out-of-school time is a major concern facing families across the nation. Finding safe and enriching settings may be especially challenging for families who have children with disabilities. The goal of this study was to learn more about the school-age care and activity needs of these families as well as the perspectives of the providers who care for children with disabilities.

The findings in this report are based on surveys of families in four Georgia counties conducted in 2003-2005 as well as the results of focus groups and interviews with parents and school-age providers conducted in 2005. In this study we sought to answer the following questions:

   ♦   *Where are school-age children with disabilities when they are not in school and are away from their parents?*

   ♦   *What problems or concerns do families have with these arrangements?*

   ♦   *What settings do parents want for school-age children with disabilities? What prevents them from accessing these settings?*

   ♦   *What joys and challenges do providers experience in working with children who have disabilities?*

   ♦   *According to parents and providers, how can the school-age care & activity system be improved to better serve children with disabilities?*

Introduction to the Study

Method

Surveys. A four-page survey (in English and Spanish) was produced and sent home to 5,892 families with school-age children in two urban counties, one suburban Atlanta county, and one rural county in south Georgia (DeKalb, Muscogee, Douglas & Colquitt Counties). Schools were selected so as to be representative of all types of schools in each county. The survey instrument is included in Appendix A.

Surveys were sent home with children in two kindergarten, third, sixth, and eighth-grade classrooms (as appropriate) in the target schools. One county also surveyed families of tenth-graders. Half of the families provided information on their youngest school-age child; the remaining families reported on their oldest child in kindergarten through twelfth grade. The total number of surveys returned was 2,228, of which 2,191 were usable surveys about school-age youth. The average response rate across counties was 38% (range = 21% to 54%).

Focus Groups & Interviews. Families who have children with a wide range of physical, cognitive and behavioral disabilities were invited to participate in focus groups. School-age providers from a wide range of settings (e.g., after-school and recreation programs, family child care providers, respite care providers, informal caregivers) were invited to attend provider focus groups. Parents and providers were identified through local community professionals such as inclusion coordinators, family support personnel, and child care resource and referral staff. Parents also were recruited through a listserv of families who have children with disabilities.

Parents and providers who could not attend the focus groups were invited to participate in individual phone interviews. Snowball sampling (where participants suggest other potential participants) was used to recruit

additional phone interview participants. Parents and providers in rural counties were especially targeted for phone interviews because the low population density in these areas made it difficult to conduct focus groups. We also targeted individuals who were under-represented in the focus groups, such as ethnic minorities and informal caregivers. For both the parent and provider samples, data collection ended when few new issues were raised by participants.

In total, 29 parents attended one of five focus groups and 8 additional parents participated in phone interviews. Thirty-two parents had a school-age child with at least one disability. (For this report, we focus only on the comments of parents with school-age children.) Thirty-five providers attended one of six focus groups and eight additional providers were interviewed. More information on the counties in which participants lived (parents) or worked (providers) is listed on pages 9 and 14 of the report. In addition to attending the focus groups, parents and providers also completed a demographic questionnaire.

The same questions were used for both the focus groups and interviews. Parents were asked about the care and activity settings they currently use for their child, problems they have with their current arrangements, what settings they would like to have and what challenges they experience in accessing their preferred settings. Providers were asked about the joys and challenges of working with school-age children with disabilities and what supports would help them better serve these children. Both parents and providers were asked how the school-age care system could be improved to better meet the needs of school-age children with disabilities.

Analyses

Surveys. The numbers and percentages listed in this report refer to the responses of those families who answered each question. Separate chi-

square or t-test analyses, as appropriate, were used to investigate whether the responses of families who have children with disabilities differed from the responses of families with typically-developing children. Results of analyses that reached statistical significance ($p < .05$) are reported.

Focus Groups & Interviews. Data from the focus groups and interviews were combined for analysis. For simplicity's sake, we use the term "focus group sample" in this report for the combined group. Grounded theory guided the qualitative analyses. Using the constant comparative method recommended by Glaser and Strauss (1967),[1] data were collected and analyzed with the aim of generating a theory that is 'grounded' in the natural context in which the inquiry takes place.

Data were analyzed using the Nudist (N6) 6.0 software program. Using three types of coding (open coding, axial coding and selective coding), researchers looked for common patterns, themes and regularities, as well as contrasts, paradoxes and irregularities in the focus group and interview data. The final stage was selective coding where the researchers identified six categories that served as the basis for making recommendations on how to improve the school-age care and activity system to better serve school-age children with disabilities.

Comparing Survey and Focus Group Data. Graphs comparing survey and focus group data are provided and the groups are compared, although statistical analysis was not possible due to the great disparity in the two sample sizes. We looked for convergence and divergence in findings across the survey and focus group samples.

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[1]Glaser, B. & Strauss, A. (1967). *The discovery of grounded theory.* New York: Aldine de Gruyter.

The Children

Survey Children . Survey parents indicated that 15% (312) of the target children have a disability, a figure very similar to that provided by the four school districts (12%). The specific condition was determined in two counties (one urban and one rural). ADHD (63%), health problems (28%), physical disabilities (5%), autism (2%), mental retardation (1%) and other disabilities, such as speech and learning disorders (16%) were reported by parents. Thirteen percent of parents selected more than one disability category.

About half of the children are male (1044 or 48%) with rates being higher for children with disabilities than for typically-developing children (59% versus 46%). Ninety percent (1,959) of the children were in kindergarten to eighth grade. In part, there are fewer high school students in the sample because the survey was distributed to families with high school youth in only one county. Children with disabilities were somewhat older than typically-developing children (see Figure 1).

Figure 1. Target Child's Grade
(Survey Sample)
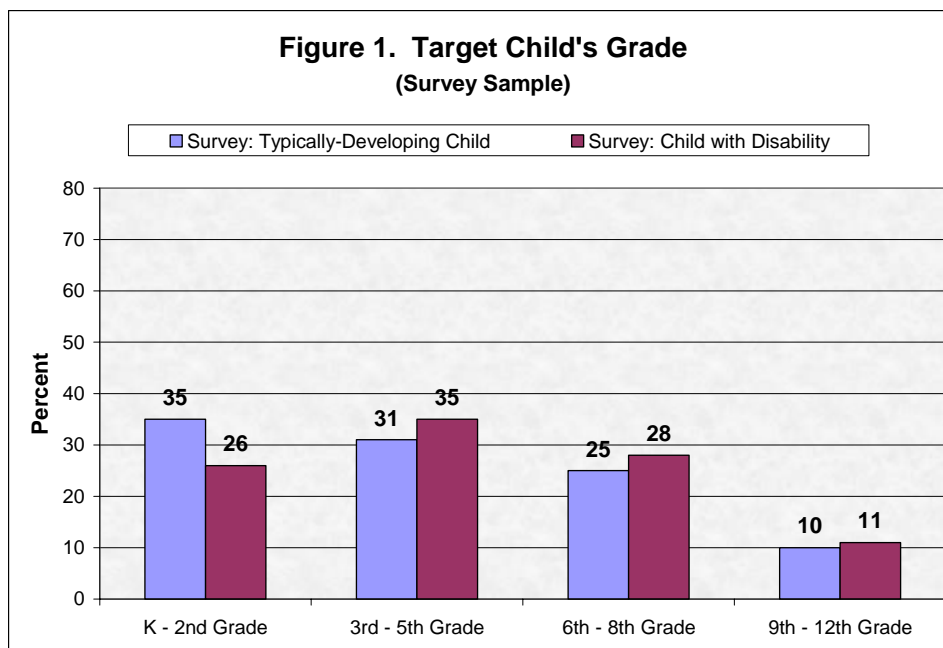
Characteristics of Participants

The survey sample was highly diverse both racially and economically. Caucasian (967 or 46%), African American (39%), Latino(a) (7%), Asian/Pacific Islander (2%), Native American (1%), and multi-racial (6%) children were all represented.   Averaging across counties, the total population of children in the school districts included 39% Caucasian, 50% African American, 7% Latino(a), 1% Asian/Pacific Islander, 0% Native American, 2% multi-racial children. African American children were therefore somewhat under-represented and Caucasian and multi-racial children were somewhat over-represented in our survey sample.

As can be seen in Figure 2, the disability rate was highest for multi-racial children, next highest for Caucasian children, and lower for African American and Latino(a) children (Data for Asian/Pacific Islander and Native American children are not presented in this figure because of the very small number of children in these racial/ethnic groups).

Figure 2. Disability Rates by Race/Ethnicity of Child
(Survey Sample)
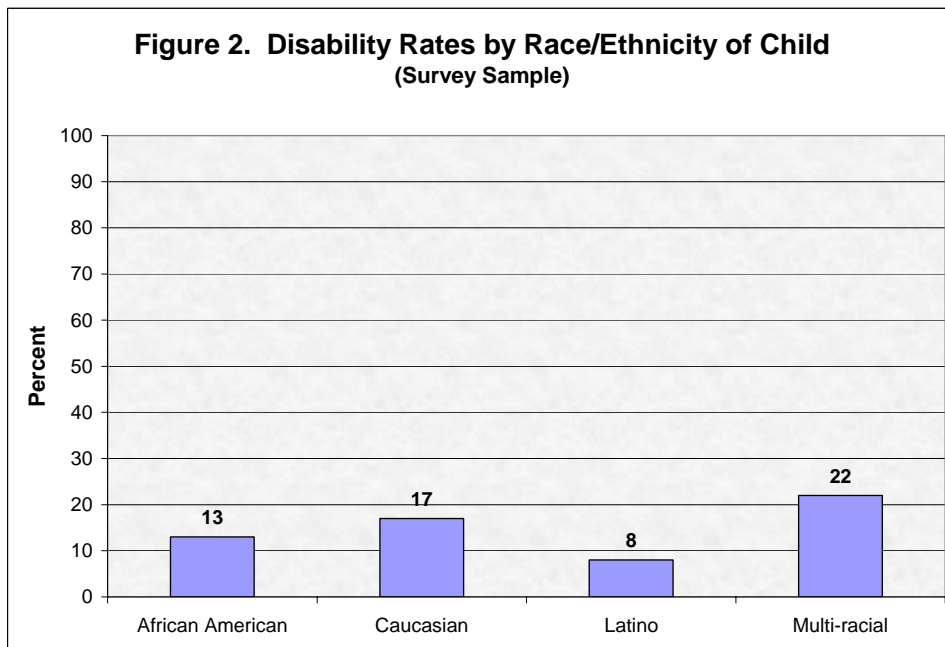
We suspect that this variation may be due to several factors. Some racial/ethnic groups may have less access to health care and therefore may not have a specific diagnosis for their child. It is also possible that certain conditions are more likely to be considered disabilities in some cultures than others.

About half of the survey children (1048 or 50%) are eligible for free or reduced-price lunch, very similar to the average of 54% reported by the school districts for the total population of children. Children with disabilities were more likely than typically-developing children to be eligible for free or reduced-price lunch (60% versus 47%, respectively).

Focus Group Children. The focus groups and interviews included families with school-age children having a wide variety of disabilities. The severity of the disability ranged from mild to very severe according to parents. Sixty percent of the children had multiple disabilities, a figure much higher than found in the survey sample. Almost half of the school-age children had a cognitive impairment and one third had autism (see Figure 3). The "other" category primarily included specific conditions, such as "megacephaly."

Figure 3: Disability of Child
(Focus Group Sample)

Disability	Percent
Down's Syndrome	16
Hearing Impairment	6
Cognitive Impairment	47
Pervasive Dev Disorder	12
Spina Bifida	6
Behavior Problems	19
Lang/Speech delay	19
Cerebral Palsy	16
Physical disability	9
Autism	34
Visual Impairment	16
ADHD	12
Other	31
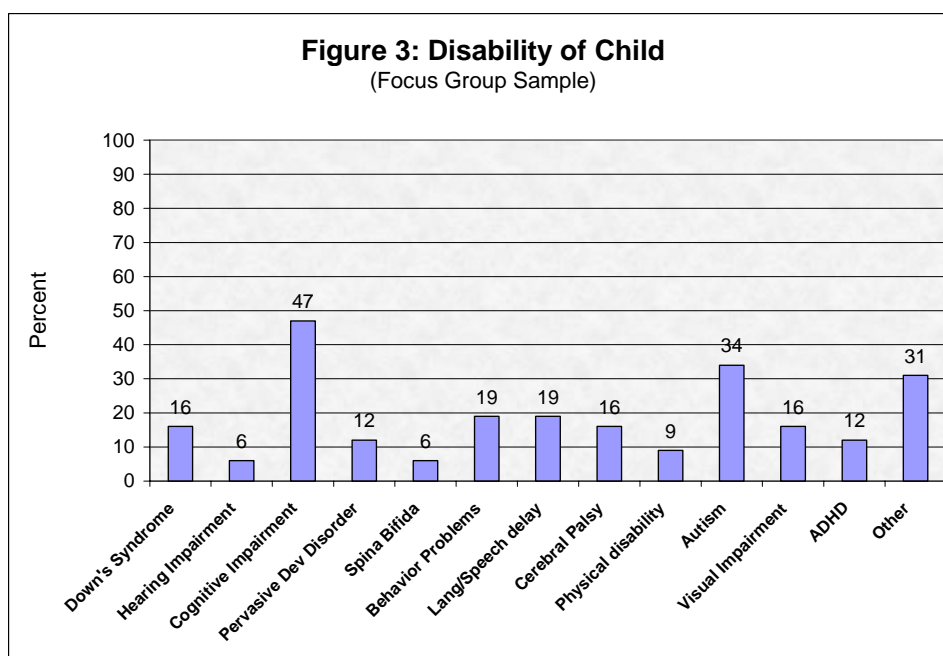
Characteristics of Participants

Because children with disabilities cannot always be assigned to a particular grade in school, we report the age group of the children rather than their grade. These age groups correspond roughly to the K-2, 3-5, 6-8, and 9-12 grade categories used for the survey results, with an additional category added for children who were older than 18 years.

Sixty-two percent of the children in the focus group sample were over 10 years of age (Figure 4), just the opposite of the survey findings where 61% of the children who had disabilities were in kindergarten to 5th grade.

Figure 4. Target Child's Age Group
(Focus Group Sample)
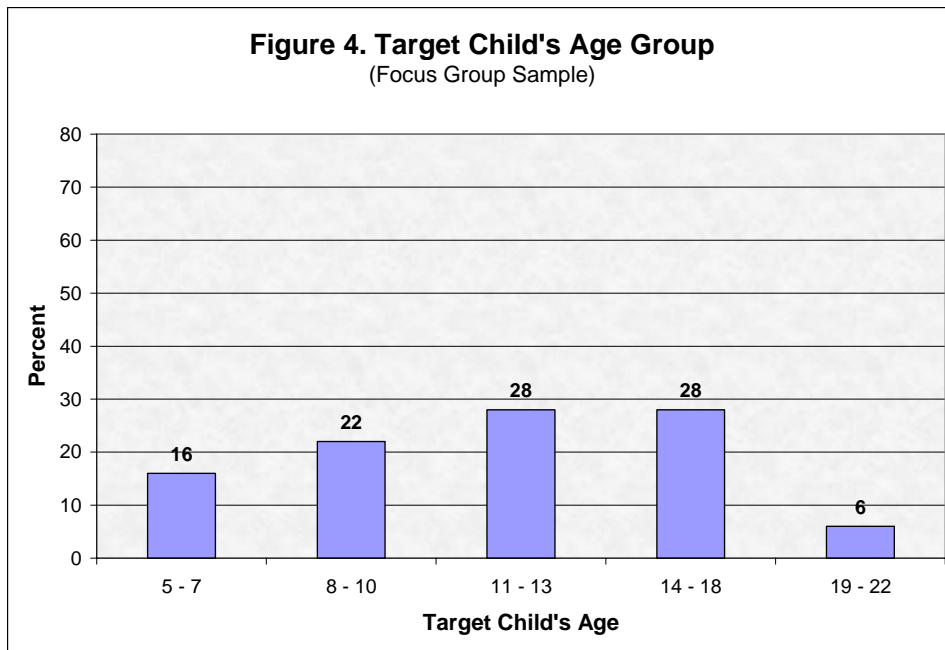
Two-thirds (66%) of the children in the focus group sample were male, a somewhat higher percentage than found in the survey sample (59%).

Although we did not ask about the race/ethnicity of the target children in the focus groups, we know that 81% of the participating parents are Caucasian and 19% are African American. Sixteen percent of the target children in the focus group sample are eligible for free or reduced-price lunch, which is much lower than the 46% found in the survey sample.

The Families

Because we collected similar family demographic information from both the survey and focus group sample, we will directly compare the two samples on each measure rather than presenting each group separately.

Where Families Live. As can be seen in Figure 5, the survey sample was fairly equally distributed across rural areas and towns, small cities and large urban areas. There was no difference by the disability status of the child in the size of the community in which families lived.

Figure 5. Where Survey Families Live
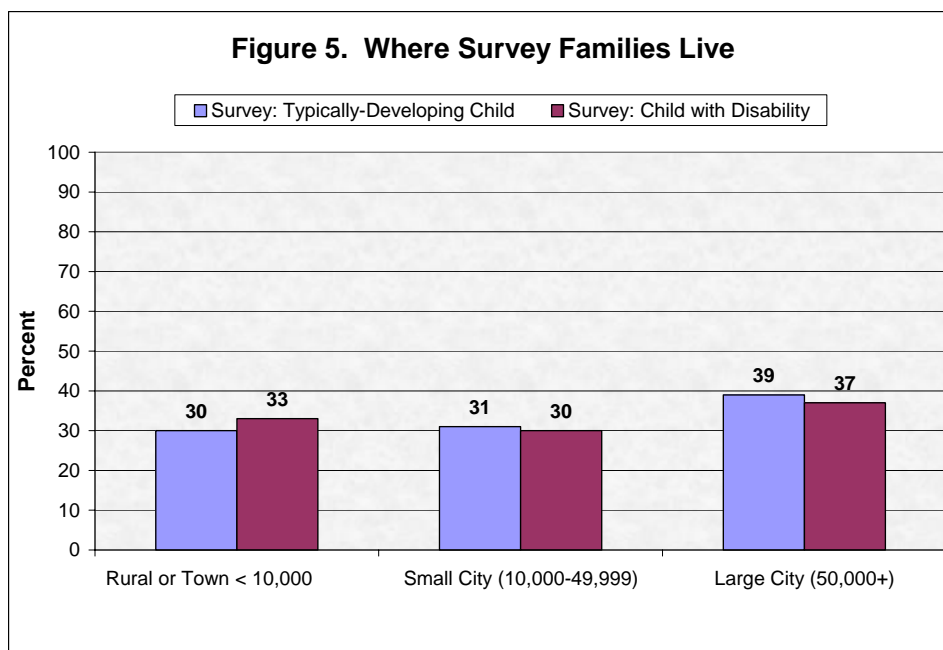
Parents in the focus group sample were from nine counties (Butts, Cherokee, Chattooga, Cobb, Columbia, Coweta, Dougherty, Rockdale and Tift). Using Bachtel's[2] county classification system, three participants were from an urban county, 23 were from suburban counties, and 11 were from rural growth counties.

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[2]Bachtel, D. C. (2003). *The four counties concept.* Athens, GA: Department of Housing and Consumer Economics.

Characteristics of Participants

Family Type. One third (699 or 32%) of the families responding to the survey are single parents, which is fairly similar to the average Census 2000 percentage across the four counties (36%). The number of single parent households was higher, however, for survey families who have children with disabilities than for families with typically-developing children (40% versus 31%, respectively). Among the focus group sample, 28% of the families were single parents, a much lower percentage than found in the survey.

Family Income. Survey respondents were classified into three income categories, with 42% earning less than $30,000, 25% earning $30,000 - $59,999 and 33% earning $60,000 or more per year. As can be seen in Figure 6, survey families who have children with disabilities are more likely than survey families with typically-developing children to earn less than $30,000 per year. As can also be seen in this figure, families attending the focus groups were more likely than survey families to be middle income.
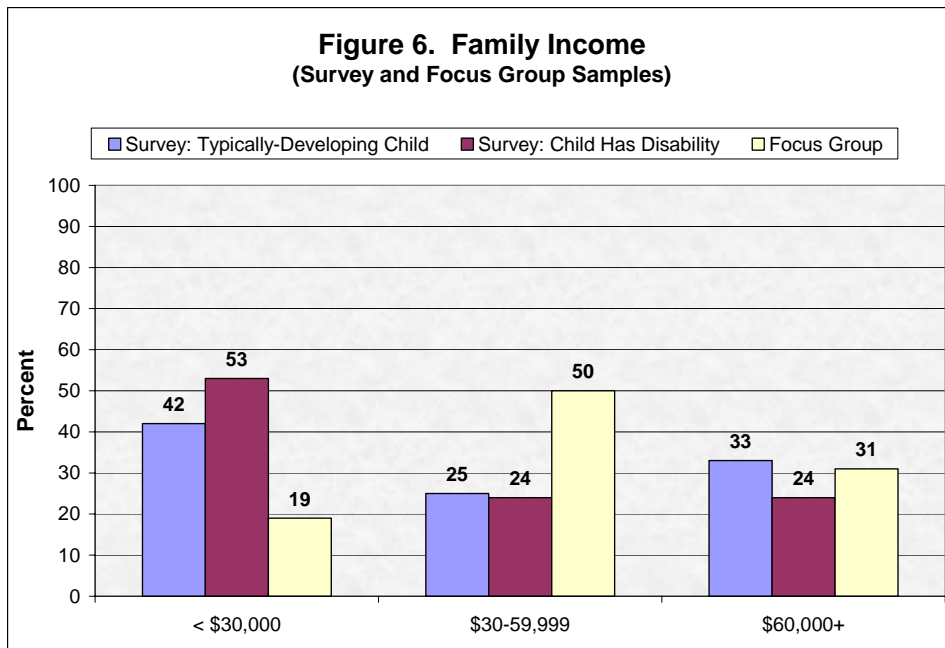
Figure 6. Family Income
(Survey and Focus Group Samples)

Parental Employment. The majority (387 or 57%) of the single parent families responding to the survey were employed full-time. One in five single parents (22%) was not employed. There was no significant difference in the work patterns of survey parents by the disability status of their child. As can be seen in Figure 7A, single parents attending the focus groups were more likely than survey parents to be unemployed.

Figure 7A. Employment: Single Parents
(Survey and Focus Group Samples)

Legend: ☐ Survey: Typically-Developing Child   ■ Survey: Child Has Disability   ☐ Focus Groups

Category	Survey: Typically-Developing Child	Survey: Child Has Disability	Focus Groups
Not Employed	22	24	50
Employed PT	18	24	12
Employed FT	60	51	38

Y-axis: Percent (0–100)
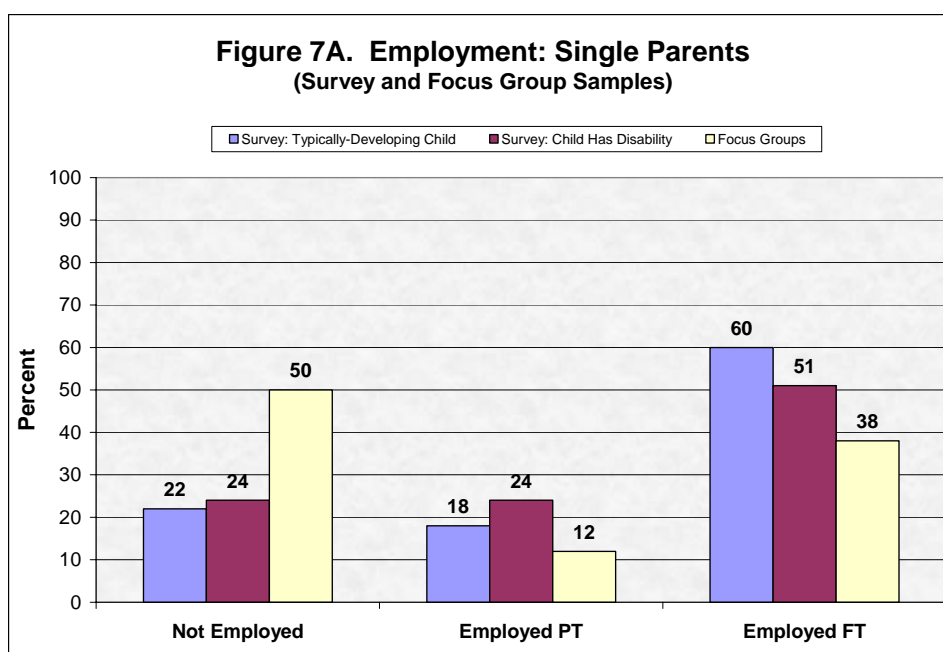
Characteristics of Participants

Among survey respondents, 71% of two-parent households had both parents employed, with 42% having both parents employed full-time. One parent was unemployed in 27% of the families and both parents were unemployed in 2% of the families. Again, there was no difference on these measures by the disability status of the child (see Figure 7B). Compared to survey families who have a child with a disability, two-parent families who attended the focus groups are more likely to have a parent who is not employed and less likely to have all parents working full time (see Figure 7B).

Figure 7B. Employment: Two Parent Households
(Survey and Focus Group Samples)
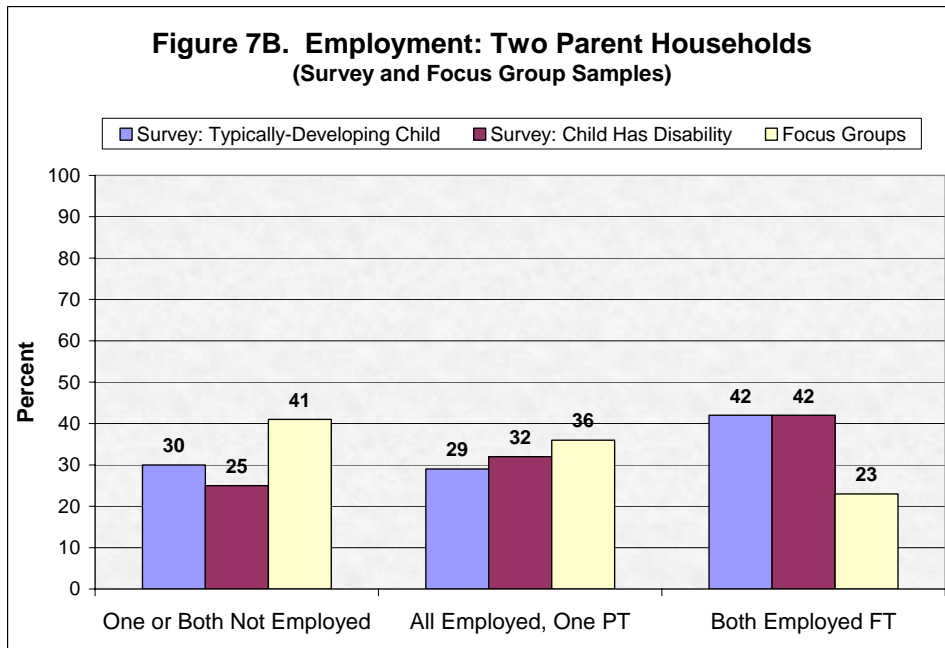
We believe that the difference in employment between the survey and focus group participants may be due to focus group families having children with more severe disabilities compared to survey families. Many families attending the focus group indicated that the severity of their child's disability made it very difficult for them to work. They indicated that few school-age care settings can accommodate children with very severe disabilities.

Comparison of Survey and Focus Group Samples.

The demographic analyses highlight several differences between the survey and focus group samples. The majority of the children in the survey sample are in elementary school, whereas the majority of the focus group sample is older. The survey sample is also more diverse in terms of race/ethnicity, socio-economic status and geographical location than the focus group sample.

The strength of the focus group sample is the inclusion of children with a wide variety of disabilities, many of whom have severe disabilities. We believe that surveying only parents in regular classrooms may have biased the survey sample toward families who have children with less severe disabilities. This may contribute to the greater likelihood of survey families who have children with disabilities to be employed compared to the focus group sample.

The time commitment for the focus groups, however, may have made it more difficult for some families to participate, resulting in the focus group sample being more representative of middle income, two-parent, Caucasian families. Moreover, although we recruited focus group families from urban, suburban and rural counties, we were more successful in suburban counties, which may also contribute to the characteristics of the focus group sample. Suburban counties tend to have more affluent populations and fewer minority families than urban and rural counties in Georgia (Bachtel, 2003)[2].

Each data collection method has strengths and weaknesses. By comparing the results from both methods we are more likely to identify the central issues affecting the full range of Georgia families who have children with disabilities.

Characteristics of Participants

The Providers

Participants in the provider focus groups and interviews were from 13 counties (Butts, Chatham, Chattooga, Columbia, Dougherty, Hall, Jeff Davis, Muscogee, Oconee, Spalding, Tift, Upson, and Whitfield). Using Bachtel's[2] county classification system, we had 14 participants from urban counties, 10 from suburban counties, and 19 from rural growth counties.

All of those attending the provider focus groups (35) and participating in the interviews (8) are female. Two thirds of the providers (28 or 65%) are Caucasian, 33% are African American, and 2% are Asian.   As can be seen in Figure 8, the age of the providers varied from early adulthood through retirement age, with most of the providers being between 25 and 64 years of age.

Figure 8. Age of Providers
(Focus Group Sample)
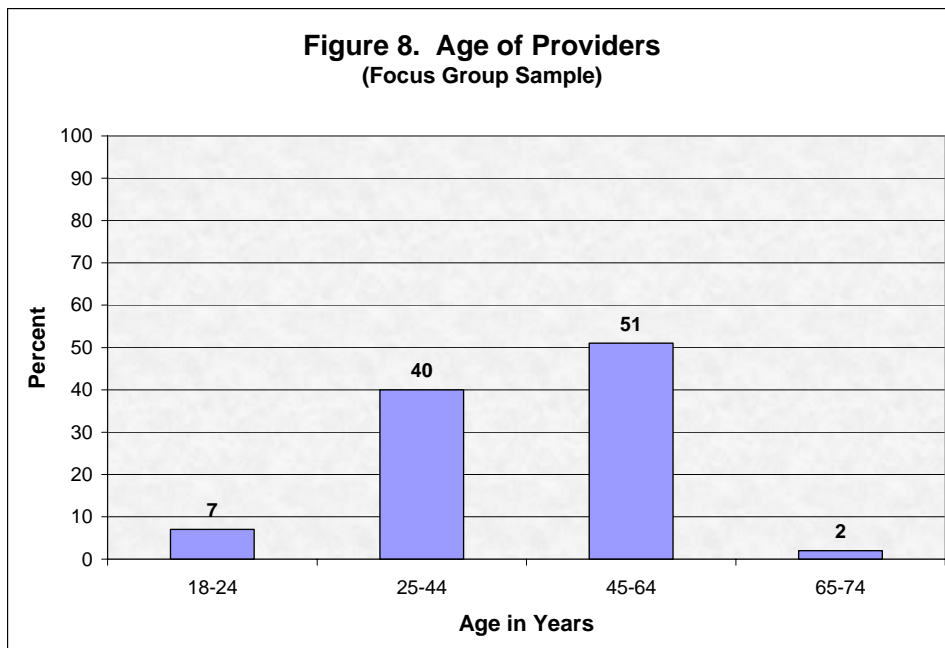
Most of the providers (62%) are married and 79% have children of their own, ranging in age from less than one year to 41 years. Two thirds of the focus group participants (29 or 67%) work full-time.

Almost half (20 or 48%) of the professionals attending the focus groups have a four year degree or more (see Figure 9).

Figure 9. Education Level of Providers
Focus Group Sample
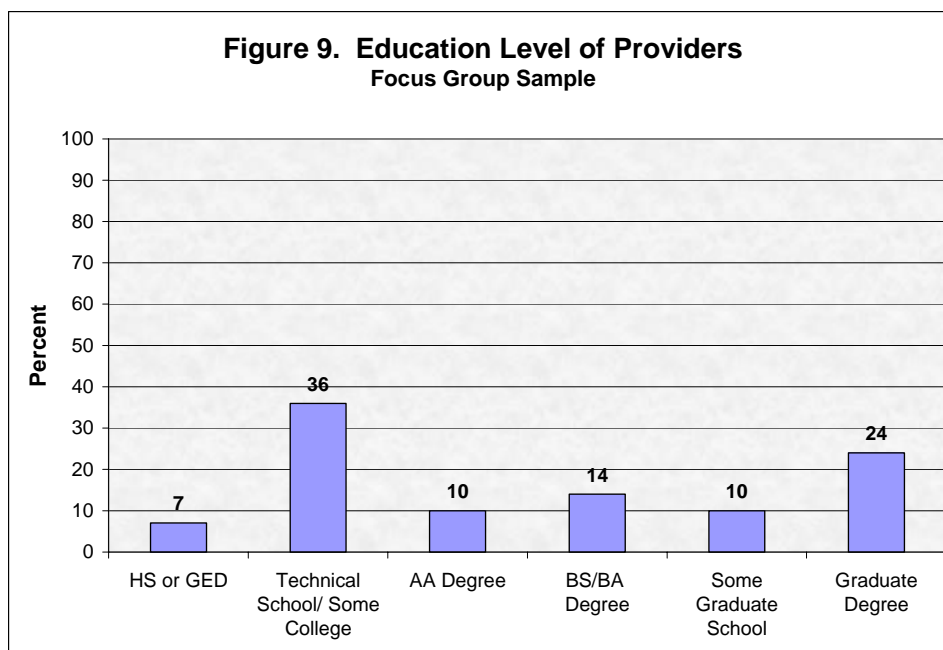
The group included administrators of after-school and youth programs (30%), lead and assistant staff members (28%), group home and family child care providers (21%), program volunteers (5%), and program support staff such as family support specialists and therapists (16%).

Forty-percent (17) of the providers work in an afterschool program in a school (19%), child care center (19%), or community-based setting such as a YMCA (2%). Almost one-third of the providers (13 or 30%) care for or provide services to children in their own homes or the child's home. Other providers work in settings offering short-term enrichment classes and summer camps (14%). The remaining focus group participants (16%) worked in schools and community agencies.

Characteristics of Participants

Many providers (12 or 59%) work in settings that serve school-age children who are 12 years old or younger. Two-thirds (67%) of the providers work in programs that also served preschool children.

As can be seen in Figure 10, the providers varied substantially in how long they had been in their current position.

Figure 10. Provider's Years of Experience
Focus Group Sample
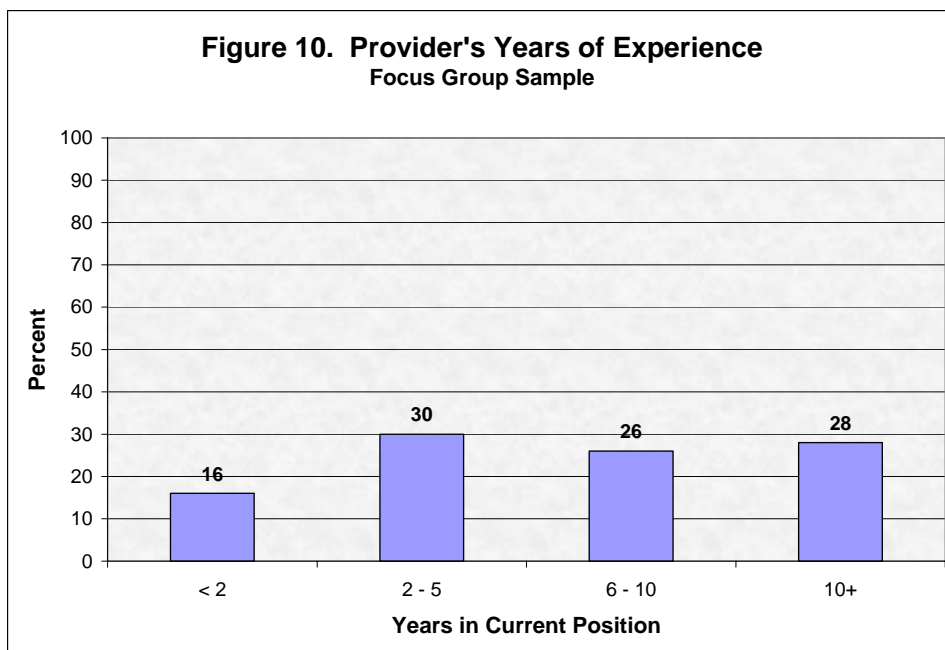
In summary, the provider focus groups included professionals from a wide variety of school-age care and activity settings. The group included administrators, those who work directly with children, and professionals who support or advocate for youth with disabilities. They work in home-based, facility-based, and drop-in settings, some of which offer year-round care, others of which include 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.

Where Do Children Spend Their Time?

Where do children go when not in school? Are children with disabilities in the same types of settings as typically-developing children? To answer these questions we asked survey parents to indicate <u>every</u> type of care they normally use before and after school in a typical week. About one third of families (777 or 36%) checked more than one setting.

As can be seen in Figure 11, children with disabilities were in the same settings as typically-developing children. Children with disabilities were, however, somewhat more likely to be in three or more different settings each week compared to typically-developing children (14% versus 10%).

Figure 11. Typical Out-of-School Arrangement
(Survey Sample)

	Survey: Typically Developing Child	Survey: Child with Disability
Home with Parent	76	76
With Adult Relative	24	26
Afterschool Program/FCC	19	22
Meeting, Lesson, Club, Activity	16	16
Home with Siblings	12	10
With Friend, Neighbor, Sitter	10	12
Home Alone	3	3
At Work	2	2
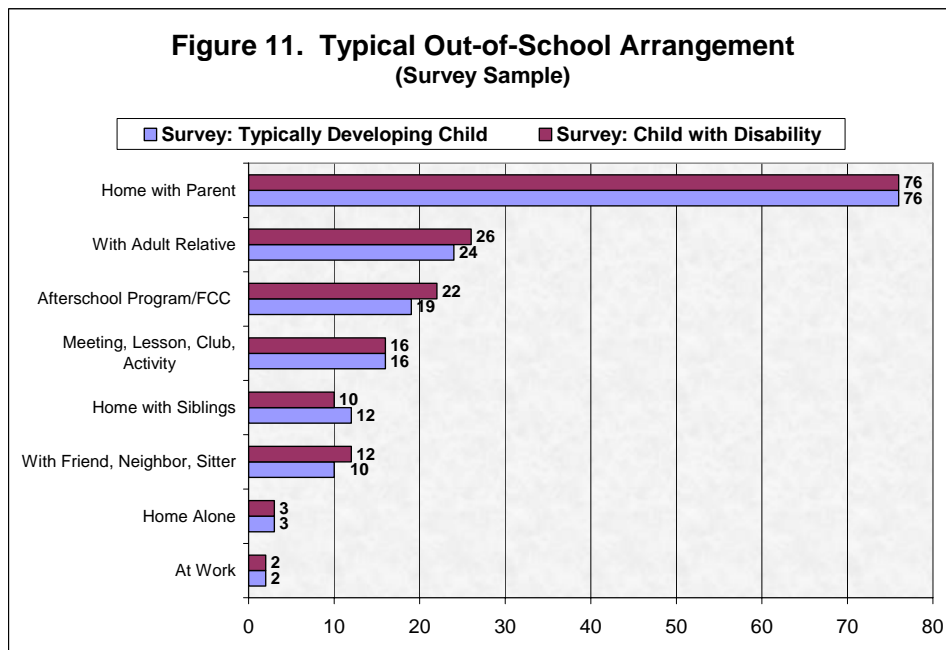
Family, Friends & Neighbors. Most families (1,617 or 76%) indicated their child was home with a parent at least one day each week. This finding suggests that many families are able to arrange their schedules so a parent can be at home with the child for at least some of the hours before or after school each week.

Where Children Spend Time

Over one in five school-age children are regularly with an adult relative (25%). One in ten children is with neighbors or friends of the family or a teenage sitter (11%).

One in every eight school-age children (12%) is at home with brothers or sisters without an adult present. Being home with siblings increased systematically with age from 4% of children in kindergarten to 27% of high school youth.

Self care by children is used less often by families. Only 3% of school-age youth are home alone on a regular basis without an adult present. No children in kindergarten to 2nd grade were regularly left home alone. The figure increased to 7% for middle and high school youth.

Community Settings. About one child in five (19%) attends an after-school program each week. Some children attend the program at their school (9%). Other children are at a child care center (4%), another community location (e.g., YMCA/YWCA, Boys & Girls Club, church) (5%), or a family child care home (1%).

Participation in a meeting, lesson, class, team practice, youth club or recreation activity is also a common setting for school-age youth when they are not with parents. Over one in six survey families (16%) use these settings.

Finally, a small number of youth (2%) are at work. These are primarily high school youth.

Settings used by Focus Group Families. Figure 12 compares the responses of focus group families to the responses of survey families who have children with disabilities. As can be seen in this figure, the incidence of care by friends and neighbors was identical for the focus group and survey samples. Parental care was slightly higher in the focus group sample, while care by adult relatives was slightly lower compared to the survey sample.

Figure 12. Current Out-of-School Settings
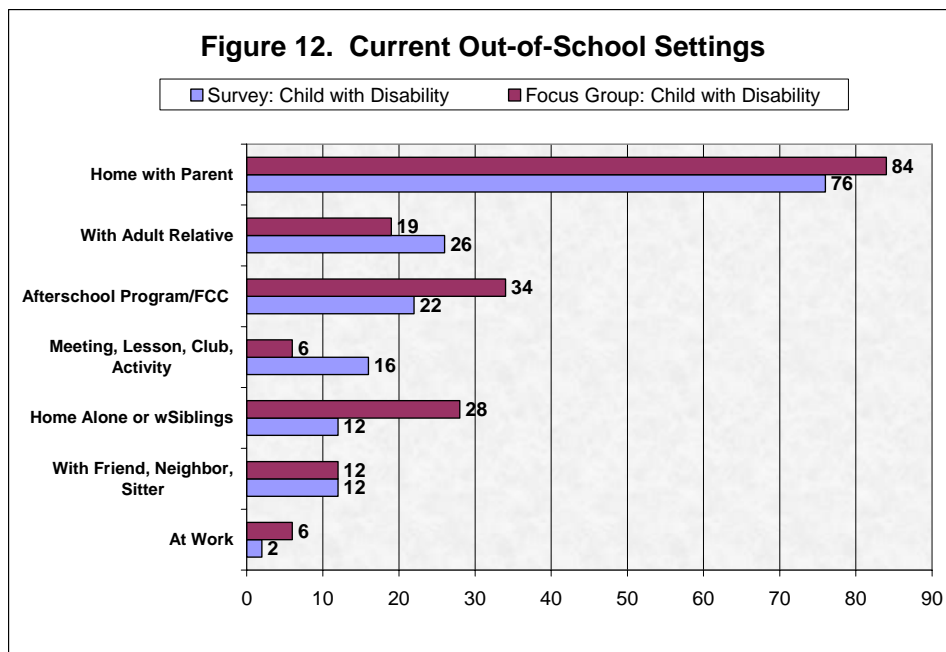
Self and sibling care was much higher in the focus group sample than in the survey sample of families who have a child with a disability. In addition, children with disabilities in the focus group sample were more likely to be in an after-school program and less likely than children with disabilities in the survey sample to be in activities and clubs.

There are several possible reasons that may explain the differences between the survey and focus groups. The greater use of self and sibling care by focus-group families may be related to the higher proportion of older youth

in this sample. Further analysis of the survey responses support this hypothesis. Survey families indicated that 24% of middle and high school youth with disabilities were left alone or with siblings, a figure similar to the 28% found among focus group families where almost two-thirds of the youth were older.

The differences between the focus group and survey families in use of self and sibling care, after-school programs and short-term activities also may be related to variation across the two groups in the types or severity of the children's disabilities. We suspect that the focus group sample had children with more severe disabilities compared to the survey sample. The use of sibling care may be higher among these families because fewer options may exist in the community for children with more severe disabilities. Moreover, parents may prefer to enroll children with severe disabilities in after-school programs in the child's school (which may be better adapted to the child's disability) or in a family child care home (that has fewer children per adult) rather than enroll the child in enrichment activities and clubs where the setting may not be as well adapted to the child's needs or there may be many more children per adult.

Focus group parents supported the idea that accessibility issues are key to inclusion of children with disabilities in after-school activities. Features like ramps, railings, wider doors, accessible rest rooms and wheelchair-supportive vans for transportation are needed to fully accommodate children with physical disabilities. As the parent of an 11-year-old explained, families cannot enroll children if these accommodations are not available.

> *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 into.*

Focus group families indicated that the severity and type of disability are factors that determine whether or not children are included in after-school settings. Overall, parents felt that the more severe the disability, the more difficult it is to find appropriate school-age care. One parent suggested that since a lot of focus is on accommodating children with severe disabilities, children with milder disabilities sometimes get neglected.

Children with more severe disabilities are likely to have special conditions, such as not being toilet-trained, that may make it more difficult to include them in some after-school settings. Some children with disabilities may be 9 to 10-years-old or older when they are toilet trained.

In addition to the severity of the disability, the type of disability also makes a difference. Focus group parents felt it is more difficult to find settings that can accommodate children with behavioral disabilities compared to children with physical disabilities. The parent of an 8-year-old with schizophrenia explained:

> *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.*

Children with behavioral disabilities may disrupt others in the class and need more one-on-one care that is hard for providers to give. Some children with behavioral disabilities are violent, destructive, hurt others and are flight risks. The parent of a 12-year-old autistic child said:

> *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.*

Where Children Spend Time

> *My son's 12 and he's huge. He's big and as tall as I am. He's*
> *very violent when he's not medicated. 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.*

Parents also felt that providers are not trained in how to support children with behavioral disabilities. This makes it harder for providers to include these children in their settings. A parent of a 9-year-old child with autism explained:

> *My son doesn't need any special physical accommodations. But*
> *he does need one-to-one attention and someone who's properly*
> *trained to deal with an autistic kid. There's very few of them in*
> *this area who is trained. I don't know why that is. These people*
> *need training.*

Finally, parents attending the focus groups provided one additional explanation for the greater use of care by family members. They reported that their children were sometimes asked to leave programs shortly after they began. In some cases, the providers informed parents about problems with the child and worked with the parents to improve the situation. In other cases, however, parents did not receive any communication from providers until they were informed that their child must leave. Because of this, parents believe that children with disabilities experience less continuity of care. These disruptions in care may discourage parents who have severely disabled children from using care beyond the family. This challenge is evident in the comments of the parent of the 8-year-old child with schizophrenia:

> *My son, this year, was kicked out of the after-school*
> *program on day four. Last year, he made it 4-1/2 weeks*
> *and he was kicked out, never to return. They do give you*

> *three strikes and you're out. Last year he was kicked out, once he was hospitalized; they didn't even want to deal with him. The other thing is that they also offer tutoring as part of their program. He was thrown out because of behavior issues. Because they can't handle those. I want to add that they all kick them out without a conference or anything, because of bad behavior. They never stop to think that these kids have different behaviors that we need to be trained differently for and so they're all kicked out for bad behavior.*

All of these factors may contribute to the differences observed between survey and focus group families in the after-school settings they use for their school-age children.

In summary, many children with disabilities are in the same settings as typically-developing children. Most school-age children are cared for by parents before and after school, at least some time each week. Care by family members is also common, with self and sibling care being more likely for older children.

About one in five children regularly attends an after-school program or family child care home. There is evidence that some children with disabilities—especially those with more severe disabilities—may utilize after-school programs to a greater extent than short-term enrichment activities.   We suspect that this may be due, in part, to differences in the extent to which these settings can accommodate children with certain disabilities. Many after-school settings are housed in schools which typically have been adapted for children with disabilities. In contrast, short-term enrichment activities are usually held in other community locations, many of which may have fewer accommodations.

Satisfaction with Arrangements

Satisfaction with Arrangements

We asked survey families to indicate how satisfied they are with the arrangements for their school-age child. Half (1004 or 54%) of the families are very satisfied with the arrangements they currently use for their school-age youth. Almost one in five families (18%) is dissatisfied with how their school-age youth spends his or her time. As can be seen in Figure 12, survey families who have children with disabilities are more likely to be dissatisfied with the arrangements they use compared to families whose children do not have a disability.

Figure 12: Satisfaction With Arrangements
(Survey Sample)

□ Survey: Typically-Developing Child ■ Survey: Child with Disability

	Dissatisfied	Somewhat Satisfied	Very Satisfied
Typically-Developing Child	16	27	56
Child with Disability	25	28	47

Percent
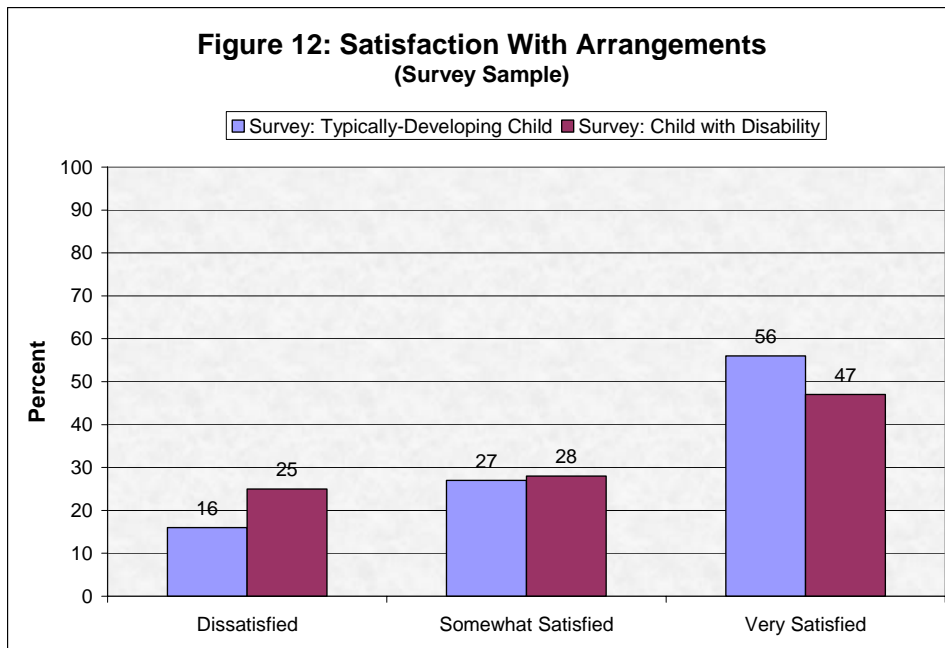
Problems with School-Age Arrangements

We asked survey parents, "What problems do you have with your <u>current</u> arrangements?" On average, families reported three challenges, ranging from 0 – 25 problems across families. One family in three (635 or 33%) had <u>no</u> problems with their current arrangements.

Survey families who have children with disabilities were less likely than other families to say they have no problems (21% versus 36%, respectively) and reported more problems overall (3.6 versus 2.6 problems, respectively).

What types of problems do families experience? Figure 14 lists the top five problems for families who have children with disabilities and families with typically-developing children. The top four problems were identical for both sub-groups of families, although families who have children with disabilities experience these problems to a greater extent than do families with typically-developing children.

Figure 14: Top Five Problems

Problem	Survey: Typically-Developing Child	Survey: Child with Disability
Not affordable	26	34
Finding summer care	21	29
Don't know what's available	19	25
Holidays, vacations, breaks	17	25
Evening/weekends	13	19
Worry about safety	15	16

Percent of Families Selecting
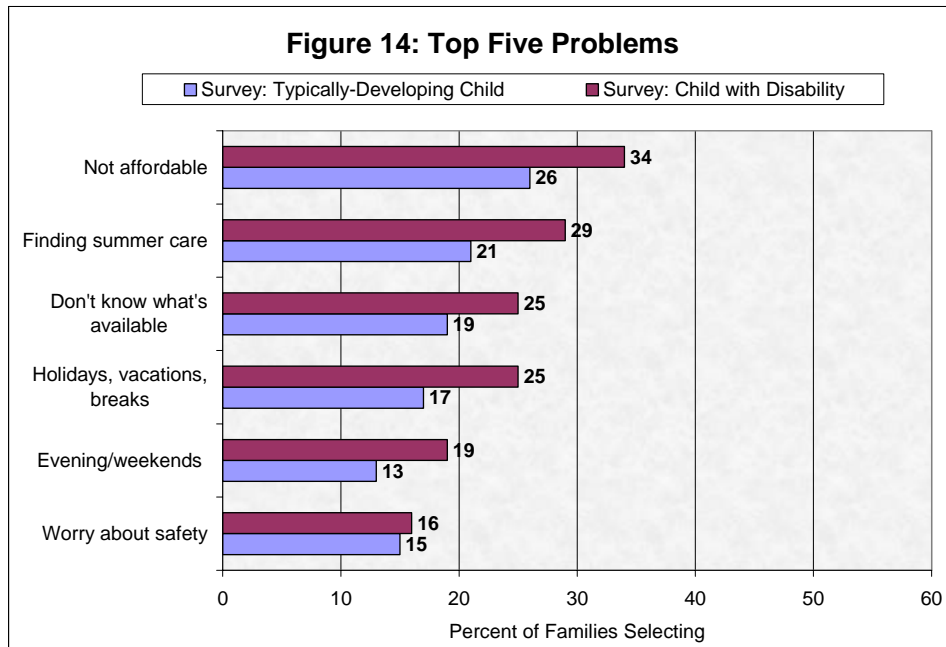
Problems with Arrangements

1. Affordability. The number one problem, reported by 27% of all survey families, is programs and activities costing more than the family can afford. Cost was of greater concern to survey families who have children with disabilities than families with typically-developing children (34% versus 26%). As can be seen in Figure 15, cost is of concern to a significant portion of both low and moderate-income families.

Figure 15. Percent of Families with Affordabilty Concerns (Survey Sample)

□ Survey: Typically-Developing Child   ■ Survey: Child with Disability

Income	Survey: Typically-Developing Child	Survey: Child with Disability
< $30,000	41	45
$30,000 - 59,999	28	34
$60,000+	6	6
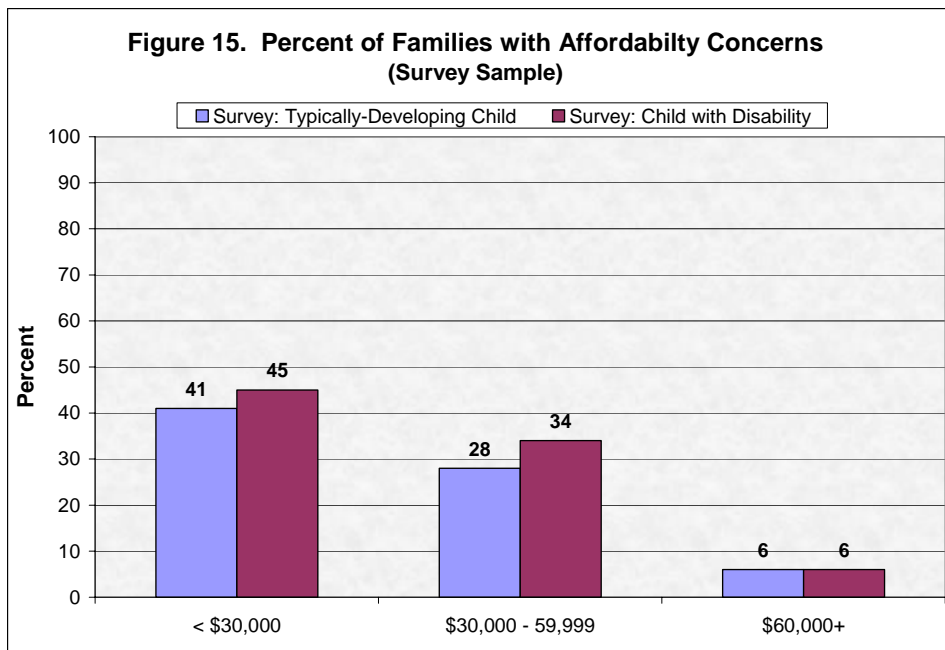
Parents attending the focus groups provided insight into why affordability is of greater concern to families who have children with disabilities. As one parent said, *Having a child with a disability eats up your income*. Some parents must reduce their work hours to care for their children which, in turn, reduces their family income. And even for families with health insurance, the out-of-pocket costs for medication, therapists and doctor bills are considerable. One parent shared this example of how bills can mount up: *I pay over $2,000 a month right now, cash out of pocket, for therapies and doctor's bills.*

Focus group parents also supported the view that moderate income families struggle to care for their school-age children with disabilities. These families earn too much to be eligible for the subsidies available to low-income families. The parent of a 7-year-old with autism said:

> *My husband is a state employee and its not like we have private sector money like some of the other parents. That's really tough. We don't get a lot of grants or funding because of what income level we are in, like the mid …okay, we're not low and we're not high. But yet we're high enough and we have been denied a lot of times for some grants and for funding I have tried to apply for.*

2. Summer Care. Finding places for their children to go during the summer is the second most common problem, reported by 22% of all survey parents. Again, this figure was higher for families who have children with disabilities than for families of typically-developing children (29% versus 21%, respectively).

Parents attending the focus group also mentioned summer care as a major concern. They agreed that there is not much available even for typically-developing children and to find settings that accommodate children with disabilities can be a real challenge. The parent of a 15-year-old with spina bifida outlined the challenges she faces each summer:

> *I have 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 that when school gets out, he'll sit at home all summer.*

3. Don't Know What's Available. Not knowing what programs or activities are available in the community is a problem for 21% of the survey families. This was a problem for one in four families who have children

with disabilities (25%) and one in five families of typically-developing children (19%).

Parents attending the focus groups agreed that many families do not know what is available. Parents said they mainly find out about care options through trial and error or from other parents. Some parents expressed frustration that their pediatricians only told them that their child had a disability and nothing more about the resources that were available to them. The parent of a 12-year-old with autism and ADD related her reactions when she first learned of her child's diagnosis:

> *I remember walking out of that office and having not a clue what to do. There was no one to help me, there was nothing. You call the schools, they don't know.*

Some parents do not know about inclusion coordinators and their roles in helping parents find child care. A parent of an 8-year-old with Down's syndrome related:

> *… a lot of people are not aware of the inclusion coordinator…There are opportunities. It's just that people don't know about it. They've basically done the research for us parents, of what facilities out there are accepting and willing to take our children. Then you're not getting the door slammed in your face every time*

4. Holidays, Vacations, and Breaks. Locating care or activities for times when school is not in session during the academic year (e.g., holidays, vacations, breaks and early dismissal days) was mentioned by 18% of families. Again, this was a greater problem for families who have children with disabilities than for families with typically-developing children (25% versus 17%, respectively).

Many families rely on recreation programs for times when school is out. But, according to focus group parents, these opportunities are more limited for children with disabilities. One parent of a 12-year-old with ADHD and mental delay explained:

> *They don't have anything for special needs children. The*
> *Department of Recreation offers things like t-ball, softball*
> *for typically-developing children, but there is nothing*
> *offered for children with special needs.*

5a. Evenings, Nights, & Weekends. Overall, 14% of families indicated that they had problems finding care or activities in the evening, at night or on weekends. This issue was the number five concern of families who have children with disabilities and the number six concern of families with a typically-developing child.

The challenge of finding care in the evenings was especially salient in the focus group sample. Many families found it very hard to attend the focus groups because of problems finding child care. As one parent said: *I was looking for a babysitter today because we have no child care. To get here tonight I had to pull a bunch of strings.*

5b. Worry about child's safety. Overall, 16% of survey families indicated that they worried about their child's safety before and after school. Although this percentage was very similar for families of children with disabilities and typically developing children (16% versus 15%), this was the number five problem for parents of a typically-developing child and the number eight concern for families who have children with disabilities. It was clear from other items on the survey and from the focus groups that some families who have children with disabilities are highly concerned about their child's safety.

Problems with Arrangements

Survey parents of children with disabilities were more likely than parents of typically-developing children to worry that the person caring for their child may not treat their child the way they would (12% versus 8%).

Focus group parents expressed fear that their child may fall, get hurt, run away from the setting, or get hit by a car. They also worried about the use of inappropriate—and potentially abusive—discipline techniques.

> *…parents with special needs children think, oh my gosh, when is the phone going to ring? Is my child going to throw a chair at someone? 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.*
> [Parent of an 11-year-old child with Aspergers]

> *[There are] some that are well run. But there are some that you just have to ask yourself—Why would a parent with a conscience put their child here? And I've been to some that looked great— and they've got the glistening paint on the wall—and you know, the staff come up there, turned around and slapped one on the head and walked off. And if you—these people aren't dealing well with children at all, much less prepared to deal with children with disabilities.*
> [Parent of an 11-year-old child with autism]

Parents who have non-verbal children are especially worried about how their child is treated. This concern is evident in the comments of the parent of a 9-year-old with autism:

> *My son is also non-verbal too. 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.*

Some parents also worry about their child hurting others. If the child is severely disabled or is a threat to other children in the setting, parents sometimes lose hope and choose to take care of the children themselves. A parent of an 8-year-old with autism shared, *They told me they had a problem, but they would try to work through it. But I decided to take him out because he kept running away and I didn't want him to get hit by a car.*

Parents feel more secure when children are around familiar people — especially those who have special training and have fewer children to care for which allows the providers to give more one-on-one care. The parent of a 17-year-old with mental retardation explained:

> *Because my child is having ambulation problems and I don't want him to fall or something, its kind of uneven terrain, and if I have someone to help him then hopefully they can watch him and he can still have fun. But just to have more supervision, so that…for safety.*

There were also several other problems that are greater challenges for families who have children with disabilities than for families of typically-developing children according to survey and focus group families.

Lack of options. Among survey respondents, families who have children with disabilities were more likely than families with typically-developing children to say that there were no activities in their community that met their needs (19% versus 11%), that they had a hard time finding care for their child with a disability (13% versus 2%), and that it was hard when their school-age child was ill (18% versus 10%) or they had to change their work hours (16% versus 12%). Clearly, some families are not able to access the options they need for their school-age youth, and this is of even more concern to families who have children with disabilities.

Problems with Arrangements

Focus group parents also raised the special challenge of trying to find care in rural areas:

> *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….*
>
> [Parent of an 8-year-old with multiple disabilities]

> *I'd like to echo that, and we feel persecuted…in rural Georgia. I mean that seriously. And when we first see the diagnosis of a child with a disability, I remember driving back from Atlanta with that--we had to go up there to get a diagnosis—and thinking, you know, what do we have in southwest Georgia to help this child?*
>
> [Parent of an 11-year-old with autism]

Several other problems are of special concern to families with disabilities, according to the parents who attended the focus groups.

Selective Exclusion. Some parents felt there was selective exclusion of children with disabilities from some after-school programs and activities. Although by law families have the right to enroll their child in programs, parents pointed out that, ultimately, it is the program administrator's decision whether or not to accept a child. The administrator will not enroll the child if the child is viewed as a liability. They tell the parent that they do not have any openings or that they do not have adequate resources to support the child, according to parents attending the focus groups. The parent of the 8-year-old with cystic fibrosis provided this explanation: *Most people come up with an excuse. Like the potty training or either they don't have an opening.*

The parent of a 13-year-old with autism also provided another potential example:

I know of one parent right now who is actually paying for her son's para-pro to do after-school care for him in her home because her school refused to allow her son in their after-school program.

Transportation. Transportation also poses special problems for families who have children with disabilities, especially when the programs are far away from where they live and work or they must drive in heavy traffic. Besides the time and expense that all families experience with long commutes, some children with disabilities become very tired or stressed by long commutes. This is especially true for children with behavioral issues who often have a hard time sitting still for long time periods and tend to become very restless.

If a child is in a wheelchair and has to go to two or three different places for therapy and after-school care, getting the wheelchair in and out of the car several times can be exhausting for parents. And for many families, the situation is compounded by having to transport several children to different places. This may be why survey parents who have children with disabilities were more likely than parents of typically-developing children to say that it was hard if they could not take all their children to the same place (11% versus 7%).

Even when transportation is provided by others, parents worry about children who have limited physical or cognitive skills because they need more supervision to ensure they make it to their destination. A parent of a child with serious behavior problems explained: *If you've got a child changing buses two or three times…there are safety issues.*

Older children. While finding care for older children is a problem for all families, the situation is even more difficult for families who have children

Problems with Arrangements

with disabilities. Sometimes older children are placed in settings with
much younger children. A parent of a 13-year-old with autism explained:

> *But I think it gets harder to find somebody willing to watch them
> as they get older. I mean, when they're smaller, it's not as
> noticeable if there are delays. Or the other kids are more
> receptive. But like, you know, if they're sixteen or twenty, if you
> send them to a day care center—they're five years old!*

Some typically-developing middle school youth can stay at home alone.
Many children with disabilities cannot. Even more than at younger ages,
parents of older children with disabilities have to use "piece-meal" care.

Lack of Appropriate Accommodations. Parents attending the focus
groups highlighted several accommodation issues that are challenges for
families who have children with disabilities. These include:

- the lack of access to certain activities or failure to adapt activities
  to accommodate the child's needs;
- more limited opportunities for social interaction with
  typically-developing children;
- lack of acceptance by parents of typically-developing children; and
- inappropriate behavior management techniques and concerns for
  their child's safety.

Although children with disabilities may be present in after-school
programs and activities, they may not be able to fully-participate in certain
activities (such as field trips) that may require special transportation for
the child or in outdoor play and games that require physical activity. A
parent of 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.*

Challenges also arise when the curriculum is not adapted to meet the needs of children with disabilities. For example, autistic children need more structure than typically-developing children. Ambiguity and lack of structure tend to make them very uncomfortable. Being in a small room or even a large room with many children causes some autistic children to be overwhelmed. The parents of two autistic children explained:

> *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.*
> [Parent of a 16-year-old]

> *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]

Children with disabilities need opportunities to interact with typically-developing children in order to develop friendships and gain social skills. This is especially important for older children who increasingly look to their peers for support and approval.[3,4]

_____

[3]Abery, B. & Simunds, E. (1997). The 'Yes I Can' Social Inclusion Program: A prevention approach to challenging behavior. *Intervention in School and Clinic*, 32, 223-234.

[4]Owens, K. B. (2002). *Child and adolescent development: An integrated approach.* CA: Wadsworth Group.

Problems with Arrangements

Until very recent years it was impossible to find inclusive after-school, or even school settings, because everybody was so used to what I call the short-bus mentality. You know—everybody was isolated and we had special schools and special rooms. So the full inclusion, that's one of the real challenges that people are really looking for…If somebody would open tomorrow the disability after-school [program]—not really what anybody wants. They just want an inclusive setting.
      [Parent of an 11-year-old with autism]

…As they get older and stuff, they don't want to be around their mother and stuff. And when it's a younger person…I mean these kids…I guess it depends how impaired they are, but these kids, they want to be around people, too, besides their parents and their families.
      [Parent of a 17-year-old with mental retardation]

We had an IEP at the end of the school year and we were discussing summer school and I told them what I thought she really needed was more social interaction because in the classroom she's in, 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 a social environment. Because that's where she is more challenged. And she likes to be social even if she is autistic—she likes attention.
      [Parent of a 16-year-old child with PDD]

Sometimes parents of typically-developing children make inclusion of children with disabilities more difficult. The parent of a 20-year-old with Down's syndrome put it this way:

Personally, I think the children don't have the problems. It's the adults and how the adults handle it. Then the children just feed off of that. The kids don't care—that's just another kid for them to play with—they really don't care. But if they have an adult that's not accepting, it's different.

Ratios, Staff Training & Communication. Parents attending the focus groups felt that many of the problems that arise in after-school settings are the result of too many children per adult, lack of training and communication problems.

Focus group families believe that the number of children per adult is too high to provide adequate supervision to children with disabilities. Many of these children need more one-on-one care to keep them safe and promote development. This level of attention is not possible when there are many children per adult. As one parent commented: *It had many children and not enough workers. Not enough teachers watching him and giving him attention like he should get.*

Some parents felt that family child care settings are better able to support children with disabilities because these providers care for fewer children. But these settings have other issues that must be addressed. Because they care for so few children, family child care providers have more trouble affording the accommodations often needed for children with disabilities. The wide age ranges of children in many family child care homes also can make it harder to provide developmentally-appropriate activities.

Survey parents who have children with disabilities were more likely than parents of typically-developing children to say they wished the people caring for their children had more education and training (15% versus 10%, respectively). Focus group parents supported this finding,

indicating that teachers need training to understand specific disabilities and effective ways to work with the children—especially in terms of behavior management. The parent of a 16-year-old with persistent developmental delay expressed this concern:

> *I think it is lack of knowledge, you know, lack of training. It's well-meaning people wanting to do well. But it falls down to a lack of understanding of the different types of disabilities I think.*

Focus group parents also see communication as being key to promoting a positive inclusion experience for all involved. Parents would like after-school providers to inform them immediately when problems arise so that parents can help overcome the challenge, rather than simply waiting until the situation has gone so far that the provider has to dismiss the child from the setting. The parent of a 6-year-old with Down's syndrome explained:

> *There have been some situations where I wish that they would have talked to me about certain things and I may have, could have given them some input as to better ways to handle behavior issues and so forth.*

Finally, parents would like greater collaboration between classroom teachers, therapists and school-age care providers so that the child gets integrated, holistic care and the after-school providers have access to experts to better support the child in the after-school setting.

In summary, four out of five families who have children with disabilities report some problems with their arrangements. The top four problems identified by survey families who have children with disabilities were identical to survey families of typically-developing children and families who have children with disabilities. Many families struggle with cost, not

knowing what is available, and finding care for summer and during the academic year when school is not in session. Families who have children with disabilities experience these problems to a greater extent than do families with typically-developing children.

Even when programs are available, however, families who have children with disabilities have more problems accessing them. Accessibility issues are most severe for families who have special transportation needs, older children, and children who need greater supervision and accommodations in order to be fully involved in the program, such as those with behavioral or severe disabilities.

Some families who have children with disabilities believe that their children are subject to selective exclusion when they are told that the program is full or that the setting cannot support the child's needs. Parents who have children with disabilities are also concerned about high adult-child ratios, inadequate staff training, insufficient communication between staff and parents, and the lack of collaboration between classroom teachers, therapists and after-school providers.

Effects on Economic Development

Balancing Work and Family

Being able to access enriching and safe programs and activities affects not only children and their families, but also may affect employers and the local economy. One in every eight survey families (224 or 12%) indicated that a parent was prevented from working due to the lack of good school-age care. Over one in five survey families (422 or 22%) indicated that parents are prevented from working as many hours as they would like because of the lack of good school-age care.

We also asked parents if they had to miss work in the last year because their school-age child was ill. Almost half of survey families (875 or 44%) responded "Yes," missing an average of five days of work over the last twelve months. Although these missed days are well within the number of vacation and sick days most workers receive each year, having to care for sick children may place a special strain on working parents.

As can be seen in Figure 16, families who have children with disabilities are especially likely to experience problems in balancing their work

Figure 16. Effect on Parent's Ability to Work

Legend: ☐ Survey: Typically-Developing Child ■ Survey: Child with Disability

Category	Typically-Developing Child	Child with Disability
Lack of Care Keeps from Working	11	14
Lack of Care Restricts Work Hours	21	29
Missed Work in Last Year Due to Sick School-Age Child	44	50

and family lives. In particular, they are more likely to have to restrict their work hours than families who have typically-developing children.

Participants attending the focus groups provided stark examples of the problems parents experience in balancing work and family, especially single parents and those without social support. A parent of an 8-year-old with schizophrenia shared: *I'm a one-parent family and I recently lost my job because of child care issues. I can tell you that that's your only hope.* A center director from south Georgia provided another example:

> *A woman came in my office a couple of weeks ago, her little boy has autism and her mother had been keeping him. But now, she was sick and couldn't keep him any more. She couldn't find anybody else. If she didn't find somebody fast, she was going to have to quit her job. She was a single mother.*

Clearly, many families struggle as they attempt to balance work and family life and the struggle is even greater for families who have children with disabilities. This is an issue not only for families, but also for communities. Families may be forced to accept welfare or Medicaid if they can't work or they lose health benefits because they can only work a few hours each week. Moreover, the local labor force is adversely affected when families cannot work or must reduce their work hours due to the lack of good school-age care. This can have a negative effect on employers and weaken the local economy.

What Families Want

What Families Want

Survey families were asked about five possible supports: providing resources to the after-school programs or the relatives, friends and neighbors they already use; being able to enroll their child in after-school programs, enrichment activities and youth clubs; and having their child participate in a work or volunteer experience.

One in four families (608 or 29%) did not need any additional supports. Families who have children with disabilities were less likely than families with typically-developing children to say this (23% versus 30%, respectively).

Figure 17 lists the percent of all survey families who wanted each support and the percent of families who selected it as their top choice.

Figure 17: What Families Want
Survey Sample: All Families
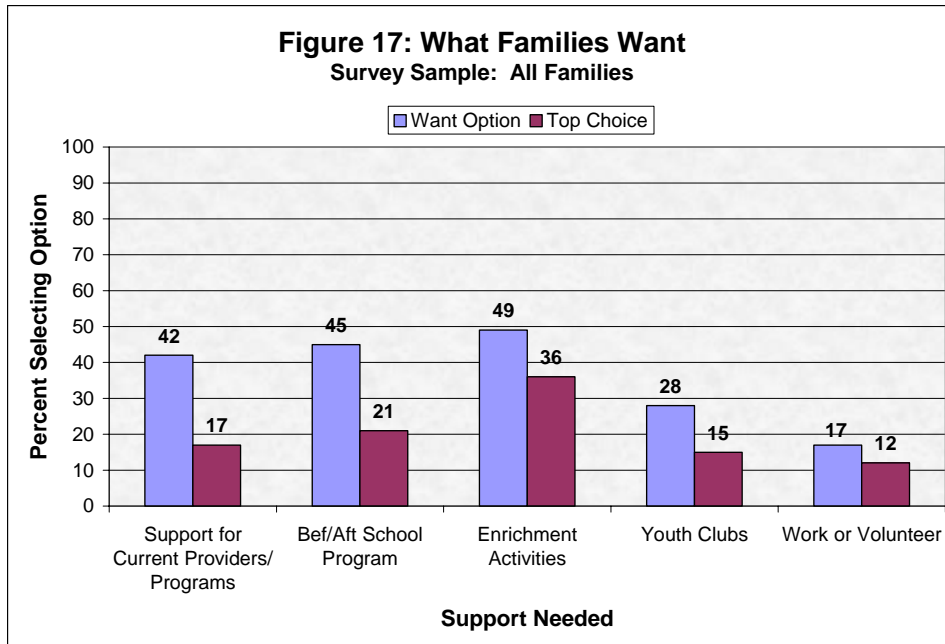
As can be seen in Figure 18, when families can select multiple options, parents who have children with disabilities are slightly more interested than families with typically-developing children in each option.

Figure 18. Supports and Settings Desired by Disability Status of Child

	Survey: Typically-Developing Child	Survey: Child with Disability
Support for Current Providers/Programs	41	50
Bef/Aft School Program	43	52
Enrichment Activities	47	55
Youth Clubs	27	32
Work or Volunteer	16	21
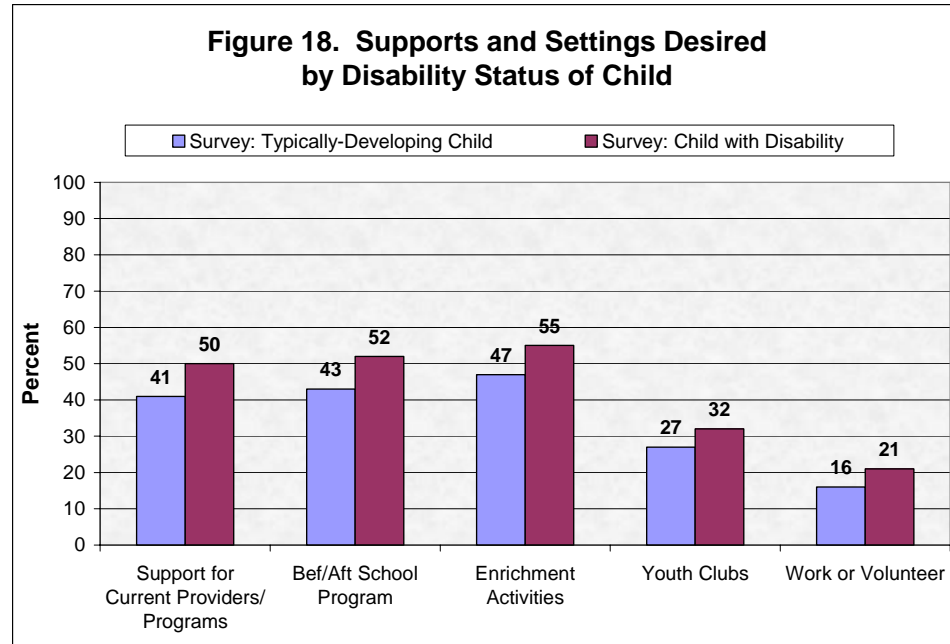
There was no difference by the disability status of the child, however, in what families want most. All families were <u>most</u> interested in having more enrichment activities for their children (see Figure 17).

Support for Existing Programs. Half (154 or 50%) of the survey families who have children with disabilities want more supports for the caregivers and programs they already use. These supports might include funding for salary enhancements to attract highly qualified staff or for the purchase of equipment and materials to improve the quality of their child's experience.

For the relatives, friends and neighbors (informal caregivers) who care for children, support may include transportation or scholarships so that

children can attend enrichment activities some days each week or providing caregivers with ideas and materials for enrichment activities.

Enrichment Activities & Clubs. Many survey parents who have children with disabilities are interested in having their child attend enrichment activities including artistic expression (e.g., art, dance, music), academic subjects (e.g., math, science, reading), sports, hobbies (e.g., cooking, crafts, games), and computers. Fifty-five percent of these families (169) indicated an interest in enrichment activities, with 36% listing this as their top choice. One in three families (97 or 32%) who have children with disabilities want to enroll their children in youth clubs, such as Scouts, 4-H, Girls Inc., or Campfire, with 15% of families listing this as their top choice.

Work or Volunteer Experiences. One in five families (64 or 21%) who have children with disabilities wish their child could participate in a work or volunteer experience, with 11% of families listing this as their top choice. These options are of greater interest to families with youth in middle and high school. Providing exposure to jobs and the workplace is an essential strategy for helping youth identify potential careers and for promoting a strong local labor force.

After-school Programs. One survey family in every two (160 or 52%) who have children with disabilities is interested in enrolling their child in an after-school program that meets every week, although only one in five families (22%) selected this as their top option.

Nine percent of the families (14) requesting an after-school program already use this option, at least some days each week. Eight of these families currently use an after-school program at a school, four use a community-based program and two families use an after-school program at a child care center. These families may have expressed interest in

another after-school program because they cannot access their current program to the extent needed, perhaps due to affordability issues or because the program does not offer needed services such as care on holidays, breaks, or summer.

As can be seen in Figure 19, Survey families who have children with disabilities were significantly more likely than families with typically-developing children to need care during the summer, on early release days, school breaks, holidays, and on weekends.

Figure 19. When Care is Needed
(Survey Sample)

□ Survey: Typically-Developing Child ■ Survey: Child with Disability

Category	Typically-Developing Child	Child with Disability
After School	70	75
Summer	51	63
School Breaks	46	58
Early release days	40	53
Holidays	28	44
Weekends	23	40
Evening	22	26
Before School	18	20
Bef/Aft Kindergarten	6	4
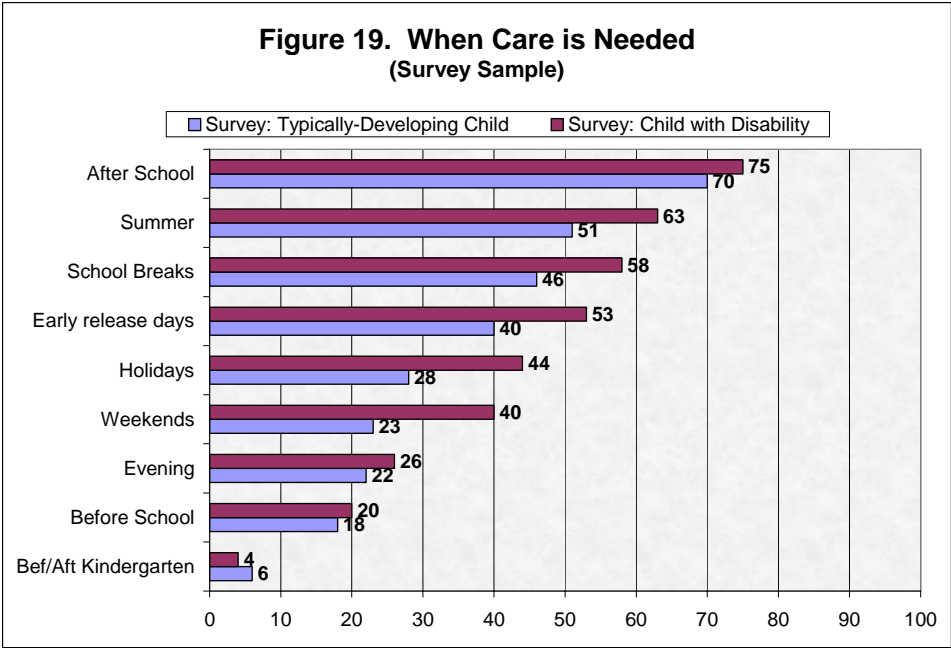
Over three fourths of survey families who have children with disabilities need after-school care, almost two thirds want summer care, and over half of these families would use the program on early release days and school breaks.

We also asked survey families who have children with disabilities where they would like to have the after-school program. Families could select

more than one option. About half of the families who do not already use an after-school program want the program at their child's school (43%) or a community location (60%) such as a Boys & Girls Club, YMCA, or church. These families were more interested than families with typically-developing children in having their child attend an after-school program at a community location (60% versus 45%).

About one fourth of the families (27%) want the program located at a child care center. Fewer families are interested in having their school-age child attend a family child care home (9%).   The same pattern was observed for families from urban, suburban and rural counties.

Focus group parents were asked, "If it were an ideal world, what kinds of care settings and options would you like to have for your child?" Parents unanimously agree that they would like to have more after-school care settings in their own communities that are inclusive. Ideally, they would like all schools to offer inclusive after-school programs so that parents would not have to worry about transporting their child from one place to another or about their child's safety on the bus. If that is not feasible, focus group parents would like one school to offer an inclusive after-school program, with children from several schools bused to that site.

As mentioned earlier, by "inclusive" parents mean more than just accepting a child with disabilities. It means making facilities physically accessible to all children. Parents also want their child to be completely involved in the program even if this requires modifying activities or, if the child has a very severe disability, having enough staff to offer the one-on-one attention the child needs. Parents would also like to see the concept of Individualized Education Plans (IEPs) extended to the after-school setting, with therapists available in that setting as well. And the age limits of the program should be extended so that older children with disabilities can remain in a familiar setting.

Parents also would like after-school settings to have more flexible hours so that parents can hold full time jobs. Consistent with the survey findings, focus group parents want more options for children with disabilities in the summer, on holidays and other times when school is not in session.

Parents also feel that it is important to sensitize other people about children with disabilities. Similar to the diversity training increasingly required by the corporate world for its employees, diversity training could be provided to all those involved with children having disabilities, including school staff, after-school program staff, other children in the setting and the parents of those children.

Parents also want changes in the system to make it easier for families to find appropriate settings for their children. Parents interact frequently with their pediatricians. They feel that doctors should help them learn more about the resources available to help them find care, such as inclusion coordinators. Families would also like to see more parent and sibling support groups so they can better exchange information and gain support from each other. Finally, parents feel that the state benefits for children with disabilities should be based on the severity of the disability or the functionality of the child, rather than using income as the sole determiner of subsidies.

In summary, parents who have children with disabilities want the same settings desired by families with typically-developing children. Some families want more resources for the caregivers and programs they already use. Many families want more access to enrichment activities and some want their child to attend an after-school program, youth club or volunteer/work experience. Finally, families want help learning what programs and activities are available. They also want inclusive settings, where children with and without disabilities can be fully engaged in the activities and interact with one another.

Access Barriers

Access Barriers Families Experience

We asked the 1,508 survey families who wanted additional resources, programs and activities for their school-age youth about seven factors that potentially keep them from accessing their preferred settings. These barriers are different from the problems we discussed earlier in that they are barriers to what families WANT to have rather than problems families <u>currently</u> have with the arrangements they <u>already</u> use.

The 1,245 families responding to this question reported an average of 1.7 barriers that prevent them from accessing their preferred settings for their school-age children. Families who have children with disabilities reported more access barriers than families with a typically-developing child (1.9 versus 1.6, respectively).

Figure 20. Access Barriers by Disability Status of Child
Survey Sample

□ Survey: Typically-Developing Child   ■ Survey: Child With Disability

Barrier	Typically-Developing Child	Child With Disability
Don't Know What's Available	43	42
Can't Afford	38	50
Transportation	27	32
Don't Need My Needs	19	27
Not Available	23	25
Child Won't Go	5	9
Don't Like What's Available	5	5
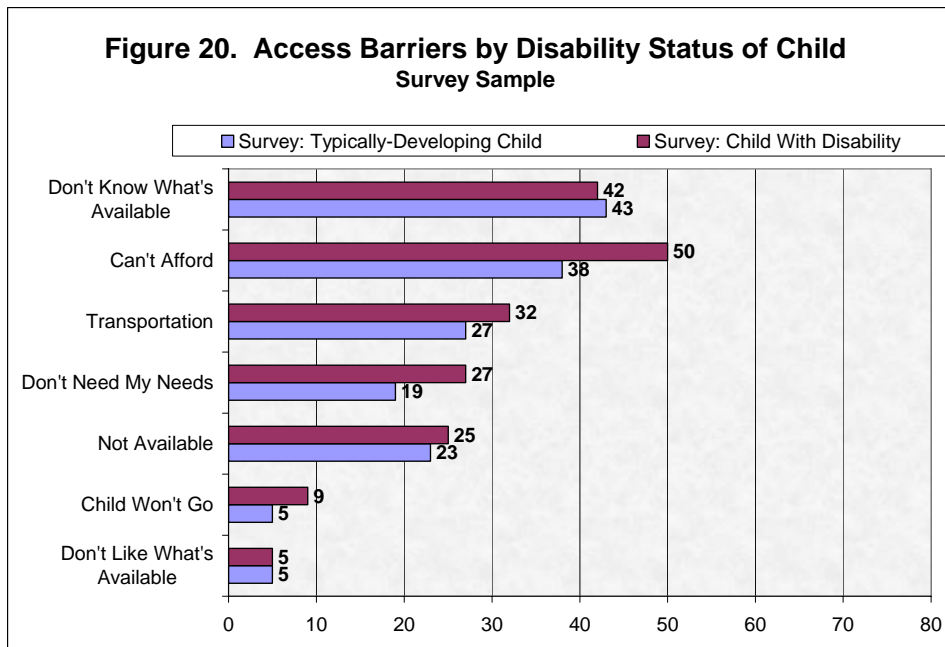
1. Not Knowing What's Available. As seen in Figure 20, not knowing what is available in the community is the barrier most often reported by survey families. This is a problem for almost half (43%) of all families and did not differ by the disability status of their child.

2. Affordability. Cost is a barrier for over one in three survey families (40%), and is more of a burden for families who have a child with a disability than for families with a typically-developing child (see Figure 20). As can be seen in Figure 21, cost is a barrier for substantial numbers of both low and moderate-income families.

Figure 21. Cost As A Barrier to Preferred Settings
Survey Sample

Legend: ■ Survey: Typically-Developing Child ■ Survey: Child has Special Need

Income	Typically-Developing	Special Need
< $30,000	55	65
$30 - $59,999	40	46
$60,000 +	11	11
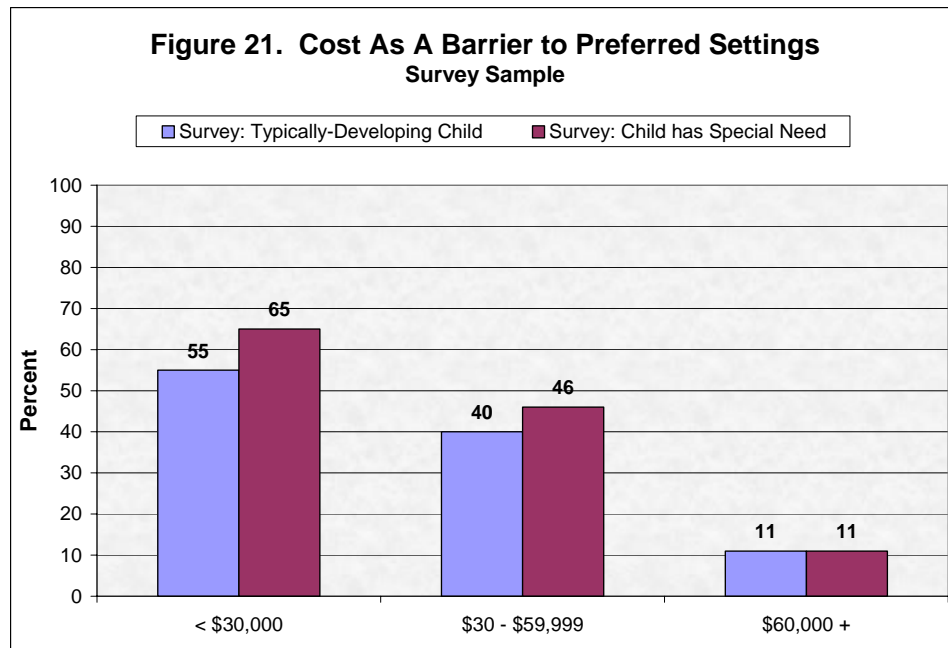
3. Transportation. Transportation is a problem for over one in four survey families (28%) and does not differ by the disability status of the child.

4. Accessibility. Not being able to find programs or activities that meet their needs--in terms of location or times, for example--is a barrier for one in five (20%) survey families. This is a greater barrier for families who have children with disabilities (27% versus 19%).

4. Availability. Not having the programs they want in the community was mentioned as a problem by one survey family in four (24%) and did not differ by the disability status of the child.

Access Barriers

Two other barriers were reported by a few families: children not wanting to attend and parents being dissatisfied with the available programs.

6. Six percent of families said their child was not interested in or refused to attend the program, activity or club. This access barrier was twice as high for families who have a child with a disability than for families who have a typically-developing child (9% versus 5%, respectively).

7. Some families (5%) were also dissatisfied with the activities and programs that are available for their school-age children. This did not differ by the disability status of the child.

In summary, not knowing what is available and affordability are the major barriers that prevent families from accessing their preferred school-age care and activity settings, with cost being a somewhat greater barrier to families who have children with disabilities. Transportation, times and locations that do not meet family needs, and programs not being available in the community are barriers for about one in four families, with time and location barriers being more common among families who have children with disabilities.

As communities work to expand programming for school-age youth with disabilities it will be important to consider these challenges. If these barriers are not addressed, it is unlikely that families will be able to access the programs and activities they desire for their school-age youth.

The parent survey and focus groups provided rich detail on the needs of families. In the next section we examine the perspective of the providers of school-age care and activities.

The Joys of Working with School-age Children

Working with children who have disabilities can be deeply rewarding for all involved according to providers who attended the focus groups. Providers gain so much from children with disabilities. Unconditional, open and honest love are a few of the things that children with disabilities give to providers. Several providers also mentioned that children with disabilities seemed to appreciate them more than did the typical 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 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 joy for many providers is seeing improvements in school-age children with disabilities. 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 don't 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 the 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.

It is this acceptance—when other children and parents are able to see beyond the disability and recognize the person—that has brought true joy to many providers.

In summary, many 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.

Challenges Providers Experience

Just as with typically-developing children, providers experience some challenges as a result of caring for children with disabilities. Many of the issues providers mentioned were also identified by the parents of children with disabilities. A few challenges were uniquely raised by providers.

Training. A recurring issue raised by virtually all providers was the lack of training on caring for children with disabilities. Although providers are required to attend a certain number of training hours per year, there is almost no training offered on children with disabilities. An assistant teacher in an urban child care center who works exclusively with children having disabilities explained:

> *The training I have been to has focused around the general population. They might touch bases on a child with ADHD or a wheelchair. But to focus on children with special needs—that's almost non-existent.*

The director of a child care 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 special needs kids and there are so many disorders.*

Because they lack training, providers do not feel confident working with children who have disabilities. They wish they knew more about using adaptive equipment, administering medications, promoting independence, balancing the needs of all children in the setting and, especially, behavior management. An assistant teacher in an urban child care 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.*

Provider Perspective: Challenges

Other providers expressed similar needs:

What to do with the child that don't want to interact with the 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.
　　　　　　　　[Assistant director in a suburban after-school program]

I mean even to keep the child 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.
　　　　　　　　[Group home provider from suburban county]

All the other children were picking up his habits and his language and his anger…It's hard on us, I think sometimes, because you don't want to have to give up on them. You don't know what else to do.
　　　　　　　　[Family child care provider from a suburban county]

Staffing. Many providers feel that they do not have enough staff to effectively care for children with disabilities. Given their specialized needs, many children with disabilities—especially children with behavioral and emotional issues—require more attention and supervision.

It is not only a matter of having a sufficient number of staff, but also an issue of staff quality, training and attitudes. As the 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 high turnover, less educated and trained personnel, and the occasional staff member who is just "in it for the paycheck," all make it difficult to provide the level of care needed. The low pay combined with having small numbers of children with disabilities in programs also makes it challenging to attract staff with college degrees in special education.

The attitude of staff towards children with disabilities has a big impact on whether or not they are included in the setting. Some providers are afraid to care for children with disabilities because they do not know what to do, are worried about hurting the child, are concerned for the safety of the other children, or fear being held liable if something happens.

> *It's 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 child care 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.*
>   [Group home provider in a suburban county]

In addition to being afraid, the extra work involved in caring for children with disabilities can also dampen motivation. 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.*

Provider Perspective: Challenges

Even if the director is positive and encouraging of including children with disabilities, it can be a struggle to motivate the staff who interact with the child on a daily basis. An urban child care center staff member explained:

> *Now he has started the running bit. And I think the director at the child care 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.*

Parents. Providers often 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 can be a source of tension between providers and parents, particularly when providers try to encourage more independence in the child. A therapeutic recreation provider, who is also a parent of a child with mental retardation, said:

> *I was once 'just a parent.' When I came to work here, you see, my son and I have grown so much. Because 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 that when I wasn't here, he wouldn't be able to live either. That's what a lot of parents do.*

Other providers agreed:

> *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 they can do for themselves.*
> <div align="right">[Suburban family child care provider]</div>

> *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. 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]

Conversely, providers are equally frustrated when parents are not involved enough with their child. 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 with disabilities. The director of a child care center shared this example:

> *I've had a couple of children that I tried to do my very best with that I had to give the parents a notice that I wouldn't be able to keep them here. I didn't have the talent to take care of them and the parents would not communicate to me what was going on. There were, and 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 for some providers. Providers are faced with a myriad of issues when parents do not disclose their child's disability, including the safety of the child and the 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 she has 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. One little boy--the mother said he was perfectly fine— kicked out a window…Her sadness is that 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 with other parents in the program. Parents of typically-developing children sometimes worry about the safety of their children. They also sometimes question why special accommodations are being made for a child with disabilities.

Continuity of Care. 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 is a challenge for many providers.

Lack of communication between the school and school-age providers can hinder the provider's ability to help 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 modification procedures that are being used in that setting. 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.*

This challenge was of concern to providers in many 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.*
> [Group home provider]

This broken bridge of communication can occur 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 child care provider quoted above went on to say: *I do get copies of his IEP, but, you know, 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 all this means.*

Providers who have not worked extensively with children with disabilities may be more likely to have problems deciphering the forms used by school and other professionals. But even when there are therapists or other professionals available in the after-school setting, the lack of communication often still persists, according to providers.

Another frustration expressed by providers was the lack of a centralized source of information for providers to get information on school-age children. Many providers cited the Babies Can't Wait program as a great

resource for younger children. However, when children reach the school-age years, some providers complained about losing this valuable resource because there was not a comparable level of support. A center director 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 come out to the centers and 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 Referrals are available to provide some support to school-age providers, they are stretched very thin and providers often do not know about the assistance they can provide.

Funding. Financial constraints limit the resources available to providers which can affect their ability to care for children with disabilities. Paying for the extra staff necessary to have the smaller teacher-child ratios that are often needed to effectively incorporate children with disabilities is prohibitive for many school-age programs.

At school, some children with disabilities have paraprofessionals or shadows to help them in the classroom. This same level of one-on-one care cannot be accommodated in most school-age settings because of limited funding. A group home provider explained:

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

Equipment Accommodations. The lack of access to adaptive equipment
was another barrier cited by both after-school program staff and family
child care providers. In some cases, providers can afford to make
modifications but do not know where to get the needed equipment. A
family child care provider from a rural county explained:

*I had to figure everything out for myself. I had no support from
anybody to encourage me, help 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.*

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 group home provider put it this way: *I mean any
piece of equipment is expensive even for normal child care. But a child
with special needs is even more expensive because even if you don't
have that many of the children, you have to have those.*

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 group home provider 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 it.*

Provider Perspective: Challenges

Instructional Accommodations. Developing individualized care plans, modifying activities, and arranging the physical environment to support children with disabilities are areas that many providers feel they have little experience with. Many providers are not aware of modifications—even simple ones—that could allow the child to participate. Consequently, some children with disabilities are excluded from activities that could be modified to include them. A child care 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 children with disabilities can have very unique needs. It can require more ingenuity, time and experimentation on the part of the provider to find ways of modifying activities and the setting for each child. An after-school staff member in a child care center explained: *Every single child with a disability has such individual need. And they have such individual learning styles and it's trying to figure it out.*

Balancing the right amount of assistance and the need to promote independence in children can also be difficult for some providers who may be tempted to do more for children with disabilities. Many providers must learn ways to appropriately challenge and adapt activities to include children with disabilities.

> *We have levels of expectations for typical children, but in our own mind we sometimes alter that for special needs children 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]

Even when providers are able to provide appropriate accommodations,
however, the slow progress of some children with disabilities can be hard.
It can take a long time before noticeable change occurs in some children.
As a center-based staff member said:

*You want to see all those warm fuzzies. 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 really realizing whether you have or not.*

In summary, providers mentioned many of the same challenges identified
by parents. Like parents, they are frustrated by not having sufficient staff,
equipment or training to provide the level of support some children with
disabilities need. They, too, would like better communication between
families, the school, therapists and the after-school program. Providers
also wish they had as many community resources for supporting school-
age youth with disabilities as they do for preschool children who have
disabilities.

Providers also highlighted ways in which the parent-provider relationship
can be strengthened. In some cases, providers need more information
from families—about the home situation, the child's preferences, what
works well with that child. With other families, however, the main

challenge is knowing how to help parents recognize that over-protecting children can also be damaging to the child.

As was the case with parents, the challenges experienced by providers guided their responses to what they would like to have in an ideal world. We outline in the next section what providers say they need to be able to better support children with disabilities.

What Providers Want

The needs of providers focused primarily on training, resources and communication. The idea of resources went beyond the simple need for more money (which is also needed) and included many ideas that can be implemented at relatively low cost.

Training. 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 would be very appreciated.*

Being able to apply what was learned in training in their own setting was 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 with disability children involved. I would love to see a class like that.*

Providers requested workshops that focused specifically on children with disabilities, not just children in general. The training topics that were most requested by providers were behavior management, integrating children with disabilities into inclusive settings, balancing the needs of children

with disabilities and typical children, administering medications, and using specialized equipment, such as nebulizers.

Given the specificity of each disability and the uniqueness of each child, many providers feel that having a resource person who can come out to provide hands-on training would be ideal. The perceived level of support providers felt they had available to them varied across the counties, and appeared to be influenced heavily by the degree of involvement of the inclusion coordinators in school-age care and activity settings.

As mentioned earlier, many providers found Babies Can't Wait to be a wonderful resource for preschool programs and wanted a similar resource for school-age children with disabilities. A group home provider explained:

> *It's very difficult to have a workshop that could be 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. To have that resource to pull in for after-school children, like she said, Babies Can't Wait, they're great. They just come right in and do just want we need. We don't have the resource for after-school children.*

But another possible source of individualized training are parents of children with disabilities. As one inclusion coordinator with a child care resource and referral 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."*

Providers said they also need training in how to work more effectively with the parents of children with disabilities. Parents also need training, however, 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 what is going on at home, and the benefits of relaying information about effective behavior management methods.

Parents and providers need training in communication and problem solving skills that will enable them to negotiate differences such as how much independence a child is ready for and how much support is reasonable to expect in the after-school setting.

Providers also feel training is needed for the general public to increase awareness about children with disabilities in the entire community. This training would increase understanding of and exposure to children with disabilities and reduce some of the pressures placed on many providers by parents of typically-developing children.

> *Actually, in reality, we all have disabilities. So we try to tell the children that. You know, some people's are more severe than others. But we all have disabilities.*
>   [Community-based after-school program staff member]

It is this shift in thinking and the increased exposure to children with disabilities that will reduce fears among typically-developing children and their parents and also build community support for better meeting the needs of children with disabilities.

Providers also requested training on how to promote better interaction 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. Or it might be training on how to help typically-developing children interact successfully with a child who has behaviors that could potentially be harmful. A child care 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. They are playing constantly around him without being scared.*

According to providers, training must touch all parts of the system—the school-age providers, children with and without disabilities and their families, and the larger community—in order to result in true improvements.

Greater Resources. Providers report they need more resources to be able to better serve all children with disabilities. More staff is definitely needed. But as was said earlier by both parents and providers—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 who have disabilities. Suggestions on cost-effective ways to lower child-staff ratios also are needed.

The high cost of adaptive equipment and modifications makes it difficult to accommodate children with disabilities, especially in small centers and

family child care homes. Providers would like information and technical assistance to enable them to apply for grants to cover these costs.

Greater access to information about the needs of school-age children with disabilities is required. The focus groups often became platforms for providers to share information about services that were offered and different resources that were available in their community. Providers want both greater awareness of the resources that are available and more information on school-age children with disabilities.

A Team Approach. Providers stressed the need for greater collaboration between the providers, parents, teachers, therapists, and other professionals who work with a child in order to have a more integrated, team approach. Providers would like suggestions on how to better communicate with parents who have children with disabilities and to be a resource to them. A group home 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.*

Providers also feel there needs to be more communication with the child's school. Children with disabilities spend the majority of their day in the school. Teachers or para-professionals who work closely with children with disabilities could provide useful insight into learning and behavior management strategies and how to incorporate the children into the setting. Providers would like a resource within the school whom they can contact to learn more about how to best support a child. They would like information in the IEP to be in layman's terms so that providers can easily utilize the information.

What Providers Want

Providers also 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. A family child care provider shares her experience in working with a therapist about a child with Down's 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.*

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.

But inclusion coordinators also stressed that providers have to be willing to take the time needed to use these resources if they are made available. 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.'*

Finally, providers want strategies for how to effectively manage communication across multiple individuals. School-age programs have higher child/staff ratios than preschool programs, which 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 child care 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.*

Journals can also be effective ways to promote 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.*

Accommodations. Providers want more ideas for how to modify activities, adapt the physical setting, and communicate more effectively with children who have disabilities. 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 kind 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 put on music that might be helpful.*
> [Center-based after-school program staff member]

What Providers Want

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.
> [Group home provider]

Providers want more access to specific ideas such as these. In particular, 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 with 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.

So—what do providers want in an ideal world? They want pretty much the same things as parents—the training and resources needed to provide inclusive settings for children with disabilities, more interaction between all individuals who support those children, and greater understanding of and sensitivity to disability issues on the part of the larger community.

Overview of Results

This investigation involved surveys, focus groups and interviews with 2,225 parents and 45 providers across 21 Georgia counties to better understand how school-age children with disabilities spend their after-school hours and the changes needed to better meet the needs of these children. By using three data collection methods and considering the perspective of both parents and providers, we are able to provide a comprehensive assessment of the school-care and activity system available to Georgia families who have children with disabilities.

The providers attending the focus groups value the opportunity to involve children in their programs. They enjoy seeing the children develop and they are rewarded by the love and affection children with disabilities give them. They also believe that children with disabilities enrich the lives of typically-developing children, helping them to develop compassion and to gain new skills for interacting with others.

This receptivity may, in part, explain why we found few differences in how children spend their out-of-school time between survey families who have children with disabilities and survey families of typically-developing children. Three fourths of all school-age youth spend at least some time before and after school in the care of parents. About one in four school-age youth are with adult relatives and one in ten school-age youth are home with siblings or cared for by a friend, neighbor or sitter. About one child in five attends an after-school program every week while one in six children is involved in recreation and enrichment activities. Less than five percent of school-age youth are home alone or at work. These settings are used primarily by older youth.

Focus group data, however, indicated that school-age children with disabilities may be somewhat more likely to attend after-school programs

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and less likely to be enrolled in short-term enrichment and recreation activities than typically-developing children. We believe that this is the case primarily for older children and those with severe disabilities, since the differences were evident in the focus group but not the survey data.

Comments by focus group parents and providers indicated that accessibility issues may underlie the differences observed across the survey and focus group samples. After-school programs typically run five days a week during the academic year or year-round and are often located in schools, which already are adapted to the needs of children with disabilities. It may be easier for families to access school-age programs that are housed in these settings. More extensive hours may also generate greater income that can be used for equipment and instructional accommodations.

In contrast, providers of short-term activities may generate less income than providers of after-school programs, making it more difficult to afford adaptations. 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.

There also was evidence that families who have children with disabilities must use a "patchwork" of care to a somewhat greater extent than families of typically-developing children. One in seven survey families who have children with disabilities said their child was in three or more settings each week, compared to only one in ten families with a typically-developing child. Focus group families supported this finding, describing how they had to piece together many different settings each week to allow the parents to work.

Satisfaction and Problems: Although children with disabilities and typically-developing children are in fairly similar settings each week,

families who have children with disabilities are less satisfied and report more problems with these arrangements. Only one in five survey families said they have no problems with the school-age care and activity arrangements for children with disabilities. In contrast, over one in three families who have typically-developing children said they have no problems.

Affordability, finding care when school is not in session, and not knowing what options are available in the community are of greatest concern to families of school-age children. These issues are of even more concern to families who have children with disabilities.

Cost is a barrier for substantial numbers of low- and moderate-income families with school-age children. It is not until families earn $60,000 or more each year that affordability becomes less challenging for families.

Both survey and focus group data indicate that families who have children with disabilities are more likely to be single parents, who typically have lower incomes. The survey data also indicated that families who have children with disabilities are more likely than families of typically-developing children to reduce their work hours, which also reduces family income.

The high cost of medical care for children with disabilities leaves less money for after-school programs and activities. Families also have higher transportation costs when programs do not have accessible vans and buses. All of these factors help explain why cost is viewed as a greater burden by families who have children with disabilities compared to families of typically-developing children.

Finding care during the summer, holidays, and breaks is challenging for many families of school-age children, although this was of greater concern to families who have children with disabilities.

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Although some after-school programs in Georgia provide care during times when school is not in session, many do not.[5] As a result, many families enroll their children in short-term enrichment and recreation programs on days when school is not in session. As indicated earlier, families who have children with disabilities find it more difficult to access these short-term community settings, which reduces their options.

About one in five families indicated that not knowing what was available in the community was a real challenge. Again, families who have children with disabilities said this was an even greater problem for them. In addition to the struggle all families have in identifying programs and activities that meet their needs, families who have children with disabilities must also determine if the program is adapted to the special needs of their children and, more importantly, if the program will accept their child.

Although the Americans with Disabilities Act (ADA) requires programs to make reasonable accommodations to include children with disabilities, providers and parents agreed that this was not always the case. Providers may want to accept children who have disabilities but do not do so because they worry that they don't have enough staff or that they cannot afford the needed accommodations. Parents believe that providers sometimes said they had no openings so as to avoid having to enroll children with disabilities.

In addition to having trouble accessing existing programs, some families have trouble findings programs at all. This is especially likely in rural areas where lower populations make it more difficult to provide a wide variety of programs and activities.

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[5]Todd, C. M. & Brumbeloe, S. T. (December, 2002). *The characteristics and training needs of school-age care programs in the Larger Metro Atlanta Area.* Atlanta, GA: Georgia School Age Care Association.

Another challenge for families who have children with disabilities is finding appropriate settings for older children. Most school-age programs serve children only through 12 years of age. Children with disabilities, however, may need to be in a supervised setting throughout the teenage years; it would be inappropriate to leave them home alone or with younger siblings. Growing interactions with peers is a defining characteristic of adolescence. Children with disabilities are at great disadvantage if they do not have the opportunity to interact with children at all, have little opportunity to interact with typically-developing children, or are only able to interact with much younger children.

One in seven families worries about their child's safety when they are away from home. While the prevalence of this problem did not differ by the disability level of the child in the family, families who have children with disabilities clearly have a broader range of safety concerns. For example, parents of children who have conditions that result in violent behavior are concerned that their child may hurt other children or run away from the setting. And families whose children are non-verbal worry that their child will not be able to tell them if something is wrong.

Transportation issues can also be more challenging for families who have children with disabilities. Besides the time and expense all families experience, some children with disabilities have more trouble sitting still for long periods of time and become very restless. Moreover, parents who have children in wheelchairs can become exhausted if they have to get the chair and child in and out of the car many times in a day. Even when transportation is provided by others, parents worry that children who have more limited physical and cognitive abilities will get hurt getting on and off the van or bus.

Providers also raised challenges that must be overcome in order for them to fully include children with disabilities into their programs. They are

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frustrated by not having sufficient staff, training or equipment to provide the level of support some children with disabilities need. The prevalence of entry-level positions combined with low salaries and having few children with disabilities in many programs makes it challenging to attract staff with extensive training related to children with disabilities. In addition, the cost of physical accommodations to the building, vans or buses may be cost-prohibitive, especially for smaller programs and family child care homes which derive lower levels of income.

Providers also need help knowing how to adapt their curriculum and activities to meet the needs of children with specific disabilities. They are concerned by the lack of communication and coordination between schools and the after-school setting, which makes it more difficult for providers to support the developmental and learning goals established for children.

Parents and providers both agreed that at times, parents of typically-developing children are not supportive of including children with disabilities in the program. Both groups felt that diversity training was needed to help all involved—providers, parents, children, teachers, decision-makers, and the public in general—better understand how to promote full inclusion of children with disabilities into the program.

Providers also described the need for stronger parent-provider relationships. 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.

What do families and providers want? Parents who have children with disabilities want the same type of programs and supports for their children as all families want, but they want them to a somewhat greater extent. Families who have children with disabilities especially would like to enroll their child in enrichment activities. Having greater access to school-age programs and youth clubs, such as Scouts, 4H or Girls, Inc. is also of interest to families. Families with older youth are also interested in volunteer or work experiences for their child.

One question that arises from the survey results is why families who have children with disabilities are more likely than families of typically-developing children to want additional programs and activities even though they report using these settings at the same rate as other families. There are several possible explanations for this finding.

First, we know that families who have children with disabilities are less satisfied and have more problems with their current arrangements compared to families with typically-developing children. As a result, they may be more likely than other families to want to change their arrangements. Alternatively, it is also possible that families who have children with disabilities believe their children need <u>more</u> experiences outside the home to promote optimal development than do families of typically-developing children.

Providers, too, have specific needs that must be addressed. They want enough staff with specialized training and the materials and equipment needed to fully accommodate children with disabilities into their settings. They also want more interaction between all individuals who support these children—parents, school personnel, and therapists—and a greater understanding of and sensitivity to disability issues on the part of the larger community.

Conclusions

The results of this study indicate that the current school-age care and activity system is not working as well as it should for many Georgia families. But the system works even less effectively for families who have children with disabilities. In order to improve the school-age care and activity system, local decision-makers must address the barriers that keep families from accessing their preferred school-age settings and providers from offering the level of support needed by children with disabilities.

Ensuring an adequate school-age care and activity system requires that:

- There are adequate programs and activities available, especially in rural areas and for older youth;
- Programs and activities are affordable for both low- and moderate-income families;
- The times and locations of programs meet families' needs;
- There is adequate transportation with appropriate accommodations;
- Providers have adequate levels of staff with specialized training and the equipment and materials needed to fully include children with disabilities;
- Providers can access local and state resources specifically focused on the inclusion of <u>school-age</u> children with disabilities;
- Diversity training is available for children, parents, providers and the larger community;
- Families can easily find out about the programs, activities and services that are available in the local community; and
- Providers can easily locate the supports they need to foster the full inclusion of children with disabilities into their programs.

Although these are ambitious and potentially costly goals, we were impressed by the number of low-cost ideas parents and providers suggested during the focus groups. In the next section we identify some ways communities can begin to put in place the needed supports.

Supporting Providers, Families & Youth

Fully supporting school-age children with disabilities, as well as the school-age providers who care for and educate them, will require a combination of top down and bottom up approaches. In the following sections we provide six ways in which changes at the state and local levels can foster the full inclusion of children with disabilities in school-age programs and activities.

1. Increase awareness of existing resources.
Many resources already exist to help families who have children with disabilities locate the school-age care and activity settings they need for their children and to help providers include children with disabilities in their programs. In many cases, however, parents and providers do not know about these resources. Therefore, the first step should be to promote greater awareness of these supports.

Four key systems currently serve as a conduit for information on children with disabilities:
- Pediatricians and mental health professionals
- Schools
- Child care resource and referrals (CCR&Rs)
- Georgia School Age Care Association (GSACA)

Pediatricians and mental health professionals often provide parents with the first diagnosis of their child's disorder. Following diagnosis, parents are tied into the public school support system for children with disabilities. Many parents also use the services of child care resource and referrals to find care for their preschool-age children. Moreover, school-age providers list their programs with and receive training from the CCR&Rs. The Georgia School Age Care Association is also a major provider

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of training and technical assistance to school-age programs throughout the state.

We recommend that two brochures—one for parents and one for school-age providers--be developed listing the services provided by Babies Can't Wait, Child Care Resource and Referral inclusion coordinators, and the resources available through websites, such as Parent to Parent of Georgia (www.parenttoparentofga.org). Multiple copies of the parent brochure should be provided for distribution by health professionals, schools and child care resource and referral parent counselors. Copies of the provider brochure should be distributed by CCR&Rs, GSACA and other organizations who support school-age care and activity providers.

A cover letter should accompany these brochures explaining the importance of sharing this information with parents at the time of diagnosis, when IEPs are discussed, and when CCR&R parent counselors first learn that a family has a child with a disability. The brochures should be designed to photocopy well and permission should be given to duplicate copies as needed. A number to call to obtain more brochures should also be listed on the brochure for groups who do not have the financial resources to duplicate the material themselves.

2. Increase access through improved accommodation.
Parents and providers agree that lack of accommodations prevents many children with disabilities from full inclusion in school-age programs and activities. The situation appears most severe for family child care and group home providers, small programs, and community-based organizations that offer short-term enrichment and recreation programs involving many different locations. This issue can be addressed through:

- Disability-focused groups developing short fact sheets for school-age providers outlining transportation, equipment and instructional accommodations typically needed for specific disabilities;

- Child care resource and referral agencies (CCR&Rs) identifying model homes and programs that have successfully included children with disabilities and facilitating interaction (meetings, tours) between these model programs and other providers in the community;
- CCR&Rs and other groups making parents and providers aware of existing local grants that can be used to adapt school-age programs to the needs of children with specific disabilities;
- Local foundations and other groups increasing or earmarking grants available to home- and facility-based school-age providers to modify cars, vans, facilities and equipment to accommodate children with a wider variety of disabilities. These grants should be available to providers of recreation and enrichment programs and youth clubs as well as school-age care facilities.
- Increased funding and changes in state policy to allow parents of children with disabilities to use flexible Family Support funds to support out-of-school experiences. These funds could be used to lower adult-child ratios or to hire a companion to accompany a severely-disabled child to enrichment activities. Changes in these policies should take into account the needs of both low and moderate-income families and should give consideration to the severity of the disability in addition to the income-level of the family.

3. Foster Collaborations and a Team Approach

The key to promoting full inclusion of children with disabilities in school-age programs and activities is collaboration and a team approach at all levels. At the program level parents of children with disabilities and program staff must develop trust, open communication and joint problem solving approaches. Communication between therapists, the schools and the after-school program setting is also critically important to ensure that the child experiences consistency across these settings. At the state level, collaboration is needed between groups that support families with disabilities and the agencies and organizations that support school-age programs and providers.

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To foster collaborations, we recommend that:

- At the state and regional levels, groups such as the Governor's Council on Developmental Disabilities, Family Connection, Medicaid, Bright from the Start, the Georgia Schoolage Care Association, the Georgia Afterschool Investment Council and the Georgia Child Care Resource and Referral Association should meet to develop a joint agenda for addressing the issues raised in this and other reports;

- At the community level, meetings should be organized between school districts and after-school providers to identify ways to share information and collaborate to ensure consistency of approaches across the home, school and after-school settings.

- At the program level, brochures should be developed for providers and parents outlining steps for ensuring the sharing of information and effective communication and problem-solving techniques. For example, journals kept in the child's cubby can be an easy way to foster communication between home, school and the school-age care setting. Portfolios can show the unique characteristics of each child and also record their progress.

4. Increase Provider Training

Parents and providers agree that training is vitally important to the successful inclusion of children with disabilities in school-age programs and activities. Much more training related to school-age children is needed. This training should include ideas on how to adapt the setting to the unique needs of children with specific disabilities. The training should include:

- A brief discussion of possible causes and typical attributes of children with the disability;

- Discussion of how the disability is likely to be expressed in the school-age setting;

- Specific ideas for facility, transportation, activity and instructional accommodations needed to successfully include children with the disability in school-age programs, and potential funding sources;

- Sources of additional information and technical assistance on the specific disability.

In addition to expanding the amount and type of training, it is also important to consider alternative delivery methods. Ensuring adequate training for school-age providers is even more challenging than is the case for early childhood program staff.[5] There is more diversity of program formats across school-age settings. Some programs run every day throughout the entire year. Others offer only after-school programming during the academic year while still others offer only short-term enrichment and recreation activities. Moreover, programs have different goals. Needed accommodations and interactions with families therefore will be somewhat different in each of these settings.

There are also staffing differences between early childhood and school-age programs and activities. Volunteers and part-staff who also work other jobs are much more prevalent in after-school settings than early childhood programs. This raises special challenges for trainers. For example, program staff who also have other jobs may find it more challenging to find the time to attend training. Moreover, the relatively shorter hours worked by many staff make it even more challenging for them to afford the registration and travel costs associated with training.

To address the training needs of school-age providers we recommend:
- Increasing the number of workshops for school-age providers on working with children who have disabilities. Mini-grants could be made available through *Bright From the Start* to foster the development of new training modules.
- Involving parents and providers in the creation of workshops and training materials and encouraging them to become part of the formal training system through meeting the requirements of relevant training certification programs.
- Developing video-based training and fact sheets on specific disabilities for use in workshops or as self studies. The use of self-studies is often discouraged out of fear that the provider will not fully process the information without an instructor present. Unless

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actual assessments of learning are used, however, there is no guarantee that providers attending workshops have mastered the material either. Video-based self studies are a very cost-effective way to provide training on specific disabilities in the face of high staff turnover or few children with a specific disability. They are also especially useful in rural areas where there may be too few providers to offer group training.

- Expanding access to training scholarships for school-age providers. Current scholarship programs should be examined to ensure that they are open to providers of short-term enrichment and recreation programs and respite care providers as well as school-age child care personnel. Training scholarships should cover the full cost of attending training, including wages, registration fees, and travel costs.

- Developing special training for providers on the Child and Parent Services (CAPS) program who provide home-based care to low-income school-age youth. Past research[6] shows that the majority of CAPS providers are African American women who care for related children, half of whom are school-age. These providers live primarily in rural areas and are required to have eight hours of training each year. Due to the greater incidence of disabilities among low-income children, it is likely that providers on the CAPS program care for many school-age children with disabilities. Training that is developed for this audience should take into account informal caregivers' unique relationships with the children in their care and their prevalence in rural areas where it is more challenging to provide group training.

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[6]Todd, C. M., Robinson, V., & McGraw, L. A. (April, 2005). *Contextual Influences on Informal Caregivers: Implications for Training.* Paper presented at the Biennial Meeting of the Society for Research in Child Development, Atlanta, Georgia.

5. Increase Availability

The results of the survey and focus groups indicated that <u>all</u> families are struggling with finding enriching and safe settings for their school-age children. In particular, there is need for more school-age options for

- Times when school is not in session (e.g., summer, early release days, holidays, breaks)
- Older children; and
- Rural areas

We recommend that community-based task forces be established to explore how these gaps in services can be addressed, ensuring that the options developed are fully inclusive of children with disabilities. This task force should have broad membership, including families who have typically-developing children as well as families who have children with disabilities; current and potential providers of school-age care and activities; educators and trainers; economic development representatives; and potential funders.

Innovative approaches are likely to be needed to address the challenges outlined above. For example, in rural settings innovative use of facilities that are available (schools, churches, libraries) may allow expansion of school-age programs. Allowing families who have older children with disabilities to use Family Support Funds to hire a companion who could provide transportation and one-on-one attention in programs is another innovative approach that might be considered.

Another approach is to consider how parents of children with disabilities may be able to strengthen the school-age care and activity system. Some parents who have children with disabilities are not able to work full time. Perhaps these parents could receive the training needed to work in school-age programs on a part-time basis, or to develop a group home that offers an inclusive program for older school-age youth on days when

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school is not in session. By identifying the unique needs of the community and by considering the full resources available in that community, the availability of quality, inclusive after-school programs and activities can be increased.

6. Expand Disability Awareness

After-school settings are complex systems. When a child who has a disability enters the program, information and support is needed for <u>all</u> sub-groups in that system—the child who has the disability and typically-developing children; the parents of all the children in the program, and program staff.

Inclusion of school-age children with disabilities raises special issues not found with younger children.[3, 7] As children approach adolescence, the nature of friendship changes and youth become especially concerned with outward appearances. As children move outward from the family, parents must develop new parenting styles that allow increasing autonomy for the youth while continuing to carefully monitor their activities and the peer groups with which they associate.

We recommend that a curriculum be identified or developed for use by program staff when including school-age children with disabilities into after-school settings. The curriculum should include activities, such as those provided in the *Yes I Can Social Inclusion Program,*[3] to help youth in the setting be ready to welcome and form friendships with children who have specific disabilities. Fact sheets and brochures for parents are also needed, both for the family of the child with disabilities and for parents of typically-developing children. This information should help parents: understand the benefits of inclusion for both the child with the disability

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[7] Berk, L.E. (2004). *Human development across the life span.* [3rd Ed.] Boston, Allyn and Bacon.

and typically-developing children, inform parents of specific ways they can be supportive of the process, and encourage open communication with staff should any concerns arise.

Education is also needed to sensitize the larger community to diversity issues and to help the larger community recognize not only the immediate benefits, but also the long-term social and economic impacts of inclusive programs on the community. The long-term benefits of including children with disabilities can offset the short-term societal costs that may be needed to fully accommodate children with disabilities in school-age settings.

This is similar to the arguments made by Lifton[8] about the benefits to society of high-quality child care programs. The economic viability of communities is enhanced when parents of school-age youth with disabilities can be fully employed and the availability of high-quality after-school programs ensures that they can focus their full attention on their work. Moreover, attending high quality school-age programs and activities fosters the optimal development of school-age youth with disabilities and increases the likelihood that they will be well-adjusted and fully employed as adults. The local economy is also enhanced when school-age providers use local businesses to purchase the equipment and materials needed to more fully accommodate children with disabilities. Moreover, the tax base expands when more employees are hired by school-age providers to provide better adult-child ratios.

The use of mass media can be a cost-effective way to reach the general public. We recommend the development of high-quality TV and radio

_____

[8]Lifton, N. (2001). Child care is a labor issue. *Social Policy,* 31 (3). Downloaded May, 2001 from http://www.socialpolicy.org/SP01/ sp-spring-01-lifton2.html

Conclusions

public service announcements and news releases for local newspapers to help citizens better understand specific disabilities and to inform the general public about the short- and long-term social and economic benefits of full inclusion.

Recent research highlights the benefits to children and society of high quality school-age care and enrichment activities.[9,10,11] By ensuring <u>all</u> children—including children with disabilities—have access to quality school-age care and activity settings we promote the well-being of the next generation, help parents become fully engaged in work, and create thriving communities.

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[9]Larson, R. W. (2000). Toward a psychology of positive youth development. *American Psychologist*, *55*, 170-183.

[10]Morrissey, K. M.; Werner-Wilson, R. J. (2005). The relationship between out-of-school activities and positive youth development: An investigation of the influences of communities and families. *Adolescence*, *40*, 67-85.

[11]Simplins, S. D., Ripke, M., Huston, A. C., & Eccles, J. S. (2005). Predicting participation and outcomes in out-of-school activities: Similarities and differences across social ecologies. *New directions for youth development*, 105, 51-69.

For More Information

More information on the results can be obtained from:

Zolinda Stoneman, Professor & Director
Institute for Human Development and Disability
Rivers Crossing
University of Georgia
Athens, Georgia 30602
(706) 542-4827
zo@ihdd.uga.edu

Christine M. Todd, Professor
Child and Family Development
114 Dawson Hall
University of Georgia
Athens, GA 30602
(706) 542-4830
ctodd@fcs.uga.edu

Appendix: Survey Instrument

The following materials were used to collect data for this study:

- Parent Survey
- Parent Focus Group Protocol
- Provider Focus Group protocol
- Focus Group Parent Demographic Survey
- Focus Group Provider Demographic Survey

Copies of these materials are provided in this section.

SURVEY OF SCHOOL-AGE CARE NEEDS

Please answer each question as it best describes you and your family. There are no "right" answers. DO NOT put your name on this form. Put the completed form in the envelope and <u>seal it</u> so no one will see your answers.

I. CURRENT SCHOOL-AGE ARRANGEMENTS

Shade Circles Like This--> ●

Not Like This--> ⊗ ☑

1. Thinking JUST of your <u>school-age</u> children, what grades (K to 12) are they in this year?
(Fill in ALL that apply)

○ K   ○ 1st   ○ 2nd   ○ 3rd   ○ 4th   ○ 5th   ○ 6th   ○ 7th   ○ 8th   ○ 9th   ○ 10th   ○ 11th   ○ 12th

List the grade of your youngest school-age child (in K - 12th grade) _____. Answer questions about this child ONLY.

2. What school does your youngest school-age child attend?   ○ My child is home schooled

_____   _____
  Name of School   City/Town School is in

Is this an:
○ Elementary School   ○ Special Focus School (Magnet, Charter, Academy, etc.)

○ Middle School   ○ Private School (Including church-based)

○ High School

3. What is the gender of your youngest school-age child?
○ Male   ○ Female

4. How does your youngest school-age child spend his/her time before and after school during a <u>typical</u> week?
(Fill in ALL that apply)

(Fill in ALL that apply)

A. ○ **Child is at home <u>WITH </u>AN ADULT or sitter**   with . . . . . .   ○ Parent(s)   ○ Adult relative
                                                              ○ Teenage sitter   ○ Adult non-relative

(Fill in ALL that apply)

B. ○ **Child is at home <u>WITHOUT </u>AN ADULT:**   ○ TOTALLY alone

○ with brothers or sisters   [ ][ ] [ ][ ] [ ][ ] [ ][ ]

Ages of brothers and sisters child is with
(when no adult is home)

(Fill in ALL that apply)

C. ○ **Child is at SOMEONE ELSE'S home**   with . . . . . .   ○ teenage sitter   ○ adult friend or neighbor
                                              ○ adult relative   ○ adult child care provider
                                                                  (who cares for children in her home)

(Fill in ALL that apply)

D. ○ **Child is at a before/after school child care PROGRAM:**   ○ at a child care center
                                                                    ○ at the child's school
                                                                    ○ at a community location (e.g., YMCA, Boys & Girls Club, Church)

E. ○ **Child is at a meeting, lesson, class, team practice, youth club, recreation ACTIVITY, etc.**

F. ○ **Child is at WORK.**

Please go on to the back of this page!

5. Tell us about any problems you have with the arrangements for your youngest school-age child.
(Fill in ALL that apply)

○ a. My community doesn't have the care or activities I want for my youngest school-age child.

○ b. I don't know what programs/activities are available in the community.

○ c. My before/after school care arrangements are not dependable.

○ d. I can't take all my children to the same place.

○ e. It's hard to find programs/activities that share my family values and/or respect my culture.

○ f. I have trouble finding programs/activities for my school-age child with special needs.

○ g. I worry about my youngest child's safety before and after school.

○ h. The activities available are not well planned or lack structure.

○ i. It's a problem that my child's homework is not getting done in the after school program.

○ j. My youngest child misses out on activities or time with friends.

○ k. My youngest child doesn't like his/her before and/or after school arrangements.

○ l. The programs or activities are not open late enough after school.   *If yes, how <u>late</u> do you need care?* _____ P.M.

○ m. The programs or activities are not open early enough before school.   *If yes, how <u>early</u> do you need care?* _____ A.M.

○ n. Finding care or activities during evenings/nights/weekends is a problem.

○ o. Finding care or activities on school holidays/vacations/breaks/early dismissal days is a problem.

○ p. Finding care or activities during the summer is a problem.

○ q. It is hard to find programs/activities where they speak my language.

○ r. It is hard to drop off/pick up my child on time because of traffic or other transportation problems.

○ s. I have to drive too far to get to the programs/activities.

○ t. My youngest child doesn't have transportation to or from the programs/activities.

○ u. The programs/activities cost more than I can afford.

○ v. It's a problem if I need to change my work hours or work overtime.

○ w. It's hard to find care when my youngest child is sick.

○ x. I worry that the person(s) caring for my youngest child may not treat my child the way I would.

○ y. I have trouble coordinating my child's care or activities.

○ z. I wish the people caring for children in our community had more education or training.

○ aa. There needs to be more discipline in the programs/activities in our community.

○ bb. My child's caregivers or program staff don't ask for my input as much as I would like.

○ *I do not have any problems with the before/after school arrangments for my youngest school-age child.*

6. Overall, how satisfied are you with these arrangements for your youngest school-age child?
(Fill in ONE)

○ Very <u>dis</u>satisfied - - I definitely would change my care if I could.

○ Somewhat <u>dis</u>satisfied - - I might change my care if I could.

○ Somewhat satisfied - - I probably would NOT change my care if I could.

○ Very satisfied - - I definitely would NOT change my care if I could.
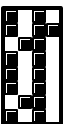
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III. TELL US WHAT YOU NEED!

7. Check the options below that you would LIKE to have for your youngest school-age child.
(Fill in ALL that apply)

○ **A. More resources for family members, friends or neighbors who care for my youngest school-age child.**
(For example: Homework helpline to call; educational videos or computer software for use at home; transportation so my child can sometimes attend special youth activities at school or in the community; ideas and materials for fun and educational activities my child can do)

○ **B. More resources for the program, activities, or family child care home my youngest school-age child ALREADY attends.**
(For example: Funding for special activites, equipment, materials, field trips; More training workshops available for staff; scholarships so staff/volunteers can attend training; salary supplements to keep well qualified people caring for or providing activities to my child)

○ **C. I wish my youngest school-age child could go to a high quality before and/or after school program every week.**

Where should this program be? (Fill in ALL that you would *seriously* consider)

○ **At a child care center:** ○ near my home   ○ near my work

○ **At the home of a licensed child care provider:** ○ near my home   ○ near my work

○ **At the child's school**

○ **At a community location (e.g., YMCA, Boys & Girls Club, Church)** *Which one?*_____

When? (Fill in ALL that you need)
○ Before school   ○ After school   ○ Before/after kindergarten   ○ Evenings   ○ Weekends
○ Holidays   ○ School breaks   ○ Early release days   ○ Summer

Which days? (Fill in ALL that you need)
○ Monday   ○ Tuesday   ○ Wednesday   ○ Thursday   ○ Friday   ○ Saturday   ○ Sunday
Will the specific days vary each week? ○ No   ○ Yes

○ **D. I wish my youngest school-age child could go to more supervised classes and activities.**
(For example: music, art, computers, sports, science, math, photography, cooking classes, etc.)
What activities for your oldest child are you most interested in? _____

○ **E. I wish my youngest school-age child could be in a youth club like Boy/Girl Scouts, 4-H, Girls Inc., Campfire, etc.**

○ **F. I wish my youngest school-age child could get a job or volunteer experience.**

○ *I do not want any of the above options. I am completely satisfied with the options I ALREADY use.*

8. Which ONE option from above would you like MOST for your youngest school-age child? ☐
(Please write the letter from above in the box)

9. What makes it hard to use the above options?
(Fill in ALL that apply)
○ They are not available in my community   ○ My child doesn't want to go or is not interested in activity

○ I don't know what is available   ○ My family can't afford it

○ I don't like the programs/activities that are available   ○ No transportation to get to programs/activities

○ The programs/activities don't meet my needs
   (e.g., wrong hours, times, locations, etc.)

Please go on to the back of this page! ■

10. The lack of good school-age care keeps me (or my spouse) from working.

○ No, false ○ Yes, true

11. The lack of good school-age care keeps me (or my spouse) from working as many hours as we would like.

○ No, false ○ Yes, true

12. In the last year, have you been absent from work because your oldest school-age child was ill?

○ No ○ Yes If yes, how many full- or part-days did you miss? ☐☐

V. FAMILY INFORMATION *We ask this information to see if different kinds of families have different needs.*

13. I live in a...(Fill in ONE)

○ Rural area or small town ○ Large town ○ Small city ○ Large city or suburb
(Less than 2500 people) (2,500 to 9,999) (10,000 to 49,999) (More than 50,000)

14. What is your zip code? ☐☐☐☐☐

15. How safe do you feel in your neighborhood (Fill in ONE)

○ Very unsafe ○ Somewhat unsafe ○ Somewhat safe ○ Very safe

16. How many adults live in your household during the week? (Fill in ONE)

○ 1 parent

○ 1 parent and 1 or more other adults (grandparent, roommate, etc.)

○ 2 parents (or stepparents)

○ 2 parents and 1 or more other adults

17. In your household, how many hours per week are parents/guardians employed?

You?	**Other parent/guardian?**
○ None	○ None
○ 1 to 20 hours/week	○ 1 to 20 hours/week
○ 21 to 35 hours/week	○ 21 to 35 hours/week
○ Over 35 hours/week	○ Over 35 hours/week
	○ Not Applicable, does not live in home

Where do you work?
○ In the county we live in ○ In another county

Where does other parent/guardian work?
○ In the county we live in ○ In another county

City/Town you work in:_____

City/Town other parent works in:_____

18. Are your children eligible for free or reduced price lunches?

○ No ○ Yes

19. Does your child have a special need?

○ No ○ Yes **If yes, what type?**
○ ADHD ○ Autism
○ Health Problem: _____
○ Physical Disability
○ Mental Retardation/Down Syndrome
○ Other:_____

20. What is your youngest child's race?

○ Asian/Pacific Islander

○ Black/African American

○ Caucasian/White

○ Hispanic/Latino(a)

○ Native American/American Indian

○ Multi-racial

21. What is your total yearly gross family income?

○ Less than $15,000

○ $15,000 to $29,999

○ $30,000 to 44,999

○ $45,000 to $59,999

○ $60,000 to $74,999

○ $75,000 and above

THANK YOU! You are now done with the survey. Please put your survey in the attached envelope, <u>seal it</u> and write your child's school name across the seal so we know that no one has read your answers.

Send your survey to school with your child or mail it in the postage paid envelope to:
Parent Survey, 114 Dawson Hall, The University of Georgia, 240 Riverbend Road, Athens, GA 30605-98512
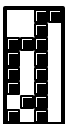
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Focus Group Questions for Parents

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 activites would you ideally like your child to be involved in?

- 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?
    - (P*robes: 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).*

- 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?
  - 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.

- Ideally what types of school-age care and activities would you like to have for your child? *(Probe: quality indicators)*
- 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?

Focus Group 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.

Get Started/Participant 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.

- 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.

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.)
   - o 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?
   - o Obviously your programs serve some youngsters, what else is available for children? What is available during the non-school hours, with working parents?
   - o (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?
   a) **If not,** what stops you from including them in your setting?
      - o 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?
      - o Is there any kind of support that could help you include them in your program?

   b) **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,
      - *Balancing the needs of children with disabilities with that of other children,*
      - *Striking a balance between supporting them and fostering independence in them,*
      - *Promoting friendships between them and other children,*
      - *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? If so,
   - Describe the relationships between your setting and professionals from the medical, social services or special education fields?
   - 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.
   - 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?
   - 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?

SCHOOL-AGE PARENT/GUARDIAN INFORMATION SHEET

We'd like to ask you some general information about you and your family.
We will use this information to better understand you and your family situation. You do not have to answer any questions you do not want to.

1) What are the ages of your children living at home? ____ ____ ____ ____ ____ ____

2) What is the age of your child who has a disability?   _____

3) What is the gender of your child who has a disability?   O Male   O Female

4) What type of disability does your child have? (check all that apply)
   O Down Syndrome   O Language/Speech delay
   O Fragile X   O Cerebral Palsy
   O Hearing impairment   O Physical Disability
   O Cognitive/Mental delay   O Muscular Dystrophy
   O Pervasive Developmental Delay (PDD)   O Autism
   O Spina Bifida   O Visual Impairment
   O Behavioral problems   O ADHD (Attention Deficit Hyperactivity Disorder)
   O Other: (Please describe) _____

5) What type of classroom does your child attend? (check ONE)
      O Regular education
      O Special education
      O Other: (If not only in regular classroom or only in special education classroom, then please
        describe your child's classroom situation: _____

6) What is your relationship to the child?   O Mother
                                                    O Father
                                                    O Other (Please specify:_____)

7) Including yourself, how many adults live in your household?   _____

9) How many hours per week are parents/guardians employed outside the home?
   a) Mother/guardian: (check ONE)   (b) Father/guardian: (check ONE)
      O None   O None
      O 1-20 hrs/wk   O 1-20 hrs/wk
      O 21-35 hrs/wk   O 21-35 hrs/wk
      O over 35 hrs/wk   O over 35 hrs/wk
      O Not applicable (does not live at home)   O Not applicable (does not live at home)

10) Is your child eligible for free or reduced price lunches?   O Yes   O No

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:
- **O** parent(s)
- **O** adult relative
- **O** adult non-relative
- **O** teenage sitter

At an after-school program
- **O** at a child care center
- **O** at a school
- **O** at a community location (e.g, YMCA, church)

At home without an adult:
- **O** with brothers & sisters, friends or alone

Child is somewhere else
- **O** at a meeting, lesson, class, team practice, youth club, or recreation activity
- **O** cared for by parent at the parent's worksite

At someone else's house with:
- **O** adult relative
- **O** adult friend or neighbor
- **O** adult child care provider
- **O** teenage sitter

- **O** child is at a work or volunteer experience
- **O** with friends (no adult present)

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

At home with:
- **O** parent(s)
- **O** adult relative
- **O** adult non-relative
- **O** teenage sitter

At an after-school program
- **O** at a child care center
- **O** at a school
- **O** at a community location (e.g, YMCA, church)

At home without an adult:
- **O** with brothers & sisters, friends or alone

Child is somewhere else
- **O** at a meeting, lesson, class, team practice, youth club, or recreation activity
- **O** cared for by parent at the parent's worksite

At someone else's house with:
- **O** adult relative
- **O** adult friend or neighbor
- **O** adult child care provider
- **O** teenage sitter

- **O** child is at a work or volunteer experience
- **O** with friends (no adult present)

13) What is your gender?   **O** Male   **O** Female

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

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

16) What age range are you in? (Check ONE)

O 18 – 24 years   O 55-64 years
O 25 – 34 years   O 65-74 years
O 35 - 44 years   O 75 years and above
O 45 – 54 years

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

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

18) What is your family's total yearly income? (check ONE)

O Less than $15,000   O $45,000-$59,999
O $15,000-$29,999   O $60,000-$74,999
O $30,000-$44,999   O $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)

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

2) Are you a part-time or full-time employee in this job?
   O Part-time   **O** Full time

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

   O In my home or someone else's home
   O After school program in a school
   O After school program in a child care center
   O After school program in a community organization
       (such as YMCA, Boys & Girls Club, etc).
   O Short-term educational or recreational activities for school-age children before or after school
       (e.g., soccer, crafts, hobbies, music lessons, art lessons)
   O Youth development/leadership program
       (e.g., 4H, Scouts, Girls, Inc, Campfire, etc.)
   O A youth prevention/intervention program
   O 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)
   O Less than 2 years
   O 2 - 5 years
   O 6 - 10 years
   O Over 10 years

6) How many years of experience do you have in your current position? (Check ONE)
   O Less than 2 years
   O 2 - 5 years
   O 6 - 10 years
   O Over 10 years

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

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

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

9) What is your gender?   O Male   O Female

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

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

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

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

        O White, non-Hispanic, non-Latino(a)   **O** Hispanic or Latino(a)

        O Black/ African American   **O** Asian

        O American Indian or Alaska Native   **O** Multiracial

        O Native Hawaiian or Other Pacific Islander   **O** Other (please specify: _____)

Do you have children of your own? **O** Yes **O** 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? **O** Yes   **O** No

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

Thanks !