

RHODE ISLAND DEPARTMENT OF HUMAN SERVICES

LEVEL OF CARE CRITERIA

**MEDICAL ASSISTANCE ELIGIBILITY UNDER
THE KATIE BECKETT OPTION**

AUGUST 1, 2006

TABLE OF CONTENTS

1.0	INTRODUCTION	
1.1	Rationale	
2.0	THE TEFRA/KATIE BECKETT OPTION	
2.1	Background	
2.1.1	Subsequent Developments	
3.0	STATE OF RHODE ISLAND KATIE BECKETT ELIGIBILITY POLICY	
3.1	Summary of Institutional Level of Care	
3.1.1	Hospital (Appendix A)	
3.1.2	Psychiatric Hospital (Appendix B)	
3.1.3	Intermediate Care Facility for Mentally Retarded (Appendix C)	
3.1.4	Nursing Facility (Appendix D)	
4.0	RHODE ISLAND ELIGIBILITY PROCESS	
4.1	Application	
4.2	SSI Disability Determinations	
4.3	Institutional Level of Care Determinations	
4.4	Redeterminations for Continued Katie Beckett Eligibility	
5.0	LEVEL OF CARE CRITERIA: CONSIDERATIONS RELEVANT FOR ALL APPLICANTS	
5.1	Specialized Interventions	
5.2	Functional Daily Living Skills	
5.3	Safety/Safety Awareness	
5.4	Health/Skilled Nursing Services	
5.5	Family Impact	
5.6	Hospitalization/Other Placement	
APPENDIX A	Level of Care Criteria: Hospital	
APPENDIX B	Level of Care Criteria: Psychiatric Hospital	
APPENDIX C	Level of Care Criteria: Intermediate Care Facility For Mentally Retarded	
APPENDIX D	Level of Care Criteria: Nursing Facility	
APPENDIX E	Clinical Redetermination Guidelines	

1.0 INTRODUCTION

The United States Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) gave states the option to extend Medicaid eligibility to children with disabilities when they are cared for at home rather than in an institutional setting. Section 134 (a) of TEFRA authorizes states to use a separate process for determining the eligibility of children with disabilities who, while living at home with their families, are unable to obtain Medicaid because the family income and assets exceed allowed amounts. This process is the defining feature of what is commonly known as the Katie Beckett Option. This document presents the criteria used by DHS clinicians to determine if a child meets the institutional level of care required for Katie Beckett eligibility.

1.1 Rationale

In Rhode Island, the Department of Human Services (DHS) is the designated State agency for Medicaid. As such, DHS is charged with the responsibility to see that all policies and procedures pertaining to the Medicaid program conform to Federal law.

2.0 THE KATIE BECKETT OPTION

Katie Beckett is the name of the child with special needs whose parents petitioned the Federal government for her to receive Medicaid services at home instead of in a hospital. Prior to TEFRA, if a child with disabilities lived at home, the parent's income and resources were automatically counted (deemed) as available for medical expenses. If the same child was institutionalized for greater than 30 days, only the child's income and resources were counted, increasing the likelihood that a child would qualify for Medicaid. This often forced families to institutionalize their children to get them the complex medical care their conditions required. Under the Katie Beckett Option, financial qualification is based solely on the child's income and resources.

Statutory provisions for Medicaid eligibility under this option are found in Section 1902 (e)(3) of the Social Security Act and are listed below. This is the legal authority for the state of Rhode Island to provide Katie Beckett optional coverage. In order for a child to establish Medicaid eligibility under this option, it must be determined that:

- The child is 18 years of age or younger and living at home
- The child meets Federal criteria for childhood disability
- The child requires a level of care provided in a hospital, nursing facility or intermediate care facility for the mentally retarded (ICF/MR)
- It is appropriate to provide care for the child at home
- The estimated cost of caring for the child outside of the institution is not expected to exceed the estimated cost of treating the child within an institution

In order for the State to qualify for Federal funding, DHS must ensure that eligibility is determined in conformance with the above requirements.

2.1 Background

Prior to July 2004, the Department of Mental Health, Retardation and Hospitals (MHRH) and two divisions within DHS (Long Term Care and Healthcare Quality, Financing, and Planning) shared responsibility for the Katie Beckett eligibility process. Overall responsibility was then transferred to the Center for Child and Family Health (CCFH), the center within DHS that administers Medicaid benefits for children with special health care needs.

To insure a consistent process, CCFH developed guidelines for determining Katie Beckett eligibility. These guidelines (level of care) were promulgated in October of 2005, and a public hearing was held in November of 2005. As a result of this public hearing, the draft guidelines were withdrawn. Subsequently, a workgroup of parents, advocates, state representatives, clinical specialists and staff from CCFH met over several months to review and revise eligibility criteria. This document is a result of that collaboration.

2.1.1 Subsequent Developments

In January of 2006, DHS established a centralized unit within CCFH for determination of Katie Beckett eligibility. Social caseworkers and a Special Eligibility Review Team (SERT) that includes a physician, licensed psychologist, and a registered nurse staff the unit. The social caseworkers assist families applying for Katie Beckett. The SERT reviews all of the clinical materials for the determination of Katie Beckett eligibility. Responsibilities of the Katie Beckett unit include outreach and education to families, and providing support during the application process, and ensuring that the process of determining Medicaid eligibility is fair and non-biased.

Information about the Katie Beckett Option is available on the DHS website (www.dhs.ri.gov) as well as by calling the DHS Info-line (462-5300) and requesting the Katie Beckett Unit. Consistent with CCFH practices, multilingual resources for families are provided via phone (DHS Info-line), TDD, and written information.

3.0 STATE OF RHODE ISLAND KATIE BECKETT ELIGIBILITY POLICY

In Rhode Island, the Katie Beckett Option is reserved for children with disabilities under the age of 19 who live at home. A child eligible through the Katie Beckett Option has access to the same set of services that are available to children who are Medicaid eligible.

To qualify for Medical Assistance through the Katie Beckett Option, the following criteria must be met:

- Child is under 19 years of age or younger and living at home
- Child is a Rhode Island resident and a United States citizen, or an eligible non-citizen in accordance with DHS policy Section 0300.25.05, 0304.05.10.05, and 0316.05

-
- Child meets Federal criteria for childhood disability. Under Title XVI of the Social Security Act, a child under age 19 will be considered disabled if he or she has a medically determinable physical or mental impairment or combination of impairments that cause(s) marked and severe functional limitations, and that has lasted or can be expected to last for a continuous period of not less than 12 months, or can be expected to result in death. A complete description of the Social Security Administration requirements can be found in *Disability Evaluation Under Social Security* (also known as the Blue Book). Please refer to: SSA Pub. No. 64-039; January 2005
 - As provided in 42 Code of Federal Regulations §435.225 (b)(1), the child must require the level of care provided in a hospital (or psychiatric hospital), intermediate care facility for the mentally retarded (ICF/MR), or nursing facility. This means that, without appropriate interventions and supports (both at home and in the community), the child would either reside in an institution or be at immediate risk for institutional placement
 - The Medicaid costs of caring for the child at home do not exceed the Medicaid cost of appropriate institutional care

3.1 Summary of Institutional Level of Care

Facility-specific institutional level of care criteria is found in Appendices A-D. The following is a brief and general description of each type of facility for informational purposes.

3.1.1 Hospital (Appendix A)

Hospital level of care is appropriate for children who continuously require the type of care ordinarily provided in a hospital, and who, without these services, would require frequent hospitalizations. This level of care is highly skilled and provided by professionals in amounts not normally available in a skilled nursing facility but available in a hospital.

3.1.2 Psychiatric Hospital (Appendix B)

Psychiatric hospital level of care is appropriate when the intensity of the child's mental health needs are so severe that, without proper home and/or community interventions, the child would be at immediate risk for hospitalization.

3.1.3 ICF/MR (Appendix C)

ICF/MR level of care is appropriate for individuals who require the type of active treatment typically provided by a facility whose primary purpose is to furnish health and rehabilitative services to persons with mental retardation or related conditions including developmental disabilities.

3.1.4 Nursing Facility (Appendix D)

Nursing facility level of care is appropriate for children who do not require acute hospital care, but who, on a regular basis, require licensed nursing services, rehabilitation services, or other health-related services ordinarily provided in an institution. Nursing facility level of care is usually inappropriate for children with behavioral health needs, mental illness or mental retardation, unless the needs associated with these conditions are secondary to a more acute physical disorder.

4.0 RHODE ISLAND ELIGIBILITY PROCESS

4.1 Application Procedures

To initiate an application for the Katie Beckett Option, parents or guardians can call the Katie Beckett Unit at CCFH to request information about the eligibility process, obtain an application, and/or arrange for an appointment with a social caseworker. The following signed documents are required by CCFH to begin the process of determining level of care eligibility:

- *Katie Beckett Application and Recertification Form*
- *Katie Beckett Parent/Guardian Questionnaire*

CCFH must render an eligibility decision within 90 days of receipt of the above-referenced forms. During this 90-day period, the social caseworkers from the Katie Beckett Unit may require additional information.

4.2 Social Security Income (SSI) Disability Determinations

SSI disability is defined as a medically determinable physical or mental impairment that results from anatomic, physiological, or psychological abnormalities. A physical or mental impairment must be established by medical evidence consisting of signs, symptoms, and laboratory findings. The SERT at CCFH reviews all relevant material to determine if a child meets Federal disability criteria.

4.3 Institutional Level of Care Determinations:

The SERT reviews all necessary documentation to determine if a child meets an institutional level of care. The following information is required:

- The Katie Beckett Parent/Guardian Questionnaire
- Documentation from providers of care that address the child's condition, functioning and treatment needs
- Documentation of supportive services, if provided, such as special education, occupational therapy, physical therapy, and speech/language therapy

The SERT **may** also request additional information including:

- Medical Evaluations:
 - Pediatrician Evaluation or Relevant Records
 - Hospital Clinic Notes
 - Hospital Discharge Summaries
 - Neurological Evaluation
 - Psychological Evaluation with IQ
 - Psychiatric Evaluation including Global Level of Assessment (GAF) or Children’s Global Level of Assessment (CGAF)
 - Developmental Evaluation
 - Physical Therapy Evaluation and Treatment Summary
 - Occupational Therapy Evaluation and Treatment Summary
 - Speech and Language Evaluation and Treatment Summary

- Other:
 - Educational Evaluation
 - Individual Educational Plan (IEP)
 - Individual Family Service Plan (IFSP)
 - Other Specialty Evaluations
 - CEDARR Family Center Care Plan

4.4 Redeterminations for Continued Katie Beckett Eligibility

Medicaid requires that all recipients be re-evaluated for financial and clinical eligibility on a periodic basis. DHS policy requires that financial redeterminations be made once a year. At the time of the initial determination, a date is established for redetermination of clinical eligibility. Typically, this is three years from the initial review. However, at the time of the initial determination, the SERT may, on a case-by-case basis, alter the period of eligibility (Appendix E).

5.0 LEVEL OF CARE CRITERIA: CONSIDERATIONS RELEVANT FOR ALL APPLICANTS

Information that specifically addresses the nature and extent of a child’s condition(s) will be reviewed with respect to functional abilities and overall medical, developmental and/or behavioral health presentation. The needs of the family in caring for their child at home and in the community are considered when determining level of care. These criteria consider a broad range of factors including but not limited to: the severity of the child’s condition; the intensity of the services required; and the extent to which various other medical issues mitigate or exacerbate the child’s condition or service needs.

The following factors are evaluated in determining all institutional levels of care: specialized interventions; functional daily living skills; safety and safety awareness; health and nursing

services; family impact; and other placement considerations. A child need not meet all factors to be eligible, but all factors, including how the child's special needs impact the family, will be considered to gain a full understanding of the level of care required. Needs noted under any of these factors are relevant to eligibility for all applicant children.

5.1 Child Requires or is Receiving Specialized Interventions

This incorporates the child's need for a combination of special, multidisciplinary interventions (e.g., medical, educational, psychological, physical therapy, occupational therapy, speech/language therapy, nutrition, or other health-related services) and family supports or specialized services that are of extended duration, and are individually planned and coordinated. Interventions are directed towards:

- The acquisition of the behaviors necessary for the child to function with as much self-determination and independence as possible
- The prevention of deceleration, regression, or loss of optimal functional status. The child requires an individualized program of training, therapies, and services designed to assist the child to achieve, improve, or maintain the highest possible level of independence in daily living
- The provision of treatment, family support, and/or specialized assistance that continues throughout the child's daily routine (home, school, and community)
- The use of active treatment to support a child who has a degenerative and/or terminal condition

5.2 Functional Daily Living Skills

The purpose of this section is to understand a child's ability to function independently from a parent or caregiver while engaged in performing activities of daily living. Consideration is given to the child's age and the usual expected developmental level of functioning for his particular age group. The process of defining severity of functioning takes into account all documented information from parents, caregivers, teachers, professionals and others that have evaluated the child. In understanding the child's functional ability, no single piece of information will be taken in isolation (e.g., test scores) when determining severity of impairment. The degree of developmental delay, cognitive/communicative function, social function, personal function, and health function is reviewed.

In defining the severity of functional limitations, Federal regulations refer to (see: Disability Evaluation under Social Security) "marked" as more than moderate but "less than extreme." A marked limitation may arise when several activities or functions are impaired, or even when only one is impaired, as long as the degree of limitation interferes with the ability to function independently, appropriately, effectively, and on a sustained basis at home, school, and in the community. "Extreme" limitation means a limitation that is "more than marked" or, in other words, very seriously interferes with day-to-day functioning.

A child is considered to have functional limitations when *extreme in one or marked in two or more* of the following major life activities:

- Self-care: the ability to complete daily activities enabling a child to meet basic life needs for food, hygiene and appearance
- Learning-Cognition: the ability to acquire new behaviors, perceptions, and information and to apply this knowledge to new situations
- Social: the ability to establish and maintain age appropriate social relations including play
- Language-Communication: the ability to receive and express language enabling the child to both understand and communicate ideas and information to others
- Mobility: the ability to use fine and gross motor skills, and to move from one place to another with or without mechanical aids
- Self-Direction: the ability to make decisions and take control over behavior, emotions, and personal life
- Safety: the ability of a child to be safe may reflect different concerns depending on the medical, developmental or psychiatric condition(s) of a child. A child's well-being is threatened when he or she is unaware of safe behavior and the potential consequences of acting in an unsafe manner. Safety concerns may also become evident for a child whose physical limitations and/or medical fragility require an intensity of care that, if not met, would be life threatening
- Health and Physical Well-Being: the ability of the child to experience optimal health and sustain health habits

5.3 Safety/Safety Awareness

Safety and Safety Awareness means that due to the child's developmental, behavioral, or medical condition(s), the child is at risk for harm to self or others. The child demonstrates a lack of consistent behavioral controls and age-appropriate decision-making or judgment. This also includes a child whose medical fragility requires an intensity of care to maintain life.

5.4 Health/Skilled Nursing Services

Skilled nursing services are provided to children living at home who have significant medical needs and require complex nursing treatments, personal care, specialized therapy, and medical equipment to enhance or sustain their lives. The child's daily routine is substantially altered by the need to complete these specialized, complex, and time consuming treatments. They may be diagnosed with neuromuscular disease, cardiac or respiratory disease, cancer, metabolic disorders, or any number of medical conditions that threaten their ability to survive without

proper supportive care. These children have chronic health care needs that require health and related services beyond those required by children generally.

5.5 Family Impact

The ability of the family to care for the child and meet their child's needs will be considered. The opportunity to share this information is provided in the *Katie Beckett Parent/Guardian Questionnaire*.

5.6 Other Placement Considerations

There may be a variety of causes for placement of a child in a structured setting, which may or may not be directly related to impairment severity and functional ability. Placement in a structured setting in and of itself does not equate with finding of disability. As with all other considerations used in determination of level of care, the SERT assesses *severity* of functioning with regard to the degree of impairment and the child's functional ability.

Appendix A
Level of Care Criteria
Hospital

Hospital level of care is appropriate when a child requires an extensive array of health care services throughout the day, which may include:

- Daily skilled medical treatment that is more complex than nursing facility level of care due to an unstable medical condition
- Skilled observation multiple times during a 24-hour period due to health needs and the potential for status changes that could lead to rapid deterioration or life-threatening episodes
- Skilled assessment and intervention multiple times during a 24-hour period to maintain health and prevent deterioration that includes:
 - Medical monitoring, assessment, and intensive medication regimen for the child's medical condition
 - Recognition of changes in the child's condition that require prompt interventions to avert complications
 - Provision of hands-on comprehensive medical interventions and treatments
 - Modification of treatment plans throughout the day based on the child's condition

Appendix B Level of Care Criteria Psychiatric Hospital

Psychiatric hospital level of care is appropriate when the child's behavioral health condition causes significant disruption in the child's ability to function at home, school or in the community. The intensity of the child's behavioral health needs is so severe that, without proper interventions in the home and/or community, the child would be at immediate risk for hospitalization. This may relate to failed outpatient treatment or barriers to care that would otherwise have improved a child's functioning. A child is considered to have functional limitations when *extreme in one or marked in two or more* of the following:

- The child demonstrates a serious deterioration in the ability to safely and adequately care for himself (e.g., unable to initiate and maintain grooming, hygiene, toileting, or eating); or
- The child exhibits thought processes that are impaired (e.g, distorted perceptions, poor judgment, inability to distinguish reality, or poor communication) and interfere significantly with daily life; or
- The child displays severe and persistent dysregulated mood and/or severe disturbance of affect. Emotional control is disruptive and incapacitating such that emotional responses are inappropriate most of the time; or
- The child exhibits a serious and imminent risk of harm to self or others due to a psychiatric illness, as evidenced by:
 - Recent or history of suicidal ideation
 - Recent or history of suicide attempt
 - Recent or history of self-mutilation that is medically significant and dangerous
 - Recent or history of assaultive behaviors that can lead to serious injury to others
 - Recent or history of serious physically destructive acts
- The child demonstrates a chronic destructive pattern such as repeated unprovoked violence toward family members that severely limits his functioning in the family

Appendix C
Level of Care Criteria
Intermediate Care Facility for Mentally Retarded (ICF/MR)

ICF/MR level of care is appropriate for individuals who require the type of active treatment typically provided by a facility whose primary purpose is to furnish health or rehabilitative services to persons with mental retardation or related conditions (42 Code of Federal Regulations §440.150).

42 Code of Federal Regulations §483.440 (a) and (b) defines active treatment as “aggressive, consistent implementation of a program of specialized and generic training, treatment, health services, and rehabilitative services that is directed toward: a) the acquisition of behaviors necessary for the child to function with as much self determination and independence as possible; and b) the prevention or slowing of regression or loss of current optimal functional status.” The need for these services must be on a continuous basis.

The degree of structure, supervision, training and/or supports necessary to ensure safety and promote attainment of objectives is equal to that which would be provided in an ICF/MR. For young children, consideration is given to the child’s age and the usual expected developmental level of functioning for his/her particular age group.

Prior to determining whether or not an individual meets ICF/MR level of care, they must meet criteria for developmental disabilities, mental retardation, and/or related conditions including autism spectrum disorders. DHS uses the following statutes to define developmental disabilities, mental retardation and related conditions.

Definition of Developmental Disabilities:

The term “developmental disabilities” means “severe and chronic delays” that are manifested before the individual attains the age of 22 years and are typically evident during infancy or early childhood. Developmental disabilities can be the result of a congenital or acquired condition.

- The *U.S. Code Definition of Developmental Disabilities* states that, “Children with a developmental disability or mental retardation experience substantial impairments of general intellectual functioning and adaptive behavior requiring continuous supervision, monitoring and redirection of behaviors to a greater degree than other children in the child’s particular age group. There is a need for continuous and active treatment for medical, behavioral or developmental needs including the capacity to successfully complete activities of daily living. Children with developmental disabilities demonstrate substantial functional limitations in three or more of the following major life activities: Self Care, Receptive and Expressive Language, Learning, Mobility, Self-Direction, Capacity for Independent Living, and Economic Self-Sufficiency.”
- 42 Code of Federal Regulations §1385.3. Developmental disability is defined as a “severe, chronic disability of a person 5 years of age or older, which is attributable to a mental or physical impairment or combination of mental and

physical impairments; is manifested before the person attains age 22; is likely to continue indefinitely; results in substantial functional limitations in three or more areas of major life activity: 1) self-care; 2) receptive-expressive language; 3) learning; 4) mobility; 5) self-direction; 6) capacity for independent living; and 7) economic self-sufficiency; and reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are of lifelong or extended duration and are individually planned and coordinated." *The Federal definition also states that developmental disability can also be applied to infants and young children from birth to age 5 "who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided."*

Definition of Mental Retardation:

Mental retardation is a particular state of functioning that begins in childhood and is characterized by limitations in both intelligence and adaptive skills.

- The American Association on Mental Retardation defines mental retardation as “a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18. A complete and accurate understanding of mental retardation involves realizing that mental retardation refers to a particular state of functioning that begins in childhood, has many dimensions, and is affected positively by individualized supports. As a model of functioning, it includes the contexts and environment within which the person functions and interacts and requires a multidimensional and ecological approach that reflects the interaction of the individual with the environment, and the outcomes of that interaction with regards to independence, relationships, societal contributions, participation in school and community, and personal well being (*American Association on Mental Retardation, 2002*).”
- 34 *Code of Federal Regulations* §300.7(c)(6). The Individual with Disabilities Education Act (IDEA) defines mental retardation as “. . . significantly sub-average general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance.”

Definition of Related Conditions:

42 *Code of Federal Regulations* §435.1009. Related conditions is defined “as a condition, other than mental illness, which is found to be closely related to mental retardation because it is likely to last indefinitely, requires similar treatment and services, constitutes an impairment of general intellectual functioning, and results in substantial limitations in three or more of the following: self-care, understanding and use of language, learning, mobility, self direction, and capacity for independent living.”

Appendix D Level of Care Criteria Nursing Facility

A nursing facility level of care is appropriate when the child requires complex skilled nursing care or comprehensive rehabilitative interventions throughout the day including the following:

- The child requires specialized professional training and monitoring beyond those ordinarily expected of parents
- The child requires skilled observation and assessment several times daily due to significant health needs
- The child has unstable health, functional limitations, complicating conditions, cognitive or behavioral conditions, or is medically fragile such that there is a need for active care management
- The child's impairment substantially interferes with the ability to engage in everyday activities and perform age appropriate activities of daily living at home and in the community, including but not limited to bathing, dressing, toileting, feeding, and walking/mobility
- The child's daily routine is substantially altered by the need to complete these specialized, complex and time consuming treatments and medical interventions or self-care activities
- The child needs complex care management and/or hands on care that substantially exceeds age appropriate assistance
- The child needs restorative and rehabilitative or other special treatment

Appendix E

Clinical Redetermination Guidelines

At the time of the initial clinical determination, both the severity of the child's condition and prognosis are reviewed. In each instance, the child's medical, physical, psychological, and developmental needs are assessed. At this time, the clinical re-determination date is established. Typically, this is three years from the initial clinical review. However, for continued eligibility, the child must meet the level of care criteria as discussed in this document. Therefore, for some children, the periodicity of eligibility will be more or less than three years. The SERT uses the following criteria in these cases:

- A period of eligibility more than three years may be appropriate for a child with a long-term disabling condition(s) that is not expected to change within three years

- A period of eligibility less than three years may be appropriate for a child with an acute condition that is expected to improve or resolve within three years

Refer to Section 4.4 regarding overall requirements for redetermination of Katie Beckett eligibility.