

**Real Choice Systems Change Grants
for Community Living:
A Feasibility Study to Consider
Respite Services for
Children with Disabilities in Maryland**

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CENTER FOR HEALTH PROGRAM
DEVELOPMENT AND MANAGEMENT

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Executive Summary

Under a grant awarded by the Centers for Medicare & Medicaid Services (CMS) to the Maryland Department of Health and Mental Hygiene (DHMH) in September 2003, a feasibility study was undertaken to assess respite services for children with disabilities in Maryland. Under the leadership of the Mental Hygiene Administration (MHA), a group consisting of members of the Maryland Caregivers Support Coordinating Council (MCSCC) and staff from the Center for Health Program Development and Management at the University of Maryland, Baltimore County (UMBC) performed the following tasks: analyzed regulations, conducted surveys, and developed a demonstration model.

The project had three major components, as follows:

1. Compiling and analyzing an annotated list of the Code of Maryland Regulations (COMAR) that pertain to respite
2. Conducting two surveys: one of agencies that provide respite services to families of children with disabilities, and the other of the families themselves
3. Developing a demonstration model that would provide “a respite service operated in the manner of a Medicaid service” as prescribed in the CMS request for proposals

Analysis of Regulations

Respite services are mentioned in five separate titles in COMAR, though the vast majority of these are in Title 07—Department of Human Resources (DHR), the state social service agency; and Title 10—Department of Health and Mental Hygiene, the state public health agency. DHR’s regulations contain eight chapters and its programs primarily address families in crisis and children at risk of abuse or neglect. The DHMH regulations include ten chapters and most of the references to respite services are found in chapters that address Medicaid waiver programs.

The number of regulations pertaining to respite services is an indication of how dispersed they are in Maryland. Each program describes, in more or less detail, the eligibility for and limitations of respite services to distinct groups of people. Some regulations are very prescriptive, defining a specific number of hours, payment rates, provider qualifications, et cetera, while others are very open as to how families can use funds for respite services (e.g., families can hire a neighbor or family member for the best price). It has been expressed that some resourceful families are only able to receive the quantity of respite services that they need by applying to multiple sources.

Surveys

After the regulations were analyzed, two surveys were conducted: one of agencies that provide respite services to families of children with disabilities, and one of the families themselves.

A survey was sent to agencies around the state to gather their perspectives on and experiences with providing respite services. Throughout the state of Maryland, six jurisdictions have only



one agency providing respite services. For some disabilities, these jurisdictions have no respite services at all. Half of the responding agencies reported being at 100 percent capacity and having a waiting list. Agency concerns included: limited funding and consequent limits to the quantity of service that they could provide, which was described as “hardly meaningful and sufficient”; sustainability; and administrative issues, such as difficulty invoicing and receiving authorization.

Families shared similar issues and were further concerned about lack of parental involvement, limited scheduling flexibility, location of services, and lack of awareness of policies and procedures. About one third of the families that responded were *not* using respite services at the time of the survey. This was because some had already used up their benefit and others were never eligible for the benefit because their incomes/assets were deemed too high, although in reality they could not afford respite services.

Demonstration Model

The objective to develop a model as if it were a Medicaid service was a challenge because in the past, respite services were not federally allowable under the Medicaid State Plan, and therefore not an eligible Medicaid benefit. Additionally, even though respite may be included as a benefit in Medicaid home- and community-based services (HCBS) waivers, it is unusual for a state to have these waivers solely for a single service. HCBS waiver programs offer services to certain populations in the community as alternatives to institutionalization. Participants in the waiver programs must meet an institutional level of care. Under federal regulations, institutional care in the context of HCBS waivers is defined as care in a hospital, nursing facility, or intermediate care facility for the mentally retarded (ICF-MR). Individuals needing this level of care typically need services beyond the scope of respite services in order to remain safely in the community.

The model outlined in this paper assumes that a portion of state respite funds will be used as the state match for a Medicaid waiver which would provide respite services, up to 300 percent of the Federal Poverty Level (FPL), to families with children who have a disability. Further, a portion of the current state funds would be designated to provide respite services for families *above* 300 percent of the FPL.

The main features of the model are to:

- Pool funds from agencies currently providing respite services to families of children with disabilities (DHR and DHMH, including the Developmental Disabilities Administration and MHA) and from other child-serving agencies, where children’s involvement is the outcome of negative social situations that might be reversed by the provision of respite services
- Establish an interagency oversight entity to manage the process and insure equity among the populations that would now receive respite services through the new system
- Insure seamless use of the service for families regardless of which program portal they use to access respite services (i.e., the family should not have to fill out additional applications or make more contacts if they are deemed eligible at any point of entry)

- Prioritize the allocation of resources using instrumentation that assesses family need, including the severity of the child’s disability, family burden, and stress, in a manner that is accurate, equitable, and fair
- Address respite care as an alternative to institutional care

In addition to the model described above, the feasibility study acknowledges a new opportunity presented by the Deficit Reduction Act (DRA) of 2005, which allows states to amend their state plans to offer home- and community-based services, such as respite, as a state plan optional benefit. Although this option only covers individuals with incomes at or below 150 percent of the FPL, it does permit states to provide services to individuals who do not meet the institutional level of care provided in a hospital, nursing home, or ICF-MR. The requirements outlined under the DRA for the content of the state plan are complex and the service cannot be limited to children.

If the model outlined in this report were to be implemented, it would need to be further developed and the state would need to address funding and sustainability, data management, and system-level issues. While funding the model is partially enabled by the use of existing state dollars, new funds or the reallocation of existing resources will be required to support the initial activities of creating the interagency oversight entity and other administrative activities.

Sustainability opportunities lie largely in the hopes that the model will be incorporated into the lifespan model now being developed by the MCSCC. The children’s respite demonstration model would benefit from the visibility of the MCSCC lifespan respite model in both the political and social sense, and by not being seen as competition for resources focused on older adults, age 50 plus, and young individuals, age 18-64, with disabilities.

In order to evaluate and improve program performance and administration, it will be necessary to develop data management approaches that capture information that is salient, accurate, and validated by the various involved parties. Currently, it is difficult to understand who is receiving respite services, in what amount, and at what cost. It is clear that there is unmet need, but this need has not been quantified.

On the system level, it will be important to establish processes that fairly allocate resources among all disability groups. Agency staff will need to understand the needs of populations whom they do not usually serve. At the same time, it will be no small effort to move funds from established programs and budgets, requiring interventions such as regulatory changes or executive orders.

The goal of the model is to create a statewide program for respite services with a single point of entry for all eligible children with a disability. The proposed model faces significant administrative, fiscal, regulatory, and perhaps even statutory challenges. However, given the need for respite services, it is important to address these challenges.

Introduction

In July 2003, on behalf of the Maryland Caregivers Support Coordinating Council (MCSCC),¹ the Mental Hygiene Administration (MHA) applied to the Centers for Medicare & Medicaid Services (CMS) for a Real Choice Systems Change Grant to conduct a feasibility study on respite for children. A grant was awarded in the fall of 2003 to:

- Identify a relevant target group
- Describe the scope and type of respite available
- Develop a phase-in strategy
- Develop a cost model and preliminary cost projections
- Estimate the number of people likely to need and access respite support over time
- Describe any offsetting of public funds or private savings that may result as a by-product of the respite services
- Include an analysis of the impact of a state-specified limit on the maximum amount of respite per annum

The Center for Health Program Development and Management at the University of Maryland, Baltimore County (UMBC) was subcontracted to work with a steering committee of the MCSCC to conduct the feasibility study. The demonstration project model, developed as an outcome of this project, was created by a work group that consisted of MCSCC members and other interested parties.²

Background

As presented in the original proposal for this project,³ at the time of applying for grant funding, Maryland had just completed an 18-month process of studying the needs of caregivers and the availability of respite care and other family support services. The current care system for children and adolescents with developmental, mental health, and other disabilities, as well as the accompanying system of family supports and respite care, is fragmented among various agencies of state government. Among these agencies are various separate units of the public health system, including the Developmental Disabilities Administration, Family Health Administration, Mental Hygiene Administration, and an array of Medical Assistance-supported waivers and other special programs. In addition, state and local education systems, the child welfare system, and others—including the juvenile justice system—play significant roles in assuring the well-being

¹ The Maryland Caregivers Support Coordinating Council (MCSCC) is a body of governor-appointed consumers, advocates, and representatives of government agencies serving caregivers. Early work of the MCSCC indicated that respite services throughout the life cycle had the highest priority of all identified service needs. MCSCC activities and reports can be viewed on its website at <http://www.dhr.state.md.us/oas/mcsc.htm>.

² Non-council members of the work group included a representative of the DHMH Medicaid Administration and the Executive Director of The Maryland Coalition of Families for Children's Mental Health.

³ The *background* is taken largely from the original proposal prepared by Thomas Merrick, who, at the time of the application, was a member of the MCSCC and Chief of State and Federal Programs at the DHMH Mental Hygiene Administration.



of children, further fragmenting the system of support and care of children. Each of the three major public health administrations noted above offers its own distinct respite care service for families of children with disabilities. Some families also access respite through the Department of Human Resources (DHR), and some grandparents through the Department of Aging under the auspices of the National Family Caregiver Support Program.

Research on the regulatory framework that governs respite care in Maryland found that respite care is subject to 35 distinct chapters of regulations in the Code of Maryland Regulations (COMAR). These regulations were promulgated under the aegis of three major state departments, which include seven separate service-providing administrations. Included in these regulations are those governing two home- and community-based services (HCBS) waivers that offer services to families whose children have developmental disabilities and autism. Other HCBS waiver programs offer services to adults.

The overall challenge of the current respite care system is best described by the testimonial reports of family members given in a number of statewide public forums held by the MCSCC in 2001. Family members spoke of the system's confusing and overlapping set of eligibility requirements and their bewilderment about where to obtain coherent information about how to access services for their children. These problems notwithstanding, there are a number of strengths within the Maryland respite care system that bear mention. These strengths include:

- Creation of the MCSCC in 1999, by legislative mandate and executive appointment, to begin coordination processes for respite and support services in the state
- Creation of the Maryland Respite Care Coalition, a private, non-profit organization dedicated to expanding the availability, access, quality, and value of respite care
 - The Coalition has sponsored an annual Respite Care Awareness Day, an event that has stimulated great interest in respite care, including the sponsorship of the legislation that created the MCSCC
- Creation of the Custody Relinquishment Council to study and make recommendations for alternatives to the practice of custody relinquishment as a means for families to access otherwise inaccessible health services
 - This group has recommended increased respite care to the Governor as one strategy to prevent relinquishment
- Activities by respite-providing agencies to inform/train families in securing respite services:
 - The Office of Genetics and Children with Special Health Care Needs in Family Health offered a series of regional seminars on access to respite care programs
 - MHA conducts quarterly meetings that include core service agencies, providers, and families, to discuss respite resources and barriers, training needs, and advocacy strategies
 - The Developmental Disabilities Administration offered statewide training for families on finding, choosing, and training a respite care provider to work with them in the care of their child

A number of critical problems in the current delivery of respite and family support services have been identified and are outlined as follows:

1. There is a clear shortage of respite care resources for families in Maryland. Those that do exist are fragmented in a number of separate state and federal funding sources that have differing models, regulatory requirements, and eligibility criteria.
2. The burdens experienced by caregivers in the absence of respite constitute an enormous social problem not only for the entire state, but also for families in the areas of employment, finance, personal and marital stress, legal matters, and other social issues.
3. Families report that there is no clear centralized source of information about respite and other family support services. As a result, families are confused about where to seek help.
4. The mechanism for the funding of services lacks a single rate structure for providers. Currently, there are different rates for similar services in the different programs: some with requirements for means testing of the family, and others without any financial eligibility criteria. Different rate structures may make sense for different populations/levels of need. However, it does not always appear that the current rate structures are necessarily based on level of need or difficulty in handling the target population.
5. While respite care is available in some areas of the state, it is unevenly available for all populations. Families may be eligible for a program that does not exist in their community or, if it does exist, there may be waiting lists.
6. Respite providers within the various fragmented programs have a wide and uneven range of skills. Training requirements are unequal across programs, as is the quality of the care.

Findings

This study consists of several components that, together, comprise a comprehensive view of Maryland respite services for children with disabilities. As part of this study, a review of state regulations that govern the provision of respite services was conducted, and a thorough listing was compiled and analyzed. Separate surveys polled providers of respite services and families of children who have disabilities. Lastly, a work group, composed of MCSCC members knowledgeable of children's respite services in Maryland, used the aforementioned products to develop a model that could be used as a basis for a demonstration project. While children with serious emotional disturbance (SED) were the model's target group, care was taken to keep replicability and expansion to all children with disabilities. Complete reports of the regulation analysis, surveys, and documents supporting development of the model can be found in the appendices of this document.

The goal of the demonstration project, per the original CMS Request for Proposals, was to develop a model to offer respite services to a target group of children with disabilities "as if it were a Medicaid service...[building] in elements that are responsive to individual needs and offer the opportunity for consumer direction." Recent developments in Medicaid through the Deficit Reduction Act (DRA) of 2005 may offer additional opportunities for offering respite services, and will be briefly explored in the presentation of the model.

Regulatory Issues⁴

As previously mentioned, Maryland regulations that govern the provision of respite services are varied and widely distributed among several departments and agencies. While this approach facilitates focusing services on specific needy populations, the variability and, in some cases, redundancy, make it difficult for professional helpers and consumers alike to navigate the system and obtain needed services.

The majority of programs affecting children are described in regulations for the state's social service agency (the Department of Human Resources, or DHR) or the public health agency (the Department of Health and Mental Hygiene, or DHMH), under Medicaid and other programs.

DHR programs focus on services and supports for persons at risk of abuse or neglect (children and adults); family preservation/family unification services for families at risk of dissolution; and assistance and support services for people with non-developmental disabilities.

DHMH programs that offer respite services are primarily Medicaid HCBS waivers. This is because Medicaid, until the creation of the DRA in 2005, did not allow respite care outside of HCBS waivers. This may be partly because there is a continuing debate as to whether respite

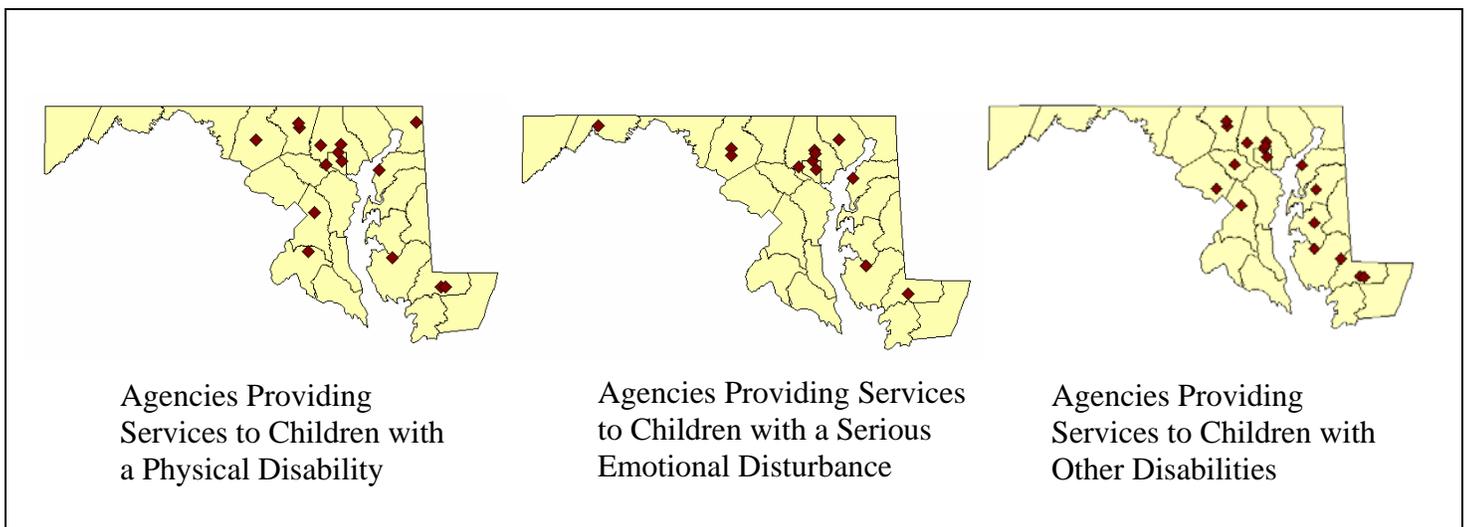
⁴ A complete regulatory analysis is located in Appendix 1.

services should benefit the eligible recipient or the caregiver, whereas federal Medicaid services are directed solely at the eligible recipient.⁵

Provider Survey

Of 163 Maryland respite service agencies surveyed, 29 agencies that provide services to children responded. Among these 29 agencies, 12 provide services to children with SED (6 of these provide care for this population only), 15 provide care for children with physical disabilities, and 17 provide care for children with any disability (see Map 1). Six Maryland jurisdictions are served by only one or two of the responding agencies. The remaining jurisdictions have between three and six providers. As shown in the maps below, while all jurisdictions are served by at least one agency, agencies are not always conveniently located for the consumer. There are jurisdictions in the further parts of Western Maryland, Southern Maryland, and the lower Eastern Shore that do not have an agency within their borders. Also, almost half of the responding agencies reported that they were at 100 percent capacity and have waiting lists.

Map 1: Distribution of Providers of Respite Services to Children by Disability Type



Agencies were asked to share their concerns about the Maryland respite care system that would make them unwilling or unable to continue to provide services to children with disabilities. In general, concerns centered around funding (especially end-of-year shortfalls), the lack of understanding some decision makers have about the importance of respite, and the lack of placement options (foster parents and overnight). Specifically, agencies made the following comments:

⁵ The definition of respite services is debated nationally in terms of the target person, resting on how to describe eligibility and how to establish outcomes. The likely solution is to accept that the benefits of respite services flow far beyond the individual whose status makes the respite care needed, and that the individual, as well as those who *use* the respite service, are better off.

- Lack of funding would affect delivery of respite services.
- It is difficult to help funding sources understand the preventative nature of regular respite. This is a cost-effective program that prevents more costly services and keeps families together by empowering parents to keep their children with disabilities at home.
- There is occasional shortage of money at the end of the fiscal year.
- Sustainability remains an issue.
- Invoicing and obtaining authorizations is very difficult.
- The main obstacle is recruitment and training of foster parents. There is no money to use for recruitment of families, which makes starting a program difficult.
- We are concerned as providers that families get very little respite—currently 5 hours of respite per month is authorized for most clients, which is hardly meaningful and sufficient.
- Although most agencies indicated that they had waiting lists for respite, one indicated that they didn't have sufficient number of clients.
- There is a lack of appropriate day placements for extended stays funding.

Family Survey

Surveys were distributed to families of children with any disability through the providers identified in the provider survey process, as well as through the networks of membership and advocacy organizations. One hundred sixteen families responded on behalf of 133 children.

About a third of the families who responded said that they are not currently using respite services because they either did not qualify for assistance, had reached the maximum allowed benefit, or could not afford it. Other reasons included:

- Income considered too high to qualify for assistance, but in reality cannot afford
- Not aware of services
- Not hearing from agency after applying
- Overwhelming process/red tape
- Skepticism of strangers caring for child
- Unable to find caregivers/few options

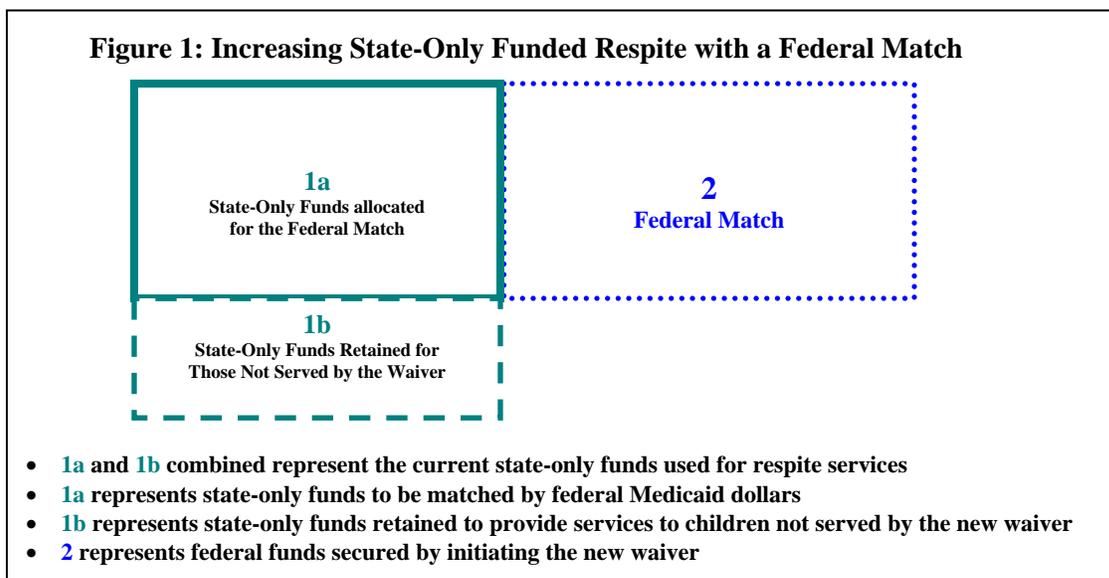
Although the target group for the feasibility study was children with SED, SED and non-SED were both factors in the analysis to allow a comparative picture of the experience of families whose children have SED. The analysis showed that SED families were less likely to use companion-only respite care than weekend or overnight, out-of-home, and emergency/crisis respite care. SED families reported being on Medicaid two and a half times more than non-SED families and were half as likely to report not having enough hours of services.

There were interesting similarities and differences in reports of satisfaction between SED and non-SED families. Both types of families reported less than 80 percent satisfaction with awareness of policies and procedures surrounding respite services, response time for service

requests, and the number of hours of service. However, the non-SED families fell below an 80 percent threshold in three additional areas: parent involvement, satisfaction with the location of services, and scheduling flexibility. Collectively, families reported that respite services could be improved through better information, access, and quality of respite workers, as well as a less complex and more responsive system. Cost is also a concern for families, including those who are more affluent.

Demonstration Model and Project Development

A work group of volunteers from the MCSCC and two key external stakeholders met over a four-month period to distill the findings of the previous study components and develop a model of how respite services might be delivered as if it were a “Medicaid service.” As mentioned in the *Regulatory Issues* section above, respite has not been considered an eligible benefit under regular Medicaid because it is not federally allowable under the Medicaid State Plan. However, respite is allowed as a benefit in HCBS waivers.⁶ As part of HCBS waivers, respite is seen as an element to assist the caregivers of the older adults and people with disabilities served by the waivers. Under federal home- and community-based service rules, residential treatment centers (RTC) are not considered institutions and therefore states have been unable to receive approval for home- and community-based services waivers for children with serious emotional disturbances (SED). The basic fiscal principle of the demonstration project model is to maximize current state funds by securing matching funds through the Federal Medical Assistance Percentage (FMAP) process. Figure 1 shows how state funds can be enhanced through this process.



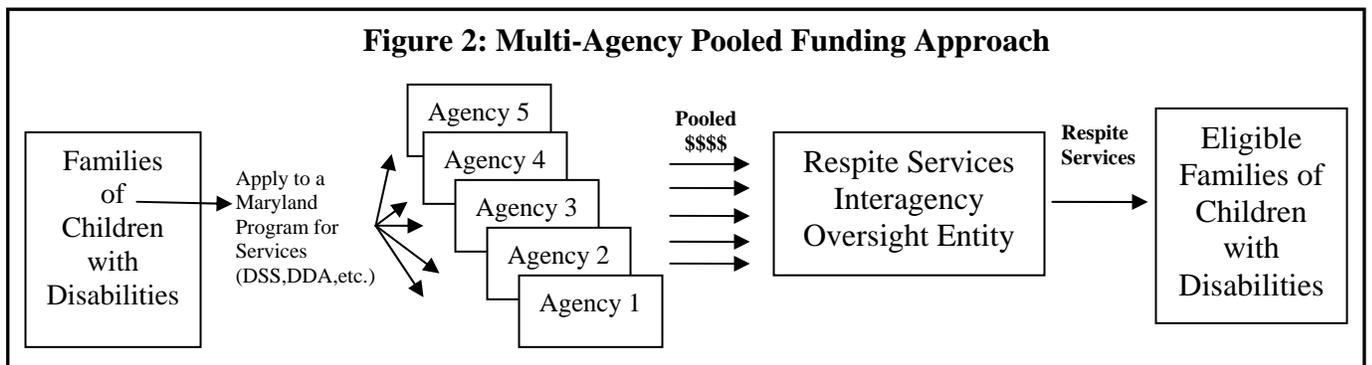
Concern for families who need assistance but are not eligible for Medicaid led the work group to design a unique model. In this model, a portion of state respite funds would be considered for the

⁶ Maryland has five waivers: Older Adults, Living at Home, Autism, Developmental Disability, and Traumatic Brain Injury (TBI). The TBI waiver does not include respite care services.

FMAP, while a smaller portion would be held back to use on a sliding-scale basis for “grey” area families who have incomes that exceed the financial eligibility for the proposed program but still find it financially onerous to afford respite care.

Based on the model, one million dollars of state-only funding, using assumptions for costs of respite services that were extrapolated from current approaches, could serve 212 children. Using 75 percent of these state-only dollars and securing a federal match would increase funding from \$750,000 to \$1,500,000 for Medicaid waiver eligible children (up to 300 percent of the FPL) and serve 319 children. An additional 53 children, who would not be eligible for the waiver respite services (families above the 300 percent FPL threshold), could be served using the retained, non-matched federal dollars (\$250,000). Altogether, based on the current assumptions, an additional 160 children⁷ would be served.

Funds for the model are anticipated to be pooled and to come from various agencies that currently fund respite services for children and families, and from entities that will possibly experience lowered utilization, such as the Department of Juvenile Services, the public mental health system, or the social service system. Figure 2 shows this funding approach.



In addition to fiscal considerations, several guiding principles were incorporated into the model, including:

1. **Consumer Direction/Flexibility:** Current state programs fluctuate from having very restrictive use of funds (in terms of number of hours, provider qualifications and payment, location of services, etc.), to having few restrictions beyond the availability of resources. The goal for the demonstration is to create a system that incorporates the opportunity for families to take advantage of a more structured system (i.e., a system that is available on a voluntary basis for those who prefer greater supports but allows families to opt out of these provisions to the extent that regulations allow).

⁷ Or more, depending on the allocation of resources.

2. **Streamlined Eligibility/No-Wrong-Door Approach:** As a centralized process for securing respite services that would serve families entering through multiple program/portals, it is desirable for securing respite services to be seamless for families. However a family enters the system of care, if they are found to be in need of respite services, they are directly connected to the respite services authority as though it were a service integral in the program/process in which the family was already involved. Ideally, no additional applications, phone calls, or eligibility processes should be apparent to the family, but rather managed among and within agencies and their staff.

The model includes accommodation for varying levels of providers in regard to skills and credentials. Because there is a higher cost of care in level 3 than in level 2, the number of children are adjusted accordingly (i.e., dollars were allocated to levels proportionately, not evenly).

3. **Eligibility and Prioritization of Services:** Currently, families are deemed eligible for state-supported respite services due to a qualifying event such as child disability, family dissolution or threatened dissolution, and other issues that threaten the well-being of the child (abuse and neglect, chronic and severe illness, etc.). Limited resources necessarily mean that all of those in need of services will either not get any services or may not get all of the services desired. Current systems include de facto rationing in the way various providers allocate dollars. For example, in some cases, dollars are allocated on a first-come first-serve basis, with a portion held back for needy latecomers; others decrease the benefit amount below what is statutorily allowed in order to serve more people; and another allows families to buy as much service as they can for a set amount.

Built into the proposed model is the use of an assessment instrument that will provide an additional guidance to eligibility determinations and the allocation of resources. Additionally, the instrument will determine factors such as the severity of the child's condition and family stress and burden (financial/social/emotional).

The model is designed to fairly and equitably allocate resources without giving preference to a particular category (as current fragmented funding streams do), which does not allow the broad subjectivity of many current approaches.

Recommendations for Implementation

The model provides a basic framework for transforming service gaps and fragmented approaches that serve portions of special groups into a more coherent delivery system for respite services. There is a need for change in how service delivery systems are currently structured by regulation or practice (“silo-ed,” or single agencies serving special groups), up to and including regulatory change. A focal entity needs to be identified or created to facilitate the further development and implementation of this model. A critical action that would support the synergistic cooperation of various efforts to increase and improve respite services would be the adoption of a universal definition of respite within the state.

Broadly, outstanding issues and recommendations fall into the following categories: funding and sustainability; data management, including developing tools and measures that can be used across agencies; and system development.

Funding and Sustainability

Opportunities for funding are identified in the model itself since respite services are currently paid for with state dollars. Start-up money could be pooled from the existing programs; however, it would be difficult to gain acceptance from the various entities because they would have to reconfigure their programs and budgets to participate in this interagency process. Sustainability will be aided by the fact that the model could be incorporated into the lifespan respite model being developed by the MCSCC and other MCSCC efforts to promote respite as a social and health policy issue. As a component of a lifespan model, children would not have to compete with other aging and disability groups.

It is worth mentioning that while the demonstration project model was in the final stages of development, two additional Medicaid opportunities arose through the DRA of 2005. Though regulations are still being formulated at the federal level, states appear to have the following options for covering respite services under the DRA:

1. Apply for one of the ten RTC demonstration waiver projects. This waiver would allow Maryland to provide home- and community-based services to children under age 21 with SED. The theory is that these children would otherwise be removed from their families and placed in a psychiatric residential treatment facility in order to receive needed services. The waiver package could include respite services. Children participating in this demonstration must require RTC level of care.
2. Apply for a state plan amendment to offer respite services as a home- and community-based service for disabled individuals up to 150 percent of the FPL. This option does not require that the individual meet an institutional level of care, although it does require the state to establish needs-based criteria for determining whether the individual is eligible for the HCBS option established by this provision. It also requires an assessment of the individual’s support needs and capabilities. Because states are able to target based on geography and establish the number of individuals served under the home- and community-based state plan option, they would be able to control the development and

growth of the program. However, the new DRA provision does not allow states to target based on the age of the individual in need of the service.

Data Management

The fragmentation of the current respite service delivery system, as evidenced by regulations across multiple agencies and programs, is accompanied by as much variability in data. It is difficult to ascertain how much money is actually spent, how much service is actually delivered, and how many people are actually served. Common data systems with agreed upon elements would facilitate implementation and evaluation opportunities, including monitoring outcomes and improving service delivery. A focal entity, with the appropriate technical assistance, should be responsible for receiving and managing this data. In addition, providers must be required to participate in the data collection process.

Important data elements include numbers served, length of service, unduplicated counts, unmet need, level and type of service, cost, and measures of family functioning and satisfaction. Currently, it is difficult—if not impossible—to gauge the depth of unmet need. Waiting lists, which are needed to monitor the ongoing demand for respite, are maintained inconsistently or not at all. Also, with the ultimate goal of reducing out-of-home placement, measures must be created to capture this outcome as it relates to the delivery of respite services.

System Development

For the development of a new respite service delivery system, which will entail modification of existing systems and processes, it would be helpful for Maryland to adopt a universal definition of respite. The issue of whether respite is a service for the child or for the family should be set aside. The fact is that respite services benefit both the child and the family because an intact family is in the child's long-term interest.

A complete review of the information learned through the family and provider surveys should be incorporated into the new program since families and providers are in the best position to know what is needed to improve service delivery. In fact, there needs to be caregiver/family input into the entire process, from planning to implementation to evaluation of any respite initiative that may be approved.

Another need identified through the feasibility study is the identification of an assessment and evaluation tool that measures child and family functioning stress. The ability to accurately and equitably establish the need for respite services and to prioritize the allocation of limited resources is essential. This is especially true considering the expectation that people previously served by programs that only considered the need of a focal population will have to consider need *across* programs and population groups. Though it may sound contrary to the use of an objective tool for identification and prioritization of need, families must be involved in the decision of when or whether to terminate services, as well as the amount of respite services that they might want to use.

Future Steps

This report provides the groundwork necessary to support the expansion of quality respite services. Future plans for expanding respite services need to include a commitment to this effort across agencies and departments. Without this commitment to funding and sustainability, data management, and system development, it will be unlikely that there will be an expansion of respite services. The state also needs to decide whether to apply for Medicaid coverage of respite services and if so, under which waiver or state plan option. The ultimate goal is to provide a rational delivery system for respite services for disabled children throughout Maryland. While it is recognized that modifications would need to be made, this model represents the input of multiple diverse stakeholders and provides the basis for a researched and integrated approach to respite delivery for children and their families.

**Appendix 1: Summary Table and Analysis of Respite Regulations
Contained in the Code of Maryland Regulations**

Analysis of Respite Regulations Contained in The Code of Maryland Regulations (COMAR)

October 2005

Prepared for the Maryland Caregivers Support Coordinating Council under a Real
Choices Systems Change Grant: Respite for Children



CENTER FOR HEALTH PROGRAM
DEVELOPMENT AND MANAGEMENT

Introduction

Five Code of Maryland Regulations (COMAR) titles mention respite either as a program or a benefit within a program. Some of these mentions are simply definitions, or list respite among other available benefits/services. Some describe the process of providing respite (requirements for individuals and/or agencies to qualify, apply, report, or make claims for payment), or mechanisms for the client to receive services (eligibility—categorical, financial, etc.).

The five COMAR titles with respite mentions are:

- Title 07—Department of Human Resources
- Title 10—Department of Health and Mental Hygiene
- Title 14—Independent Agencies
- Title 31—Maryland Insurance Administration
- Title 32—Maryland Department of Aging

This report will summarize the chapters and regulations wherein respite is mentioned in each of these titles.

TITLE 07—DEPARTMENT OF HUMAN RESOURCES

Subtitle 01—Office of the Secretary

The Citizen’s Review Board for Children⁸ advocates for children in foster care briefly mentions respite in COMAR as a service to assist family reunification. In August 2005, the CRBC proposed “formalized and reliable respite care” as one of our “essential supports” needed for children/families in foster care. Additionally, they mention that funding is capped and that every year funds run out before the end of the year, curtailing needed services and putting children at risk.

Subtitle 02—Social Services Administration

The following five chapters cover various child and family programs to address situations where children are not safe due to abuse neglect. Each provides respite as a service to assist caregivers of these children (family, relatives or foster parents).

Chapter 01—In-Home Family Service—respite care related to family unity/re-unification.

Allows the use of flex funds to pay for respite care.

Chapter 07—Child Protective Services—Investigation of Child Abuse and Neglect

Chapter 09—Kinship Care Program

Chapter 11—Out-of-Home Placement Program

Chapter 21—Treatment Foster Care

⁸ The Citizen's Review Board for Children (CRBC) was established by the Maryland State legislature as the Foster Care Review Board in 1978 to spur efforts to provide permanence in the lives of foster children.

Subtitle 06—Community Services Administration

Chapter 11 describes Respite Care Services program of the Department of Human Resources. Respite services under this program are subsidized per a sliding-fee scale, for children or adults with functional or developmental disabilities, who live in Maryland, and whose family incomes do not exceed 150 percent of the State’s median income, adjusted for family size. Respite services can be delivered in the home or a respite care facility. In this program, up to 24-hours of hourly care (of duration less than 10 hours in a 24-hour period), or up to 14 days of daily care (periods of at least 10 hours) are allowed each state fiscal year. The regulation describes Level I (supervisory and personal care) or II care (skilled care by a health practitioner). Deems a care provider as “qualified” based on the assessment of the fiscal provider or the family caregiver.

TITLE 10—DEPARTMENT OF HEALTH AND MENTAL HYGIENE

Title 10 of COMAR are regulations of various programs within the Department of Health and Mental Hygiene, including Subtitles 07-Hospitals, 09-Medical Care Programs, 11-Maternal and Child Health, 21-Mental Hygiene Administration, and 22-Developmental Disabilities Administration.

Subtitle 07—Hospitals

Home Health Agencies (Chapter 10) authorizes provision of respite services to disabled or elderly persons as an in-the-home service provided by home health aides for the purpose of enabling continued residency in their own home.

Hospice Care Programs (Chapter 21) authorizes hospice care programs to use inpatient care services for providing respite, directs the hospice program to arrange respite services for caregivers as part of the interdisciplinary plan of care, and mentions the patient’s right to be informed of this option.

Subtitle 09—Medical Care Programs

Medical Care Programs encompass the array of programs and services managed by the state public health agency, including its Medicaid program (which includes end-stage kidney and dental services, and a variety of waivers), Maryland Children’s Health Program (MCHP), and pharmacy assistance and discount programs.

Subtitle 09 includes eight chapters that mention respite services. Four of these chapters are Medicaid Waivers for special populations (the developmentally disabled, adults with traumatic brain injury, older adults, and children with autism spectrum disorder). The other chapters are concerned with nursing services for children in the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program, hospice care, HealthChoice (Maryland’s Medicaid managed care program), and specialty mental health system services under HealthChoice.

Community-Based Services for Developmentally Disabled Individuals Pursuant to a 1915(c) Waiver (Chapter 26) provides guidance for the coverage, limitations and payment of respite services to waiver participants. Under these regulations, respite services can be provided only to waiver participants who receive residential habilitation or option services in their home. Respite services can be provided in a state residential center (up to 45 days in any 12-month period) or a community residence (up to 14 consecutive days to a total of 28 days in any 12-month period) licensed to provide residential habilitation services. Services are “time-limited and temporary relief for primary informal caregivers...”.

Hospice Care (Chapter 35) authorizes provision of services and describes payment procedures for inpatient respite care—short term care to provide rest or relief for caregivers providing care in the home. The inpatient respite care rate is applicable for up to 5 consecutive days, and then at the routine home care rate. Providers may not bill for more than 20 percent of the aggregate number of hospice days provided to all participants during the cap period (November 1st through October 31st of the next year).

Home and Community-Based Services Waiver for Adults with Traumatic Brain Injury (Chapter 46) does not mention respite as a covered service, but does specify that respite is not covered for participants residing in out-of-home facilities.

Home/Community-Based Services Waiver for Older Adults (Chapter 54) provides guidance regarding requirements for participation as a provider of respite services, services covered and limitations, and payment procedures. Covered services include planned, crisis or as needed respite, provided in the participants home, a Medicaid-enrolled nursing facility, or an assisted living facility. Room and board is covered if respite is overnight and out-of-the-home. Respite services are limited to 12 units (hours) of service per day and 14 days during a 12-month period. Rates are \$9/hour for self-employed respite workers, \$11.50/hour when respite workers are from an agency/facility, \$120/day in a nursing facility, or \$64/day in an assisted living facility. Residents of assisted living facilities are not eligible. Respite services can not be billed for on the same day as personal care services or assisted living services, and cannot be paid to a spouse.

Home and Community-Based Services Waiver for Children with Autism Spectrum Disorder (Chapter 56) Respite services are to be intensive one-on-one interventions delivered in the client’s home to individuals who can not care for themselves on a “short-term basis” in the “absence of or need for relief of participant’s family that normally provides care.” Individuals receiving residential habilitation services may not be eligible for respite services. Providers of respite services under this waiver must have qualifications specific to the care of children with Autism, be supervised by an appropriately certified or licensed professional, and not be a member of the waiver participant’s family. Further provider requirements include a check of references and criminal background, and high school completion or equivalency. Reimbursement can not be for more than 24 hours per date of service or 168 hours for a 12-month period. The maximum rate is \$19.51 per hour.

Early and Periodic Screening, Diagnosis, and Treatment: Private Duty Nursing (Chapter 53) merely specifies that respite is not a covered service.

Maryland Medicaid Managed Care Program: Definitions (Chapter 62) Defines respite services available to Medicaid recipients who are eligible for services under the Specialty Mental Health System (see below).

Maryland Medicaid Managed Care Program: Specialty Mental Health System (Chapter 70) allows respite care as a component of mental health services, not reimbursable by Medicaid “as State resources permit...”

Subtitle 21—Mental Hygiene Administration

Mental Hygiene Regulations for Community Mental Health Programs—Respite Care Services (COMAR 10.21.27) and the associated fee schedule (COMAR 10.21.25). The target group for respite services under these chapters are children with severe emotional disturbance and adults with serious and persistent mental illness. The service is provided in a community-based setting (in-home, out-of-home in an appropriately licensed home or facility) on a short-term basis, either partial day or overnight. Residents of therapeutic group homes or other health facilities (as in Health-General Article, Title 19, Annotated Code of Maryland). are not eligible. The goal is to support the continued ability of the individual to continue living in the community by “freeing the caregiver temporarily from care responsibilities”. Services includes an assessment, a plan of care, including medication administration, participation in school/work/medical therapies/et. al. activities. Services can be on call or on site up to 24 hours/day and 7 days/week.

Fee Schedule—Mental Health Services—Community-Based Programs and Individual Practitioners (Chapter 25) provides the reimbursement rates for programs that provide respite services to eligible children and adults. Child fees are \$150/day for support in a facility and up to \$12/hour or \$120/day for in-home respite care. An enhanced reimbursement is offered if the child is deaf or hard-of-hearing (\$188/day in a facility, or \$15/hour or \$150/day in the home.

Community Mental Health Programs—Respite Care Services (Chapter 27) describes in detail who is eligible to be a respite provider and how an individual is referred, assessed, and approved for respite services. Programs are eligible to participate if they are approved as mobile treatment services, outpatient mental health clinics, or psychiatric rehabilitation programs. While the regulations do not specify the qualifications of providers, it does direct the need for a written plan that incorporates all aspects of the individual’s care needs and states that providers must demonstrate training and experience adequate to address those needs. A list of minimum knowledge requirements for providers is presented.

Subtitle 11—Maternal and Child Health—Children’s Medical Services for Children with Special Health Care Needs (CSHCN)

Includes respite services as a component of comprehensive care services to CSHCNs as a family support. Funded by a Title V Maternal and Child Health Services Block Grant. (CHSCN are birth to age 22 years with a “disabilities and handicapping conditions, chronic illnesses, and

conditions, health-related educational problems, health-related behavioral problems, and those at risk for these conditions.”). Families at or below 200% FPL, who are not served by other public programs, are eligible.

Subtitle 22—Developmental Disabilities Administration (DDA)

DDA regulations include respite care as a component in several of its programs—1) the Individual Plan, 2) the Family and Individual Support Services Program Plan, 3)the Community Residential Services Program Service Plan, 4) the Behavior Support Services Program Services Plan, and 5) Respite Services in the State Residential Center. The regulations describe the requirements for eligibility and extent of respite services available.

For Community Residential Services, respite care is available up to 45 days in any year period, for up to 28 consecutive days. The Waiting List Equity Fund will cover 28 days in any 1-year period for up to 14 consecutive days.

TITLE 14—INDEPENDENT AGENCIES

Residential Child Care Programs (Chapter 5) contain 4 regulations that pertain to respite services offered by two types of residential child care programs, licensed and monitored by the OCYF . They are: 1) community-based behavioral respite for up to 30 days to children with SED, and, 2) psychiatric respite care on a residential basis on hospital grounds, for children who have been discharged from an inpatient psychiatric stay, as a transitional service prior to placement in a community-residential program. These regulations are related to MHA regulations in COMAR 10.21.25 and 10.21.27.

TITLE 31—MARYLAND INSURANCE ADMINISTRATION

Subtitle 10—Health Insurance—General and Subtitle 14—Long-Term Care

Describes respite care as a required component of all long term care insurance policies in Maryland, Medicare Part A—Hospital Services, and Medicare hospice programs

TITLE 32—MARYLAND DEPARTMENT OF AGING

Subtitle 02—Provider Regulations

Describes respite as a service in the Continuing Care at Home Program and stipulates that if respite is not provided, an explanation must be given in the Agreement.

Respite Regulation Summary from the Code of Maryland Regulations

This document delineates the various titles, chapters and regulations of the Code of Maryland Regulations (COMAR) that reference the term “respite”. In some cases, respite is merely mentioned as a component of care, and others, it is the primary objective of the regulation and describes in detail how respite care services should be delivered, including the eligible population, payment structures and licensing of providers.

Regulation descriptions/summaries are either paraphrased or the exact wording of the COMAR text. When the chapter or regulation specifically focused on respite care services in an extended or complex fashion, the entire chapter or regulation was copied into the appendix (Department of Human Resources Respite Services Program and Department of Disability Respite Services).

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
07 Department of Human Resources	01 Office of the Secretary	06 Citizen’s Review Board for Children	.02	.01 CRBC’s purpose is to review cases of children in out-of-home placement, monitor child welfare programs, and make recommendations for system improvement. Respite care is available as a time-limited family reunification service that is made available, after an out-of home placement, to parents and legal guardians to facilitate the reunification process.	(B29) Defines respite as a service to facilitate “Time-Limited Family Reunification Services”, as a type of temporary childcare to families in crisis, during the first 15 months of out-of-home-placement.
	02 Social Services Administration (SSA)	01 In-Home Family Services	.03	In-Home Family Services function is to promote the safety and well-being of children and their families, preserve family unity, and prevent out-of-home placement through providing, referring, and coordinating services.	Defines respite care as one of a list of services accessed in order to achieve family unity within a safe environment, through coordinating, providing, or referring by the agency.
			.10	.01 Children who are at risk of maltreatment due to prevailing conditions, practices, or behaviors within their families are eligible.	Describes the use of “flex funds” to pay for services in this chapter, including respite care, within the following constraints: <ul style="list-style-type: none"> • Family eligibility for the particular program • Benefit to the child’s health and welfare • Preventing out-of-home placement • Reunification of a child that has been placed in out-of-home placement • Maximum expenditure not more than 80% of average foster care placement for each at-risk child in the family

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
07 cont.	02 cont.	07 Child Protective Services— Investigation of Child Abuse and Neglect	.02	Child Protective Services function is to stop abuse and neglect through investigation of and initiation of protective and other services. .01 & .03 Service may be initiated, regardless of economic circumstances, for a child, including a disabled infant with a life-threatening condition, of a family who is under investigation for suspected abuse or neglect in order to promote safety, reduce risks, and remedy the effects of abuse or neglect.	(26b) Includes respite care as a type of out-of-home care that is provided to a child in a setting other than the home of the child’s parent or guardian, as covered in this chapter.
		09 Kinship Care Program	.07	Kinship care is designed to preserve families by accommodating the needs of children, and their parents or caregivers, with the goals of permanency and prevention of the need for out-of-home placement. .01 – Children who have been committed to a local department or placed with kinship parents or caregivers because of abuse, neglect, dependency, or abandonment are eligible for service so that children are healthy and safe, and family stability and unity is maintained.	(D17) Describes the use of “flex funds” to pay for services in the Kinship Care Program, including respite care.
		11 Out-of-Home Placement Program	.03	.01 & .04 Children who are abused, abandoned, neglected, or at risk of serious harm, until the end of the month when they turn 18, or until 21 so long as the child is in school, a vocational or job training, or has special needs.	(48)(b)(v) Defines respite as a service to facilitate “Time-Limited Family Reunification Services”, as a type of temporary child care to families in crisis. <ul style="list-style-type: none"> • “Time-limited family reunification services” including respite care must be made available to the parents or legal guardian to facilitate the reunification of the child during the first 15 months of out-of-home placement

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
07 cont.	06	11 Respite Care Services	.01	Individuals that reside in Maryland are eligible for respite if they are: a family with an individual with a developmental or functional disability; an individual with a developmental or functional disability, who does not reside with a family; or an individual with a developmental or functional disability living in a foster home	Purpose – short-term care for adults or children with development or functional disabilities; provides a period of rest and renewal for the family; prevents out-of-home placement and assists the individual to achieve greater independence; planned intervals, crisis, or on an as needed basis.
			.02		Definitions – See Appendix
			.03	See Appendix	Eligibility— See Appendix
			.04		Application Process— See Appendix
			.06		Delivery of Respite Care Service— See Appendix
			.07		Limitations— See Appendix
			.08		Re-determination and Reconsideration— See Appendix
			.09		Termination— See Appendix
			.12		Approval of a Respite Care Home— See Appendix
			10 Department of Health and Mental Hygiene (DHMH)		07 Hospitals
21 Hospice Care Programs	.02	Terminally ill persons eligible for Medical Assistance.		(B8) Defines respite as a “purpose” for inpatient hospice care services.	
	.10			(D3) Describes the responsibility of the hospice care program to reflect in the Interdisciplinary Plan of Care to its efforts to arrange respite services for caregivers.	
	.21			(B9) Describes patients’ rights in hospice to information about short-term inpatient options for services including respite.	

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
10 DHMH <i>cont.</i>	09 Medical Care Programs	26 Community Based Services for Developmentally Disabled Individuals Pursuant to a 1915(c) Waiver	.01	The 1915 (c) Waiver overrides the statutory requirements limiting coverage for home and community based services under the State’s Medical Assistance Plan. Individuals with severe, chronic disabilities who require support services, as defined in Health-General Article, §7-403(c), or individuals with developmental disabilities, as defined in Health-General Article, §7-101(e), and are 1915(c) waiver participants, are eligible for respite care.	(B30) Defines respite care as a service for waiver participants to provide time-limited and temporary relief for primary informal caregivers from ongoing responsibilities, and as “back-up” service for a crisis or emergency involving the primary caregiver.
			.03		(D) Describes conditions for residential habilitation or residential options services providers to provide respite services as needed in a State residential center or community residence licensed under COMAR 10.22.03.02A(9)(b) and (c) to provide respite care.

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
10 DHMH cont.	09 Medical Care Programs cont.	26 Community Based Services for Developmentally Disabled Individuals Pursuant to a 1915(c) Waiver cont.	.08	- continued	Describes covered respite services: <ul style="list-style-type: none"> • For waiver participants who receive residential habilitation or residential option services in their home or in an individual family care home • Limited to 45 days per any 12-month period in a State residential center • Limited to 14 consecutive days at a time and to a total of 28 days per any 12-month period • Room & board is included in the reimbursement of providers of residential habilitation or residential option services
			.10		Limits payment on the same date to one service among respite, personal assistance, or residential habilitation
			.13		(3e) Describes payment procedures allowing room & board as a respite cost, and (5) holds payment for respite care as described in .01(B30), until amendment covering the service is approved by the Health Care Financing Administration.
		35 Hospice Care	.01	Hospice care services are routinely provided in a place of residence occupied by a participant by hospice employees. Services include: nursing care; physician services; medical social services; and counseling.	(B3) Defines the “cap period” as the 12 months from November 1st to October 31 st the following year for the annual limitation on reimbursement at the general inpatient and inpatient respite rates. (B22) Defines respite as short-term care given to a participant in order to provide rest or relief to family or others routinely furnishing at-home care to the participant.
			.06	(B25) Terminally ill individuals, who are recipients of hospice care and have a medical prognosis of a life expectancy of 6 months or less	Describes covered services: inpatient respite in a hospice (42 CFR Section 418.100) or hospital, skilled nursing facility, or nursing facility (42 CFR Section 418.100(a) and (e)).
			.07	if the illness runs its normal course, are eligible for respite.	Describes limitations of Program payment to include respite et al. for recipients of Medicare Part A.

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
10 DHMH <i>cont.</i>	09 Medical Care Programs <i>cont.</i>	35 Hospice Care <i>cont.</i>	.08	- <i>continued</i>	<p>(B3) Describes payment for inpatient respite: maximum of 5 days at a time at the inpatient respite rate, and on day 6 forward, at the routine or continuous home care rate, as appropriate. Inpatient respite care may not be provided when the participant is a resident of a nursing facility.</p> <p>(C2) Inpatient respite may not be provided when the participant is a resident of a nursing facility; aggregate number of inpatient care (general and respite) cannot exceed 20% of all hospice care furnished by the provider in the cap period.</p> <p>(C3, e, i) Describes reimbursement to the Program if provider is overpaid for inpatient respite care.</p>

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
10 DHMH <i>cont.</i>	09 Medical Care Programs <i>cont.</i>	46 Home and Community-Based Services Waiver for Adults with Traumatic Brain Injury	.11	<p>The Home and Community-Based Services Waiver for Adults with Traumatic Brain Injury provides residential habilitation services, day habilitation services, and supported employment services, at various levels, for individuals who meet technical requirements under COMAR 10.09.46.03 B. These requirements include:</p> <ul style="list-style-type: none"> • Individual must be between 22 and 65 at the admission to the Waiver • Is diagnosed with traumatic brain injury by a qualified physician, as defined in COMAR 10.09.46.01 B(21) • At least 22 when traumatic brain injury occurred • Is receiving State care and is not enrolled in another waiver program under § 1915 © of the Title XIX of the Social Security Act • Is clinically appropriate • Does not cost more than alternative placements 	(D4) Stipulates limitation that respite care is NOT covered for a participant resident in an out-of-home facility.
		53 Early and Periodic Screening, Diagnosis, and Treatment: Private Duty Nursing	.05	10.09.53.01 – EPSDT means the provision of healthcare under 42 CFR 441.50 et seq., so that growth, development, and/or health problems can be assessed, detected, and/or treated. Private duty nursing provides skilled nursing services, delivered by an R.N. or L.P.N. in the recipient’s home or other location as determined by normal life activities, to Medical Assistant recipients under 21 years old who require more individual and continuous care than is available under the home health program.	(A23) Stipulates limitation that respite services are NOT covered in this chapter, by the Program.

Title/ Department	Subtitle	Chapter	Regulation	Program Description/ Eligibility	Regulation Summary
10 DHMH <i>cont.</i>	09 Medical Care Programs <i>cont.</i>	54 <i>cont.</i>	.32	<i>- continued</i>	Limit to: <ul style="list-style-type: none"> • 12 units of service per date of service for respite care • 14 dates of service per 12-month period for respite care • Prohibits reimbursement for combinations of respite care, personal care, or assisted living services under this chapter and state plan personal care under COMAR 10.09.20, on the same day of service
			.33		Payment: a qualified provider shall bill the Program for each hour of covered services not to exceed: <ul style="list-style-type: none"> • \$9 per hour for respite care by a self-employed worker • \$11.50 per hour for a respite care worker employed by an agency or facility, except in a nursing or assisted living facility • \$120 per day for respite care in a nursing facility • \$64 per day for respite care in an assisted living facility

Title/ Department	Subtitle	Chapter	Regulation	Program Description/ Eligibility	Regulation Summary
10 DHMH <i>cont.</i>	09 Medical Care Programs <i>cont.</i>	56 Home and Community-Based Services Waiver for Children with Autism Spectrum Disorder (ASD) <i>cont.</i>	.07	<p>The Autism Waiver pertains to certain specified statutory requirements limiting coverage for home and community based services under the Medical Assistance Program.</p> <p>10.09.56.02 Eligibility is determined by a multidisciplinary team that considers:</p> <ul style="list-style-type: none"> • Child’s age is between 1 and end of the school year in which individual turns 21 • Is developmentally disabled and has ASD • Is receiving early intervention services • Has an IFSP or IEP • Receives more than 12 hours per week of special education, but requires more intensive therapeutic program or is participating in a Home and Hospital Program • Is identified through public education or early intervention services • Can be maintained in community with the Autism Waiver services • Chooses, and documents, Autism Waiver over ICF-MR • Is not enrolled in Medicaid waiver programs under § 1915 (c) of Title XIX of Social Security Act 	<p>Specifies qualifications of providers of respite care for children with ASD:</p> <ul style="list-style-type: none"> • Possess adequate liability insurance and bonding • Professional training (psychologist, special educator, professional counselor, nurse, social worker, or occupational therapist, qualified developmental disabilities professional per COMAR10.09.26.01B(26), Board Certified Behavior Analyst or individual with a masters degree or doctorate in special education or a related field and at least 5 years training/consultation in ASD); and, at least one year of experience working with children with ASD. • Technical training and supervised by a professional as above, pass reference and criminal background check, at least high school diploma or equivalency

Title/ Department	Subtitle	Chapter	Regulation	Program Description/ Eligibility	Regulation Summary
10 DHMH <i>cont.</i>	09 Medical Care Programs <i>cont.</i>	56 Home and Community-Based Services Waiver for Children with Autism Spectrum Disorder (ASD) <i>cont.</i>	.16	<i>- continued</i>	<p>Describes covered services:</p> <ul style="list-style-type: none"> • Intensive one-on-one interventions • Rendered by a qualified licensed/certified professional or technician supervised by a qualified professional • Include services provided to participants who are unable to care for themselves • Provided short-term due to absence or need for relief of the participant’s family who normally provide care • Provided in the participant’s home or residence • May be provided in a youth camp certified by DHMH under COMAR 10.16.06 • May not be provided by a family member, available to residents receiving residential habilitation services, and not provide worker’s or participant’s room & board
			.21		<p>Limitation regarding respite:</p> <ul style="list-style-type: none"> • (B.) May not receive reimbursement for residential habilitation services on the same date of service as respite care • (F.5., 6.) Reimbursement for respite care for no more than 24 hours of respite care for a date of service, or 168 hour of respite care for a 12-month period
			.22		(C.2.e.) Payment for respite services reimbursed at the maximum rate of \$19.51 per hour.

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
10 DHMH <i>cont.</i>	09 Medical Care Programs <i>cont.</i>	62 Maryland Medicaid Managed Care Program: Definitions	.01	Certified Medical Assistance benefits recipients, as in COMAR 10.09.24, who are either categorically needy, for example public assistance recipients, or medically needy, for example aged, blind, or disabled individuals who also meet certain income and asset criteria, are eligible so long as they also meet COMAR 10.09.70 criteria stating that Medicaid waiver-eligible individuals with mental disorders (in accordance with the referral procedures under .06B of this chapter).	(173) Defines respite care, according to COMAR 10.09.70, as a short-term service in a community-based setting to assist a home caregiver with maintaining the recipient in the home by temporarily freeing the caregiver from the responsibility of supervision.
		70 Maryland Medicaid Managed Care Program; Specialty Mental Health System	.10	Mental Hygiene Administration’s (MHA) requirements for specialty mental health services (SMHS) for waiver-eligible enrollees of managed care organizations (MCOs) or participants in the Rare and Expensive Case Management (REM) program are outlined. COMAR 10.09.70 eligibility requirements stated above apply.	(C.2.d) Includes respite care as a non-Medicaid-reimbursable service that can be offered to “waiver eligible” individuals, when state resources permit. ⁹
	11 Maternal and Child Health	03 Children’s Medical Services Program	.03	Program provides specialized medical, surgical, and related rehabilitative evaluation and treatment services for children with special health care needs. (B.19) Individuals, birth to 22 years old, with disabilities and handicapping conditions, chronic illnesses and conditions, health-related educational problems, health-related behavioral problems, and those at risk for these conditions are eligible.	(21)(j) Defines respite care as a component of family support service, one of a list of health services in providing “comprehensive care”.

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
10 DHMH <i>cont.</i>	21 Mental Hygiene Regulations	25 Fee Schedule – Mental Hygiene Services – Community- Based Programs and Individual Practitioners	.02	Program establishes reimbursable provider fees for mental health services received by a Medicaid or State-supported services recipient. Adults with a serious and persistent mental illness, who are over 18 and are Medicaid or State-supported services recipients, or children with a serious emotional disturbance, who are under 18 and Medicaid State-supported services recipients, are eligible.	(8) (B)(x) Includes respite care as a component of the “Mental Health Program” under COMAR 10.21.27. (17-1) Defines components of respite care. (a) For adults with serious and persistent mental illness or a child with serious emotional disturbance. (b) Provided on a short-term basis in a community setting. (c) Help individuals remain in their home by providing enhanced support or a temporary alternative living situation, or freeing the caregiver temporarily from care responsibilities.

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
10 DHMH cont.	21 cont. Mental Hygiene Regulations	25 cont.	.08	- continued	Reimbursement for respite care for adults with a serious and persistent mental disorder/child with serious emotional disturbance, who are severely impaired as follows: <ul style="list-style-type: none"> • Child – general support in a facility \$149.50 per day or in home (when need for short-term, one-on-one support is documented and approved by the CSA) \$12 per hour up to a maximum of \$120 per day • Adult-general support in a residential rehabilitation program is \$65 per day
		27 Community Mental Health Programs – Respite Services	.02	10.21.27.01 Program outlines the staffing and service requirements for respite care service providers. Individuals are eligible for respite according to 10.21.07.05 (see appendix).	Defines components of respite care <ul style="list-style-type: none"> (a) For adults with serious and persistent mental illness or a child with serious emotional disturbance (b) Provided on a short-term basis in a community setting (c) Help individuals remain in their home by providing enhanced support or a temporary alternative living situation, or freeing the caregiver temporarily from care responsibilities
			.03		Approval The Department shall grant approval to a program to be eligible to receive state or Federal funds for providing respite care services if the program: <ul style="list-style-type: none"> A. Is approved as: <ul style="list-style-type: none"> (1) A mobile treatment services (MTS) provider under COMAR 10.21.19; (2) An outpatient mental health clinic (MHC) under COMAR 10.21.20; or (3) A psychiatric rehabilitation program (PRP) under COMAR 10.21.21; and

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
10 DHMH cont.	21 cont. Mental Hygiene Regulations	27 cont. Community Mental Health Programs – Respite Services	.03 cont.	- continued	<p>B. Meets the requirements of this chapter, including approval to provide either or both of the following specific respite care services:</p> <ul style="list-style-type: none"> (1) In-home respite, in an individual’s place of residence. (2) Out-of home respite, in a home or facility that is appropriately licensed, registered, or approved, based on: <ul style="list-style-type: none"> a) The age of the individuals receiving services.
			.04		<p>Program Model</p> <p>A. The program director shall assure that respite care services are:</p> <ul style="list-style-type: none"> (1) Designed to fit the needs of the individuals served and their caregivers; and (2) As needed in an immediate situation, to resolve or ameliorate a problem in the living situation. <p>B. As approved under this chapter, a program may provide respite care services as needed for an individual:</p> <ul style="list-style-type: none"> (1) With advance planning; or as needed in an immediate situation, to resolve or ameliorate a problem in the living situation.
			.05		<p>Referral, Eligibility, Screening, and Acceptance for Respite Services – See Appendix</p>
			.06		<p>Respite Service Provided – See Appendix</p>
			.07		<p>Conclusion of Respite Episode – See Appendix</p>
.08	<p>Respite Staff – See Appendix</p>				

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
10 DHMH cont.	22 Developmental Disabilities	01 Definitions	.01	Under COMAR 10.22.01.01 (15) developmentally disability is a severe chronic disability that is attributable to a physical or mental impairment or combination of these, other than the sole diagnosis of mental illness, that is: <ul style="list-style-type: none"> • Like to continue indefinitely • Manifests before age 22 • Results in an ability to live independently without external support or regular assistance Reflects the need for a combination and sequel of special, interdisciplinary, or generic care, treatment, or other services that are individually planned and coordinated	(8) Defines “behavioral respite” to mean relief service provided by a community residential licensee to meet an individual’s behavioral needs. (12)(b)(is) Defines respite as a component of “Community Supported Living Arrangements.” (49) Defines respite as relief services provided to the family or care provider to meet planned or emergency situations.
		05 The Individual Plan	.03		Excludes individuals receiving respite services in the community requirement of an Individual Plan, developed not more than 30 days after receiving services.
		06 Family and Individual Support Services (FISS) Program Service Plan			Includes respite as a service to support families.

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
10 DHMH <i>cont.</i>	22 Developmental Disabilities <i>cont.</i>	08 Community Residential Services Program Service Plan	.03 <i>cont.</i>	- <i>continued</i>	<p>E. Respite Services</p> <p>(1) A site may be licensed to accommodate additional individuals for respite services.</p> <p>(2) Respite services for an individual:</p> <p>(a) May not exceed 45 days within any one year period.</p> <p>(b) May not be provided for more than 28 consecutive days.</p> <p>(c) May not be provided unless the licensee is provided with current health, emergency, and any other information that is essential to the licensee's ability to provide appropriate care for the individual; and</p> <p>(d) May be provided for IFC Care providers only to the extent permitted by the IFC care provider contract.</p> <p>F. A licensee providing respite services shall:</p> <p>(1) Ensure that the health and safety needs of the individuals are met; and</p> <p>(2) Comply with COMAR to 10.22.04 and 10.22.05 if the individual has an IP, and 10.22.10 if the individual has a behavior plan.</p>

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
10 DHMH <i>cont.</i>	22 Developmental Disabilities <i>cont.</i>	10 Behavior Support Services Program Service Plan	.03 <i>cont.</i> See appendix for wording of entire chapter.	.02 The program is designed to assist individuals who exhibit challenging behaviors in acquiring skills, gaining social acceptance, and becoming full community participants.	(C.4.) Includes behavioral respite services as a behavior support service.
		11 Respite Services in the State Residential Center		10.22.11.04 – Eligibility: B. Have an appropriate evaluation with the diagnosis of mental retardation. C. Have needs that are able to be met effectively while at the SRC. D. Not be in receipt of full residential services in a community program, except with the approval of the Director.	See appendix for wording of entire chapter.

Title/ Department	Subtitle	Chapter	Regulation	Program Description/ Eligibility	Regulation Summary
10 DHMH <i>cont.</i>	22 Developmental Disabilities <i>cont.</i>	12 Eligibility for and Access to Community Services for Individuals with Developmental Disability	.03 <i>cont.</i>	.02 Excludes those individuals who have been committed to DHMH through the Maryland court system.	<p>Defines respite as a service available under:</p> <ul style="list-style-type: none"> • Community Supported Living Arrangements (6-1.i.) (a set of services to assist an individual with developmental disability or an individual eligible for support services only in those non-vocational activities necessary to enable that individual to live in the individual's own home, apartment, family home, or rental unit, with no more than two other recipients of these services), and • “Family support services” (12.f) a program designed to enable a family to provide for the needs of a child with a developmental disability living in the home)

Title/ Department	Subtitle	Chapter	Regulation	Program Description/ Eligibility	Regulation Summary
10 DHMH <i>cont.</i>	22 Developmental Disabilities <i>cont.</i>	15 Waiting List Equity Fund (WLEF)	.02	Addresses the regulations for the management and use of money in the WLEF. 10.22.15.06 – Eligibility: The Individual shall: A. (3) Leave State residential center on or after October 1, 1995 to be served in community-based services as specified in Regulation .05A of this chapter (4) Be in the community on the waiting list for community-based services in one of the following categories: o Crisis resolution o Crisis prevention o Current request	(8.b.vi.) Defines respite as a component of Family Support Services, a program designed to enable a family to provide for the needs of a child with developmental disability living at home. (See above).
			.03		(14) Defines respite as short-term care not to exceed 14 consecutive days or 28 days in a 12-month period, for the relief for the person with whom the developmentally disabled person usually lives.
			.07		C. (2)(c) In establishing the funds available to an individual for the WLEF ¹ , subtracts the cost for respite care in accordance with Health-General Article, §7-509, Annotated Code of Maryland, which is based on the identification of the actual, specific costs directly attributable to serving individuals in the SRC with respite care services.
					State that the Administration shall ensure that WLEF is used to provide respite care among other services, to eligible individuals.

Title/ Department	Subtitle	Chapter	Regulation	Program Description/Eligibility	Regulation Summary
14 Independent Agencies	31 Office for Children	05 Licensing and Monitoring of Residential Child Care Programs	.02 & .03	<p>The program oversees the process of licensure and monitoring of residential child care programs for children and youth, and establishes the procedures which applicants must follow in order to obtain licensure.</p> <p>14.31.05.03 (2a) and (35a) Children with developmental disabilities, who require specialized living arrangements, support services and activities are eligible.</p>	<p>.02 Defines psychiatric respite in terms of a service component of Residential Child Care Programs under the oversight of Departments of Human Resources, Health and Mental Hygiene, and Juvenile Services.</p> <p>.03 (B8) Community-based behavioral respite occurs in a licensed community-residential setting for children with serious emotional disturbance for no more than 30 days.</p> <p>.03 (B33) Psychiatric respite is a transitional service, a residential program on hospital grounds, for children discharged from an inpatient psychiatric hospital, in anticipation of community placement.</p>
		06 Standards for Residential Child Care Programs	.17		.17 Describes the requirements for written policies for admission, individual service plans, behavior plans, and discharge from residential child care programs, including those that provide psychiatric respite care . (E) If behavioral support services are offered, then behavioral respite services are included.
		07 Specialized Licensing Standards	.02 & .14	Specialized Licensing Standards establish licensing and monitoring standards that supplement or alter the core licensing standards of COMAR 14.31.05 and 14.31.06 for particular types of residential child care programs.	.14 For community mental health programs that provide respite care services, imposes requirements of COMAR 14.31.05, 14.31.06, and 10.21.27 (Mental Hygiene regulations for Community Mental Health Programs – Respite Care Services).

Title/ Department	Subtitle	Chapter	Regulation	Program Description/ Eligibility	Regulation Summary
14 Independent Agencies <i>cont.</i>	31 Office for Children <i>cont.</i>	07 Specialized Licensing Standards <i>cont.</i>	.02 & .14 <i>cont.</i>	.02 Describes licensing standards for residential child care programs, including community mental health programs providing respite care.	
31 Maryland Insurance Administratio n	10 Health Insurance— General	05 Minimum Standards for Medicare Supplement Policies	.19	Provides standardization of coverage and simplification of terms of Medicare, to ease public understanding, and provide full disclosures to persons eligible for Medicare by reason of age.	In the outline of Medicare supplemental coverage, mentions Respite Care Benefits under Part B miscellaneous.
		06 Standards for Medicare Supplement Policies	.13	Applies to all Medicare supplement policies and certificates under group Medicare supplement policies held by Maryland residents.	Under Medicare (Part A)—Hospital Services—Per Benefit Period, lists inpatient respite as a benefit Medicare pays under hospice care.
		09 Hospice Care Benefits	.02	Applies to hospice care benefits of health insurance contracts written on an expense-incurred basis, non-profit health service plan contracts, and individual or group contracts issued by an HMO.	(B.10.) Defines respite care as temporary care provided to the terminally ill insured to relieve the family caregiver from the daily care of the insured.
	14 Long-Term Care	01 Long-Term Care Insurance	.02	Applies to all long-term care insurance policies in Maryland, non-profit health service plans, HMOs, and PPOs, without superseding other laws and regulations.	(17.b.iii.) Defines respite care services as a component of home health care services.

Title/ Department	Subtitle	Chapter	Regulation	Program Description/ Eligibility	Regulation Summary
32 Maryland Department of Aging	02 Provider Regulations	02 Certificate of Registration for Continuing Care at Home Providers	.22	“Continuing care at home agreement” is outlined and defined as meaning furnished provider services to individuals who are 60 years and older and not related to the provider by blood or marriage, for the life of the subscriber or a period of over a year.	Stipulates that continuing care at home agreements shall specifically state the case when respite care is not provided.

**Title 07 (DHR) Subtitle
06 (Community Services Administration)
Chapter 11 Respite Care Services**

Appendix

07.06.11.02 Definitions.

A. In this chapter, the following terms have the meaning indicated.

B. Terms Defined.

- (1) "Administration" means the Community Services Administration of the Department of Human Resources.
- (2) "Applicant" means an individual with a developmental or functional disability, a family member, a caregiver, or an authorized representative of the individual with the disability, who is applying for respite services.
- (3) "Caregiver" means the individual who customarily cares for the individual with a developmental or functional disability. The caregiver may live in a residence other than that of the individual with the disability.
- (4) "Consumer" means an individual with a developmental or functional disability, a family member, an informal caregiver, or an authorized representative for the individual with a disability, who receives respite care services.
- (5) "Developmental disability" means a severe, chronic disability which:
 - (a) Is attributable to a mental or physical impairment or a combination of physical and mental impairments, including a head injury;
 - (b) Is manifested before an individual is 22 years old;
 - (c) Is likely to continue indefinitely;
 - (d) Results in a substantial functional limitation in three or more of the following areas of major life activity:
 - (i) Self-care;
 - (ii) Receptive and expressive language;
 - (iii) Learning;
 - (iv) Mobility;
 - (v) Self-direction;
 - (vi) Capacity of independent living; and
 - (vii) Economic self-sufficiency; and
 - (e) Reflects an individual's need for a combination and sequence of special interdisciplinary or generic care, treatment, or other services which are lifelong or of extended duration and are individually planned and coordinated.

- (6) "Family" means one or more adults, with or without children, related by blood, marriage, adoption, or legal guardianship, residing in the same household with an individual with a developmental or functional disability.
- (7) "Functional disability" means a severe, chronic disability which:
 - (a) Is attributable to a mental or physical impairment or combination of mental and physical impairments;
 - (b) Is likely to continue indefinitely;
 - (c) Results in substantial functional limitations in three or more of the following areas of major life activity:
 - (i) Self-care;
 - (ii) Receptive and expressive language;
 - (iii) Learning;
 - (iv) Mobility;
 - (v) Self-direction;
 - (vi) Capacity for independent living; and
 - (vii) Economic self-sufficiency; and
 - (d) Reflects an individual's need for a combination and sequence of special interdisciplinary or generic care, treatment, or other services which are lifelong or of extended duration and are individually planned and coordinated.
- (8) "Health practitioner" means any person who is authorized to practice healing under the Health Occupations Article.
- (9) "Level I care" means supervisory and personal care, and may include any or all of the following:
 - (a) Household and personal assistance services, which include light housekeeping services, chore services, assistance with meals and special diets, food preparation, dressing, shopping, escort service, writing letters, and reading to consumers;
 - (b) Personal care services, which include assisting with bed baths and care of mouth, skin, and hair, assisting in bathroom use or in using a bedpan, helping in and out of bed, assisting with ambulation, transferring from bed to wheelchair, assisting with equipment such as walkers and crutches, helping with prescribed exercises and tasks which have been taught by professional health personnel, and assisting the individual with the developmental or functional disability to follow a medically prescribed regimen.
- (10) "Level II care" means skilled care delivered by a health practitioner.
- (11) "Local department" means the department of social services in a county or Baltimore City or the Montgomery County Department of Health and Human Services.
- (12) "Provider" means a public or private nonprofit agency or local department, which provides respite care services under a contractual agreement with, or direct grant from, the Administration or a local department.

- (13) "Qualified care worker" means a person who, by training, experience, or authorization is qualified to deliver the care needed and who has been designated as such by a respite services provider or the family caregiver.
- (14) "Respite care" means short-term care of individuals with developmental or functional disabilities in order to temporarily relieve the family or caregiver.
- (15) "Respite care facility" means a designated program, location, private home or center, outside of the consumer's residence, where respite care is given.
- (16) "Service plan" means a written document which records pertinent information the provider considers essential for providing respite care services, including:
 - (a) Eligibility;
 - (b) Amount and level of respite care services;
 - (c) Any fee required;
 - (d) Records referring the applicant to other sources for services identified as needed, but not available from the provider; and
 - (e) Assessment of the family's respite care needs.
- (17) "Subsidy" means functions available from the Administration to assist in the payment of respite care service fees if total income of applicants eligible for respite services is less than 150 percent of the State's median income adjusted to family size.
- (18) "Total income" means the sum of income received by applicants eligible for respite care services minus medical expenses.

07.06.11.03 Eligibility.

A. Eligibility for Respite Care Services. Except as provided in §B of this regulation, the following individuals are eligible for respite care services:

- (1) A family residing in Maryland with an individual with a developmental or functional disability;
- (2) An individual in Maryland with a developmental or functional disability, who does not reside with a family; and
- (3) An individual in Maryland with a developmental or functional disability living in a foster home.

B. Exception. Except for an individual with a developmental or functional disability living in a foster home, an individual with a developmental or functional disability living in a supervised or protected situation under the administration of a public or private agency is not eligible.

C. Eligibility for Subsidy.

- (1) A family or an individual with a developmental or functional disability receiving a subsidy is required to pay a fee as set out in a fee schedule published by the Administration.

- (2) A family or an individual with a developmental or functional disability eligible for respite care services may be eligible for a subsidy if the family's or the individual with the disability's total income is less than or equal to 150 percent of the State's median income adjusted to family size.
- (3) If the family's or the individual with the developmental or functional disability's annual income equals or exceeds 150 percent of the State's median income, the family or individual with a disability pays the full fee for care.

07.06.11.04 Application Process.

A. An applicant seeking respite care services shall apply to the provider of the services. If the local department does not provide the services, it shall refer the applicant to a provider. The provider shall inform the applicant about the eligibility requirements, rights, and obligations under the program. The applicant shall complete the application on a form approved by the Administration. The completed application shall include:

- (1) The date of application;
- (2) The name of the individual with the developmental or functional disability;
- (3) The address of the applicant, and phone number, if any, of the nearest phone for emergencies;
- (4) The name and address of the caregiver;
- (5) The school or day program in current use by the individual with the developmental or functional disability;
- (6) The living arrangement of the applicant, including information about the household composition;
- (7) The amount and source of total income;
- (8) Medical or psychological information provided by a health practitioner which enables the provider to determine that the applicant is an individual with a developmental or functional disability and the type and level of care needed;
- (9) The name, address, telephone number, and relationship of the applicant to the individual with the developmental or functional disability; and
- (10) Authorization for the release of medical and psychological information.

B. Notice to Applicant.

- (1) Within 30 days after receipt of the application the provider shall notify the applicant in writing that the application is incomplete, has been accepted, or has been denied.
- (2) If the application is incomplete, the notice shall state:
 - (a) The parts of the application which have not been completed; and
 - (b) That if the application is not completed within 30 days, the provider is required to deny the application.

- (3) If the application is accepted, the notice shall state:
 - (a) The amount of services to be delivered;
 - (b) The type and level of service to be delivered;
 - (c) The schedule for use of the service;
 - (d) The amount of any fee to be paid;
 - (e) That eligibility and financial status are redetermined if a change occurs that might affect the eligibility or financial status, and at least every 12 months;
 - (f) That the service statement is reviewed and amended if a change occurs, and at least every 12 months; and
 - (g) The right to, and method for, obtaining a fair hearing.
- (4) If the applicant is denied, the notice shall state the:
 - (a) Reason for denial;
 - (b) Specific regulation supporting the decision; and
 - (c) The right to, and method for, obtaining a fair hearing.
- C. The provider shall deny the application if:
 - (1) The medical or psychological information does not indicate that the applicant is an individual with a developmental or functional disability, or a family member or caregiver of a person with a developmental or functional disability; refunds are not included. The total income includes items deducted from salaries and wages such as withholding taxes or social security.
- C. Medical Expenses. Medical expenses are deducted from total income if the medical expenses are:
 - (1) Related exclusively to the expenses of the individual with the developmental or functional disability, such as prosthetic devices, but not expenses which would apply to other members of the applicant's household, such as cold remedies;
 - (2) Documented as paid by a valid receipt;
 - (3) Not covered by any insurance or other payment coverage; and
 - (4) Calculated for the preceding 12 months.

07.06.11.06 Delivery of Respite Care Service.

- A. Care Record. If an application is accepted, the provider shall develop and maintain a care record for each recipient of the service. The care record includes the:
 - (1) Completed application;
 - (2) Service plan;
 - (3) Records of each redetermination and reconsideration;
 - (4) Records of termination and disposition of the case; and
 - (5) Records of service delivery.
- B. Level of Care. The levels of care are:
 - (1) Level I care; and
 - (2) Level II care.

- C. Method of Delivery. Respite care services may be delivered either in the residence of the individual with the developmental or functional disability or in a respite care facility.

07.06.11.07 Limitations.

- A. Respite care services, within one State fiscal year, are available as follows:
 - (1) On an hourly basis, up to a total of 24 hours of care provided in periods of less than 10 hours in any 24-hour period; and
 - (2) On a daily basis, up to 14 days of care with 1 day being not fewer than 10, or more than 24 hours in any 24-hour period.
- B. An unused day of care may be converted into hours, with 1 day equal to 10 hours.
- C. Respite care services may not be used to substitute for routine paid attendant care.
 - (2) The application remains incomplete 30 days after notice to the applicant under §B(2) of this regulation; or
 - (3) The applicant's need for care exceeds the level of care available through the provider.
- D. Respite care services may be provided for an individual with a developmental or functional disability in a crisis situation before completing the application, at the discretion of the provider.

07.06.11.05 Application for Subsidy.

- A. If the total income is less than or equal to 150 percent of the State's median income adjusted to family size, the applicant may be eligible for a subsidy.
- B. Income amounts are included in the total income only if they are regular and ongoing. That is, one-time payments such as gifts or income tax
- C. Qualified care workers may care for individuals in the household other than the individual with a developmental or functional disability, only if the provider determines that such an arrangement will not compromise the quality of care received by the individual with the disability. The number of individuals cared for may not exceed a total of five and any financial arrangements for household members without a developmental or functional disability may not include respite care subsidy funds.
- D. Respite care services may not be provided if:
 - (1) A subsidy is required and all provider funds have been expended or obligated; or
 - (2) All care worker time has been committed.

07.06.11.08 Redetermination and Reconsideration.

- A. A redetermination of eligibility for respite care service and subsidy, and reconsideration of the service statement is required:

- (1) If a change occurs which affects eligibility or the need for service; and
 - (2) At least every 12 months.
- B. The provider shall document in the care record the determination and reconsideration and include:
- (1) The current living arrangements;
 - (2) A written statement of subsidy status, and the amount and type of services for which the family is eligible; and
 - (3) Any necessary revisions to the service statement.

07.06.11.09 Termination.

- A. The provider shall terminate services if:
- (1) The provider and consumer agree that the respite care service does not meet the needs identified in the service statement;
 - (2) Requested by the consumer;
 - (3) The consumer is unable to pay the provider's fee;
 - (4) The consumer has moved from the area served by the provider;
 - (5) The consumer cannot be located by the provider at the time of redetermination;
 - (6) The individual with a developmental or functional disability requires a level of care that exceeds the level of care available through the provider; or
 - (7) The individual with a developmental or functional disability moves into a supervised or protected living situation under the administration of a public or private agency other than a foster home.
- B. If the provider decides to terminate services, the provider shall send a notice to the consumer that includes the:
- (1) Reason for the termination;
 - (2) Specific regulation supporting the decision; and
 - (3) Right to, and the method for obtaining, a fair hearing.

07.06.11.10 Appeal Rights.

Each applicant for or a consumer of services, or an individual acting on behalf of an applicant or consumer, may appeal the denial, reduction, or termination of a service, or failure to act upon a request for service with reasonable promptness to the Hearings Unit of the Social Services Administration. The requirements and procedures in COMAR 07.01.04 apply.

07.06.11.11 Qualification of Care Workers.

- A. Qualification of care workers is done by the providers using a form approved by the Administration. The minimum requirements for a qualified care worker are:
- (1) 18 years old or older;

- (2) Education sufficient to enable the worker to deliver the care needed;
 - (3) Personal characteristics that are needed to deliver care to an individual with a developmental or functional disability;
 - (4) Training or experience necessary to enable the person to deliver the care needed as evidenced by a training certificate or designation by the provider or consumer based on experience; and
 - (5) Good physical and mental health, as certified by a licensed physician.
- B. The provider shall report to the Administration the methods used to ensure that the care workers are qualified to deliver the care required.

07.06.11.12 Approval of a Respite Care Home.

- A. Approval of a respite care home is made by the provider, including the determination of the number of individuals with developmental or functional disabilities who may be cared for at one time in the home.
- B. The minimum requirements for a location to be approved as a respite care home are:
- (1) Physical accessibility for the individual with the developmental or functional disability;
 - (2) Hot and cold running water;
 - (3) Functioning smoke detectors;
 - (4) Operable telephones;
 - (5) Inside bathroom facilities that are in good working condition;
 - (6) Sewage disposal and drinking water that meets local codes;
 - (7) Operable and safe heating and cooling systems;
 - (8) Operable refrigerator and stove;
 - (9) Food storage space protected against invasion of rodents, insects, dust, water leakage, and other sources of contamination;
 - (10) Furniture, including a separate bed and any special equipment adequate for the comfort and safety of the individual with the developmental or functional disability; and
 - (11) Satisfactory performance on a health and fire safety checklist established by the Administration.
- C. Respite care facilities other than a home shall maintain licensure as appropriate.
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**Title 10 DHMH Subtitle
21 Mental Hygiene Administration
Chapter 27 Community Mental Health Programs – Respite Services**

10.21.27.05 Referral, Eligibility, Screening, and Acceptance for Respite Services.

A. Referral. An individual or the individual's caregiver may request respite care services, or an agency providing mental health treatment or support services to an individual may refer the individual for respite care services.

B. Eligibility.

- (1) An individual is eligible to receive respite care if:
 - (a) The individual is a participant, as described in COMAR 10.21.25.01D(2), in the public mental health system;
 - (b) The individual has a diagnosis that is listed in COMAR 10.09.70.10;
 - (c) The individual is:
 - (i) An adult who has serious and persistent mental illness and who lives independently or in a family-like setting, or in a residential rehabilitation program (RRP) under the provisions of COMAR 10.21.22, or
 - (ii) A child who has a serious emotional disturbance and who lives with a parent, guardian, or other primary caretaker in a family-like home, or in a foster home under the provisions of COMAR 07.02.11 or 07.02.21; and
 - (b) The services are preauthorized, as needed, by the Administration's administrative services organization (ASO) according to the provisions of COMAR 10.21.17.02-1A.
 - (2) An individual is not eligible to receive respite care if the individual is a resident of a therapeutic group home (TGH) licensed under COMAR 10.21.07 or a facility licensed under Health-General Article, Title 19, Annotated Code of Maryland.
- C. Screening. Upon receipt of a referral for respite care, the program director shall ensure that respite care staff:
- (1) Conduct a screening assessment with the:
 - (a) Individual for whom respite care services are requested;
 - (b) The caregiver or significant other, if any; and
 - (c) Referral source, if any;

- (2) Evaluate whether the respite care is needed:
 - (a) At a specific future time;
 - (b) Immediately; or
 - (c) Intermittently;
- (3) Outline, in consultation with the individual and the caregiver, a preliminary plan, including the schedule for respite care, for the services to be provided in accordance with this chapter;
- (4) Based on consultation with the individual and, if any, the referral source, document:
 - (a) The expected duration of the respite care;
 - (b) The frequency, level, and type of staff contacts needed, such as staff availability:
 - (i) At a minimum, on call, 24 hours per day, 7 days per week, or
 - (ii) On site for up to 24 hours per day, 7 days per week; and
 - (c) If applicable, medications that are prescribed for the individual; and
- (5) Inform the individual and the caregiver of the rules for the respite care episode.

D. Acceptance. Upon acceptance of an individual for respite care, staff assigned by the program director, in consultation with the individual and the caregiver, shall:

- (1) Perform an assessment of:
 - (a) The individual's and the caregiver's strengths and needs, and
 - (b) Interventions needed by the individual during respite;
- (2) In order to ensure continuity of care, document information regarding, at a minimum, the individual's participation in:
 - (a) Outpatient mental health treatment,
 - (b) Psychiatric rehabilitation,
 - (c) School,
 - (d) Work, or
 - (e) Other scheduled activities;
- (3) Taking into consideration the needs under C (4) and D (2) of this regulation, formulate an initial plan for respite services, including the:
 - (a) Schedule for providing respite care,
 - (b) Location,
 - (c) Level of staff support,
 - (d) Schedule of the individual's activities during respite, and
 - (e) Needed interventions to facilitate the individual's remaining in or returning to the living situation.

10.21.27.06 Respite Services Provided

The program director shall ensure that:

- A. Services are planned according to the duration, frequency, and location of the respite care;
- B. An individual receives services according to a plan that includes:
 - (1) Based on the initial plan under Regulation .05D(3) of this chapter, a schedule of the individual's activities during respite,
 - (2) When needed, medication monitoring, and
 - (3) The frequency and intensity of staff support;
- C. Services are coordinated with an individual's individual treatment plan or individual rehabilitation plan;
- D. Respite staff document a plan to be implemented in the event of a crisis; and
- E. Staff provide referrals or coordinate referrals with other current treatment providers, as needed, for additional services for the individual.

10.21.27.07 Conclusion of Respite Episode

- A. **Planned Conclusion.** At the agreed upon time of conclusion of a respite care episode, the program director shall assure that staff document a summary of the episode in the individual's record.
- B. **Individual's Discontinuation of Services.** If an individual elects to discontinue services before the planned conclusion of a respite episode, as described in §A of this regulation, the program director shall:
 - (1) Promptly notify the individual's caregiver or designated emergency contact;
 - (2) If the individual is a child, discharge the child only to an adult who is legally responsible for the child;
 - (3) Notify the CSA and the Administration's ASO of the action; and
 - (4) Assure that staff document a summary of the episode in the individual's record.
- C. **Program's Recommendation to Discontinue Services.** If the program director recommends discharging an individual who does not comply with the program's rules or for whom the program's services are not appropriate, the program director shall follow the provisions outlined in §B of this regulation.

10.21.27.08 Respite Staff

- A. Respite Care Program Director. The MTS, OMHC, or PRP program director shall either:
 - (1) Carry out the respite care program director's duties that are delineated in this chapter; or
 - (2) Appoint a respite care program director with sufficient qualifications, knowledge, and experience to execute the duties of the position.
- B. Respite Care Specialists. The respite care program director shall employ a sufficient number of staff who:
 - (1) As determined by the program director, have sufficient qualifications and experience to carry out the duties of the position;
 - (2) Before providing services, have training applicable to the service, including, at a minimum, training in:
 - (a) Mental illness and emotional disorders;
 - (b) Psychiatric medications;
 - (c) Crisis intervention;
 - (d) Family interactions; and
 - (e) For staff who provide services to children:
 - (i) Growth and development, and
 - (ii) Behavioral intervention; and
 - (3) As permitted under the Health Occupations Article, Annotated Code of Maryland, and as privileged by the program, are available to carry out the:
 - (a) Program model described in Regulation .04 of this chapter; and
 - (b) Activities outlined in an individual's respite care plan under Regulation .06 of this chapter.

Title 10 DHMH
Subtitle 22 Disabilities Administration
Chapter 11 Respite Services in the State Residential Center

10.22.11.01 Scope

An applicant for a license for a residential childcare facility or a residential childcare program may seek a variance or waiver under this regulation. This chapter applies to licenses regulated by COMAR 10.22.03, 10.22.11, 10.22.14, 10.23.02, and 10.47.01 if the population of the facility is comprised of at least 90 percent children and if they are not regulated by the Health Resources Planning Commission through the Certificate of Need process.

10.22.11.02 Purpose.

This chapter addresses the provision of respite services in the SRC for individuals currently living in the community.

10.22.11.03 Provision of Services.

Before respite services are utilized in the SRC, all efforts are made by the Administration to provide individuals living in the community with respite services in the community. Only when there are no other appropriate alternatives available are respite services provided in the SRC.

10.22.11.04 Eligibility.

To be eligible to receive respite care in the SRC, the individual:

- A. Shall be eligible to receive services funded by the Administration;
- B. Shall have an appropriate evaluation with the diagnosis of mental retardation;
- C. Shall have needs that are able to be met effectively while at the SRC; and
- D. May not be in receipt of full residential services in a community program, except with the approval of the Director.

10.22.11.05 Length of Stay.

Respite services in the SRC may only be provided to an individual for not more than:

- A. 45 days per calendar year; or
- B. 28 consecutive days.

10.22.11.06 Procedures for Respite Requests.

- A. The individual's proponent or licensee shall direct requests for respite services to the appropriate regional office.
- B. The regional office shall arrange for the following:
 - (1) The completion of a formal application;
 - (2) The collection of information to substantiate a diagnosis of mental retardation; and
 - (3) A meeting with the individual, proponent, or the licensee to discuss the terms and conditions of respite services.
- C. The proponent or licensee shall complete all forms required for respite services.
- D. The regional office shall render a written decision to the proponent or licensee within a week of the receipt of the completed application.
- E. On entering, the SRC shall arrange for a medical examination or nursing assessment as is appropriate to the individual.
- F. The SRC shall enter into a contract with the proponent or licensee, which at a minimum contains:
 - (1) A statement that the acceptance of an individual for respite services is not considered an admission as defined in Health-General Article, §7-101(c), Annotated Code of Maryland;
 - (2) A mutually agreed upon date on which the SRC may not provide respite services; and
 - (3) A designated time for the licensee or proponent to return the individual to the individual's community residence.

10.22.11.07 Procedures for Leaving Respite Services.

- A. The SRC shall arrange for a medical examination or nursing assessment as is appropriate to the individual at the time the individual leaves respite services and shall document the findings.
- B. The SRC shall document information about the individual's response to respite services.
- C. The proponent or licensee shall return the individual to the individual's community residence at the time agreed to on the admission document.

10.22.11.08 Daily Programs.

- A. The SRC shall provide appropriate daily activities during the time the individual is in respite services.
- B. The SRC shall make every attempt to maintain the individual in the individual's vocational or day activity during the period of respite services and document the reasons if the individual is unable to attend.

10.22.11.09 Individual Records.

The SRC shall maintain a complete record for each individual receiving respite services.

10.22.11.10 Funding.

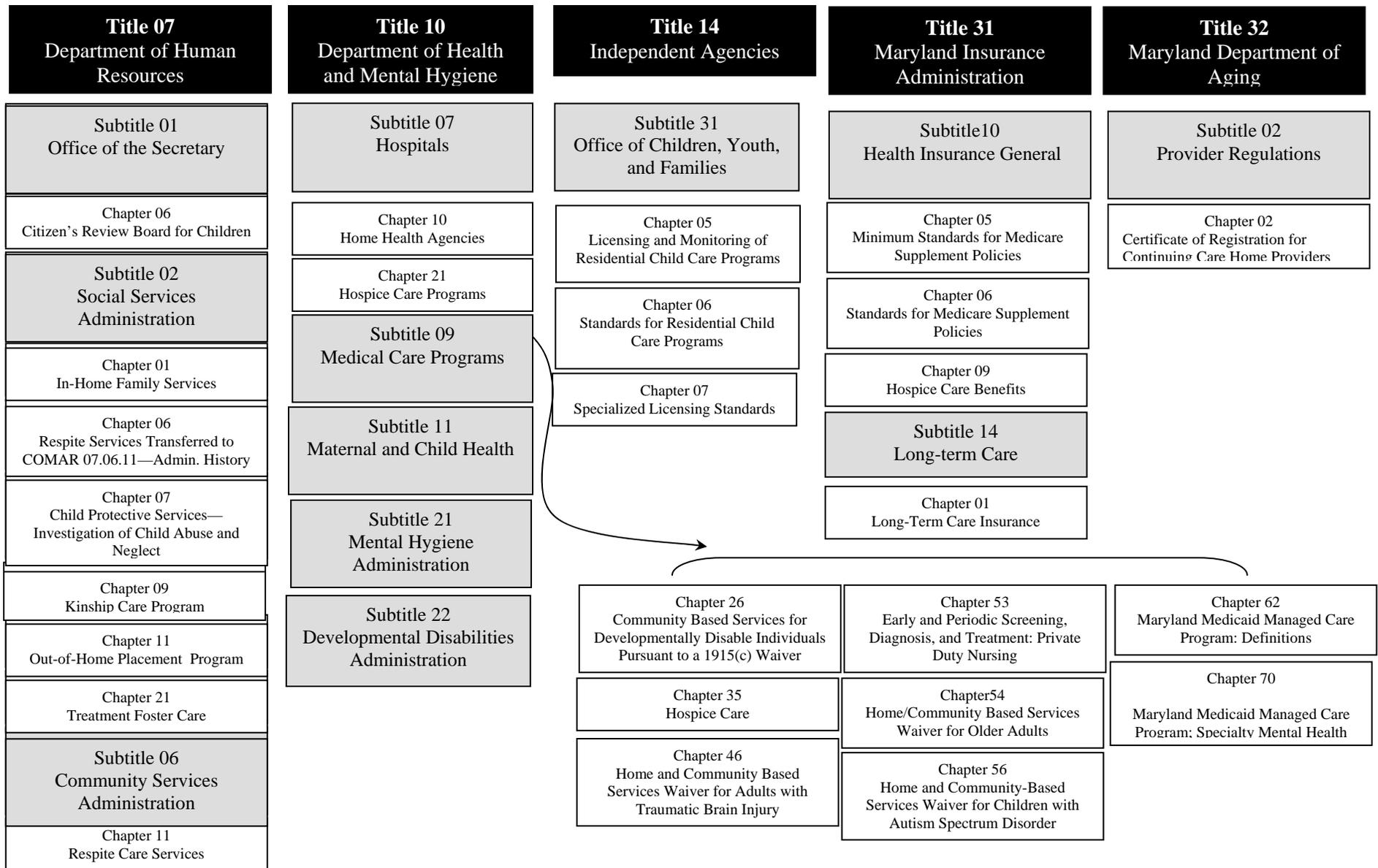
The Department's Division of Reimbursement shall determine the cost of respite services in the SRC pursuant to Health-General Article, §16-201, Annotated Code of Maryland.

**Maryland Code/Health-General /Title7. Developmental Disabilities
Law/Subtitle 5
State Residential Centers for Individuals with Mental Retardation/ § 7-
509. Respite care [Amendment subject to abrogation].**

- (a) *Defined.* - In this section, "respite care" means care that is made available for an individual with developmental disabilities to provide relief for the person with whom the individual ordinarily lives.
- (b) *Reservation of beds for respite care.* -
 - (1) Each State residential center shall provide respite care for families caring for individuals with developmental disabilities in their home.
 - (2) Beginning in fiscal year 2006:
 - (i) The Holly Center, the Potomac Center, and the Brandenburg Center shall each reserve not more than 4 percent of its total beds for respite care; and
 - (ii) The Rosewood Center shall reserve at least 2 percent, but not more than 4 percent, of its total beds for respite care.
- (c) *Limitation on length of time.* - Respite care for an individual may not exceed 45 days within any 1-year period or 28 consecutive days.

- (d) *Choice of State or community setting.* - Notwithstanding subsection (b) of this section, families caring in their homes for individuals with developmental disabilities, who have been approved to receive respite care by the Developmental Disabilities Administration, shall have a choice of obtaining respite care in a State residential center or a community setting.
- (e) *General Fund appropriation.* -
- (1) The Governor shall include in the annual budget bill a General Fund appropriation for the purpose of providing respite care in a State residential center or a community setting for families caring for individuals with developmental disabilities in their homes.
- (2) (i) The General Fund appropriation in paragraph (1) of this subsection shall be in addition to and may not supplant funds already budgeted for respite care.
- (ii) No funds may be transferred from community services for individuals with developmental disabilities to pay for respite care provided in a State residential center.
- (f) *Indicators.* - Beginning in fiscal year 2006, the Department shall include in the managing for results indicators submitted with its annual budget request an indicator of the satisfaction families experience with respite services provided in a State residential center.

[1986, ch. 636, § 2; ch. 637, § 2; 2004, ch. 178.]



**Appendix 2: Survey of Providers of Respite Services for Children
in Maryland—Final Report**



Survey of Providers of Respite Services for Children in Maryland

February 2005



CENTER FOR HEALTH PROGRAM
DEVELOPMENT AND MANAGEMENT

Background

A brief survey was distributed to 163 agencies know to provide respite services to ascertain which agencies provided services to children and to learn more about provider services, fees, capacity, and their overall experience as respite providers in Maryland. Twenty-nine agencies responded to the survey as providing respite services to children (other responding agencies were not child respite providers)

A. Responding Agencies

Agency	Location
Abilities Network	Towson, MD.
Allegany County Health Dept - Therapeutic Foster Care	Cumberland, MD.
Baltimore County Department Of Health	Towson, MD.
Bay Shore Services Organization	Salisbury, MD
Catholic Charities Center For Family Services	Aberdeen, MD.
CHANGE, Inc.	Westminster, MD.
Chesapeake Care Resources, Inc.	North East, MD.
Children's Choice	Stevensville, MD.
Charles County HARc	Waldorf, MD.
Core Service Agency of Harford County	Bel Air, MD.
CPL/Center For Progressive Learning	Owings Mills, MD
Crossroads Community, Inc.	Centreville, MD.
Delmarva Community Services, Inc.	Cambridge, MD.
Easter Seals Delaware and Maryland's Eastern Shore Camp Fairlee Manor	Chestertown, MD.
Epilepsy Assoc. Eastern Shore	Salisbury, MD.
Family Education Center	Elkton, MD.
Kennedy Krieger Institute	Baltimore, MD.
Maple Shade Youth & Family Services, Inc.	Mardela Springs, MD.
MENTOR Maryland	Easton, MD.
Respite Services of Montgomery County	Rockville, MD.
Royal Nurses, Inc.	Frederick, MD.
Talbot County Family Support/Early Head Start	Easton, MD.
The ARC Of Baltimore	Towson, MD.
The Arc Of Carroll County	Westminster, MD.
The Arc of Howard County	Ellicott City, MD.
The Arc Of Prince George's County	Largo, MD.
United Cerebral of Central Maryland- The Delrey School	Catonsville, MD.
Villa Maria	Timonium, MD.
Way Station - Camp Journey	Frederick, MD.
Wicomico County DSS	Salisbury, MD.

B. Provider Concerns

Providers were asked to share their concerns about the system of respite services to children in Maryland that would make them unwilling or unable to continue to provide services to children with disabilities. Generally concerns centered around funding, especially end-of-year shortfalls, the lack of understanding some decision makers have about the importance of respite, and placement options (foster parents and overnight). The following lists their comments.

- Lack of funding would affect delivery of respite services.
- Difficulty helping funding sources understand the preventative nature of regular respite. This is a cost-effective program that prevents more costly services and keeps families together by empowering parents to maintain their difficult children in their [homes]
- Occasional shortage of money at the end of the fiscal year.
- Sustainability
- Invoicing and obtaining authorizations is very difficult.
- The main obstacle is recruitment and training of foster parents. There is no with which to use for recruitment of families which makes starting a program difficult.
- We are concerned as providers that families get very little respite - currently 5 [hours] of respite per month is authorized for most clients- hardly meaningful and sufficient.
- Not enough clients
- Appropriate day placements for extended stays funding
- Rate of reimbursement which effects rate of payment to provider; Limited respite providers; Regulations and requirements of providers and agency, multiple regulations and conflicting regulations between state agencies; Lack of authorization
- Availability of funding sources
- Regulatory issues
- The lack of providers in the area make it difficult to provide the respite needed to all
- We are able to provide some funding through rolling access funds and a private grant through UCP. The biggest issues is finding workers
- We could not provide respite without grants. Out of pocket is approx. \$14.00 hour full fee. Families pay a share of cost approx. \$5.00 hour. Many different skills are needed by staff. Staff training is extensive, with personal care and behavioral redire[ction skills]

C. Ages Served

Most serve children of all ages, but two serve only younger children (age 4 years and under) or school age (5-17 years).

Ages	# Serving This Age Group
0-4 yrs.	2
0-17 yrs.	19
5-17 yrs.	8

D. Type of Child Disability Served

The feasibility study of which this survey is a component will focus on children with Seriously Emotionally Disturbance (SED). Providers were asked what child disability groups they serve. Twelve of the 29 provide services to children with SED, with six of those serving children with SED only.

Type of Disability	# Serving This Disability Type
SED Only	6
Physical Disability Only	4
Phys/SED	1
Phys/Other	5
Other	7
Phys/SED/Other	5

E. Incomes Served

Nearly all of the reporting agencies have no income limitations for service delivery.

F. Service Location

The site of respite service delivery is an important feature to families. Some prefer services in their home, where for others, out-of-home services may be preferred. Providers were asked the location of services they provide

Service Location	# Providing Service in This Location
Other Out-of-Home	24 (<i>only out-of-home = 9</i>)
In client's home	18 (<i>only in client's home = 2</i>)
Group or Alternative living unit	7
Institutional	5

G. Capacity

Access to respite services due to lack of providers and waiting lists are problems often encountered when seeking services with limited availability. Providers were asked their current capacity to ascertain the availability of services among the respondents. Almost half were at 100 percent of their capacity at the time of the survey, and about one-fifth were at 50 percent or less capacity.

Percent of Current Capacity	# of Agencies Responding
100%	14
75%	9
50% or Less/NA	6

H. Waiting Lists

Waiting List—8

No Waiting List—6

I. Number of Agencies Reporting Service per County

	# of Agencies Reporting		# of Agencies Reporting		# of Agencies Reporting
Allegany	2	Charles	2	Prince George's	4
Anne Arundel	5	Dorchester	6	Queen Anne's	5
Baltimore City	6	Frederick	4	Somerset	3
Baltimore County	8	Garrett	2	St. Mary's	1
Calvert	2	Harford	5	Talbot	7
Caroline	6	Howard	7	Washington	2
Carroll	6	Kent	4	Wicomico	6
Cecil	5	Montgomery	4	Worcester	5

**Appendix 3: Maryland Respite Care Survey for Families of
Children with Disabilities—Final Report**

Maryland Respite Care Survey for Families of Children with Disabilities

September 2005

**A study conducted for the Maryland Caregivers Support Coordinating Council
by the Center for Health Program Development and Management
at the University of Maryland, Baltimore County
under contract with the Department of Health and Mental Hygiene,
Mental Hygiene Administration**



CENTER FOR HEALTH PROGRAM
DEVELOPMENT AND MANAGEMENT

Family Respite Survey

In the fall of 2004, a survey of families in Maryland who have one or more children with a disability was conducted as a component of a feasibility study, the purpose of which is to design a demonstration project that includes respite care for children as a “Medicaid like” service. Other components included a survey of providers of respite services to families of children with disabilities, a study of relevant state regulations, and ultimately a proposed demonstration, including cost modeling.

The family survey was distributed through state networks that provide services to families of children with disabilities, including providers, membership, and advocacy organizations. Respondents were able to return the survey in postage-paid envelopes or complete the survey online.

Survey Development

Researchers, working with the Maryland Caregivers Support Coordinating Council (MCSCC) developed a brief survey to query families of children with disabilities about their respite services experiences. The survey was focused on capturing the basic experience of families of children with disabilities in regard to acquiring and using respite services, including type and location, cost, quantity, and satisfaction.

Sample Description and Analytic Approach

This was a convenience sample survey. In all, 116 families, with a total of 133 children with disabilities, responded. The larger number of children than families is due to the fact that some families have more than one child with a disability. Among the 116 responding families, 98 families reported information on one child, 26 families reported information on two children, and 9 families reported information on three children.

The target group for the feasibility study, of which this survey is a component, is children with severe emotional disturbance (SED). This analysis will compare the SED to the non-SED population, and when appropriate, include overall (including all families) statements.

Table 1: Distribution of Responding Families in Regard to Use of Respite Services and Child SED Status

	Families Not Using Respite Services	Families Using Respite Services	
Families with one or more child(ren) with SED	5	28	
Families with one or more non-SED disabled child(ren)	27	56	
Total	32	84	Grand Total= 116

Findings are presented for families of children with a non-SED disability and for families of children with SED. Variations in the number (denominator) used varies depending on how many

families answered a particular question. Families who answered that they are not currently using respite services were instructed NOT to respond to questions 2 through 8, although a few did so and are included in the analysis.

Data is presented in descriptive forms only since convenience sampling was used in the survey design. Response rates and probability statistics are not appropriate.

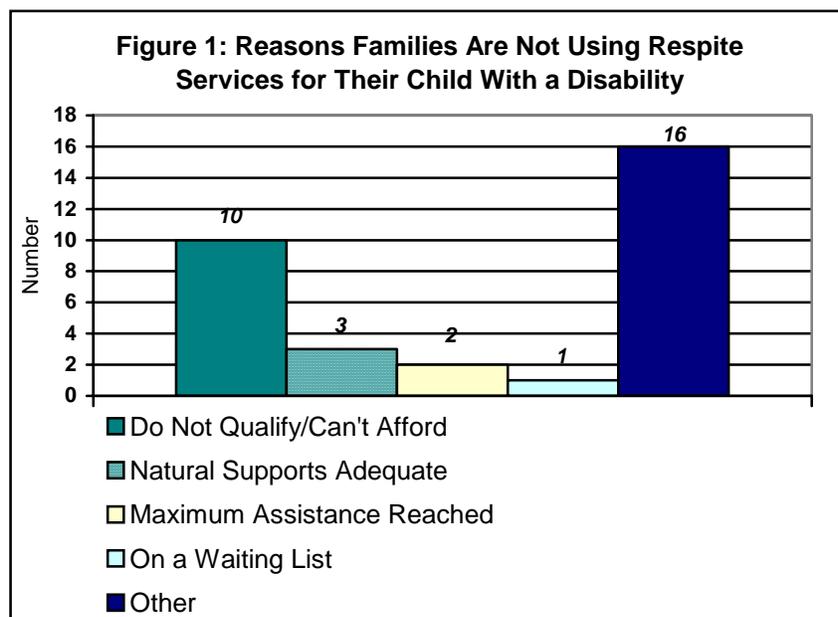
FINDINGS

Families Not Using Respite Services

Families were asked at the beginning of the survey whether they were currently using respite services for their child with a disability. If they were not using respite services, they were to indicate the reason and then skip to the end of the survey to provide information about their child and family.

Thirty-two families said that they did not currently use respite services for their child, including six families of children with SED. See Figure 1. The largest single reason for not using respite services was that they could not afford the services and/or did not qualify for assistance. “Other” reasons (n=16) included:

- Income too high to qualify for assistance, but cannot afford
- Not aware of services
- Not hearing from agency after applying
- Overwhelming process/red tape
- Skepticism of strangers caring for child
- Unable to find caregivers/few options



Types of Respite Services Used

Families were asked to check off the types of respite services that they used in the past twelve months. Three categories of answers were provided: 1) an urgency-oriented response (planned or emergency/crisis), 2) a “level” of provider (companion or nursing/medical), and 3) a time of week (weekend and/or overnight). Multiple responses were allowed.

Families of children with SED were more likely to use all types of respite services than the non-SED families, except in the nursing/medical and companion only categories. For both groups, planned weekend respite was used most often. See Table 2.

Table 2: Type(s) of Respite Services Used by Families

	Non-SED (%)	SED (%)
Weekend	29	47
Planned	36	39
Overnight	16	22
Other	6	11
Nursing/Medical	5	3
Emergency/Crisis	5	8
Companion Only	10	6

Note: *More than one type could be selected.*

Families of children with SED were slightly more likely to use overnight, or emergency respite services, and slightly less likely to use companion or nursing/medical respite services. Weekend respite services were used much more by the SED families.

Location and Hours of Services Used

Families were asked to select whether respite services are received in their own home, a group setting/out-of-home setting, or some other out-of-home setting, and how many hours of services were used annually in each location and on a weekend basis.

Among families of children with non-SED disabilities, 29 percent receive respite services *in the home*. Among SED children, 33 percent receive respite services in the home. Overall, the average use of in-the-home respite services was 80 hours a year, with a range from 5 to 280 hours.

Among families of children with non-SED disabilities, 24 percent receive respite services in a *group setting/out-of-the-home setting*. Among SED children, 42 percent receive group setting/out-of-home respite care. Overall, the average use of group setting/out-of-home setting respite services was 105 hours a year, with a range from 4 to 576 hours.

Among families of children with non-SED disabilities, 18 percent receive respite services in *other out-of-the-home settings*, with 5 of 13 reporting a camp, and 8 of 13 reporting the home of the respite provider. Among families of children with SED, 31 percent reported other locations, including camp, care provider’s home, and various arrangements with the care provider such as visits and “overnight” stays.

Among families of children with non-SED disabilities, 29 percent reported using *weekend respite*. Families of children with SED use weekend respite services at 47 percent. Overall, the average use of weekend respite services was 137 hours a year, with a range from 12 to 570 hours.

Table 3: Location of Respite Service Delivery

	Non-SED (%)	SED (%)
In-Home	29	33
Group-Setting/Out-of-Home Setting	24	42
Other Out-of-Home Setting	18	31
Weekend	29	47

Note: More than one response allowed. Includes 84 families using respite services.

Fees Paid for Respite Services

Fees for respite services vary in quantity, depending on how much service a family is allocated by a particular program and whether the service is used on an hourly, daily, or weekly basis. Families were asked to report how much was paid on the basis of these varying amounts of time.

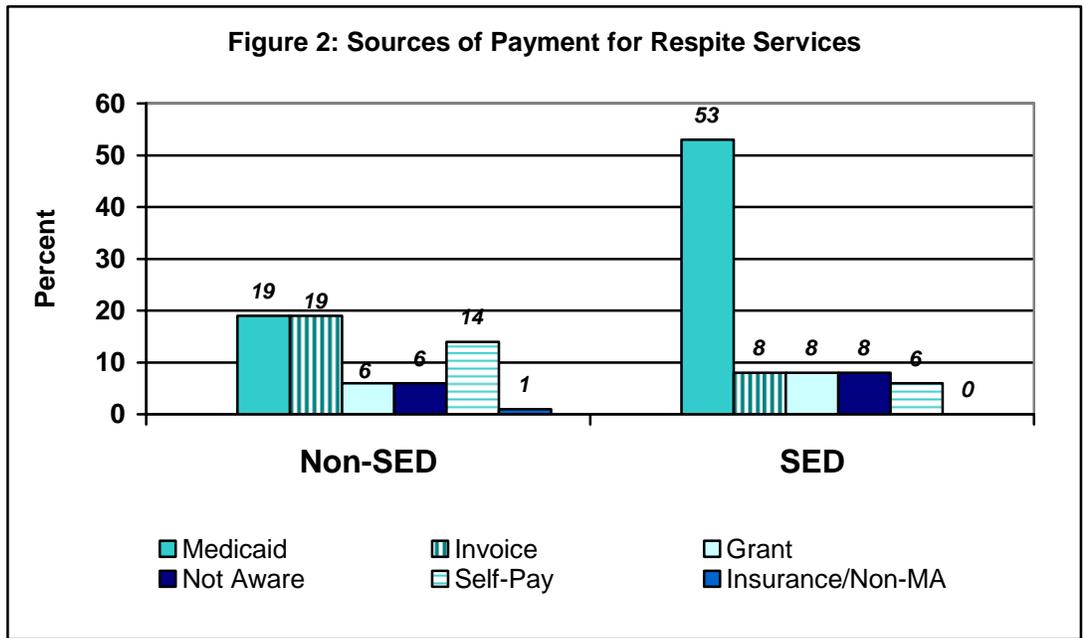
On a *per hour* basis, 16 families¹⁰ reported paying from \$4.50-\$11 (an average of \$8.72). One family reported paying on a *per day x 8 hour* basis at \$750. On a *per day x 24 hour* basis, seven families reported a range of \$60-\$160 (an average of \$119). On a *weekly* basis, three families reported paying from \$300-\$800 (average \$550).

Note: Thirty-five percent of families reported that they did not know what fees are paid for their children’s respite services, including 26 percent of the families of children with non-SED disabilities and 56 percent of the families of children with SED.

Source of Payment for Respite Services

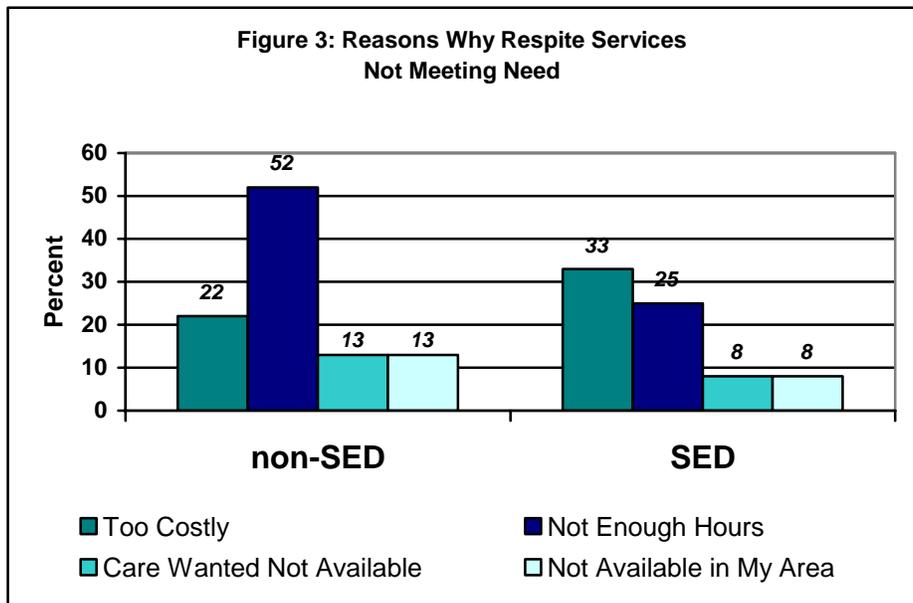
Nineteen percent of the families of children with non-SED disabilities and the majority of the families with SED children (53 percent) use Medicaid as a source of payment for respite services. Figure 2 shows all sources of payment reported. Agencies mentioned for invoicing included Arc’s, a local social service, and Developmental Disabilities Administration. Grants were received from a local health department, Arc’s, and private, non-profit organizations.

¹⁰ Fees were not reported for SED and non-SED because only two families of children with SED answered this question.



Adequacy of Quantity of Respite Services

Among families of children with non-SED disabilities who use respite services, 52 percent reported that the amount of respite services that they receive meets their need. Among families with SED children, 56 percent report receiving all the services that they need. Of those who report that their need is not met, the main reason was cost (43 percent), followed by not enough hours (29 percent), desired care not available (26 percent), or care simply not available in their area (11 percent). Families of children with SED most often selected cost, while families of children with non-SED disabilities mostly selected an insufficient number of hours of respite as the reason respite service needs are not met. See Figure 3.

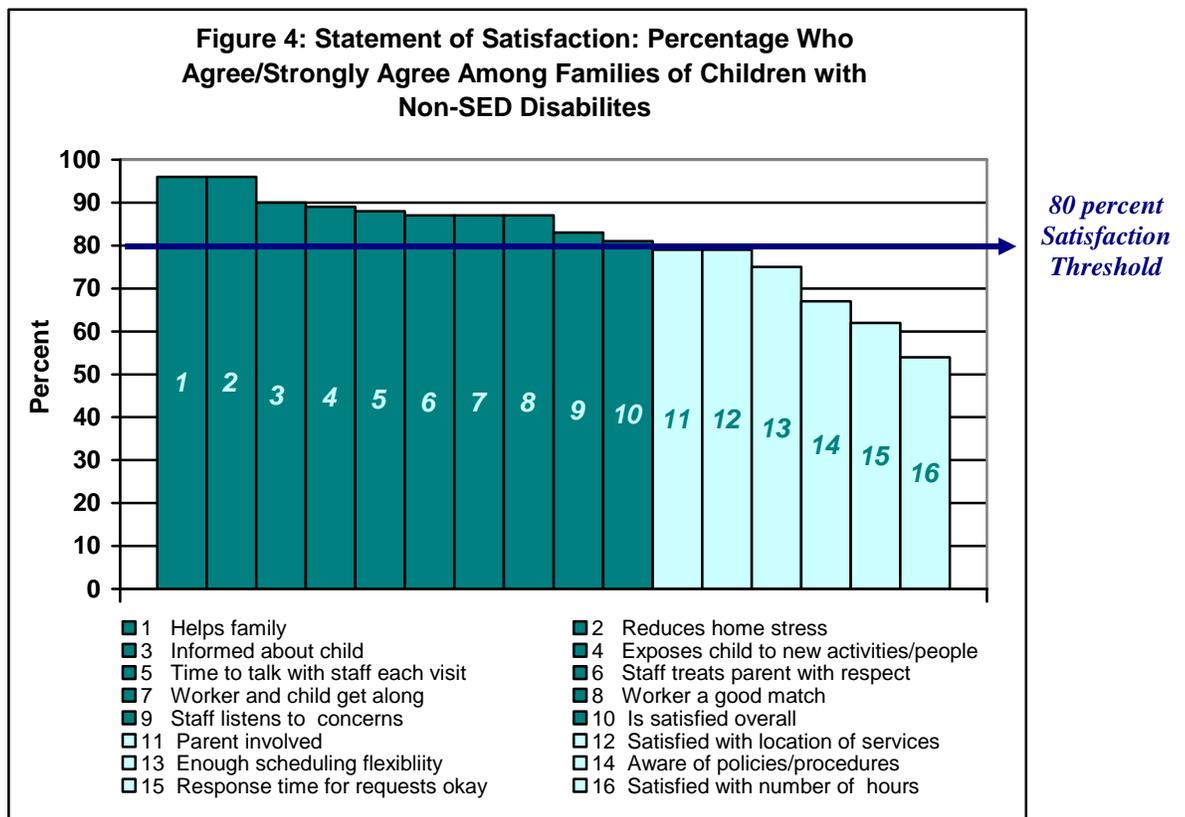


Satisfaction with Services

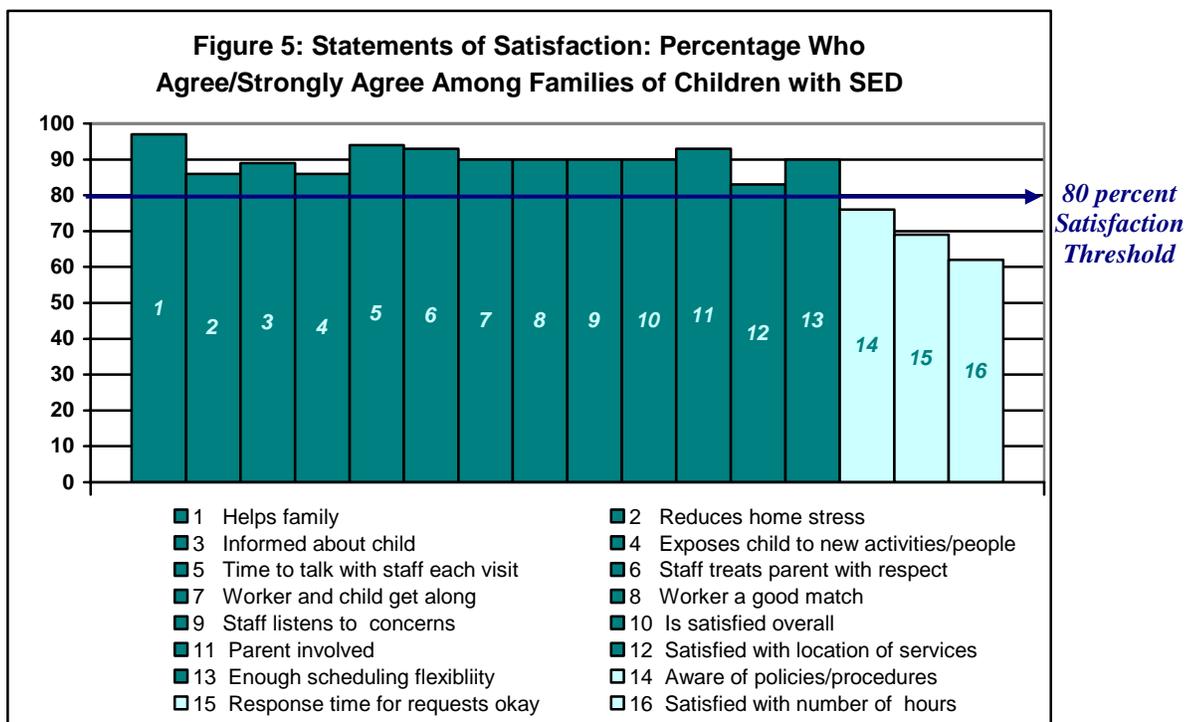
Overall, most respondents agree or strongly agree with positive statements regarding respite services, such as respite helping their children/family, getting along with the respite worker, and the respite worker being a good match. Among families of children with non-SED disabilities, less than 80 percent agree or strongly agree with six of the statements. These statements are:

- Parent involved
- Satisfaction with location of services
- Enough scheduling flexibility
- Being aware of policies/procedures
- Response time for a request for services is okay
- Satisfaction with the number of hours

See Figure 4.



The families with SED children feel more involved in the service than families without SED children. Families of children with SED expressed satisfaction below the 80 percent level for three of the six factors scored at less than 80 percent satisfaction by families of children with non-SED disabilities. See Figure 5.



The families without SED children feel that respite services reduce home stress more so than the families with SED children.

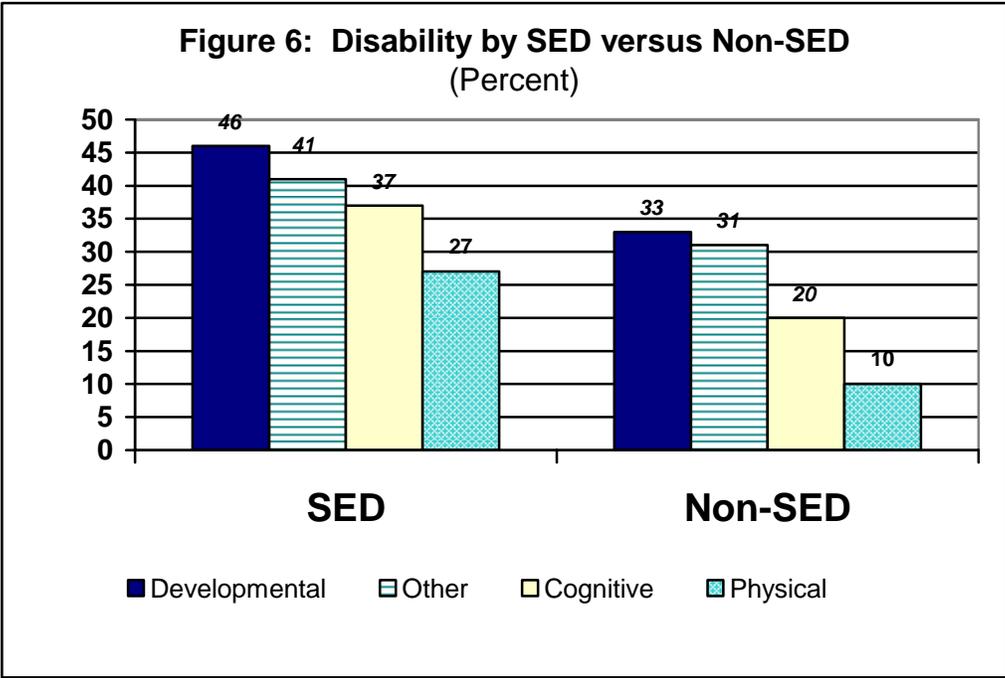
Type of Disability

All respondents were asked to provide information about their children with disabilities, even if they were not currently using respite services. A total of 97 families shared information about 132 children, including their age, disability and other conditions, and the amount of supervision required during waking hours.

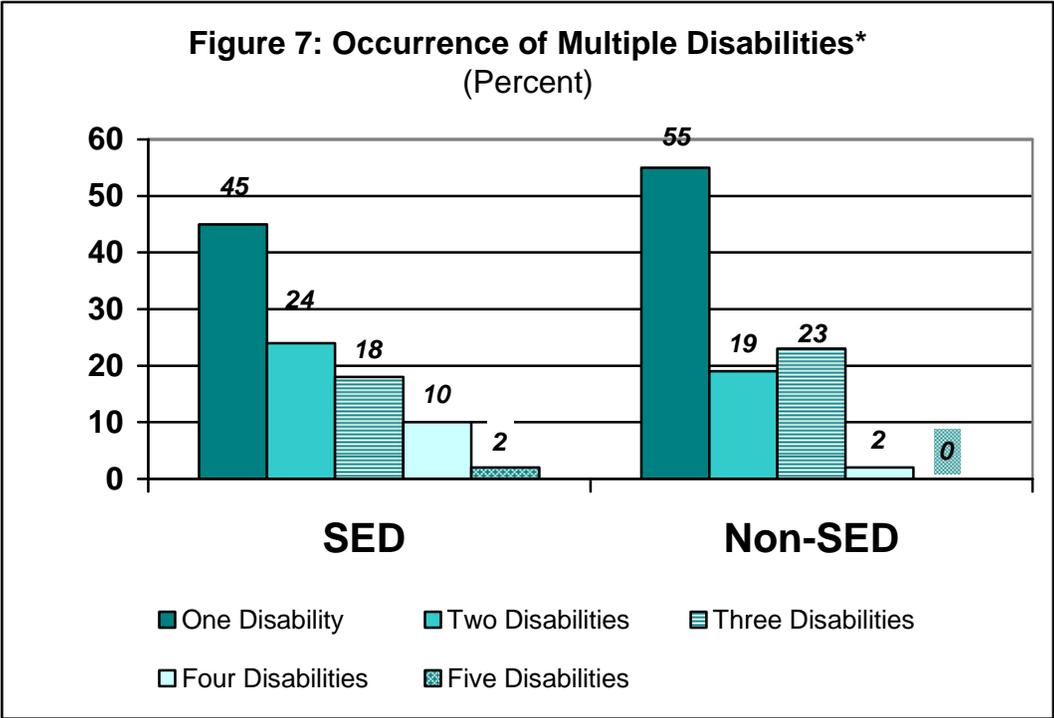
The children with SED had higher associated disability levels than the non-SED children in all disability categories.

- 46 percent of the SED children and 33 percent of the non-SED children have associated developmental disabilities:
- 41 percent and 31 percent (respectively) have “other” types of disabilities (other conditions reported were ADHD, Bipolar Disorder, Autism, Post-Traumatic Stress Disorder, Multiple Sclerosis, Diabetes, and mental retardation)
- 37 percent and 20 percent (respectively) have cognitive disabilities
- 27 percent and 10 percent have physical disabilities.

See Figure 6.



Children with SED disabilities are more likely than children with non-SED disabilities to have multiple disability issues. That is, more non-SED children have only one disability. See Figure 7.



*In determining “multiple disability”, SED is included in the count, so that for SED children with one disability, SED is the disability considered. SED children with two disabilities includes SED and one other disability, etc.

How Respite Services in Maryland Could Be Improved

Survey respondents were asked what could be done to improve respite services in Maryland. Information, access (more providers in more locations), cost, quality of workers, and less complex and more responsive systems were common themes.

“They could be better publicized—I was not aware of any respite program until I received this survey.”

Cost issues are prevalent for families with and without financial means. For families that are “better off,” services can still be priced out of the range of affordability, and they often do not qualify for assistance based on means testing.

“We have never used respite care for our child ... by the time we found out it was an option our child was already on the waiting list for residential care. An opening for residential care came before an opening for respite care.”

Families reported having to wait too long for respite services, even to the extent that they were forced to choose residential options when respite would have provided the needed support to allow them to continue to care for their child.

Scheduling issues pointed to the greater need for flexibility for working parents and the desire to incorporate some of the child’s scheduled activities into the respite period. This would free parents from some time-intensive activities and provide time away from the child. There is less actual relief for the parents/caregivers if all of the child’s needs still remain to be addressed after the respite break. This merely imposes a delay of responsibilities the parents must take on, not temporary relief from them as intended by the respite break.

The need for more and better qualified workers was mentioned, with the suggestion that pay scales be increased to attract more qualified individuals. This was cited as being especially true if children had special care needs, if their needs were intensive, or if their condition was severe/complex.

“Respite for a weekend or a week for freedom for parents to have some time without the child to have a peaceful, restful period to re-group and carry on.”

“Caregivers could be more than your average babysitter.”

Parents also desire more structured activities for children during the respite breaks, to “occupy their time and mind,” or perhaps meet other children.

Parents also asked for provider lists that are up-to-date, have good contact information, and list providers that are affordable. In addition, emergency drop-off is needed so that parents can attend to other family emergencies/urgencies.

Appendix 3: Family Survey

MARYLAND RESPITE CARE SURVEY FOR FAMILIES WITH CHILDREN WITH DISABILITIES 2005

The Maryland Caregivers Support Coordinating Council and the Mental Hygiene Administration of the Maryland Department of Health and Mental Hygiene are conducting a feasibility study focusing on the delivery of respite services to families caring for children with disabilities. Respite care is temporary or short-term care services provided to individuals who are unable to care for themselves, to provide relief or a break from care for their usual caregiver. This survey is being conducted to gain a better understanding of the experiences of families in acquiring and using respite services, in order to plan improvements to the system. **Surveys must be returned by May 16, 2005**

Please seal this survey in the postage-paid envelope provided to preserve your confidentiality. Please do not write any information on this survey that identifies who you are. Or, you may complete the survey online at www.healthcaresurveys.org/familyrespite/. For questions, call Annette Snyder at UMBC, 410-455-6386.

Thank you.

COMPLETE THIS BOX ONLY IF YOU DO NOT USE RESPITE SERVICES.

I am unable to complete this survey because I do not use respite services for my child with a disability.

Please tell us why you do not use respite services and then answer questions 9 and 10, below.

- | | |
|--|---|
| <input type="checkbox"/> My family has enough natural supports so respite care is not needed | <input type="checkbox"/> My child/family does not qualify for any programs and I am otherwise unable to afford this service, but it is needed |
| <input type="checkbox"/> My family has been put on a waiting list | <input type="checkbox"/> Other reason _____ |
| <input type="checkbox"/> My family has already received the maximum amount of respite allowed. | _____ |

1. In the past 12 months, what type of respite services have you used? Check all that apply.

- | | | |
|---|---|------------------------------------|
| <input type="checkbox"/> Planned | <input type="checkbox"/> Companion only | <input type="checkbox"/> Overnight |
| <input type="checkbox"/> Emergency/Crisis | <input type="checkbox"/> Weekend | |
| <input type="checkbox"/> Nursing/medical care. Please describe: _____ | | |
| <input type="checkbox"/> Other. Please explain: _____ | | |

2. Where are services provided? Check all that apply.

- | |
|--|
| <input type="checkbox"/> In my home |
| <input type="checkbox"/> Group setting/out-of-home setting |
| <input type="checkbox"/> Other out-of-home setting (such as Foster Family/Resource Family) Please explain: _____ |

3. What fees are paid for respite services (by you or on your behalf)?

- | | |
|-------------------------|--|
| Per hour fees | \$ _____ or, <input type="checkbox"/> Not applicable |
| Per day fees (8 hours) | \$ _____ or, <input type="checkbox"/> Not applicable |
| Per day fees (24 hours) | \$ _____ or, <input type="checkbox"/> Not applicable |
| Per week fees | \$ _____ or, <input type="checkbox"/> Not applicable |
| Other fee: | \$ _____ Please describe: _____ |
| Don't Know | <input type="checkbox"/> |

4. How are your respite services paid for? Check all that apply.

- | |
|--|
| <input type="checkbox"/> Medical Assistance (also called HealthChoice or MA) |
| <input type="checkbox"/> Insurance other than Medical Assistance |

Appendix 3: Family Survey

- Self-Pay (some or all of respite services used)
- Not aware of sources that will pay for respite
- I submit an invoice or request to a private, community-based, or government agency.

Please specify: _____

- I receive a grant(s) for my child's respite services *Please specify from where:*

Other _____

5. What type(s) of respite and how many hours of respite did you receive in the last 12 months?

- In-home respite (___hours) Out-of-home respite (___hours) Weekend respite (___hours)

6. Are you able to get all of the respite care services that you need? Yes No

6a. If you answered No to question 6, why were you unable to get the services that you needed?

- Too costly
- Not available in my area
- Type of care wanted/needed not available
- Quantity of service insufficient (Received ___hours / Needed more hours) *Write in number of hours.*
- Other _____

7. Satisfaction Scale. Check SA=Strongly Agree, A=Agree, NO/NA= No Opinion or Not Applicable, D=Disagree, or SD=Strongly Disagree. Check one box for each item.

	SA	A	NO /NA	D	SD
The respite services we receive help my family and me.	<input type="checkbox"/>				
Respite care exposes my child to new people and activities.	<input type="checkbox"/>				
The respite care we receive reduces the amount of stress at home.	<input type="checkbox"/>				
The respite worker and my child get along well.	<input type="checkbox"/>				
My respite worker is a good match with my child and family.	<input type="checkbox"/>				
I am involved in the respite process.	<input type="checkbox"/>				
There is enough flexibility in the scheduling of respite.	<input type="checkbox"/>				
I am satisfied with the number of hours of respite I receive.	<input type="checkbox"/>				
I am satisfied with the location of the respite care.	<input type="checkbox"/>				
Staff listens to my concerns.	<input type="checkbox"/>				
Staff treats me with respect.	<input type="checkbox"/>				
I have time to talk to the respite worker before each respite episode.	<input type="checkbox"/>				
I know about policies and procedure, including grievance policies.	<input type="checkbox"/>				
I am informed about my child when I am not around.	<input type="checkbox"/>				
Overall I am satisfied with the respite services I receive.	<input type="checkbox"/>				
Time between requesting respite services and receiving the service is okay.	<input type="checkbox"/>				

8. Are respite services provided by: Check all that apply

- An agency (Name and location. _____)
- A non-family member that you identified and pay
- A non-family member that you identified and do not pay
- A family member that you pay
- A family member that you do not pay
- Other _____
- Don't Know

Appendix 3: Family Survey

9. Tell us a little about your child and family:

	Age (years)	Sex	Type of Disability	Amount of Needed Supervision While Awake
Child 1		<input type="checkbox"/> Male <input type="checkbox"/> Female	<input type="checkbox"/> Physical <input type="checkbox"/> Severe Emotional Disability <input type="checkbox"/> Cognitive <input type="checkbox"/> Developmental <input type="checkbox"/> Other diagnosis(es) _____	____ hours per day
Child 2		<input type="checkbox"/> Male <input type="checkbox"/> Female	<input type="checkbox"/> Physical <input type="checkbox"/> Severe Emotional Disability <input type="checkbox"/> Cognitive <input type="checkbox"/> Developmental <input type="checkbox"/> Other diagnosis(es) _____	____ hours per day
Child 3		<input type="checkbox"/> Male <input type="checkbox"/> Female	<input type="checkbox"/> Physical <input type="checkbox"/> Severe Emotional Disability <input type="checkbox"/> Cognitive <input type="checkbox"/> Developmental <input type="checkbox"/> Other diagnosis(es) _____	____ hours per day

Age of other household member(s): _____ Household income (annual):

10. How do you think respite services could be improved? _____

Thank You

1. They could be better publicized -- I was **NOT AWARE** of any respite program until I received this survey.
2. Overnight services would be nice.
3. **MAKE IT EASIER** to go through the process. I have two sons with autism and no time to go through the red tape. My time is spent on them, all day, all night.
4. **MORE INFO** out about different programs and easier ways to find out about them.
5.
 1. **ACCESS**
 2. **COST** prohibitive (Camp Journey 150/night)
We have not been able to use respite services at Camp Journey because of **COST. UNAWARE OF OTHER RESPITE CARE.**
6. Higher hourly pay rate will attract better qualified staff.
7. We have never used respite care for our child, by the time we found out it was an option our child was already on the waiting list for residential care. An opening for residential care came before an opening for respite care.
8. Respite services could be made available to families. We receive no respite services because we **CANNOT AFFORD** to do any more than we are doing.
9. **MORE HOURS** given to families and **MORE RESPITE** care homes available
10. I believe that Respite could work better if we didn't have to wait so long for the Respite visit. and if there were **MORE RESPITE** families available. Respite is a lifesaver for the child and the family
11. Its fine with me
12. We have a very, very good relationship with our respite provider. However, she sometimes has other obligations forcing her to cancel.
13. More easily **ACCESSIBLE** especially to working parents
14. 1) Lack of professional services for children with Mental Illness. 2) Lack of proper, effective training for people working with children with intensive needs (teachers, respite workers, staff health professionals). 3) **LACK OF RESPITE WORKERS/SERVICES**
15. **MORE INFORMATION** to parents; more options
16. I wish I knew. We are still pretty new to this. Perhaps if there were more people available to provide respite care? How to do that I have no idea. Financial incentives??
17. There is a **SHORTAGE OF WELL-TRAINED QUALIFIED CARING RESPITE WORKERS.** We have found some excellent workers who are college students, but they usually do not have a lot of availability for respite. Please consider doing more recruiting on college campus
18. **INCREASED ACCESS!!!!** I cannot pay for services and have no **ACCESS** to them through my private insurance, and I do not qualify for any assistance. My child has just as severe a set of circumstances as many others--he doesn't realize he's supposed to be better
19. Provide services on a sliding scale for every person who needs them. We fall into the "gray zone" because of income. Our insurance will not cover respite or PRP services. We cannot even **ACCESS** services that are funded by medical assistance or DDA, as
20. I could pay for someone to provide care, but it is very hard to find someone who knows how to deal with my daughter who has pretty severe autism. I have family members who help, but I am

really stuck if we want to do something as a whole family.

21. It has been great!
22. **ADDITIONAL FUNDING ASSISTANCE** and providing **INFORMATION** re: people/agencies that provide the service.
23. **ACCESS** to more providers
24. In my area, there is **NOT ENOUGH INFORMATION** given to families regarding respite (or no info)
25. **MORE TRAINED PROVIDERS** for complex behavior issues.
MORE WEEKEND RESPITE homes.
26. **LIST OF PEOPLE WHO HAVE BEEN CHECKED OUT AND APPROVED AVAILABLE TO PARENTS.** The Arc is great and they provide a very good respite program. Try to match kids that come for the planned drop off times and try to meet need.

Challenge is finding people to p[rovide care]...

27. I need **MORE RESPITE** opportunities.
28. I need **MORE RESPITE** opportunities.
29. **MORE RESPITE** offered.
30. **MORE RESPITE** offered.
31. **OBTAINING FUNDS** to allow **MORE HOURS** for respite if needed. Continue recruiting families in city as well as county.
32. It would be nice to get respite care no matter what your income is. We might have an combined income of \$100,000, but we feel we are entitled to the same care as other children. We do not have any family members that can handle our son, therefore, we do no
33. I use them in 2 way it helps me and our family. It works well.
34. For my concern respite does not need to change. My respite worker I like and there is no change that I can see.
35. **RESPITE FOR A WEEKEND OR A WEEK FOR FREEDOM.** Have children in sports. Wish they (provider) could take them for their scheduled events while they are with them. There were several other respite children that go to this house at the same time. I don't
36. If they could go every weekend unless I had something planned as a family.
37. I would have time to take care of daily living activities. I would be able to bathe, wash my hair, shop, sleep, engage my son in other activities, wash cloths, clean the windows, clean the carpet, wash the car, read a book, see a movie, talk to my friend
38. **RESPITE FOR A WEEKEND OR A WEEK FOR FREEDOM** for parents to have some time without the child to have a peaceful, restful period to re-group and carry on.
39. I need some after school maybe 3 days a week to take my child out more.
40. **MORE HOURS** with ideas of recreational programs that can occupy their time and mind.
41. **HAVE MORE AGENCIES AVAILABLE** for respite care.
42. **MORE HOURS** allotted, reasonable prices to take my children outside the home to meet other children, more grants.

43. Make them available to families who do not receive any financial assistance.
44. Give much **MORE TIME FOR RESPITE SERVICES** in a 12 month period.
45. **FOLLOW THE PALM BEACH COUNTY, FL PLAN** for providing respite care workers to families. The list of respite care workers/providers that was given to me was terrible. Disconnected numbers and people that never returned calls. The list was useless.
46. **MORE HOURS.**
47. They only give respite 7 days a year. **NEED TO GIVE MORE DAYS** especially if the parent plans on working.
48. More days for children.
49. Giving **MORE HOURS** to families. Otherwise, thank you for being there.
50. When there is an emergency for the family, my family, I can't go, because I need care for my son. I think there should be a place where you could leave your child for care in a safe place. Look into that, it would improve the services.
51. Provide, **SEND LISTS OF POSSIBLE PLACES TO GO THAT ARE NOT EXPENSIVE** - add 1 more week per year or **MORE HOURS.**
52. **INCREASING THE SPEED OF APPROVAL TIME.** Being able to fax or e-mail time sheets when submitting invoice.
53. Need more outing to take my child out.
54. **MORE HOURS**
55. Everything is okay
56. More group and therapy
57. **AVAILABILITY OF FUNDS**
58. June fine.
59. It's fine.
60. **A LITTLE MORE TIME.**
61. The caregivers could be more than your average babysitter.
62. **MORE RESPITE** for single mothers
63. **INCREASE THE LENGTH AND AMOUNT OF MONEY AND TIME SPENT**, therefore enabling more services to be rendered.
64. By responding to people need when they apply for help.
65. They could call on a regular basis to keep me on target about the program and also **HELP ME FIND REPSITE CARE PROVIDERS.**
66. Helping with school problems. Introducing to other children not on drugs or not smoking, etc.
67. OK now
68. Give a listing of recommended respite providers to families. I would like to involve my child-out of home respite care - possible Group home setting. Please **SEND ME INFORMATION.** I would like to take a vacation this year. July or August 2005.

69. Could give some relief to single parent of special needs child.
70. It is fine the way it is.
71. Respite should be provided for all children even when adopted without all the red tape, etc., applications, doctor's approval, screening.
72. It is great. No improvement needed.
73. I have custody of my 2 nephews who use the program and I think its great. I also have 2 of my own children and this provides me with some much "time" to myself.
74. **MAYBE THE HOURS COULD BE INCREASED.** When Christopher stays at the Villa he has to be there before 6:00 pm on Friday evenings, I have to pick him up by 3:00 pm on Sundays. Not long enough, suppose you are out of town. You would have to rush back to pick
75. **HAVE MORE SERVICES** available.
76. **PROVIDE BEHAVIORAL TECHNIQUES TRAINING TO RESPITE CARE WORKERS,** help parents find respite care help and provide guidelines to parents to help choose respite help.
77. respite for young children - not just summer camp
78. I am satisfied with respite.
79. We have only had 2 weekends. We are new to respite. One provider didn't seem to be prepared for severity of behaviors - more training for the respite family.
80. It is new to me right now, everything is very satisfactory so far. I have nothing to add at present, seems fine, needs no improvement.
81. It took 1 year to find a respite care family that would take my son. Surprisingly it was not due to mental health issues but it was due to the diabetes. **PROVIDERS DID NOT FEEL COMFORTABLE GIVING HIM INSULIN SHOTS.**

*Phrases in red, capitalized letters are themes or important points selected by the researchers.

**Appendix 4: The Demonstration Project Model:
A Model for Respite Services for Children
With a Disability in Maryland**

A Model for Respite Services for Children with a Disability in Maryland

The following description of a model for a respite services demonstration project for children with a disability in Maryland represents the consensus of the work group considering various options as components of the model. The model is presented in as generic terms as possible, drawing on real-life specifications learned throughout the feasibility study. Surveys, analysis of state regulations, and the expert knowledge of the Maryland Caregiver's Support Coordinating Council, the Rutgers project technical assistance team, and the Centers for Medicare and Medicaid Services staff were the primary sources of information.

In reviewing this document, it is important to note that the feasibility study is focused on all children with a disability and the primary family or relative/informal caregiver with whom the child lives. While some paid caregivers might need a "respite" period from their charge, these situations need to be addressed through contractual or other arrangements with the employing institution or agency. The target group for this feasibility study is children with serious emotional disturbance; however, the model is developed to be applicable to any category of child disability.

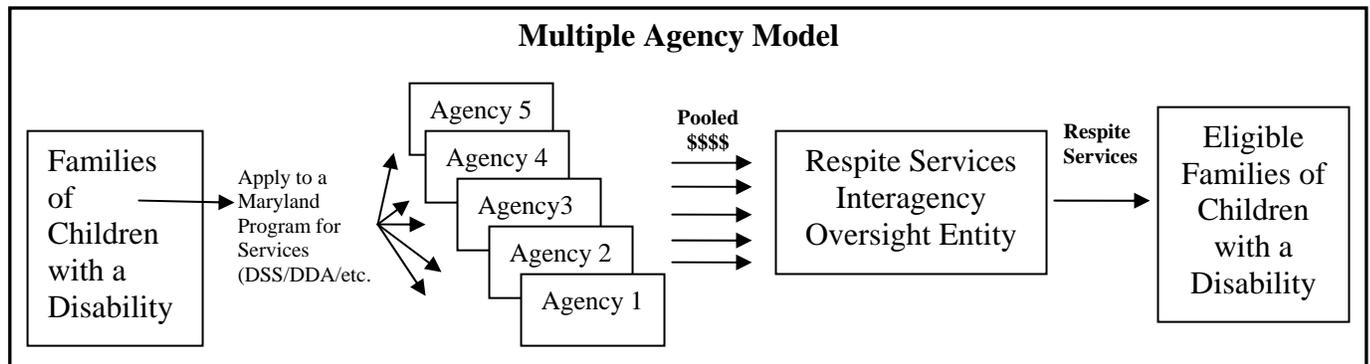
The components are:

- **Agency**—which organizational structure should administer the program
- **Application process**—consideration of ease for client and single point of entry/no-wrong-door
- **Funding approach**—state amendment, cost sharing (sliding scale/co-pay, premium, etc), waiver, etc.
- **Eligibility**—percent of federal poverty level, income, assets, category of disability/level of care, age, etc.
- **Provider selection and management**—qualifications, consumer control (selection, payment, termination, etc.), benefits, payment levels
- **Service limits**—quantity of service in regard to cost or time
- **Administrative issues**—waiting lists, termination, grievance, appeals
- **Evaluation**—consumer and provider satisfaction, measurement/benchmarks
- **CMS issues**—answers to questions posed to CMS regarding the study/model

Agency and Administrative Issues

The consensus was that a new agency not be created. The oversight of the demonstration would depend on whether the model would incorporate funds/clients for a single agency or multiple agencies. If a single agency approach is used, the agency would decide where in its current or modified infrastructure the new program would reside and how it would be managed. In the case of a single agency model, checks and balances would be embedded in the service delivery model to ensure that children in all categories of disability are included, and that the child disability that may be the focal population for the selected single agency does not become the preferred client. If a multi-agency model is selected, then a coordinating structure would be created in one of the existing agencies

to administer the program, with structured input from the partnering agencies. This new intra-agency entity would provide oversight and coordination without a new layer of bureaucracy.



The single agency and multiple agency models will vary in their governance structure. In the single agency scenario, the agency can decide where in its existing infrastructure the new service would fit, if in fact the service did not already have a home, as might be the case with MHA, DHR, or DDA. Restructuring might be required in regard to budget(s) (new fiscal accountability for federally matched funds), and may also require additional tasks or work areas to handle new structures such as evaluation activity, fiscal intermediary services (if included for a more consumer-directed model), and advisory board(s).

The multiple agency model would necessitate the creation or modification of an existing unit that would be accountable to an interagency oversight group. New administrative costs would be incurred in both approaches, but minimized so that the greatest amount of funding possible would be used for direct services. One of the greatest challenges will be to establish processes for the reallocation of funds between agencies. Options could include: an executive order issued by the governor, a legislative mandate with a formula to guide which agency would contribute and at what level, or an interagency agreement stating that agencies will voluntarily contribute at a level defined by themselves.

In Maryland, the process of pooled funds was utilized successfully in the 1980's with the creation of the State Coordinating Council for Residential Placement of Disabled Children, along with Local Coordinating Councils. The SCC and LCCs combined resources to enhance services to the target group of children through interagency coordination of services and interagency plans of care.

Application Process and Eligibility

Applying for respite services needs to be streamlined and incorporated into a single application process whether a single or multiple-agency approach is taken. If a single agency model is selected, that agency could decide if the application process is part of applying to a qualifying program or if the information from the qualifying program should be transmitted to the respite entity within the organization, seamlessly

and in a timely manner. Ultimately, the application process should not entail additional burden for the consumer and should be seamless within or among agencies. If possible, a universal application form, used to apply to any program, or after applying, used to access respite services, should be considered. The principles of “no-wrong-door”, where the consumer gets information and accesses services regardless of their point of entry, should be integrated into the process.

Waivers require that budget neutrality be demonstrated. This is typically done by stipulating that persons served would otherwise require (or be at risk for) institutionalization or require some other higher cost service; costs are then compared to per capita waiver costs. It would be difficult to consider respite services alone, but they could be bundled with other services that children with a disability need to live in the community. This is the case with six states that initiated waivers for children with Serious Emotional Disturbance (SED). So, this waiver would need to be reserved for children with a disability who have experienced (or are at risk of) out-of-home placement, who could live in the community with appropriate supports, including respite.

Up to 300% of poverty would be included under the waiver. Some respite services would be made available to “gray area” families, funded by state-only dollars, through a sliding fee scale that begins at 301% FPL. A critical decision point that remains is whose income should be considered to deem eligibility—the child alone, as in programs modeled after Katie Beckett laws, or the family, and, whether or not assets are to be considered (child’s and or family’s).

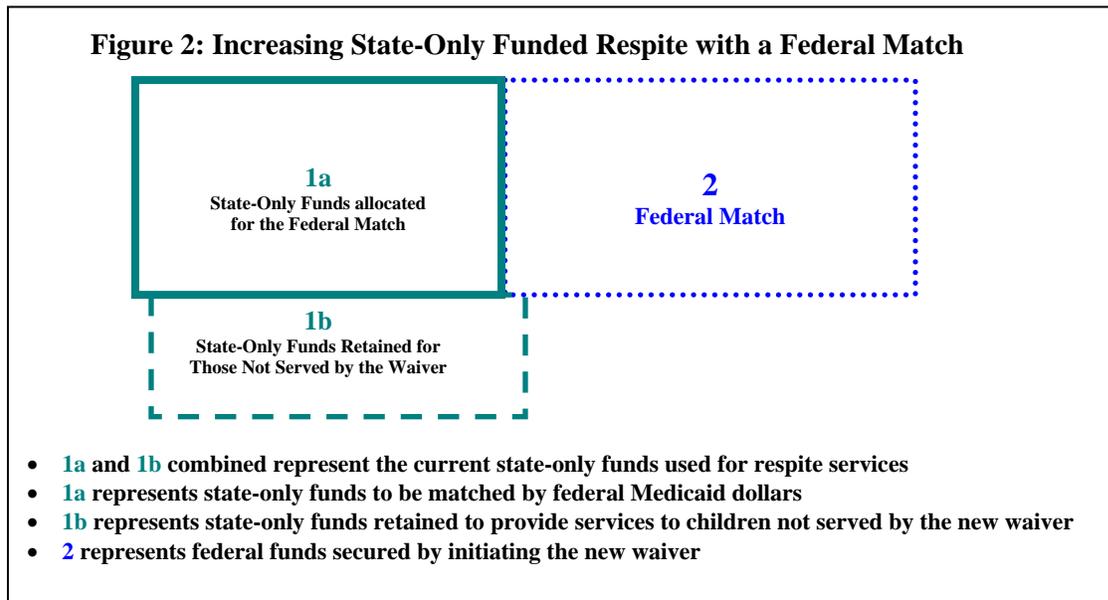
An assessment instrument is needed to measure family burden and stress¹¹, as well as the severity of the child’s disability to facilitate selection of families with greater need. Mechanisms need to be put in place to account for changes in the child’s or family’s situation that decreases their level of need for respite services, but it is extremely important not to remove respite services when the respite is the reason for the improvement in status. Families and children waiting for services should be assessed and given priority over those with much lower assessed need. Issues of service capacity and waiting lists need to be monitored so as to develop strategies for addressing unmet need.

Funding Approach

The funding stream for either approach (single or multiple agencies) entails the basic tenets of utilizing state-based funding in a Medicaid waiver to expand available dollars for the service through: 1) increasing the federal poverty level (FPL) limits, 2) securing a

¹¹ There are measurement tools to determine level of need for respite services. Combinations of such tools were used in Eric Bruns’ Vermont study of respite for children with emotional behavioral disorder (EBD) (2000). Measures used by Bruns included self-reported parental/caregiver stress, family health/functioning, negative child behavior, and predictive aspects of the need for out-of-home placement and crisis intervention. Bruns, Eric J., John D. Burchard. 2000. “Impact Of Respite Care Services For Families With Children Experiencing Emotional And Behavioral Problems” *Children’s Services: Social Policy, Research & Practice*. Vol. 3, Issue 1:39.

federal match, and 3) reserving some state respite funds for individuals who do not qualify for the waiver. (See Figure 2.)



The proposed model increases the available money for children’s respite services by doubling a portion of the current state-only respite funds through an influx of federal matching dollars, while reserving a portion of funds to cover children not eligible for the new Respite Waiver (i.e., they are over the 300% FPL). State-only funds could be maximized by consideration of cost sharing through co-payments or developing a sliding fee scale, based on family income and/or assets.

In the multiple agency approach, a portion of each agency’s state funds would be pooled for the purposes of the waiver and eligible children from each agency would receive services through the agreed-upon intra-agency respite services entity.

Consideration should be given for inclusion of agencies that may not currently provide a respite service or /benefit. It is known, for instance, that some children are multi-agency involved. Typical of this scenario is the child with mental health problems who is also involved with the juvenile justice system. Respite services could potentially be used as a step-down or diversion service.

Financial Model for a Medicaid Waiver Respite Service in Maryland

Currently, is difficult to determine the actual cost of providing respite services. Funding through most programs include consideration of administrative cost on a per unit of service basis, incorporating into the rates requirements such as outreach, provider recruitment, and training, etc. Varying approaches in the Maryland programs that offer respite services make it difficult to know the actual number of dollars and units of service rendered using a standardized definition or tracking system.

Therefore, for the purposes of this feasibility study, assumptions (see Appendix 1 for a full description of the assumptions) were established upon which to build a financial model that reflects the template in Figure 2 that describes how state only funds could be distributed to a tiered application of Medicaid Waiver respite services and state-only funded respite services. Table A, below, shows how state only funding would provide respite services with a set of assumptions regarding provider costs at three levels of credentialing/skill.

Fiscal Model for Child Respite Services

Table A: Current State Only Program

			\$/Hour	State Budget	FMAP Budget	Total Budget	Hrs. in Budget	Children Served	
Level I ¹²	State Only Program	In-Home ¹³	\$9	\$83,333	\$0	\$83,333	9,259	39	68
		Out-of-Home	\$12	\$83,333	\$0	\$83,333	6,944	29	
Level II	State Only Program	In-Home	\$18	\$166,667	\$0	\$166,667	9,259	39	72
		Out-of-Home	\$21	\$166,667	\$0	\$166,667	7,937	33	
Level III	State Only Program	In-Home	\$27	\$250,000	\$0	\$250,000	9,259	39	73
		Out-of-Home	\$30	\$250,000	\$0	\$250,000	8,333	35	
Tot./Avg.			\$19.61	\$1,000,000	\$0	\$1,000,000	50,992	212	212

Table B: Shifting 75% of State Only Program to Waiver

			\$/Hour	State Budget	FMAP Budget	Total Budget	Hrs. in Budget	Children Served	
Level I	State Only Program	In-Home	\$9	\$20,833		\$20,833	2,315	10	118
		Out-of-Home	\$12	\$20,833		\$20,833	1,736	7	
	Waiver Program	In-Home	\$9	\$62,500	\$62,500	\$125,000	13,889	58	
		Out-of-Home	\$12	\$62,500	\$62,500	\$125,000	10,417	43	
Level II	State Only Program	In-Home	\$18	\$41,667		\$41,667	2,315	10	125
		Out-of-Home	\$21	\$41,667		\$41,667	1,984	8	
	Waiver Program	In-Home	\$18	\$125,000	\$125,000	\$250,000	13,889	58	
		Out-of-Home	\$21	\$125,000	\$125,000	\$250,000	11,905	50	
Level III	State Only Program	In-Home	\$27	\$62,500		\$62,500	2,315	10	128
		Out-of-Home	\$30	\$62,500		\$62,500	2,083	9	
	Waiver Program	In-Home	\$27	\$187,500	\$187,500	\$375,000	13,889	58	
		Out-of-Home	\$30	\$187,500	\$187,500	\$375,000	12,500	52	
Tot./Avg.			\$19.61	\$1,000,000	\$750,000	\$1,750,000	89,236	372	372

Provider Selection and Management

As a social service-type model, it is desirable that this demonstration model provide as much flexibility and consumer choice as possible. Current programs that include respite

¹² 'Level' here does not imply a child's/family's priority for respite services, but rather matches the level of severity of the child's disability with an appropriate provider type.

¹³ Out-of-home respite services refers to situations where the child is removed from the home for a facility stay, usually overnight or longer. It does not reference those situations where the child is taken from the home for an outing. The difference in cost between out-of-home and in-home respite is thought to accommodate facility costs.

as a service run the gamut from very prescribed requirements for providers (certifications, licensure, bonding, etc.) to any person the family deems appropriate, sometimes outside of a parent or spouse or immediate family member. For the purposes of the demonstration, some provider selection processes may remain restrictive for children that have serious health or /mental health problems that require special skill sets for their care, meeting the requirements of some programs for medical necessity. If possible, families could be given the flexibility to opt-out of the more restrictive requirements. Agency concerns regarding liability need to be considered; this could be addressed by a signed release making the parent/custodian responsible for provider qualifications when they opt-out of the more controlled options for provider selection.

Qualifications need to be specified on an individual provider, agency, and facility basis in the case of overnight care.

Individual Provider:

- Criminal background checks
- Protective service clearance (including ‘non-criminal’ indicators)
- Skill set/expertise/education/certification or licensure to match child level-of-care needs.
- Include all immediate household members

Agency:

- Bonding
- Agency deeming a person as a “qualified care worker”
- Emergency coverage plan

Facility:

- Physical access, utilities (heating/cooling, phone), functional aspects such as bathroom and sleeping facilities, food storage and preparation, fire and safety

Consumer choice should be included at the greatest level desired by the consumer, while still providing supports for all aspects of provider acquisition and management (hiring, training, paying, evaluating, firing, etc.).

Evaluation

Evaluation is important to any new process and a requirement of this feasibility study. Identification of appropriate tools for data collection with agreed-upon elements to measure baseline status and interim findings as well as post-implementation outcomes is needed. Basic satisfaction instruments can measure family experiences, and child and family well-being measures might provide important outcome indicators.

Appendix 1: Assumptions for Child Respite Fiscal Model

1. \$1 million split 75% for waiver and 25% for State Only Program
2. 10% for administrative costs waiver only (training, family support, outreach, provider recruitment)
3. State only funds for services only (no administrative costs); for “gray area” (>300% FPL)
4. 300% FPL for waiver program
5. max hrs. = 240 hours per year, all levels
6. Level I—\$9/hr (companion only)
 - a. Level II--\$18/hr (companion, but child with special needs)
 - b. Level III--\$27/hr. (special training/experience required)
7. Distribute funds disproportionately among the three levels of care to account for the greater cost in successively higher levels, and within each level of care, split it evenly for in- and out-of-home

Child’s Disability Severity	Current Relative Cost *	New Relative Cost**	Location of Services***	Estimated Costs	Percent of State +_FMAP to Each Level
Level I	1	.75	In-Home	\$9/hr.	14.58%
			Out-of-Home	\$12/hr.	
Level II	2	1	In-Home	\$18/hr.	25%
			Out-of-Home	\$21/hr.	
Level III	3	3.25	In-Home	\$27/hr.	52.08%
			Out-of-Home	\$30/hr.	

*The assumption is that children with higher levels of severity incur higher cost per hour for respite.

** FMAP would be distributed disproportionately to consider the relative higher costs of children with more severe disabilities. The disproportionate distribution also considers the greater system cost of these children being institutionalized, a possible outcome that can be partially avoided through respite services.

*** Assumption that out-of-home placement is more costly, possible due to facility costs, transportation, etc.