



**BARRIERS TO QUALITY CHILD CARE**  
*Families of Children with Disabilities  
and Special Health Care Needs  
Speak Up*

A Report of the  
**MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL**

**January 2004**

## In Appreciation

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*Children and Family Issues Committee, Maryland Developmental Disabilities Council*  
*Coalition for Inclusive Child Care Committee of the Child Care Advisory Council*  
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## Executive Summary

Child care providers, child and disability-rights advocates, and State agencies have long recognized that barriers to inclusive child and after-school care exist for children with disabilities and special health care needs, yet the voices of families have been missing from efforts to document the scope of the problem. In the fall of 2002, the Maryland Developmental Disabilities Council identified the need for data to document the experiences of families of children with disabilities and special health care needs. The resulting information supports what advocates for children with disabilities have known for years... that there are significant gaps in the availability and, more importantly, quality of child and after-school care opportunities for children with disabilities and special health care needs.

Despite the efforts of the Maryland Child Care Administration and the child care community, there are indicators that families of children with disabilities continue to have difficulties accessing and maintaining quality child and after-school care. In 2003, the Maryland Developmental Disabilities Council gathered data from families using surveys and focus groups. Over 400 families from throughout Maryland responded to the survey and four regional family focus groups were held. From the surveys and focus groups, a description of families' child care experiences was developed and is summarized. Among the findings:

- **When asked whether they had difficulties in finding, obtaining, or keeping child care, 83% of respondents said “yes.”** When asked the reasons for these difficulties, families indicated a wide variety of problems, including the unwillingness of child care providers to accept their child, the lack of knowledge of providers, behavioral issues, and toileting issues.
- **When asked what their alternative was when they were unable to find child care, of the 307 responses 42% stated that they had quit their jobs or stopped working, 33% stated that they had relied on family members or friends, 15% had changed jobs to accommodate their lack of child care, and 2% had retired.** Another 8% reported other alternatives, including leaving their children with disabilities under the care of siblings, taking family leave, and taking their children to work.
- **76% of families who answered the question reported that they had lost income due to child care issues.** Families reported consequences from quitting their job to having to take numerous days off of work.
- **When asked whether a child care provider had ever asked that their child leave the child care program 64% of those answering the question indicated that at some point they were asked to leave a child care setting.** Conversely, 74% of those who responded to the question had at some point chosen to remove their child from a child care setting/program.
- **When asked whether they had concerns about availability of child and after-school care as their child ages, 78% of responses indicated this is an area of concern for families.** Families also relayed concerns about the availability of child care and day camps for children with disabilities and special health care needs over the summer months.

Throughout the process of listening to families and professionals, a number of recommendations have been made to eliminate the barriers that families face when seeking quality child and after-school care, some are which are below. Please see the full report for further results and recommendations.

### **CONTINUE TO SUPPORT EXISTING SERVICES**

- The Child Care Administration should maintain and expand services like the LOCATE Child Care’s Special Needs Service and Child Care Resource and Referral Services, as well as provide additional funding to further publicize and promote these services to families, particularly those living in outlying areas.
- The Child Care Administration should maintain and expand training and technical assistance services, like Project ACT (All Children Together), that provide on-site technical assistance to child care providers caring for a child with a disability.
- The Child Care Administration should continue to work in partnership with the Maryland State Department of Education’s Infants and Toddlers Program and Preschool Service Branch, as well as the Maryland Head Start Program to ensure that young children ages birth through five receive early intervention services in natural environments, including child care settings and Head Start programs.

### **TRAINING**

- The Child Care Administration should require that all approved child care courses and workshops include information on how the subject areas apply to children with disabilities and special health care needs.
- The Child Care Administration should consider “weighting” credentialing courses that address systemically underserved populations, such as children with disabilities and special health care needs.

### **QUALITY ASSURANCE**

- The Child Care Administration should develop a *Code of Ethics and Standards of Practice* for Maryland’s child care professionals that include a statement of nondiscrimination and language regarding the value of diversity and inclusive child care.
- The Child Care Administration should increase and standardize the knowledge of licensing staff regarding best practices and legal requirements for serving children with disabilities and special health care needs, and revise quality assurance/licensing reviews to include information about the child care provider’s capacity to serve such children.

### **SUPPORT**

- The Child Care Administration should support the development of local child care special needs networking groups aimed at providing local leadership and technical assistance to one another.
- The Child Care Administration should develop a database of professionals available to provide immediate technical assistance to child care providers.
- The Child Care Administration should establish a working group with the Developmental Disabilities Administration (DDA), Mental Hygiene Administration (MHA), Maryland

State Department of Education (MSDE), and other agencies to identify and implement creative uses of existing programs and resources that could support children with disabilities and special health care needs participation in community-based child and after-school programs.

## **RESEARCH**

- Working in partnership with the Maryland State Department of Education and Maryland's universities, the Child Care Administration should develop and implement a comprehensive strategy to regularly, and in user-friendly formats, offer child care workers information about research-based practices that support the inclusion of children with disabilities and special health care needs.
- Partner with Maryland's universities and colleges to develop a research agenda that supports inclusive child and after-school care for children with disabilities and special health care needs.

## **AFTER-SCHOOL AND SUMMER CARE**

- The Child Care administration should work to increase the number of inclusive after-school care programs throughout the State, particularly for middle school-aged children and youth.
- The Child Care Administration, in partnership with local school systems, the Maryland State Department of Education, the Developmental Disabilities Administration, the Mental Hygiene Administration, and other agencies and organizations, develop age-appropriate models of after-school care for high-school aged youth with disabilities.
- The Child Care Administration should clarify licensing regulations regarding children over age 12 to child care providers and families.
- The Child Care Administration, in partnership with the Department of Health and Mental Hygiene, Maryland State Department of Education, and other agencies and organizations, should identify model inclusive day and overnight camp programs and support replication activities based upon models.

In this time of fiscal uncertainty we need to find the resources to help parents participate in the workforce, support their families, and contribute to Maryland's tax base. Law and policy makers, administrators, child care providers, and families must work together to impact the child and after-school care community to improve options for families and the quality of care for children. In doing so, we will move from a compliance-based approach to one of acceptance, having a positive ripple effect on all segments of our society.

Public support of child care has grown over the last few decades resulting in improvements in Maryland's child care system. The same level of support and results must be true for children with disabilities and special health care needs. The plight of families seeking quality inclusive child and after-school care must be brought to the forefront of existing efforts to improve the lives of children and individuals with disabilities.

# **CHILD CARE FOR MARYLAND'S CHILDREN WITH DISABILITIES**

## **INTRODUCTION**

Child care providers, child and disability-rights advocates, and State agencies have long recognized that barriers to inclusive child and after-school care exist for children with disabilities and special health care needs, yet the voices of families have been missing from efforts to document the scope of the problem. In the fall of 2002 the Maryland Developmental Disabilities Council identified the need for data to document the experiences of families of children with disabilities and special health care needs. The resulting information supports what advocates for children with disabilities have known for years... that there are significant gaps in the availability and, more importantly, quality of child and after-school care opportunities for children with disabilities and special health care needs.

These gaps widen as the number of children with disabilities and significant health care needs continue to rise both in Maryland and nationally. Although finding quality child care is difficult for any family, data indicate that finding quality child care for children with disabilities and special health care needs is almost impossible.

This report is based upon regional focus groups and more than 400 surveys completed by families of children with disabilities and special health care needs. It will share some of the challenges, systemic barriers and misperceptions that exist for families seeking quality child and after-school care and activities for their children with disabilities or significant health care needs. In addition, we provide recommendations to improve Maryland's efforts to assist families in meeting these challenges.

## **BACKGROUND**

Since the end of World War II, there has been a substantial increase in participation in the labor force by women who have children under the age of 18. Overall, it is estimated that 72% of mothers work (2000 House Ways and Means Committee). This trend towards dual-income families and the increasing number of single parent led families has raised concerns about the availability and quality of child and after-school care for children.

Concerns that child care may be in short supply, of low quality, or too expensive for many families escalated during the late 1980s into a national debate over the nature and extent of the nation's child care problems. The debate culminated in the enactment of legislation in 1990 that expanded Federal support for child care by establishing two new State child care grant programs. The programs—the Child Care and Development Block Grant (CCDBG) and the At-Risk Child Care Program—were enacted as part of the Omnibus Budget Reconciliation Act of 1990 (Public Law 101-508). An earlier major welfare reform initiative, the Family Support Act of 1988 (Public Law 100-485), had also authorized expanded child care assistance for welfare families and families leaving welfare. In 1996, as part of welfare reform legislation (the Personal Responsibility and Work Opportunity Reconciliation Act, Public Law 104-193), these programs were consolidated into an expanded Child Care and Development Block Grant (sometimes referred to as the Child Care and Development Fund). This provides increased Federal funding

and serves both low-income working families and families attempting to transition off welfare through work.

States like Maryland benefited greatly from these initiatives – increasing the number of Purchase of Care (POC) Vouchers available to working families, improving licensing requirements, establishing training programs for child care providers, developing child care resource services for families, and, more recently, developing a credentialing program aimed at increasing the quality of care that children in child and after-school care receive.

The overall trend in increased workforce involvement by women has raised challenges for specific populations, such as families of children with disabilities and special health care needs. Children with disabilities are, first and foremost, children, and then children who may need support or adaptations for learning and participation. An increasing number of early childhood, educational, and after-school programs around the country are discovering the benefits of placing children with disabilities together with their same-age peers. For example, research shows that the benefits of inclusive classrooms reach beyond academics. This is particularly true of young children who are not only provided with typical peers as role models, but also given the opportunities to develop long-term friendships and social relationships. Early childhood professionals who have successfully included children with disabilities and special health care needs note that, contrary to some expectations, they needed few adaptations to meet the needs of all children. They report that rather than needing more staff or money, they typically required support from peers and specialists, training and technical assistance, and positive relationships with families.

#### **ACCESS TO QUALITY INCLUSIVE CHILD CARE**

In 1992 the Americans with Disabilities Act (ADA) established equal rights for people with disabilities in employment, state and local public services, and public accommodations, including preschools, child care centers and family child care homes. In 1995, the Maryland Committee for Children, Inc. released its report, *Improving the Inclusion of Children with Disabilities in Community Child Care Programs*. The report recognized that

*“Finding appropriate child care is challenging for most families and exceptionally difficult for families that have a child with a disability. Caregivers are often reluctant to accept children with disabilities in child care settings because of concerns about insurance, liability, environmental and program accommodations and the cost of care. Many care givers feel inadequately trained to care for a child with a disability, and fears and misconceptions result from insufficient information and experience.”*

The philosophy of inclusion supports the right of all children, regardless of their diverse abilities, to participate actively in natural settings within their communities. A natural setting is one in which the child would spend time had he or she not had a disability. Such settings include but are not limited to home and family, playgroups, child and after-school care programs, Head Start programs, kindergartens, and neighborhood school classrooms. The 1995 Maryland Committee for Children report, developed by a panel of families and child care and disability professionals, put forth a series of recommendations to improve children with disabilities’ access to community child and after-school care programs. Among them:



- Allocating additional funds to the POC program earmarked for working poor families who have children with disabilities;
- Providing subsidies directly to families of children with disabilities to help fund supplemental services such as transportation, nursing services, adaptive and medical equipment, and personal assistance;
- Expansion of specialized resource and referral services for families of children with disabilities;
- Offering grants for the specific purpose of enabling child care providers to make necessary modifications to their family child care home or child care center;
- Providing training and support for providers to enhance their knowledge and skills in caring for children with disabilities;
- Training licensing specialists to help child care providers accommodate children with disabilities;
- Establishing linkages between agencies to support and promote the inclusion of children with disabilities in community-based child care programs;
- Studying the State's practice of not including child care as an entitlement under Part H (now Part C – Infants and Toddlers Program) under the Individuals with Disabilities Education Act (IDEA);
- Encouraging the delivery of early intervention services in natural environments, including child care settings;
- Encouraging the State of Maryland to increase funding for early intervention services under the Maryland Infants and Toddlers Program.

Many of these recommendations were implemented by the Child Care Administration, in partnership with the Maryland State Department of Education and other agencies:

- Additional POC funds were earmarked for children with disabilities.
- The LOCATE Child care service for families of children with special needs was developed with funding by the Maryland State Department of Education.
- Limited grant funds were made available to child care providers for a variety of child development initiatives, including accommodating a child with a disability or special health care need.
- Project ACT (All Children Together) was funded to provide training and technical assistance to child and after-school care providers.
- In some jurisdictions, behavioral specialists and/or inclusion facilitators were supported through Child Care Administration funding.
- The Child Care Administration sought and received funding for *Healthy Child Care Maryland*, a program to increase child care providers' knowledge of health issues and provide health information through available licensed nurses.
- The Maryland Infants and Toddlers Program moved towards the provision of early intervention services in natural environments and received additional State funding as part of the Bridge to Excellence in Public Education Act of 2001.

## SYSTEMIC BARRIERS REMAIN

Despite the efforts of the Maryland Child Care Administration and the child care community, there are indicators that families of children with disabilities continue to have difficulties accessing and maintaining quality child and after-school care. In 2001, the Maryland Committee for Children surveyed child care providers relating to the availability and quality of child care for children with disabilities and special health care needs. The survey, published in their report *Child Care for Children with Special Needs*, found that:

- 74% of family care providers and 84% of group program providers agreed that child care providers are concerned with safety factors such as lifting larger children and using medical equipment.
- 65% of family care providers and 72% of group program providers agreed that children with aggressive behaviors (social/emotional problems) cannot receive the attention they need in a typical child care setting.
- 82% of family care providers and 77% of group program providers agreed that there are many liability issues caring for children with disabilities.
- 77% of family care providers and 85% of group program providers agreed that providers do not have sufficient knowledge about disabilities.
- 59% of family care providers and 72% of group program providers agreed that providers are uncomfortable diapering or assisting with toileting a child who is outside the typical age.
- 66% of family care providers and 69% of group program providers agreed that the child care community does not have sufficient knowledge about child care regulations and how they affect children with special needs.

In 2002, the Coalition for Inclusive Child Care Committee together with the Maryland Committee for Children's Special Needs Subcommittee held a focus group with the staff of agencies that support children with disabilities in community child and after-school care settings. The focus group identified the following barriers to inclusive child and after-school care:

- **Attitude of Providers:** This was seen as the largest barrier to inclusive child care. It was noted that many providers do not want to care for children with disabilities or special health care needs usually because of incorrect assumptions about the child, disability, and the effect on their work load or child care setting.
- **Lack of Knowledge:** Child care providers need basic disability awareness training to reduce stereotypes, as well as training on developmentally appropriate care, specific disabilities, successful strategies to include children, positive behavior supports, and information on community resources.
- **Physical barriers:** In particular jurisdictions (i.e. Baltimore City, Prince George's County) it is difficult to find family care providers with accessible homes.
- **Behavioral Issues:** Child care providers are not trained in the use of positive behavioral supports and do not have behavioral support plans for children with challenging behaviors.
- **Toileting Issues:** Child care providers are uncomfortable with toileting older children and are unclear on the regulations that allow toileting accommodations for children with disabilities.

- **Staffing Ratios:** The focus group members felt that the staffing ratios were high for typical children, and that for many children with disabilities and special health care needs, staff to child ratios were prohibitively high.
- **Age Issues:** Child care providers are confused about licensing and regulations to care for a child over age 12, and often receive conflicting information from licensing staff.
- **Medication Administration:** Child care providers often state that they are not insured to provide medication to children in their care.
- **Liability/Insurance:** Child care providers incorrectly believe that they must have increased liability coverage if they care for a child with a disability.

The impact of inaccessible and poor quality early childhood settings goes far beyond the early years. In 2000, the Joint Committee on Children, Youth, and Families recognized the importance of quality early childhood experiences with regard to children entering school ready to learn. The Maryland Model for School Readiness and Work Sampling System was established to track children's progress towards school readiness and support teachers to improve assessment and instructional techniques to support young children's readiness for school. The 2001-2002 School Readiness Baseline Information released by the Maryland State Department of Education shows that only 30% of young children receiving special education services were fully ready for kindergarten compared to 48% of young children without disabilities. Research shows that access to developmentally-appropriate early childhood curriculum and typical peers increases children with disabilities' academic and social progress and better prepares youngsters with disabilities and special health care needs for school and learning.

In developing this report, the Maryland Developmental Disabilities Council gathered data through multiple sources, using surveys and focus groups. A survey was sent to 850 families of children with disabilities and special health care needs through disability-related conferences, parent support groups, the Family Support Network, disability-service provider organizations, the internet, the LOCATE Child Care Special Needs Resource and Referral Service, PACT: Serving Children with Special Needs Child Care Center, and other organizations. Additionally, four regional family focus groups were held between March and July of 2003. A wide range of children's disabilities and special health care needs were included and compiled into 4 broad categories: developmental/cognitive disabilities, physical disabilities, special health care needs, and social/emotional disabilities. From the surveys and focus groups, a description of families' child care experiences was developed and is summarized.

## WHAT ARE THE EXPERIENCES OF MARYLAND FAMILIES?

### FAMILY SURVEYS

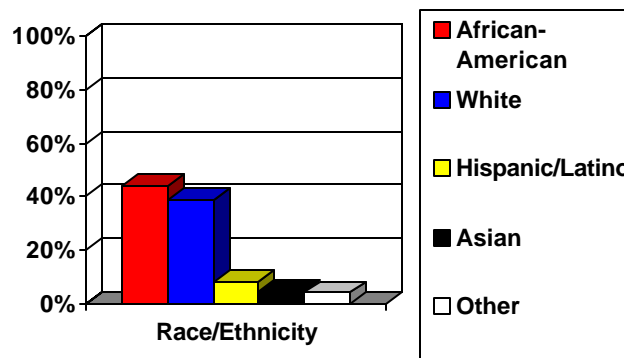
From March 2003 through July 2003, more than 850 *Barriers to Quality Child Care* surveys were distributed to parents and families of children with disabilities and special health care needs. These surveys were widely distributed and covered all geographical areas in Maryland. In addition, there was great diversity in the makeup of participants.

More than 400 surveys were returned, tabulated and reported to the Maryland Developmental Disabilities Council's Children and Family Issues Committee, as well as the Coalition for Inclusive Child Care Committee, the Special Needs Subcommittee of the Maryland Committee for Children, the Healthy Child Care Maryland Steering Committee, and the Child Care Administration's Child Care Advisory Committee.

### Demographics

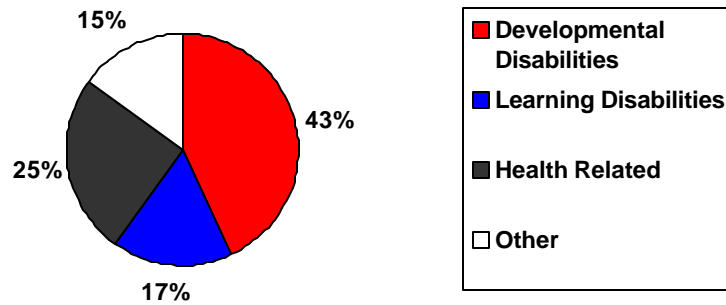
411 completed surveys (a response rate of 48%) were received from 22 counties and Baltimore City allowing input from families in rural, suburban, and urban areas of the State. The surveys reflected the racial and ethnic diversity of the State, with 44% of the respondents being African-American, 39% being White/Caucasian, 8% Hispanic/Latino, 4.5% Asian, and 4% other.

### **Race/Ethnicity**



Approximately half of the parents were married, slightly less than half reported that they were single or divorced at the time of filling out the survey, and less than 3% identified themselves as kinship caregivers (i.e. grandparents). When asked their child's diagnosis families provided detailed information with more than a third reporting multiple disabilities. Almost half the respondents reported having a child (birth-21) with a developmental/cognitive disability.

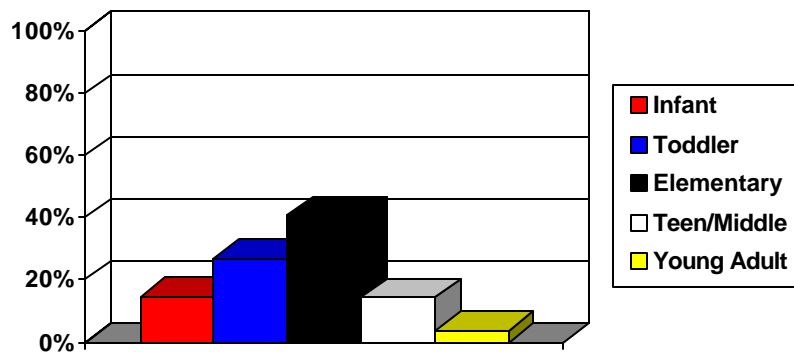
## Disability Categories



Attention Deficit Hyperactivity Disorder	84
Autism (includes PDD/Asperger Syndrome)	121
Blind/Visual Impairment	6
Cerebral Palsy	46
Deaf/Hearing Impairment	31
Developmental Delay	41
Down Syndrome	48
Epilepsy/Seizure Disorder	26
Learning Disabilities	25
Mental Health/Psychological Disorder	61
Cognitive Disabilities	28
Sensory Integration Dysfunction	43
Sickle Cell Disease	35
Undiagnosed Conditions	13
Other	48

Slightly over 14% had children ages birth through 24 months, 27% had toddlers between ages 2 and 4, over 40% had elementary school-aged children (ages 5 through 12), over 14% had teenagers aged 13 through 16, and just under 4% had young adult children ages 17 through 21.

## Age Groups

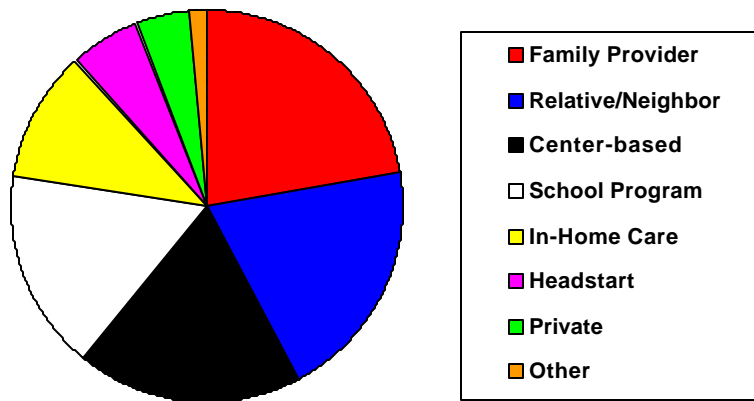


Families reported first seeking child care for their children when their child was ages birth through 2 (24%), ages 2-3 (42%), ages 4-5 (19%), ages 5-12 (13%), and ages 13-16 (2%).

Experiences with Child and After-School Care

When asked what types of child care families had used, 30% of families responding reported using family child care providers, 27% reported using a family member or neighbor, 25% reported using child care centers, 23% reported using before and after-school care programs, 15% reported using in-home care, 8% reported involvement in a Head Start program, 6% reported using nanny or au pair services, and 2% reported using another child care arrangement.

**Types of Child Care Setting/Environment**



When asked whether they had difficulties in finding, obtaining, or keeping child care, 83% of respondents said “yes.” When asked the reasons for these difficulties, families indicated a wide variety of problems. The number one barrier to obtaining and/or keeping child care was a lack of provider willingness.

**Family Member Reports of Difficulties in Finding, Obtaining, and Keeping Child and After-school Care**

REASON	#
Provider/Group unwilling to accept child	88
Cost of care/program	78
Quality of care/program	75
Lack of provider knowledge	71
Behavioral issues	61
Attitude of child care staff	60
Child’s inability to communicate effectively	57
Location of care/program	51
Size of group/facility	47
Provider concerns re: feeding issues	45
Provider concerns re: liability	41

Provider concerns re: health-related issues	39
Toileting concerns	35
Other parental attitudes	17
<b>Total Responses</b>	<b>765</b>

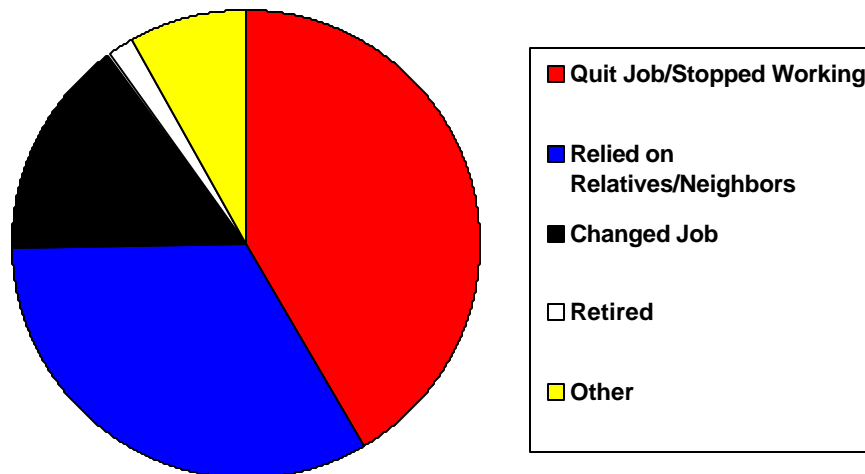
*Respondents could provide multiple responses*

While overall, 17% of families did not indicate difficulties in finding, obtaining, or keeping child care, approximately 5% of the families who responded to the survey indicated that they did not have these difficulties because they were referred to a specialized child care center such as PACT immediately upon receiving a diagnosis.

When asked what resources families used to find child care, 30% of respondents reported using LOCATE Child Care and/or the Child Care Resource and Referral Network; 26% reported using a friend, 15% reported having prior experience with a provider, 8% used a referral from their faith community, 6% used the newspaper, and less than 1% used a health care provider. Over 13% used other ways to find child care including family, neighbors, Infants and Toddlers programs, local health departments, guidance counselors, teachers, and local social services offices.

When asked what their alternative was when they were unable to find child care, of the 307 responses 42% stated that they had quit their jobs or stopped working, 33% stated that they had relied on family members or friends, 15% had changed jobs to accommodate their lack of child care, and 2% had retired. Another 8% reported other alternatives, including leaving their children with disabilities under the care of siblings, taking family leave, and taking their children to work.

**Alternatives when quality child care is not available**



Families were asked about their experiences relating to a lack of child care options and reported a wide range of consequences.

## Family Member Reports of Consequences of Lack of Child and After-school Care

CONSEQUENCE	#
Missed work on numerous days	121
Quit job/stopped working to stay home	113
Used leave time for child care issues	93
Worked alternate shift	93
Changed job and/or position	57
Decreased work hours	51
Declined promotion	49
Passed up for promotion/career advancement	16
Terminated from employment	7
<b>Total Responses</b>	<b>600</b>

*Respondents could provide multiple responses*

76% (239) of families who answered the question reported that they had lost income due to child care issues.

"I am totally disillusioned and depressed. [We] currently have in-home care 8 hours a week at \$44/hour in order to continue working. No other options are available... and it took 6 months to find this."

*Parent, Anne Arundel County*

When asked whether a child care provider had ever asked that their child leave the child care program 64% of those answering the question indicated that at some point they were asked to leave a child care setting. When asked for what reasons their child was requested to leave the program(s), parents gave the following reasons:

## Family Member Reports of Reasons Their Child Was Asked To Leave A Child Care Program

REASON	#
Child's Behavior	146
Provider felt unqualified to care for child	61
Toileting issues	56
Feeding issues	25
Liability concerns	17
Aged out of program	12
Accessibility concerns	12
Medical concerns	9
<b>Total Responses</b>	<b>338</b>

*Respondents could provide multiple responses*



Conversely, 74% of those who responded to the question had at some point chosen to remove their child from a child care setting/program. The most common reason given for removing a child from the child care setting was “provider attitudes”, however a wide variety of reasons—related and unrelated to their child’s disability or special health care need—were given.

### **Family Member Report of Reasons They Ever Removed Their Child From A Child Care Program**

<b>REASON</b>	<b>#</b>
Concerns regarding attitude of provider	104
Unhappy with care	73
Unsafe environment	62
Provider not adequately trained	56
Job change	48
Concerns regarding abusive situations*	46
Provider raised fees	25
Relocation	23
Found better care	22
Attitudes of other parents	19
Child aged-out of program	17
<b>Total Responses</b>	<b>495</b>

*Respondents could provide multiple responses*

When asked whether their child care providers had been willing to receive training to better care for their child with a disability or special health care need, 32% of those who answered said “yes” while 68% stated that their child care provider was not willing to receive additional training. When asked what efforts they as family members had made to assist their child care provider in caring for their child with a disability or special health care need, 51% of respondents said that they had worked directly with staff, 34% reported that they had provided training materials, books, or information from the internet, 9% reported that they had paid for classes, workshops, or seminars, and 6% said they had made other efforts, such as encouraging contact with medical staff, service providers.

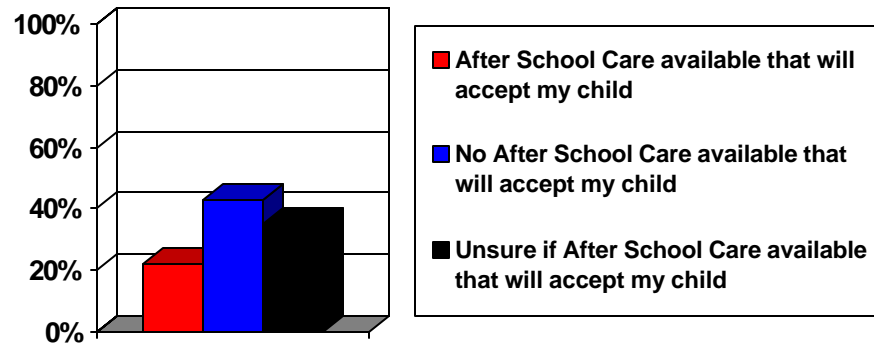
When asked whether they had sought assistance from a specialized child care training service or program, such as Project ACT or the Kennedy Krieger Institute, 36% of respondents reported that they had used such services and 64% stated that they had not. Comments from families indicated that a large number of families were unfamiliar with such services. Of those who did mention specific resources used, 55 families reported using the resources of the Kennedy Krieger Institute, 35 families reported using Project ACT, 25 families reported using a private professional, 19 families reported using PACT: Serving Children with Special Needs (also affiliated with the Kennedy Krieger Institute), and 23 reported using other resources such as Behavioral specialists or private therapists.

*\* Includes abuse from sources other than provider staff (i.e. other children)*

When asked whether they were using costly alternatives such as a nanny or au pair service due to a lack of options or quality care for their child with a disability or special health care need, 27% of respondents stated that they were.

When asked if they were aware of After-school Care programs that would accept their child, 22% of respondents stated that there were available programs, 43% stated that there were not, and 35% stated that they were unsure.

### Available After-school Program Options



When asked whether they had concerns about availability of child and after-school care as their child ages, 78% of responses indicated this is an area of concern for families.

“...My daughter’s medical needs require adult supervision at all times. We have NOT been able to locate a provider that cares for other teenagers so we have had to use a child care program that provides care to much younger children”

*Jackie, Cecil County*

Finally, comments from families also indicated that they had great difficulties finding summer care for their children with disabilities and special health care needs. Families indicated that there was a lack of available day camps and child care options throughout the summer months, and that for children and youth receiving Extended School Year (ESY) services, there was a lack of child care and camp options both at the beginning and end of the summer and on a daily basis after ESY services.

“Every year we struggle to find a day camp in our area that will accept my son and each year our frustration escalates. I went to a camp fair last year and there was only one day camp program that was a possibility. All the other camps there said they could not take my son.”

*Parent, Howard County*

## **REGIONAL CONCERNS**

During the spring and early summer of 2003, the Maryland Developmental Disabilities Council conducted four regional focus groups held in Baltimore City, Central Maryland, Western Maryland, and the upper Eastern Shore. These focus groups were not intended to be a scientific sample, but were held for the purpose of gaining qualitative information directly from families. Each group included parents of children with disabilities and/or special health care needs who were recruited to participate in the focus groups through local Infants and Toddlers programs, the Family Support Network, Partners for Success Centers, as well as Child Care Resource and Referral organizations and child care centers. The following information came from each group.

### **BALTIMORE CITY**

The participating parents and/or guardians from this focus group were primarily that of infants and toddlers (birth through five years of age). Five families participated in the focus group.

During the discussions it was apparent that all were familiar with the Child Care Resource and Referral Center, but not all had benefited from the resource. Three of the five participants expressed concerns about the inconsistencies of resources and being turned away from providers once the provider learned of their child's special needs.

Others shared that while they had been able to obtain child care, primarily through grant-funded projects, the care was short-lived due to the elimination of the program/service. All agreed that outreach was inconsistent and almost non-existent for low-income families and parents with lower educational levels.

Two of the participants expressed concerns about the low wages available to child care providers, especially those living and working in the city.

### **WESTERN MARYLAND**

This group included parents from as far west as Allegany County. The age of children represented ranged from toddlers to teenagers in this focus group. Six families participated in the focus group.

The top concern of parents from this group was simply not enough child care providers available, followed by the need for providers to be more knowledgeable about children with disabilities. Many of the parents shared that they were from low-income or one-income families and the cost of child care was too expensive for them to consider as an option.

During the discussions, several participants expressed fears of abuse and ridicule as a barrier to including children with disabilities or special health care needs. Rather than fear of abuse from

child care staff, parents in this group were more fearful of abuse from other children in the child or after-school setting.

The participants expressed disappointment over the lack of after-school programs or activities for children with disabilities and/or special health care needs in Western Maryland counties and school systems.

### **EASTERN SHORE**

Four families from the upper Eastern Shore participated in the focus group. Parents from this group were somewhat apprehensive about discussing barriers to child and after-school care. Several believed that providers were not knowledgeable in caring for their children, while others felt it was their responsibility as parents to care for their child and theirs alone. 4 families

It was clear from the discussions that parents felt there was too little outreach to families and the number of qualified providers on the Eastern Shore was minimal.

On the subject of after-school care, none of the six families present had a positive experience with after-school care.

### **CENTRAL MARYLAND**

This focus group included nine participants, both parents and grandparents. Two of the participants were fathers.

Participants expressed great satisfaction with the resource and referral services, all of which they had utilized. In addition to expressing appreciation for the resource and referral services, many had worked with specialized child care organizations (i.e. Kennedy Krieger, Project ACT) and had great success with these efforts.

Although the families agreed that specialized child care centers for children with disabilities were beneficial, all indicated that the need for specialized child care centers and services was a response to the general lack of knowledge of community child care providers, or in some cases, their unwillingness to care for children with disabilities and special health care needs. While some indicated their child care provider was willing to receive training, others expressed disappointment with the attitude of providers. More than one participant indicated that providers had more children to choose from than they could serve so why bother taking care of a child with special needs.

Still others were concerned with the number of children allowed in any one center, home, or after-school program. They had experienced incidents where their child did not receive adequate care because of the demands being placed on providers due to the number of children in the setting.

Most expressed frustration and disappointment with the lack of available after-school care programs for children with disabilities and special health care needs.

## RECOMMENDATIONS

Throughout the process of listening to families and professionals, a number of recommendations have been made to eliminate the barriers that families face when seeking quality child and after-school care. While most of these recommendations are directed to the Child Care Administration, many are directed to multiple agencies and organizations. While some of these may require additional funds, many can be implemented without fiscal impact.

### CONTINUE TO SUPPORT EXISTING SERVICES

- 1. The Child Care Administration should maintain and expand services like the LOCATE Child Care's Special Needs Service and Child Care Resource and Referral Services, as well as provide additional funding to further publicize and promote these services to families, particularly those living in outlying areas.**

Many families who were surveyed and interviewed spoke of how important these services were to them finding child and after-school care, however many families were also unaware of the services.

- 2. The Child Care Administration should maintain and expand training and technical assistance services, like Project ACT (All Children Together), that provide on-site technical assistance to child care providers caring for a child with a disability.**

Families report that the on-site technical assistance services of groups like Project ACT are vital to being able to keep their children in community child and after-school care settings.

- 3. The Child Care Administration should continue to work in partnership with the Maryland State Department of Education's Infants and Toddlers Program and Preschool Service Branch, as well as the Maryland Head Start Program to ensure that young children ages birth through five receive early intervention services in natural environments, including child care settings and Head Start programs.**

Part C of the Individuals with Disabilities Education Act requires that children under age 3 be served in natural environments – those environments the child would be in were they not a child with a disability. The Maryland State Interagency Coordinating Council has recognized the benefits of natural and inclusive environments for young children with disabilities. Research indicates that children with disabilities and special health care needs make significant gains when they receive intervention in their natural environments. Collaboration between these and other agencies and programs are essential to building the capacity of the child care community to offer quality, developmentally-appropriate care to such children.

- 4. The Department of Health and Mental Hygiene, Office of Genetics and Children with Special Health Care Needs, Maryland Medical Assistance Programs, Child Care Administration, and other agencies should maintain highly specialized child care programs for children who are medically-fragile, such as PACT: Serving Children with Special Needs, and support the development of inclusive models of care in which nursing and other health professionals are available to support children with significant health needs.**

Families who received child care through PACT spoke of their children's needs for intensive nursing and medical care beyond what is currently available in community child care settings. One parent stated that she drove from Anne Arundel County to drop off her child at PACT in West Baltimore County and then drove back to Anne Arundel County to work, a drive she repeated twice each day. Maryland must continue to support its two child care centers that serve medically-fragile children. However, barring replication in every jurisdiction, the Child Care Administration along with other agencies and groups should develop inclusive community-based child care centers with services for medically-fragile children. The Healthy Child Care Maryland project, which provides nurse consultants as a resource to child care providers, offers a template for this endeavor, if its role and impact could be increased.

## **TRAINING**

- 5. The Child Care Administration should require that all approved child care courses and workshops include information on how the subject areas apply to children with disabilities and special health care needs.**

All child care courses and workshops, whether they be on childhood development, literacy, managing behavior, or the business of child care, should address best practices for providing care for children with disabilities and special health care needs.

- 6. The Child Care Administration should consider “weighting” credentialing courses that address systemically underserved populations, such as children with disabilities and special health care needs.**

Weighting courses and workshops that relate to caring for children with disabilities and special health care needs would provide an incentive for child care providers to receive training in the area of special needs. For example, providers registered for a 3-hour course on strategies for working with children with developmental disabilities would receive credit for 4.5 hours.

- 7. The Child Care Administration, in partnership with other State agencies and organizations, should cooperate to develop and implement cross-training opportunities.**

The Child Care Administration, Head Start, local school systems, the Maryland State Department of Education, the Developmental Disabilities Administration, the Mental Hygiene Administration, and other agencies and organizations, should develop ways to provide training across professional populations (i.e. teachers, child care professionals, direct service staff, etc.). Such training would more efficiently and cost-effectively address the need for a highly qualified child-serving workforce throughout Maryland.

## QUALITY ASSURANCE

- 8. The Child Care Administration should develop a *Code of Ethics* and *Standards of Practice* for Maryland’s child care professionals that include a statement of nondiscrimination and language regarding the value of diversity and inclusive child care.**

Most licensed professionals are governed by standards of practice. The *Code of Ethics* and *Standards of Practice* should be reviewed during orientation courses for new child care providers who should be required to abide by them in order to be licensed. Both the *Code of Ethics* and *Standards of Practice* should be readily available to families.

- 9. The Child Care Administration should increase and standardize the knowledge of licensing staff regarding best practices and legal requirements for serving children with disabilities and special health care needs, and revise quality assurance/licensing reviews to include information about child care providers’ capacity to serve such children.**

Even if a child care provider does not currently have a child with a disability or special health care need in their care, it is important that discussions occur about their capacity to serve such children. A yearly discussion and review during the period of time a child care provider’s license is being renewed would highlight the importance of this issue to the Child Care Administration and encourage child care providers to increase their knowledge about children with disabilities and special health care needs.

- 10. The Child Care Administration should develop an “inclusion checklist” for providers so they can better evaluate their own capacity for serving children with disabilities and special health care needs.**

The development of a checklist would allow child care providers to assess their own capacity for serving children with disabilities and special health care needs. This self-assessment tool would highlight strengths of the child care program as well as areas in need of improvement, and would be of particular use for child care providers during initial licensing and licensing reviews.



- 11. The Child Care Administration should ensure that all child care providers receive training on the American's with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act - Nondiscrimination Under Federal Grants and Programs, and that families are aware of their legal rights.**

Many families report being incorrectly told by child care providers that the ADA does not apply to them because they are a “private business.” Family child care providers and child care centers are both covered under the ADA. Additionally, if child care providers are receiving any federal funds (i.e. TANF) they are prohibited from discriminating based on disability under Section 504 of the Rehabilitation Act.

- 12. The Child Care Administration should develop a mechanism within the Child Care Administration to take and investigate discrimination complaints, file Office of Civil Rights complaints on behalf of families, and sanction child care providers who discriminate against children with disabilities and special health care needs.**

Many families experience discrimination from child care providers who refuse to care for their child with a disability or special health care need, but they do not file Americans with Disabilities Act (ADA) complaints because of the daunting process and because ultimately they do not want to place their child with a child care provider who has been forced to follow the law. This has allowed some child care providers to discriminate openly against children and families. A family-friendly process for making discrimination complaints should be developed together with mechanisms for enforcement.

## **SUPPORT**

- 13. The Child Care Administration should support the development of local child care special needs networking groups aimed at providing local leadership and technical assistance to one another.**

Child care providers learn best from one another. The availability of a local networking group where a new provider can learn from those more experienced in serving children with disabilities and special health care needs would use the expertise available in the locality and promote mentoring relationships, leadership, and professionalism.

- 14. The Child Care Administration should develop a database of professionals available to provide immediate technical assistance to child care providers.**

Most child care providers will not participate in a workshop on diabetes, for example, until they have a child with the disease about to enter their care. Meanwhile, a workshop may not be readily available. An available pool of professionals on a variety of issues would ensure that child care providers receive some immediate telephone and on-site

training and technical assistance to care for a child until such time as they could register for training courses.

- 15. The Child Care Administration should establish a working group with the Developmental Disabilities Administration (DDA), Mental Hygiene Administration (MHA), Maryland State Department of Education (MSDE), and other agencies to identify and implement creative uses of existing programs and resources that could support children with disabilities and special health care needs participation in community-based child and after-school programs.**

Several families who responded to our survey stated that they were using DDA Family Support Service funding or Autism Medicaid Waiver funding to provide additional personnel support for their child so he or she could benefit from participating in a community-based child or after-school care program. This showed creative use of funding to meet these children's needs in the community. Further exploration of such funding support is necessary and may prove financially beneficial for the State.

- 16. The Child Care Administration and its partners should explore ways to increase private-public partnerships to make available grant funds to child care providers to support their efforts to include children with disabilities and special health care needs.**

While most accommodations for children with disabilities and special health care needs are relatively inexpensive, there are occasions in which child care providers need additional resources for environmental modifications, adaptive equipment, or other supports. Parents United for Child Care, a Boston-based organization, developed Lead to Opportunities for Youth with Disabilities (LOYD) to provide grants to after-school care programs working to include children and youth with disabilities, a potential model for Maryland.

## **RESEARCH**

- 17. Working in partnership with the Maryland State Department of Education and Maryland's universities, the Child Care Administration should develop and implement a comprehensive strategy, to regularly and in user-friendly formats, offer child care workers information about research-based practices that support the inclusion of children with disabilities and special health care needs.**

A great deal of research exists supporting the inclusion of children with disabilities in early intervention, education, and recreational settings, as well as specific strategies to support children in inclusive settings. Despite this, few child care providers are knowledgeable about these practices.

- 18. The Child Care Administration should partner with Maryland’s universities and colleges to develop a research agenda that supports inclusive child and after-school care for children with disabilities and special health care needs.**

Many of Maryland’s universities and colleges have a strong research interest in inclusive early intervention, education, and recreation. Formal partnerships may provide institutions of higher learning with demonstration sites for such research and advance the use of research-based practices in the field.

#### **AFTER-SCHOOL AND SUMMER CARE**

- 19. The Child Care Administration should work to increase the number of inclusive after-school care programs throughout the State, particularly for middle school-aged children and youth.**

Overwhelmingly, parents who responded to the survey and focus group questions expressed concerns about after-school care as their children aged. While Maryland’s After-School Opportunity Fund did begin to address the need for increased after-school care programs, these programs are often not licensed by the Child Care Administration. A number of programs funded through the After-school Opportunity Act funding were in fact “drop-in” after-school programs that are not suitable for children and youth with more significant disabilities who require trained staff and additional supports.

- 20. The Child Care Administration, in partnership with local school systems, the Maryland State Department of Education, the Developmental Disabilities Administration, the Mental Hygiene Administration, and other agencies and organizations, should work to develop age-appropriate models of after-school care for high-school aged youth with disabilities.**

Most families do not require after-school care when their children reach high school, but for many families of children with disabilities and special health care needs there continues to be a need for after-school care through to age 21. Because community-based after-school care does not exist for this age group, there is an immediate need to develop an age-appropriate alternative (perhaps tied with transition services) that supports appropriate skill development in integrated and community settings.

- 21. The Child Care Administration should clarify licensing regulations regarding children over age 12 to child care providers and families.**

Focus group discussions with families and the professionals who work with their children with disabilities and special health care needs revealed a sense of confusion about licensing requirements for older children. It was reported that many child care providers did not believe they could care for children over age 12. Child care providers should be

informed at orientation sessions and upon license reviews that they are eligible to care for children over age 12 and the process for doing so. Families should be able to readily find information about licensing requirements.

**22. The Child Care Administration, in partnership with the Department of Health and Mental Hygiene, Maryland State Department of Education, and other agencies and organizations, should identify model inclusive day and overnight camp programs and support replication activities based upon models.**

Although none of the survey questions asked about summer care, parents brought up this issue time and time again. Most families indicated that their children did receive Extended School Year (ESY) services as part of their Individualized Education Programs (IEPs), however were unable to find care on a daily basis after the education programs were complete, or during the weeks before and after ESY programs ran.

## SUMMARY

The Maryland Child Care Administration has long recognized the barriers that families of children with disabilities and special health care needs face in finding and maintaining quality inclusive child and after-school care and should be applauded for the extensive efforts that it has made to dismantle these barriers. Despite these efforts, though, families of children with disabilities and special health care needs continue to struggle to find quality care.

In this time of fiscal uncertainty we need to find the resources to help parents participate in the workforce, support their families, and contribute to Maryland's tax base. Law and policy makers, administrators, child care providers, and families must work together to impact the child and after-school care community to improve options for families and the quality of care for children. In doing so, we will move from a compliance-based approach to one of acceptance, having a positive ripple effect on all segments of our society.

Public support of child care has grown over the last few decades resulting in improvements in Maryland's child care system. The same level of support and results must be true for children with disabilities and special health care needs. The plight of families seeking quality inclusive child and after-school care must be brought to the forefront of existing efforts to improve the lives of children and individuals with disabilities.

***Children with disabilities and their family's circumstances will improve. Parents will be able to maintain their jobs and contribute to the economy. Typical children will benefit from inclusive child care and after-school care. Child care providers will receive the training necessary to care for children with disabilities and special health care needs, thereby expanding their knowledge, which in turn will benefit ALL children.***

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