Review of Progress in Developing the System of Care for Children with Special Health Care Needs

CEDARR Family Centers
A Five-Year Program Review

Rhode Island Department of Human Services
Center for Child and Family Health

August 2006

<u>Vision Statement</u>:

"All Rhode Island children and their families will have an evolving, family-centered, strength based system of care, dedicated to excellence, so they can reach their full potential and thrive in their own communities."

The Leadership Roundtable on Children with
Special Health Care Needs (1999)

EXECUTIVE SUMMARY

Purpose of Report

Over the past five years Rhode Island has undertaken a series of program steps to develop an enhanced and comprehensive system of care for families of children with special health care needs. In this report, the Department of Human Services Center for Child and Family Health focuses upon the goal put forth by the Rhode Island Leadership Roundtable for Children with Special Health Care Needs in 1999: ***"the development of a model, family-centered delivery system for children with special health care needs"***. What has been our State's progress to date in realizing this goal? To measure our progress, we pose the following questions:

1. Do the newly developed programs established as a result of the Leadership Roundtable reach families in need?
2. Has the concept of "family-centeredness" been embedded in the development of programs that partner tangibly and effectively with families?
3. Have the CEDARR Family Centers attained the performance levels set forth in the CEDARR certification standards?
4. Has Rhode Island achieved a comprehensive system of care for children with special health care needs?

Within this Report, the Department of Human Services provides an overview of a portion of the quantitative and qualitative data, which are available so that we may begin to answer these pivotal questions as we move forward.

Background

On April 14, 1999, the "Leadership Roundtable on Children with Special Health Care Needs" issued the following vision statement:

> *All Rhode Island children and their families will have an evolving family-centered, strength-based system of care, dedicated to excellence, so that each child can reach their full potential and thrive in their own communities.*

CEDARR Family Centers were envisioned as the first phase towards the ultimate goal of ***delivering family-centered, strength-based services to children and their families in the least restrictive, most appropriate setting.***

The CEDARR Initiative was designed to advance a more positive family-centered system of care, encourage clinical excellence, improve health outcomes, and promote overall cost-effectiveness for children with special medical, behavioral, or developmental health care needs. Key to this is partnering with parents to better secure and effectively use the State's system of existing health, education, and social services and to provide useful resources about family support groups, parent advocacy organizations, community resources, and special education services.

Certification standards were developed in May 2000 in collaboration with representatives from the Leadership Roundtable and members of the CEDARR Interdepartmental Team (RI Department of Children Youth and Families (DCYF), RI Department of Education (RIDE), and RI Department of Health (DOH)). CEDARR certification standards stipulate core requirements addressing the CEDARR Family Center's administration, organizational structure, program approach, service delivery system, quality assurance, and organizational capability.

In 2001 the first CEDARR Family Center (About Families CEDARR) opened its doors and began serving families. Since that time services have been provided to over 3,400 children and families.

CEDARR Performance in 2006

A review of CEDARR Family Center family surveys conducted by the Department of Human Services in 2003 and 2006, and the results of the CEDARR Chart Audit in 2006 show that movement towards achieving the goals stated in Leadership Roundtable Vision Statement has occurred as a result of the CEDARR Initiative. While further progress is needed, CEDARR Family Centers have made strong strides in incorporating family-centeredness into their programming, and in providing the level of service required in the Certification Standards. The following two tables summarize these results.

Table 1: Selected results of CEDARR Family Surveys 2003 and 2006

Survey Statement	% Positive Responses 2003	% Positive Responses 2006
I was part of the Team making decisions about my Family	89 %	87 %
CEDARR staff were sensitive to my language and cultural beliefs	97%	N/A
The people at CEDARR treated me with respect	97%	N/A
CEDARR staff were available at times that were convenient	92%	N/A
The CEDARR assessment and plans accurately described my child's history and needs	N/A	85%
The goals included in the CEDARR documents were appropriate and met my child and family's needs	N/A	82.%
I would use the services of this CEDARR again	81%	81%
I would recommend CEDARR to my family or friends	78%	81%

N/A= Question not asked in survey conducted that year

Table 2: Selected Performance Measures from CEDARR Chart Audit 2006

Standard to be Met	Percentage of Records in Compliance (by having documentation)
Does the Initial Family Assessment (IFA) document the family's strengths, supports, circumstances, & needs?	91%
Does the Family Care Plan show evidence of the family's involvement in the plan's development?	90%
Was the Initial Family Contact started within 14 days if the request was routine in nature?	78%
If the request was urgent, was crisis-follow-up provided within 24-hours?	100%
If the family is non-English speaking, was translation assistance documented?	97 %
Did the CEDARR render a decision about the Direct Service treatment plan within 21 days?	85%
Does the Family Care Plan document the CEDARRS' coordination with other programs and services?	78%

Services Available to Families in 2006

The CEDARR Initiative has also given rise to the development of new, innovative programs such as Personal Assistance Services and Supports Project (PASS) and KIDS CONNECT, as well as brought quality improvement to the existing system of services and supports.

Personal Assistance Services and Supports (PASS)

PASS was designed to promote and strengthen the ability of children with special health care needs to achieve in the following domains:

- The accomplishment of essential activities of daily living within the family home
- The ability to make self-preserving decisions
- The capacity to participate more fully in social roles and settings

KIDS CONNECT

KIDS CONNECT provides therapeutic services to Medicaid enrolled children who have special health care needs within a DCYF-licensed child and youth care center. All services provided are based upon a "therapeutic integration plan" that is developed by a licensed health care professional in consultation with the child's family and with the licensed childcare program.

During the Summer of 2003, a group of families, providers and State agency staff worked together to explore solutions and to improve access to home based services. HBTS (Home Based Therapeutic Services) at that time was the only CEDARR direct service and referral lists were extensive.

HBTS

The HBTS Challenge resulted in the implementation of new and enhanced home based therapeutic services. Service descriptions were broadened to allow children with special needs and their families to receive intervention prior to the onset of intensive HBTS. These enhanced services included direct services from licensed clinicians and group intervention/social skills groups.

CEDARR Enhanced Services

CEDARR Enhanced Services were developed to establish a mechanism by which the CEDARR Family Centers could facilitate a more immediate response to the needs of families waiting for direct services. CEDARR Enhanced Services provide families with more rapid access to licensed clinicians, therapeutic groups, and group health education sessions.

Accomplishments and Opportunities as We Move Forward

Do the newly developed programs established as a result of the Leadership Roundtable reach families in need?

- Families living in all 39 cities and towns in Rhode Island have accessed CEDARR services. Children with a broad array of special health care needs, across the pediatric age spectrum, are served by CEDARR Family Centers. Likewise, CEDARR Family Centers provide services to families with translation and communication needs.
- Utilization of the two new CEDARR Direct Services (PASS and KIDS CONNECT) continues to grow and overall system capacity continues to increase with the certification of new providers. Nonetheless, infrastructure issues have limited KIDS CONNECT enrollment, primarily availability of transportation. An opportunity exists to reach out to new partners in the community to address this issue.
- HBTS providers continue to experience challenges in recruiting and retaining home-based workers. The need for skilled home care workers contributes at least in part to the difficulty families have in timely access to services. Health care manpower is a macro-environmental issue that challenges our State. We must continue to work with health care providers to develop creative approaches to rectify this situation.

Has the concept of "family-centeredness" been embedded in the development of programs that partner tangibly and effectively with families?

- Results of the CEDARR family surveys in 2003 and 2006 show that on several key indicators of "family-centeredness" the CEDARR Family Centers scored very well. "Family-centeredness" concepts are core to the CEDARR Initiative. Our 2006 randomized audit of CEDARR Family Center charting documentation indicates considerable adherence with the CEDARR certification standards that address the delivery of family-centered care. More opportunities for improvement are available, however.

- Keeping "family-centeredness" a priority starts at the Department of Human Services. The Department will continue to use all its existing communication pathways to gain important feedback from families, advocates and providers, as well as apply quality improvement techniques to improve processes and identify "best practices" across the CEDARR Family Center and CEDARR Direct Services continuum of care.

Have the CEDARR Family Centers attained the performance levels set forth in the CEDARR certification standards?

- The 2006 CEDARR chart audit process, which was based upon the certification standards, shows that the CEDARR Family Centers' documentation is robust in the areas of client information, parental consent, use of a family-centered approach, the processing of urgent-level requests for services, and turn-around times for Direct Services treatment plans. Documentation of coordination with other programs and services is an area for the CEDARR Interdepartmental Team's further intervention with the CEDARR Family Centers. Training and technical assistance may be warranted.
- Results of the 2006 CEDARR chart audit will be used to re-examine the standards themselves in a collaborative manner with all stakeholders (parents, advocates, the Inter-departmental Team, and CEDARR agency representatives) to determine if there are opportunities for further improvements.
- Timely access to HBTS continues to be a concern. Shortages of allied health professionals who are trained to address the needs of children and youth with special health care needs in home and community-based settings affect HBTS capacity. More "human infrastructure" development is needed on a statewide basis.
- For families who are knowledgeable of the RI delivery system for children with special health care needs and who do not need linkage with community-based programs, access to CEDARR Direct Services may appear time-consuming. Refined "triaging of need" best practices can be identified in partnership with all stakeholders, resulting in enhanced operating efficiencies.

Has Rhode Island achieved a comprehensive system of care for children with special health care needs?

- With the development of PASS and KIDS CONNECT, as well as the changes made to HBTS as a result of the "HBTS Challenge" activities, Rhode Island has a more comprehensive array of health services to meet the individual needs of Medicaid eligible children with special health care needs and their families. Utilizing the work done thus far as a starting point, we have an opportunity to re-engage actively with stakeholders to ensure not only a comprehensive but also a more coordinated system of care for all children with special health care needs in Rhode Island.

Conclusion

With the assistance and collaboration of the Leadership Roundtable, Rhode Island has developed an innovative, family-centered response to the needs of Children with Special Health Care Needs and their families by launching the CEDARR Initiative. Rhode Island has taken a leadership role nationally in the way that it has chosen to provide clinical services that keep the recipients of those services, and their families, as the primary focus, through the CEDARR Family Centers. Looking back at the five years that have elapsed since the start of the process, many steps have been taken that have resulted in children and their families having access to a wider array of services to meet their individual needs. The opportunities that exist to continually improve the system can be addressed using the same atmosphere of collaboration and innovation that gave birth to the CEDARR Initiative.

The Department of Human Services will undertake the following "next steps" to address Rhode Island's system of care for children with special health care needs:

- Meet with representatives of the CEDARR Family Centers to provide feedback about the findings of the 2006 CEDARR family survey and charting documentation audit
- Meet with our community partners to identify ways to convene discussion about the next phase of overall system development
- In the Autumn of 2006, reconvene the Leadership Roundtable
- With the input of our strategic partners re-assessed the CEDARR certification standards in light of program experience to determine whether the current requirements need any modification

INTRODUCTION

This report delineates the series of program steps undertaken by Rhode Island over the past five years in an effort to develop an enhanced, comprehensive system of care for families of children with special health care needs. In this report, the Center for Child and Family Health at the Rhode Island Department of Human Services focuses upon the goal put forth by the Rhode Island Leadership Roundtable for Children with Special Health Care Needs in 1999: the development of a model, family-centered delivery system for children with special health care needs. What has been our State's progress to date in realizing this goal? To measure our progress, we pose the following questions:

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Rhode Island has taken a leadership role in developing its system of care for children with special health care needs. The CEDARR program's approach to care planning was recognized by the Health Care Reform Tracking Project in a 2003 meta-analysis funded by the National Institute on Disability and Rehabilitation Research (U.S. Department of Education), the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (U. S. Department of Health and Human Services), and the Administration on Children, Youth, and Families (U.S. Department of Health and Human Services)[1].

I. STEPS LEADING TO THE CREATION OF THE CEDARR PROGRAM

A. Health Care Needs of Children with Disabilities on Medicaid: Results of Caregivers Survey – Final Report (06/08/1998)

To better understand the needs of Rhode Island's Medicaid-enrolled children with disabilities, the Department of Human Services and the Department of Health funded a groundbreaking "caregiver" survey in 1997. This study was undertaken by MCH Evaluation, Inc., in conjunction with Brown University's Center for Population Studies. The survey was designed in active collaboration with key stakeholders, most importantly, parents of children with disabilities as well as representatives of parent advocacy groups, the Developmental Disabilities Council, the Department of Health, Department of Human Services, Department of Education, and the Department of Children, Youth, and Families.

[1] Stroul, B.A. (2003). Health Care Reform Tracking Project: Promising Approaches for Behavioral Health Services to Children and Adolescents and their Families in Managed Care Systems – Serving Youth with Serious and Complex Behavioral Health Needs in Managed Care Systems, pgs. 63 – 65.

A representative statewide sample of 257 caregivers of disabled children between one and 21 years of age was interviewed by telephone or in person from October 1997 through December 1997. Findings from this study revealed the following:

- Caregivers of children with physical/medical disabilities (such as cerebral palsy) comprised 35.2% of the sample; caregivers of children with mental health disabilities (such as attention deficit hyperactivity disorder) comprised 27.3% of the sample; and caregivers of children with developmental disabilities (such as learning disability and pervasive developmental delay) comprised 37.5% of the sample.

- In response to questions about the child's health status and functional limitations, *53.5% of the children had two or more disabilities*; almost half (49.5%) needed help with their personal care; 73.7% were limited in the kind or amount of activity in which they could engage; *and 7.1% were unable to take part at all in age-appropriate activities.*

- Approximately 14.5% of the children did not have a preventive health visit in the prior year.

- Visits to specialists varied by the child's type of disability. Children with mental health disabilities had twice the rate of specialty care visits as children with either physical or developmental disabilities.

- Caregivers reported a high level of satisfaction with their child's care; 95% stated that they were satisfied or very satisfied with their child's last visit to the doctor. Nonetheless, approximately 10% of the caregivers reported some areas for improvement on the part of the health care system, in terms of the length of time to get an appointment for their child, the doctor's knowledge of the child's primary condition, and the clinician's response to requests for referrals.

- Caregivers of children with mental health disabilities reported the most barriers to care. They were more likely to report feeling overwhelmed by their child's needs (83.4%), being unable to find child care (36.1%) and not receiving support or help from their family and friends (52.1%).

The caregivers' feedback resulted in the development of a "*top ten unmet needs*" list for children with disabilities in Rhode Island. These unmet needs were:

1. Over the counter medications (39%)
2. Support groups for parents (36%)
3. Information about their child's primary disabling condition (35%)
4. Respite care (32%)
5. Transportation (29%)
6. Dental care (27%)
7. Day care/after school care (24%)
8. Mental health counseling for their child (24%)
9. Parent education classes (22%)
10. Case management (21%)

The findings from this study were widely disseminated by the State and led the DHS Center for Child and Family Health to sponsor a series of meetings involving policymakers, parents of children with special health care needs, clinicians, legislators, educators, providers, and advocates. This ad hoc stakeholders' group became known as the Leadership Roundtable on Children with Special Health Care Needs.

B. The Leadership Roundtable on Children with Special Health Care Needs

Rhode Island's Leadership Roundtable began to meet in December of 1998 to better address the needs of families of children with *any* of the following special health care needs:

- Autism spectrum disorders
- Behavioral health needs
- Dependence on assistive technology
- Severe medical or physical disabilities
- Developmental disabilities

Parents of children with special health care needs and representatives of children's advocacy groups (including the Autism Project, Family Voices of Rhode Island, the Parent Support Network, Rhode Island Parent Information Network, and the Sherlock Center [formerly known as UAP of Rhode Island College]) were key Leadership Roundtable constituents. Other stakeholders engaged in the Leadership Roundtable included representatives from the State's agencies that serve children with special health care needs and their families (the Departments of Children, Youth, & Families; Education; Health; Human Services; and Mental Health, Retardation, & Hospitals), community-based organizations, and clinical service providers.

The Leadership Roundtable established five (5) workgroups to make policy recommendations to the State. The workgroups focused upon the following system components:

- Eligibility & enrollment
- Benefits
- Access & service delivery
- Quality
- Transitions & coordination

The Leadership Roundtable solicited feedback from all stakeholder groups, inventoried existing programs and regulations, and looked at "best practices" initiated in other regions of the country. Consensus recommendations for systems change emerged as a result of this planning process, including the call to:

- *Decrease fragmentation* within and between the systems serving families of children with special health care needs
- "*Do no harm*" when making changes to the existing systems
- *Avoid "carving out"* groups of children due to diagnostic labels

- Focus upon a *strength-based model* "with no disposable kids"
- *Support families* to their fullest potential
- Assure *a flexible and responsive delivery system* with adequate staffing, equipment, and educational resources
- *Integrate emerging research* into the system on an on-going basis

On 04/15/1999, the Leadership Roundtable issued the following vision statement:

> *All Rhode Island children and their families will have an evolving family-centered, strength-based system of care, dedicated to excellence, so that each child can reach their full potential and thrive in their own communities.*

II. OUTCOMES OF THE LEADERSHIP ROUNDTABLE

A. *Creating a Flexible System of Care*

The recommendations of the Leadership Roundtable were used by the State at the start of this decade to develop a new continuum of care for children with special health care needs. *The objective: to deliver family-centered, strength-based services to children and their families in the least restrictive, most appropriate setting*.

"Phase One" of this plan focused upon families' entry into what are often confusing health, education, and social service delivery systems. Families of children with special health care needs who participated in the Leadership Roundtable were very articulate in expressing *the need for an objective third party*, who would help parents to better navigate their child's health care environment and also provide useful resources about family support groups, parent advocacy organizations, community resources, and special education services. Charged with the Leadership Roundtable's directive to "get started", the Department of Human Services and its state agency partners implemented Rhode Island's CEDARR initiative.

Phase One activities focused upon the development of system infrastructure to provide services to Medicaid-enrolled children with special health care needs in the least restrictive, most appropriate setting. The long-term vision of the Leadership Roundtable was to fully expand access to these new services to all children with special health care needs in our State, including children with commercial health insurance coverage, in Phase Two.

B. Phase One: CEDARR Family Centers

The acronym "*CEDARR*" represents a dynamic process for engaging with families of children with special health care needs: ***C***omprehensive ***E***valuation, ***D***iagnosis, ***A***ssessment, ***R***eferral, and ***R***e-evaluation. The CEDARR network was designed to advance a more positive family-centered system of care, encourage clinical excellence, improve health outcomes, and promote overall cost-effectiveness for Medicaid-eligible children with special medical, behavioral, or developmental health care needs.

Services rendered by the CEDARR Family Centers are deemed as medically necessary under the authority of Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program. State dollars expended for this initiative are therefore eligible for Federal matching. In its capacity as the single State agency for the Medicaid program, the RI Department of Human Services (DHS) administers the CEDARR initiative.

The development and implementation of the CEDARR Family Centers has been the result of on-going and active inter-agency collaboration. The following State agencies have partnered with the RI DHS and the Leadership Roundtable to advance the CEDARR initiative: the Department of Children, Youth, and Families (DCYF), the Department of Education (RIDE), and the Department of Health (DOH). Throughout the remainder of this report, this group of State Agencies is referred to as the "Inter-departmental Team".

Through this collaborative process, certification standards were developed in May of 2000 to provide guidance to the community-based organizations that expressed their interest in establishing a CEDARR Family Center. These standards were developed in partnership with the Leadership Roundtable and with representatives from the Inter-departmental Team. CEDARR certification standards stipulate core requirements addressing the CEDARR Centers' administration, organizational structure, program approach, service delivery system, quality assurance and organizational capability.

As of March 2006, with the certification of *Empowered Families CEDARR*, there are four (4) CEDARR Family Centers in operation that serve as a gateway to health, educational, and social services for families of children with special health care needs. The CEDARR Family Centers are listed in Appendix A. The following table documents when each of the CEDARR Family Centers first achieved certification to participate in this initiative.

Certification of CEDARR Family Centers:

CEDARR Family Center	Month and Year of Initial Certification
About Families	04/2001
Family Solutions	09/2001
Families First	07/2002
Easter Seals[2]	10/2002
Empowered Families	03/2006

CEDARR Quality Panel

Since 2002, representatives of the Department of Human Services, the Inter-departmental Team, and each CEDARR Family Center have met each month to discuss CEDARR program operations and "best practices". This forum is known as the "CEDARR Quality Panel". These meetings provide an opportunity for CEDARR Family Centers to share information with their peers about program innovations.

CEDARR Basic Services

[2] Easter Seals left the CEDARR program during the Winter of 2004.

Each CEDARR Family Center must provide a core set of basic services and supports for families. Each CEDARR Family Center provides families with a cadre of basic services. All of the following services are either provided by or under the direct supervision of a licensed clinician.

- *The Provision of Special Needs Resource Information* – CEDARR Family Centers are expected to have the necessary expertise, resources, and knowledge base to enable families to inform themselves about specific health conditions, including the cause, clinical prognosis, treatments available, and availability of providers. This information must be provided in a culturally competent manner.

- *System Mapping & Navigation* – CEDARR Family Centers fully inform families of the whole system of support, services, assistance, and legal protections available to children with special health care needs. The goal of such information is to aid families in creating their own personal map so that they may successfully navigate the system. Special attention is to be paid to informing families about eligibility requirements for various programs, accessing benefits and coordinating services across various State agencies.

- *Resource Identification* – Because each family's strengths and challenges are unique, the CEDARR Family Center helps families to identify the resources that are available to them. The CEDARR Family Center assists families in learning about resources available through school systems, support groups, social programs, and community-based organizations. The focus is to empower families by providing them with information about the opportunities and supports that are available within close proximity to their home, provided in the least restrictive environment, and that enhance their integration within the community.

- *Eligibility Assessment & Application Assistance* – The CEDARR Family Center helps families learn about the requirements of various programs for children with special health care needs, including but not limited to Medicaid, Local Education Authority (LEA)/Special Education and Early Intervention.

- *Peer Support and Guidance* – Recognizing the unique encouragement and assistance that parents of children with special health care needs can acquire from interacting with other families, the CEDARR Family Center plays an important role in linking parents and extended families with their peers. The CEDARR Family Centers are expected to have formal linkages with such established parent advocacy groups as the Rhode Island Parent Information Network (RIPIN), Family Voices and the Parent Support Network.

Entry into CEDARR Services – Initial Family Contact: A family's initial contact with a CEDARR Family Center may occur via a telephone call or through a face-to-face interaction. This "*initial family contact*" with CEDARR may be due to a recommendation by the child's school, a clinician, a social worker, another parent, or any number of other trusted sources of advice in the community.

If the initial family contact reveals that the family is in immediate crisis (i.e., there is imminent risk of injury), the CEDARR Family Center must respond by providing clinical triage within fifteen (15) minutes. If the request for assistance is of an urgent nature, the CEDARR Family Center must provide crisis follow-up within 24 hours.

Initial Family Assessment: Based upon the challenges and concerns expressed by the family, an initial contact may result in the CEDARR Family Center's offering an invitation to participate in an "*initial family assessment*". If the initial family contact reveals that the family has needs that are of a non-emergent or urgent level, the CEDARR certification standards call for the initial family assessment to be scheduled within 14 calendar days.

The initiation of a family assessment may occur in the family's home, in a community location that is viewed by the parent as comfortable and private, or within the CEDARR Family Center. The family is the principal "driver" of where the initial family assessment occurs.

The initial family assessment, completed under the direction of a licensed clinician, must include the following components to determine the family's strengths and needs:

- An assessment of urgency
- A developmental history, addressing the child's physical and behavioral health and cognitive level of functioning
- The child's current and prior interactions with the health care system (including primary and specialty care and history of hospitalizations)
- The child's level of participation in programs for children with special health care needs (including but not limited to Early Intervention, Special Education, and the Child and Adolescent Services System Program)
- The family's current circumstances and its identified strengths, supports, and needs
- The family's knowledge of and linkage with advocacy groups and professional associations, such as Family Voices, the Parent Support Network, and the Rhode Island Parent Information Network (RIPIN).

Family Care Plan: As a result of this collaborative assessment process, a family may elect to further engage with the CEDARR Family Center in the development of a *family care plan.* Because "family-centeredness" is one of the cornerstone principles upon which the CEDARR initiative has been based, it is expected that the CEDARR Family Center will develop the plan of care in partnership with the child's parents and that this plan will be fully reviewed by the family at the completion of the care planning process. In order to emphasize the importance of engaging with parents in the development of the family care plan, the CEDARR certification standards require that the parents have confirmed in writing that they approve the document**.** As is the case with the individualized family assessment, the family care plan is completed under the supervision of a licensed clinician.

Depending upon the needs of the child and family, in some cases it may be most beneficial to the family to have access to a specialty clinical evaluation to aid in the development of the family care plan. To augment families' access to such specialty clinical expertise, the

CEDARR Family Center must provide access to specialists through affiliation agreements for these evaluations.

The family care plan is individualized to assist the family in its efforts to successfully address the clinical needs of their child and to enhance the family's ability to maintain a supportive home environment. As its starting point, this plan identifies and builds upon the family's strengths. The structure of the care plan must include specific and measurable objectives. The ultimate goal of this plan is to provide the family with an organized and focused approach for the parents' use, whether or not any additional services and supports are to be rendered by the CEDARR Family Center.

Family Care Coordination Assistance: In some situations, the family may decide that they would benefit most from on-going collaboration with the CEDARR Family Center. *Family care coordination* can be provided by the CEDARR Family Center to help the family to reach the goals and objectives mapped within the care plan. Through this process, the CEDARR Family Center can provide on-going assistance to the family to help them gain access to any needed health care and/or family support services. Likewise, CEDARR Family Centers' family care coordination assistance offers guidance to the family in their interpretation of information received from clinicians, their child's school, or other programs that serve children with special health care needs.

CEDARR Enhanced Services: During the Summer of 2003, CEDARR basic services and supports were augmented with the addition of "CEDARR Enhanced Services" in response to needs identified by the initial CEDARR family survey. Based on the needs expressed by families participating in the 2003 family survey, the Inter-departmental Team, families, and providers met throughout the Summer of 2003 (referred to as the "HBTS Challenge ") to explore how to address the needs of families who were waiting for direct clinical services, especially those provided within families' homes.

Although the Leadership Roundtable initially recommended in 2001 that CEDARR Family Centers should not engage in the delivery of any direct clinical services, compelling family needs led to a reconsideration of this position. As a result, CEDARR Enhanced Services were developed to establish a mechanism by which the CEDARR Family Centers could facilitate a more immediate response to the needs of families waiting for direct services. CEDARR enhanced services provide families with more rapid access to licensed clinicians, therapeutic groups and group health education sessions.

III. CEDARR FAMILY CENTERS IN 2006

Within Section III-A and III-B of this report, the Department of Human Services will provide information to address the following question.

1. Do the newly developed programs established as a result of the Leadership Roundtable reach families in need?

A. Access to CEDARR Services in Rhode Island

From April of 2001 through April 2006, CEDARR services have been provided to 3,400 of Rhode Island's children. These children live in each of Rhode Island's 39 towns and cities, with the majority residing in Providence, Pawtucket, Warwick, Woonsocket, and Cranston. Table 1 below shows CEDARR participants' town of residence by State Fiscal Year (SFY).

The majority of interactions between CEDARR staff and families occur within families' homes, although in some cases a family may request to meet with CEDARR staff either at the CEDARR agency (or its satellite location) or in another community-based setting that is convenient for the family. Appendix A shows the location of each CEDARR Center and includes CEDARR agencies' satellite offices.

Table 1: CEDARR Participants' Town of Residence by State Fiscal Year (SFY)

Child's Town of Residence	SFY 2001	SFY 2002	SFY 2003	SFY 2004	SFY 2005	SFY 2006	Total # of Children
Barrington	1	11	8	5	6	13	44
Bristol	0	2	8	4	4	9	27
Burrillville	1	2	7	12	10	7	39
Central Falls	1	7	17	43	30	39	137
Charlestown	0	3	8	4	5	6	26
Coventry	0	7	26	22	9	20	84
Cranston	3	23	43	36	48	47	200
Cumberland	0	10	25	21	16	16	88
East Greenwich	2	7	16	8	6	17	56
East Providence	0	7	31	23	28	32	121
Exeter	2	1	6	8	5	7	29
Foster	1	1	2	5	5	2	16
Glocester	1	8	2	9	6	6	32
Hopkinton	0	0	10	4	3	2	19
Jamestown	0	0	3	0	1	1	5
Johnston	5	4	13	16	12	14	64
Lincoln	0	9	22	15	18	10	74
Little Compton	0	0	1	0	0	0	1
Middletown	0	4	12	6	12	9	43
Narragansett	0	1	9	8	4	3	25
New Shoreham	0	1	1	0	1	0	3
Newport	0	4	25	22	13	15	79

Child's Town of Residence	SFY 2001	SFY 2002	SFY 2003	SFY 2004	SFY 2005	SFY 2006	Total # of Children
North Kingstown	4	8	33	36	17	17	115
North Providence	2	0	8	7	2	8	27
North Smithfield	0	1	5	0	5	4	15
Pawtucket	2	36	57	89	73	90	347
Portsmouth	0	6	11	10	10	4	41
Providence	11	124	157	199	196	185	872
Richmond	0	0	3	1	1	1	6
Scituate	0	0	4	9	3	8	24
Smithfield	1	3	5	9	4	4	26
South Kingstown	1	8	31	25	13	28	106
Tiverton	1	3	10	6	4	11	35
Warren	1	2	4	8	3	7	25
Warwick	4	29	57	55	72	56	273
West Greenwich	2	1	3	0	2	0	8
West Warwick	3	13	17	34	26	24	117
Westerly	0	5	18	21	24	15	83
Woonsocket	3	14	47	54	41	45	204
Total	**52**	**365**	**765**	**834**	**738**	**782**	**3536**

B. Children & Families Served by CEDARR Family Centers

Table 1 documents new CEDARR enrollments by State Fiscal Year (SFY) for each of the CEDARR Family Centers, covering the period from 04/01/2001 through 04/01/2006. New enrollments more than doubled in 2003, as the number of certified CEDARR Family Centers increased from two (2) agencies to four (4). As the CEDARR system capacity increased, new enrollments peaked at 834 in 2004.

During the Winter of 2004, one CEDARR Family Center (Easter Seals) voluntarily left the program. This decrease in system capacity contributed at least in part to a new enrollment decline of approximately 12 percent during 2005.

As of March of 2006, however, a fourth CEDARR Family Center has been certified (Empowered Families CEDARR). Based on annualized information for CEDARRs' year-to-date experience in SFY 2006, the Department projects that this year's new CEDARR Family Center enrollments will exceed that of 2004. Table 2 shows new CEDARR Family Center enrollments from 2001 to 2006.

Table 2: New CEDARR Enrollments by State Fiscal Year (SFY)

CEDARR Family Center	SFY 2001*	SFY 2002	SFY 2003	SFY 2004	SFY 2005	SFY 2006**	Total
About Families	52	244	325	332	227	201	**1381**
Easter Seals	-	-	87	22	-	-	**109**
Empowered Families	-	-	-	-	-	28	**28**
Families First	-	-	65	92	125	135	**417**
Family Solutions	-	121	288	388	386	282	**1465**
Total	**52**	**365**	**765**	**834**	**738**	**646**	**3400**

* Covers the period from 04/01/2001 – 06/30/2001.
** Indicates that 2006 information represents "year to date" service activity from 07/01/2005 – 03/31/2006.

Over the past five years, approximately 68% of the children served by a CEDARR Family Center are male and 32% are female. Table 3 provides this detail by year across all CEDARR Family Centers.

Table 3: Children Served by a CEDARR Family Center by Child's Gender (04/01 – 04/05)

Gender	2001	2002	2003	2004	2005	2006	Total
Female	23.08%	35.34%	32.68%	32.73%	30.22%	29.26%	**31.65%**
Male	76.92%	64.66%	67.32%	67.27%	69.78%	70.74%	**68.35%**
Total	**100%**	**100.00%**	**100.00%**	**100.00%**	**100.00%**	**100.00%**	**100.00%**

Table 4 provides detail about the primary language spoken by the children and families served by CEDARR Family Centers. Approximately 89% of the children and families speak English as their primary language; Spanish is the primary language for approximately 9% of CEDARR Family Center participants.

Table 4: Primary Language	Percentage
English	88.83%
Spanish	8.88%
Other [3]	2.29%
Total	**100.00%**

CEDARR Family Centers serve children who have at least one special health care need. Approximately one child in five (20.5%) served by a CEDARR Family Center has overlapping, multiple needs that fall into more than one of the three major groupings (medical, behavioral, or developmental). The majority (62.2%) of children receive CEDARR services due to a behavioral need. Developmental issues are present for approximately 35% of the children served through a CEDARR; 28.5% of CEDARR Family Center participants

[3] These languages include Arabic, Cambodian, Cape Verdean, Creole, Chinese, Korean, Portuguese, and Russian.

have health needs of a medical/physical nature. It is important to highlight that approximately 20.5% of the children served by a CEDARR Family Center have needs that cross two or more of these three clinical groupings.

The following series of tables describe the number of children served by CEDARR Family Centers and their demographic (age at the time of their initial CEDARR enrollment, gender, and ethnicity) characteristics, based on whether their need is behavioral, developmental, or medical in nature.

a. Children Served by a CEDARR Family Center Due to a Behavioral Health Need (04/2001 – 04/2006):

Most of the children (62.5%) access CEDARR Family Centers due to a behavioral/mental health need. Table 5 documents the number of children with a behavioral health (BH) need who have been served by a CEDARR Family Center and the specific type of behavioral health issue that led their family to the CEDARR.

Table 5: Type of Behavioral Health Issue	**#of Children**	**Percentage**
Adjustment Disorders	232	10.97%
Anxiety Disorders	152	7.19%
Attention Deficit and Disruptive Behavior Disorders	802	37.94%
Communication Disorders	53	2.51%
Dementia, Amnesic, & Other Cognitive Disorders	2	0.09%
Dissociative Disorders	1	0.05%
Eating Disorders	3	0.14%
Elimination Disorders	5	0.24%
Feeding Disorders of Infancy and Early Childhood	14	0.66%
Impulse Control Disorders	14	0.66%
Learning Disorders	37	1.75%
Medical or Physical Conditions	1	0.05%
Mental Health Conditions Not Classified Elsewhere	1	0.05%
Mood Disorders	195	9.22%
Other Behavioral Health Disorders of Infancy, Childhood, & Adolescence	41	1.94%
Pervasive Developmental Disorders	531	25.12%
Schizophrenia & Other Psychotic Disorders	8	0.38%
Sleep Disorders	2	0.09%
Substance-Related Disorders	3	0.14%
Tic Disorders	17	0.80%
Total	**2114**	**100.00%**

Table 6 shows the age at which a CEDARR Family Center first served an infant, child, or adolescent because of a behavioral health need. Slightly more than 60% of the children served by a CEDARR Family Center for behavioral health needs are between three (3) and eleven (11) years of age when they first receive services.

Table 6: Age – Behavioral Health

Child's Age At the Time of His/Her First Involvement with CEDARR	Number of Children	Percentage
Infancy – 2 Yrs. Old	127	6.01%
3 – 5 Yrs. Old	476	22.52%
6 – 8 Yrs. Old	460	21.76%
9 – 11 Yrs. Old	436	20.62%
12 – 14 Yrs. Old	367	17.36%
15 – 17 Yrs. Old	203	9.60%
18 – 20 Yrs. Old	45	2.13%
Total	**2114**	**100.00%**

As noted previously, boys represent the majority (68.35%) of the children served by a CEDARR Family Center for any (physical, behavioral, and/or developmental) reason. Table 7 documents CEDARR's male/female participation rate based upon children's behavioral health needs. Boys have an even higher rate of participation (72.09%) in CEDARR because of behavioral health needs.

Table 7: Gender (Behavioral Health)

Gender	Number of Children	Percentage
Female	590	27.91%
Male	1524	72.09%
Total	**2114**	**100.00%**

b. Children Served by a CEDARR Family Center Due to a Developmental Need (04/2001 – 04/2006):

From 04/2001 – 04/2006, there were 1,196 children (or 35% of all CEDARR Family Center participants) served by a CEDARR Family Center because of a developmental need. The majority of children with developmental needs whose families seek assistance from a CEDARR Family Center have learning disorders (39.46%). Table 8 shows the number of children served and the type of developmental issue they have experienced.

Table 8 - Developmental Need

Developmental Issue	Number of Children	Percentage
Communication Disorders	279	23.33%
Learning Disorders	472	39.46%
Mental Retardation	406	33.95%
Motor Skills Disorders	17	1.42%
Personality Disorders	22	1.84%
Total	**1196**	**100.00%**

Slightly more than 60% of the children using CEDARR services because of a developmental need were first served between three (3) and eleven (11) years of age. This finding is similar to that seen for children participating in CEDARR because of a behavioral health need. Table 9 provides the age distribution of children who had a developmental need at the time of their initial CEDARR involvement.

Table 9 – Age (Developmental Need)

Child's Age At the Time of His/Her First Involvement with CEDARR	Number of Children	Percentage
Infancy – 2 Yrs. Old	130	10.87%
3 – 5 Yrs. Old	339	28.34%
6 – 8 Yrs. Old	200	16.72%
9 – 11 Yrs. Old	189	15.80%
12 – 14 Yrs. Old	172	14.38%
15 – 17 Yrs. Old	125	10.45%
18 – 20 Yrs. Old	41	3.43%
Total	**1196**	**100.00%**

The gender distribution of children participating in CEDARR because of developmental needs is similar to that for CEDARR participants across all three types of needs (medical/behavioral/developmental). Table 10 documents CEDARR's male/female participation rate based upon children's developmental needs.

Table 10 – Gender (Developmental Need)

Gender	Number of Children	Percentage
Female	396	33.11%
Male	800	66.89%
Total	**1,196**	**100.00%**

c. Children Served by a CEDARR Family Center Due to a Medical/Physical Need (04/2001 – 04/2006):

From 04/2001 – 04/2006, slightly more than one in four children (28.5%) ever served by a CEDARR Family Center had medical or physical health needs. Table 10 shows the wide

range and complexity of health needs experienced by children who receive CEDARR services because of medical issues. An enumeration of these complex medical needs is shown in Table 11 in rank order, from the most frequently occurring to the least frequent. This listing is a partial one and represents only those medical issues that affect at least 1% of the children seen by a CEDARR Family Center.

Table 11 – Medical Need	**Number of Children**	**Percentage**
Asthma	209	21.39%
Cerebral Palsy	118	12.08%
Down Syndrome	76	7.78%
Epilepsy	72	7.37%
Unspecified Condition	41	4.20%
Unspecified Hearing Loss	40	4.09%
Other Unspecified Cause of Morbidity	35	3.58%
Unspecified Head Injury	22	2.25%
Unspecified Otitis Media	20	2.05%
Seeking Consultation	19	1.94%
Microcephalus	19	1.94%
Obesity	18	1.84%
Spina Bifida	17	1.74%
Generalized Convulsive Epilepsy	17	1.74%
Unspecified Dermatitis	15	1.54%
Unspecified Visual Loss	14	1.43%
Progressive Muscular Dystrophy	14	1.43%
Quadriplegia	13	1.33%
Congenital Hydrocephalus	12	1.23%

Slightly less than 60% of the children who have ever been served by a CEDARR Family Center because of a medical/physical health need are between three (3) and eleven (11) years of age. Table 12 shows the age distribution for these infants, children, and adolescents at the time that they were first served by a CEDARR Family Center.

Table 12 – Age (Medical Need)	**Number of Children**	**Percentage**
Infancy – 2 Yrs. Old	108	11.15%
3 – 5 Yrs. Old	235	24.25%
6 – 8 Yrs. Old	171	17.65%
9 – 11 Yrs. Old	166	17.13%
12 – 14 Yrs. Old	141	14.55%
15 – 17 Yrs. Old	107	11.04%
18 – 20 Yrs. Old	41	4.23%
Total	**969**	**100.00%**

Among the children with medical/physical health needs, males still represent the majority of CEDARR users. The percentage of females seen due to a medical need (35.09%) is greater, however, than that of their counterparts who are seen by a CEDARR Family Center because of a behavioral health (27.9%) or developmental (33.1%) need. Table 13 shows the gender distribution for infants, children, and adolescents served by a CEDARR Family Center because of a medical or physical health need.

Table 13 – Gender (Medical Need)

Gender	Number of Children	Percentage
Female	340	35.09%
Male	629	64.91%
Total	**969**	**100.00%**

Summary of data addressing whether CEDARRS reach families in need: Based upon review of CEDARR utilization data, children and families are receiving CEDARR services in each municipality in Rhode Island. Because the locus of intervention is within families' homes, accessibility is enhanced and meets the needs of families. CEDARR Family Centers are serving the families of children with a range of medical, behavioral health, and developmental needs across the pediatric and adolescent age spectrum. Likewise, CEDARR Family Centers accommodate the needs of families who may require translation or communication assistance.

C. Preliminary Review of the CEDARR Implementation Process

In this section of our report, the Department of Human Services will provide information to address the following questions.

2. **Has the concept of "family-centeredness" been embedded in the development of programs that partner tangibly and effectively with families?**
3. **Have the CEDARR Family Centers attained the performance levels set forth in the CEDARR certification standards?**

During the Spring of 2005, the Department of Human Services and the Inter-departmental Team began to plan a preliminary analysis of the CEDARR Initiative. The purposes of this preliminary analysis were to:

- Ensure that family-centered, high-quality care has been purchased and delivered
- Re-assess families' satisfaction levels with CEDARR
- Identify current needs and quantify any service delivery gaps for children with special health care needs

This preliminary analysis included the following qualitative and quantitative measures:

a. Family surveys: conducted during 2003 and re-assessed during the spring of 2006
b. A randomized audit of CEDARR Family Center records: conducted by the Department of Human Services and the Inter-departmental Team during February & March of 2006

a-i. Family Survey – 2003:

The first CEDARR parent/family satisfaction survey occurred in 2003, within the first two years of the launch of the CEDARR Initiative. To plan this initial measurement, members of the CEDARR Policy Advisory Committee partnered with the Department of Human Services and the Inter-departmental Team in the development of a survey questionnaire for families whose children received CEDARR Family Center services. The Department of Human Services mailed surveys to 865 families in March of 2003. This initial mailing resulted in the Department's receipt of 106 completed surveys, yielding a 12.3% response rate. A second mailing followed in April of 2003 and an additional 69 completed surveys were returned, bringing the response rate to 20.2%. A third and final mailing was sent in June of 2003 and 35 more completed surveys were received from families, resulting in a final response rate of 24.3%.

Table 14 shows the percentage of responses received in 2003 based on the language preferences of the families.

Table 14: Survey 2003 - Language Preference

Language	# of Responses	Percentage of All Respondents
English	195	92.9%
Spanish	15	7.1%
Total	**210**	**100.0%**

Approximately 69% (or 145/210) of the families who participated in the 2003 survey stated that their child was still actively involved with a CEDARR Family Center. Table 15 provides detail as to how long the children of these 145 families had been receiving CEDARR services. The children of 58% of these families had been involved with a CEDARR Family Center for six (6) months or less.

Table 15: Survey 2003 – Duration of Family Involvement

Duration of Involvement	# Still Active with CEDARR	Percentage Still Active
3 Months or Less	33	22.8%
4 – 6 Months	51	35.2%
7 – 9 Months	17	11.7%
10 – 12 Months	19	13.1%
More Than 12 Months	25	17.2%
Total	**145**	**100.0%**

Families were also asked to respond to a series of questions that addressed the CEDARRs' "family-centeredness" using a five-point scale with increments ranging from strongly agree to strongly disagree. Table 16 provides the findings from participants' responses to nine survey questions that address the CEDARR Family Centers' family-centeredness. A percentage was calculated (based upon the answers circled indicating either "agreement" or "strong agreement") to document how many positive responses were given for each of these questions. For each of the questions addressing family-centeredness, the percentage of positive responses equaled or exceeded eighty (80) percent, and answers for five of the nine

items were above 90%. Tables 16, 17, and 18 list all of the questions completed by families in the 2003 survey.

Table 16: Survey 2003 – Family-centeredness	
Family Survey Question	**Percentage of (+) Responses**
1. The CEDARR Center gave me written information about my rights & responsibilities as a consumer.	92%
2. The CEDARR Center helped me understand my rights & responsibilities.	89%
3. I know what to do if I have a problem with my worker or someone else at the CEDARR Center.	80%
4. The people at the CEDARR Center were sensitive to my language and cultural beliefs.	97%
5. The people at the CEDARR Center treated me with respect.	97%
6. The people at the CEDARR Center were responsive to my family's needs.	82%
7. I was part of the team making decisions for my family.	89%
8. The CEDARR Center staff met with me at times that were handy to me.	92%
9. The CEDARR Center staff met with me at places that were handy to me.	93%

Three questions addressed families' overall satisfaction with the CEDARR experience. A percentage was calculated (based upon the answers circled indicating either "agreement" or "strong agreement") to document how many affirmative responses were given for each of these questions. The series of questions addressing satisfaction are listed in Table 17.

Table 17: Survey 2003 – Satisfaction with the CEDARR Experience	
Survey Question	**Percentage of (+) Responses**
1. I would use the services at this CEDARR Center again if I needed them.	81%
2. I would recommend a CEDARR Center to my family and/or friends.	78%
3. My family's needs were met by the services and supports provided by the CEDARR Family Center.	68%

In the 2003 survey, one question addressed the CEDARRs' ability to respond in a timely manner to a family's needs. This measure is shown in Table 18.

Table 18: Survey 2003 – Waiting Time for Contact/Support	
Survey Question	**Percentage of (+) Responses**
1. I did not have to wait to receive ongoing contact and support from a CEDARR Family Center.	76%

a-ii. Family Survey – 2006:

During the Winter and Spring of 2006, the Department of Human Services sent confidential surveys by mail to the families of children who received one or more CEDARR services at any time between 07/01/04 – 06/30/05. As of 06/19/2006, 313 of the 1,578 families have returned their completed survey, yielding a 19.8% response rate.

Among the families participating in the 2006 CEDARR Family Survey, slightly more than three out of four reported that their child had been involved with a CEDARR Family Center for at least one year. Seven of the 313 parents who participated in the 2006 survey did not complete this question. Table 19 shows the duration of CEDARR involvement among the 306 parents who responded to this question.

Table 19: Survey 2006 – Length of the Family's Involvement with CEDARR

Length of Involvement	Percentage of Responses
1 – 6 Months	10.13%
7 - 11 Months	11.44%
1 – 2 Years	36.93%
2 – 3 Years	27.12%
More Than 3 Years	14.38%
Total	**100.00%**

In the 2006 survey, there were three (3) questions that addressed parents' feedback about how well the CEDARR Family Center demonstrated its family-centeredness. A percentage was calculated (based upon the answers circled indicating either "agreement" or "strong agreement") to document how many positive responses were given for each of these questions. Table 20 provides the findings from the positive replies to this series of questions.

Table 20: Survey 2006 – Family-centeredness

Survey Question	# of Responses	Percentage of (+) Responses
1. The CEDARR staff told me what to do if I have a problem with my worker or someone else at the CEDARR Center or services.	299	67.56%
2. I felt that I was part of the team making decisions for my child and family.	302	87.42%
3. The CEDARR Center assessment and plans accurately described my child's history and needs.	305	85.57%

In 2006, as in 2003, three questions addressed families' overall satisfaction with the CEDARR experience. A percentage was calculated (based upon the answers circled indicating either "agreement" or "strong agreement") to document how many affirmative responses were given for each of these questions. The series of questions addressing satisfaction are listed in Table 21. As in 2003, two of the three questions had positive responses slightly above 80%.

Table 21: Survey 2006 – Satisfaction with the CEDARR Experience	
Survey Question	**Percentage of (+) Responses**
1. I would use the services at this CEDARR Center again if I needed them.	81.30%
2. I would recommend a CEDARR Center to my family &/or friends.	81.06%
3. My family's needs were met by the services and supports provided by the CEDARR Family Center.	66.30%

In the 2006 survey, three new questions were added to seek families' perceptions about the CEDARR Family Centers' ability to develop a useful plan of care and link families with community resources. The percentage of positive responses for each of these questions is shown in Table 22.

Table 22: Survey 2006 – Family Perceptions	
Survey Question	**Percentage of (+) Responses**
1. The staff I met with knew about community services available to my child and my family.	76.14%
2. The CEDARR Center linked my family to other community agencies that provided services to my family.	74.25%
3. The goals included in the CEDARR Center documents were appropriate and met my child and family's needs.	82.4%

Discussion of findings from the 2003 and 2006 family surveys: Because of some modifications to the 2006 family survey questionnaire, the ability to fully assess trends over time has been affected. However, several key questions addressing family-centeredness and satisfaction with the CEDARR experience were included in both surveys.

In terms of overall family satisfaction with CEDARR, 80% of the respondents participating in 2003 and 2006 reported that they would use CEDARR services again if they needed them. A modest increase was noted from 2003 to 2006 in the percentage (from 78% to 81%) of survey participants who stated that they would recommend CEDARR to their extended family and/or their friends. In 2003 and 2006, over 85% of the survey participants reported that they felt themselves to be a part of the team making decisions for their family.

There were two measures first used in 2003 that showed declining scores in 2006 and these call for further attention by the Department, the CEDARR Family Centers, and the Inter-departmental Team. The first question dealt with families' reporting that their needs were met by the services and supports provided by the CEDARR Family Center. In 2003, 68% of

the survey participants gave a positive response to this question whereas 66.3% did so in 2006. The 2003 and 2006 findings for this measure warrant further investigation and the wording of this question needs additional pilot testing with families.

The other measure that had a lower score in 2006 addressed families' knowledge about what should be done if they experience a problem with their CEDARR worker. In 2003, 80% of the survey participants answered this question affirmatively. In 2006, however, the percentage of affirmative answers declined to approximately 67.5%. This finding has been targeted for discussion with the CEDARR Quality Panel.

Several core questions addressing family-centeredness were not included in the 2006 questionnaire because the measures received positive responses from 90% or more of the 2003 survey participants. These questions dealt with cultural competency, being treated with respect, and families' receipt of services at a convenient time and place. These measures will be re-incorporated within future CEDARR surveys because they are components of a family-centered approach.

Some difference was noted in the duration of CEDARR Family Center participation among families who completed the 2003 survey as opposed to those who did so in 2006. For example, 58% of the families who completed the 2003 questionnaire reported that their child had been involved with a CEDARR Family Center for six (6) months or less. In 2006, however, roughly 10 (ten) % of the survey participants indicated that their child's CEDARR involvement was less than or equal to six (6) months.

Over 75% of the families who participated in the 2006 survey reported that their child had been involved with a CEDARR Family Center for at least one (1) year. This difference in length of CEDARR involvement was not unanticipated. Following the 2003 family survey, two new CEDARR Direct Services were implemented (KIDS CONNECT and PASS). CEDARR Family Centers serve as the entry point for CEDARR Direct Services and perform the clinical review of plans of care from KIDS CONNECT, PASS, and HBTS.

During the next quarter, the Department and the Inter-departmental Team will meet with representatives of the CEDARR Family Centers to engage in dialogue about the findings from the 2006 and 2003 family surveys.

b. Randomized Audit of CEDARR Center Charts – February & March of 2006

During February and March of 2006, the Department of Human Services and representatives of the Inter-departmental Team reviewed the service documentation records (also referred to as "charts") of a randomized sample of CEDARR Family Center participants. These charting audits were conducted on-site at three of the CEDARR Family Centers: About Families, Families First, and Family Solutions. (At the time of this audit process, the fourth CEDARR site, Empowered Families CEDARR, was not yet certified for program participation.)

At each CEDARR Family Center, 5% of the records were reviewed for participants who had received at least one unit of service during State Fiscal Year 2005 (from 07/01/2004 – 06/30/2005). A randomized sample was drawn, to ensure that the records reflected an

accurate, representative "picture" of children and families served by CEDARR Family Centers during SFY 2005. This sample was based upon the following criteria:

- The child's age
- The child's gender
- The family's language preference
- The type of health need (medical, behavioral health, or developmental)
- Level of service received from the CEDARR
- Receipt or non-receipt of a CEDARR Direct Service
- The volume of services rendered by each CEDARR Center

The Inter-departmental Team created a unique standardized record review form based upon the CEDARR certification standards. The record review form contained over seventy (70) questions and addressed the following components:

- Client information – including the child's demographic information; the name of parent or guardian; the family's primary language; and whether there is need for any translation or communication assistance
- Parental consent – the presence of signed forms, including the consent to seek to obtain copies of the child's medical and behavioral health records as well copies of any Individualized Educational Plan and Individualized Family Services Plan
- Timeliness – including the date of the family's initial contact with the CEDARR Family Center and the CEDARR's responsiveness as based upon CEDARR certification standards
- Initial Family Assessment – including the family's circumstances, strengths, supports, and needs; the family's current level of knowledge about advocacy groups; whether the family needs any program application assistance; the child's physical, behavioral health, and cognitive developmental history; and the family's current interface with the health care system
- Family Care Plan – including the family's efforts to maintain a supportive home environment; the family's strengths; evidence of the family's involvement in the care plan's development; the plan's prioritized goals and objectives; the plan's sign-off by the family and the clinician; and any treatment plan(s) developed by CEDARR Direct Service providers
- Family Care Coordination Assistance – including notes indicating regular follow-up with the family and direct service providers; documentation of efforts to help the family gain access to needed services and develop skills to reduce their need for formal care coordination assistance

For each review question on the form, the record reviewer would score whether the standard was "fully met", "partially met", "unmet", or "not applicable". An example of a question that would be scored as "not applicable" is the following. If a family is English speaking, the question "If the family is non-English speaking, was translation assistance documented?" would be scored as not applicable.

Ninety (90) records were reviewed across the three CEDARR Family Centers. The following tables, organized by major component area, show several key findings from the audit process.

One of the important questions within the "Client Information" section of the audit tool addresses the provision of translation assistance to non-English speaking families. There were 34 records reviewed that indicated the family did not speak English. Table 23 shows that over 97% of these records documented that the non-English speaking families received translation assistance.

Table 23 – Provision of Translation Assistance

Standard To Be Met	# of Records Meeting Standard	Percentage Meeting Standard
If the family is non-English speaking, was translation assistance documented?	33 of 34	97.06%

Two important questions were evaluated within the "Timeliness" component of the record review: the CEDARR Family Centers' timely response to new families seeking assistance and the provision of crisis follow-up within 24 hours if the request for service was an urgent one. Table 24 addresses the CEDARR Family Centers' turn-around time in responding to new, non-urgent requests for assistance within fourteen (14) days as stipulated by the CEDARR certification standards.

Table 24 – Response to Non-urgent Requests Within 14 Days

Standard To Be Met	# of Non-urgent Requests Meeting Standard	Percentage Meeting Standard
Was the Initial Family Contact started within 14 days if the request was routine in nature?	54 of 69	78.26%

The CEDARR Family Centers' ability to provide crisis follow-up within 24 hours of an urgent level request was also evaluated. Table 25 shows that 24-hour follow-up was documented in <u>all</u> (100%) of the situations in which a new family demonstrated an urgent level request for services.

Table 25 - Crisis Follow-up

Standard To Be Met	# of Urgent Requests Meeting Standard	Percentage Meeting Standard
If the request was urgent, was crisis-follow-up provided within 24-hours?	11 of 11	100%

Based upon the recommendations of the Leadership Roundtable for Children with Special Health Care Needs, the CEDARR certification standards stipulate that CEDARR Family Centers must elicit and document a family's strengths, supports, needs, and circumstances within the initial family assessment (IFA) process. Table 26 shows that the percentage of records that contained this key documentation exceeds 90%.

Table 26 – IFA Documents Family's Strengths & Supports

Standard To Be Met	# of Records Meeting Standard	Percentage Meeting Standard
Does the Initial Family Assessment (IFA) document the family's strengths, supports, circumstances, & needs?	59 of 65	90.77%

The CEDARR certification standards require that CEDARR Family Centers involve the child's family in the development of the family care plan (FCP). This stipulation was also based upon the active participation of families in the development of the CEDARR certification standards. Table 27 highlights the finding that slightly less than 90% of the records audited met this standard.

Table 27 - FCP Documents Family Involvement

Standard To Be Met	# of Records Meeting Standard	Percentage Meeting Standard
Does the Family Care Plan show evidence of the family's involvement in the plan's development?	62 of 69	89.9%

CEDARR certification standards call for the CEDARR Family Centers to coordinate their efforts with other organizations and programs that also provide services to the family, such as the local school system's special education program. Table 28 shows that this coordination was documented in slightly less than 80% of the records that were reviewed.

Table 28 – FCP Documents Coordination With Other Services

Standard To Be Met	# of Records Meeting Standard	Percentage Meeting Standard
Does the Family Care Plan document the CEDARRS' coordination with other programs and services?	47 of 60	78.3%

Similarly, the CEDARR certification standards require CEDARR Family Centers' coordination with any of the CEDARR Direct Service providers (such as Home Based Therapeutic Services, KIDS Connect, and PASS) who work with the child and family. CEDARR Family Centers are required to provide treatment plan feedback to CEDARR Direct Service providers within 21 days. Table 29 documents the findings pertaining to Direct Service treatment plan turn-around time.

Table 29 – FCP Documents Treatment Plan Feedback

Standard To Be Met	# of Records Meeting Standard	Percentage Meeting Standard
Did the CEDARR render a decision about the Direct Service treatment plan within 21 days?	35 of 41	85.37%

Summary of data addressing "family-centeredness", compliance with certification standards:

Based upon review of the findings from CEDARR family surveys conducted by the Department of Human Services in 2003 and 2006, CEDARR Family Centers have incorporated family-centeredness within their programming. In 2003 and 2006, over 85% of the survey participants reported that they felt themselves to be a part of the team making decisions for their family.

In 2006, a new question was added to determine whether families believed that the goals included in their child's CEDARR plan of care were appropriate and met the needs of their child and family. Over 82% of the 2006 survey participants gave a positive answer to this question.

In terms of overall family satisfaction with CEDARR, 80% of the respondents participating in each survey reported that they would use these services again if they needed them. An increasingly higher percentage (81%) of 2006 survey participants stated that they would recommend CEDARR to their extended family and/or their friends.

CEDARR certification standards contain explicit directives about the need to approach families from a strengths-based standpoint and to actively engage parents and family members in the care planning process. The randomized audit of CEDARR Family Centers' service documentation records (which are frequently referred to as "charts") in 2006 corroborated the family survey feedback addressing both of these pivotal concepts. Over 90% of the records reviewed during the randomized audit showed documentation of families' strengths, supports, circumstances, and needs. Almost 90% of the records documented family involvement in the development of their child's plan of care.

With regard to other aspects of the CEDARR Family Centers' compliance with certification standards, the randomized record audit addressed the CEDARRs' ability to respond to families' needs in a timely manner. For routine requests for service, a 14-day standard is stipulated. More than three-quarters (78.26%) of the records met this 14-day standard in the event of a routine request. For urgent-level requests, 100% of the records showed compliance with the certification standards' 24-hour rule.

CEDARR certification standards that address translation and communication assistance were met in over 97% of the audited records. Such assistance is essential to ensure that CEDARR services are accessible to all potential participants.

CEDARR Family Centers are required to coordinate their work with other family service providers in the health care system, community-based organizations, and schools. Such coordination was documented in more than three-quarters (78.3%) of the records that were audited. CEDARR Family Centers' responsiveness within 21 days to new or revised treatment plan proposed by CEDARR Direct Service providers (such as Home-based Therapeutic Services, PASS, and KIDS Connect) was documented over 85% of the time.

IV. CEDARR DIRECT SERVICES

In this section of our report, the Department of Human Services will provide information to address the following question.

4. Has Rhode Island achieved a comprehensive system of care for children with special health care needs?

A. Phase Two: CEDARR Direct Services

The Leadership Roundtable set forth a broad vision for the creation of a comprehensive continuum of services for children with special health care needs in Rhode Island. Due to the ambitious scope of this process, a two-phase initiative was envisioned. The first phase of this initiative focused upon helping families of Medicaid-enrolled children to secure and effectively use the State's system of existing health, education, and social services with greater efficiency. CEDARR Family Centers were established during "Phase One" to provide these supports to families.

The second phase of this initiative focused upon the launch of model, innovative services so that all children with special needs might receive health services in the least restrictive setting possible. In addition to the important services that they offer to families of children with special health care needs, CEDARR Family Centers make a unique contribution to the development of model programs and services. Since their inception, the CEDARR Family Centers have identified the need for both new services (that had not previously existed for families in Rhode Island) as well as expanded services (that had been limited either in their scope or availability).

Through the family care planning process, CEDARR Family Centers assess and work with children with special health care needs and their families to help them gain access to and effectively use resources. In the event that system capacity shortfalls are identified, the CEDARR Family Centers enumerate this information for State policymakers. In some situations a child may be approved to receive a specific quantity of services on a weekly basis, but the program is unable to meet this need fully. The CEDARR electronic care coordination system allows the State to quantify such gaps and shortages.

As a result of the CEDARR Family Centers' feedback to State agencies about service delivery shortfalls, Rhode Island has begun to develop a more robust *array of direct services* to help families meet their children's special health care needs outside of institutional (i.e., hospitals or long-term care facilities) settings. These "direct services" include Home-based Therapeutic Services (HBTS), KIDS CONNECT, and Personal Assistance Services and Supports (PASS). These CEDARR Direct Services are described in detail in the following appendices to this report:

- Home-based Therapeutic Services (Appendix B)
- KIDS CONNECT (Appendix C)
- PASS (Appendix D)

Rhode Island's Home-based Therapeutic Services (HBTS) program was in operation prior to the work of the Leadership Roundtable. Before the launch of the CEDARR initiative, system capacity challenges were seen for children who were felt to be in need of HBTS. One factor affecting HBTS system capacity has been our State's on-going shortage of trained clinical support workers to provide health services in home-based settings.

In addition to workforce shortages, however, HBTS system capacity was stymied by the volume of children in need of non-institutional clinical services that were outside the traditional HBTS model. Intake assessments frequently revealed that many children needed unique types of clinical support services with enhanced flexibility, other than those customarily provided by the HBTS program, provided outside of institutional settings.

As a result of their interactions in the homes of families, CEDARR Family Center workers helped quantify the need for these other types of assistance. This information provided the impetus for the development of two new programs: KIDS CONNECT (see Appendix C) and PASS (see Appendix D). The first KIDS CONNECT participating agency was certified in 2003; the initial PASS agency was certified in 2005.

KIDS CONNECT provides therapeutic services to Medicaid enrolled children who have special health care needs within a DCYF-licensed child and youth care center. All KIDS CONNECT services are based upon a "therapeutic integration plan" that is developed by a licensed health care professional in consultation with the child's family and with the licensed childcare program.

PASS was designed to promote and strengthen the ability of children with special health care needs to achieve in the following domains:

- The accomplishment of essential activities of daily living within the family home
- The ability to make self-preserving decisions
- The capacity to participate more fully in social roles and settings

Through their initial family assessment and care planning processes, CEDARR Family Center workers collaborate with families to determine the types of services that best meet the needs of the child and family. In the event that a child and family have the need for a CEDARR Direct Service, the CEDARR Family Center makes a referral and requests a treatment plan.

Table 30 shows a one-year history of the involvement of CEDARR-participating children with CEDARR Direct Services. From 04/01/2005 – 04/01/2006, the number of children participating with a CEDARR Family Center has increased from 1,343 to 1,500 (a 12% increase). Likewise, during the same one-year period, the percentage of CEDARR participants who use CEDARR Direct Services has increased from 23% to 29%.

Table 30: Involvement of CEDARR-Participating Children with CEDARR Direct Services

Month	# of Children with a CEDARR Relationship	# of CEDARR Children Using CDS	Percentage of CEDARR Children Using CDS
04/01/05	1343	313	23%
05/01/05	1369	318	23%
06/01/05	1392	333	24%
07/01/05	1407	353	25%
08/01/05	1409	367	26%
09/01/05	1421	378	27%
10/01/05	1429	394	28%
11/01/05	1434	405	28%
12/01/05	1432	424	30%
01/01/06	1427	430	30%
02/01/06	1437	432	30%
03/01/06	1487	438	29%
04/01/06	1500	440	29%

What type of shift has occurred in CEDARR Direct Service utilization since the development of the KIDS CONNECT and PASS programs? Table 31 presents information about each program's contribution to the total Direct Service utilization by the type of CEDARR Direct Service provided from 04/01/2005 – 04/01/06.

Table 31 shows that by 12/01/2005 (or within the first seven months) of PASS operations, its participating agencies became responsible for at least 10% of CEDARR Direct Service utilization. During the same time period (04/01/05 – 04/01/06), HBTS declined from 90.82% to 77.37% in terms of its overall contribution to CEDARR Direct Services utilization. KIDS CONNECT also experienced a decline during this period, from representing 9.18% of the CEDARR Direct Services utilization to 7.76%.

Table 31: CEDARR Direct Service Utilization

Month	Home-based Therapeutic Services (HBTS)	KIDS CONNECT	PASS	Total Across All Types of CEDARR Direct Services
04/01/05	287	29	0	316
05/01/05	292	27	0	319
06/01/05	301	31	4	336
07/01/05	308	34	18	360
08/01/05	317	36	23	376
09/01/05	322	39	30	391

Table 31: CEDARR Direct Service Utilization				
Month	**Home-based Therapeutic Services (HBTS)**	**KIDS CONNECT**	**PASS**	**Total Across All Types of CEDARR Direct Services**
10/01/05	332	44	34	410
11/01/05	344	40	38	422
12/01/05	358	40	46	444
01/01/06	361	38	56	455
02/01/06	355	40	61	456
03/01/06	358	40	63	461
04/01/06	359	36	69	464

It was projected that as the KIDS CONNECT and PASS programs became fully operational that the rate of demand for HBTS would stabilize. As additional service options have become available, HBTS utilization has stabilized.

Full access to HBTS continues to be affected by on-going provider workforce limitations in Rhode Island. This issue is a systemic one that requires a broad-based approach with strategic inputs from Rhode Island's institutions of higher education, its secondary education system, and representatives of various health professions. Infrastructure investment is needed so that our State may increase the training and retention of culturally competent allied health professionals who are well equipped to serve infants, children, and adolescents in home and community-based settings.

As of June of 2006, there is full access to PASS services. This service continues to grow in a robust manner and appears to be very well received by families. In addition, it is possible that the PASS program may help improve Rhode Island's supply of health care workers interested in providing home and community-based services by tapping into a previously underutilized workforce. Completion of PASS training and subsequent employment by PASS agencies could result in some personal assistance workers choosing to continue to develop their skills and/or education in order to provide more clinically intensive services to children with special health care needs, such as HBTS.

The KIDS CONNECT program has seen its enrollment stay level at least in part due to transportation barriers experienced by some families of children with special health care needs. While KIDS CONNECT-certified day care services are available, transportation to and from the participating childcare center is limited for some families. As of June of 2006, there is full access to KIDS CONNECT services.

Summary of data addressing whether Rhode Island has developed a comprehensive system of care for families of children with special health care needs:

We believe that the question of whether a comprehensive system has been fully achieved is one that warrants the inputs of an expansive range of constituencies. In this report, the Department described the development of several new innovative programs (CEDARR

Family Centers, KIDS CONNECT, and PASS) designed and implemented since 2001 to meet the needs of families of Medicaid-enrolled children with special health care needs. These services, however, have not yet become available to children with special health care needs who have commercial health insurance coverage.

Rhode Island has seen considerable system-wide improvements since the call to "go forth and do" was issued by the Leadership Roundtable for Children with Special Health Care Needs. Nonetheless, the Department believes that the time has come to reconvene all its partners (families, advocates, educators, clinicians, human service providers, and public policymakers) to ensure the achievement of our mutual goal: to create and sustain a fully integrated, comprehensive system of care for all of Rhode Island's children with special health care needs.

V. OBSERVATIONS AND NEXT STEPS

This report opened with a series of four questions. Our key findings are summarized below and followed by a brief discussion of "next steps".

1. Do the newly developed programs established as a result of the Leadership Roundtable reach families in need?

    - Families living in all 39 cities and towns in Rhode Island have accessed CEDARR services. Children with a broad array of special health care needs, across the pediatric age spectrum, are served by CEDARR Family Centers. Likewise, CEDARRS provide services to families with translation and communication needs.
    - Utilization of the two new CEDARR Direct Services (PASS and KIDS CONNECT) continues to grow and overall system capacity continues to increase with the certification of new providers. Nonetheless, infrastructure issues have limited KIDS CONNECT enrollment, primarily availability of transportation. An opportunity exists to reach out to new partners in the community to address this issue.
    - HBTS providers continue to experience challenges in recruiting and retaining home-based workers. The need for skilled home care workers contributes at least in part to the difficulty families have in timely access to services. Health workforce is a macro-environmental issue that challenges our State. We must continue to work with health care providers to develop creative approaches to rectify this situation.

2. Has the concept of "family-centeredness" been embedded in the development of programs that partner tangibly and effectively with families?

    - Results of the CEDARR family surveys in 2003 and 2006 show that on several key indicators of "family-centeredness" the CEDARR Family Centers scored very well. "Family-centeredness" concepts are core to the CEDARR Initiative. Our 2006 randomized audit of CEDARR Family Centers' charting documentation indicates considerable adherence with the CEDARR certification standards that address the delivery of family-centered care. More opportunities for improvement are available, however.

- Keeping "family-centeredness" a priority starts at the Department of Human Services. The Department will continue to use all its existing communication pathways to gain important feedback from families, advocates and providers, as well as apply quality improvement techniques to improve processes and identify "best practices" across the CEDARR Family Center and CEDARR Direct Services continuum of care.

3. Have the CEDARR Family Centers attained the performance levels set forth in the CEDARR certification standards?

   - The 2006 CEDARR chart audit process, which was based upon the certification standards, shows that the CEDARRs' documentation is robust in the areas of client information, parental consent, use of a family-centered approach, the processing of urgent-level requests for services, and turn-around times for Direct Services treatment plans. Documentation of coordination with other programs and services is an area for the CEDARR Inter-departmental Team's further intervention with the CEDARR Family Centers. Training and technical assistance may be warranted.
   - Results of the 2006 CEDARR chart audit will be used to re-examine the standards themselves in a collaborative manner with all stakeholders (parents, advocates, the Inter-departmental Team, and CEDARR agency representatives) to determine if there are opportunities for further improvements.
   - Timely access to HBTS continues to be a concern. Shortages of allied health professionals who are trained to address the needs of children and youth with special health care needs in home- and community-based settings affect HBTS capacity. More "human infrastructure" development is needed on a statewide basis.
   - For families who are knowledgeable of the RI delivery system for children with special health care needs and who do not need linkage with community-based programs, access to CEDARR Direct Services may appear time-consuming. Refined "triaging of need" best practices can be identified in partnership with all stakeholders, resulting in enhanced operating efficiencies.

4. Has Rhode Island achieved a comprehensive system of care for children with special health care needs?

   - With the development of PASS and KIDS CONNECT, as well as the changes made to HBTS as a result of the "HBTS Challenge " activities, Rhode Island has a more comprehensive array of health services to meet the individual needs of Medicaid-eligible children with special health care needs and their families.
   - Utilizing the work done thus far as a starting point, we have an opportunity to continue to re-engage actively with stakeholders to ensure not only a comprehensive but also a more coordinated system of care for all children with special health care needs in Rhode Island.

   The Department of Human Services will undertake the following "next steps" to address Rhode Island's system of care for children with special health care needs:

- Meet with representatives of the CEDARR Family Centers to provide feedback about the findings of the 2006 CEDARR family survey and charting documentation audit
- Meet with our community partners to identify ways to convene discussion about the next phase of overall system development
- In the Autumn of 2006, reconvene the Leadership Roundtable
- With the inputs of our strategic partners, re-assess the CEDARR certification standards in light of program experience to determine whether the current requirements need any modification

APPENDIX A

CEDARR Family Centers

About Families - Certified in April of 2001
203 Concord Street, Suite 335
Pawtucket, RI 02860

About Families (Satellite Location)
1 Cumberland Street, 4th Floor
Woonsocket, RI 02895

About Families (Satellite Location)
1 Frank Coelho Drive
Portsmouth, RI 02871

Empowered Families - Certified in March of 2006
82 Pond Street
Pawtucket, RI 02860

Families First – Certified in July of 2002
Hasbro Children's Hospital – Room 120
593 Eddy Street
Providence, RI 02903

Solutions CEDARR – Certified in September of 2001
134 Thurbers Avenue, Suite 102
Providence, RI 02903

Solutions CEDARR (Satellite Location)
610 Ten Rod Road, Unit 13
North Kingston, RI 02852

APPENDIX B

Home-based Therapeutic Services

Home-based Therapeutic Services (HBTS) are specialized health *services that are delivered within a home or community-based setting* for children with severe behavioral health needs and/or developmental disorders. In order to receive HBTS intervention, a child must have an individualized treatment plan that has been developed in conjunction with a licensed health care professional. Once the proposed treatment plan has been approved by a CEDARR Family Center or by the RI DHS, the HBTS provider implements the delivery of services for the child within the family's home or within a community-based setting. There are two components of HBTS: specialized treatment and treatment support.

HBTS Specialized Treatment: Based on the measurable goals and objectives mapped out in the child's treatment plan, HBTS specialized therapeutic services are provided in a "one-on-one" manner by a paraprofessional home-based worker for an approved number of hours per week under the supervision of a licensed clinical supervisor. The intent of specialized treatment is to help the child increase his or her language skills, improve the child's ability to focus on a task, decrease aggression or other problematic behaviors, and improve his or her problem-solving capacity. This *treatment plan for in-home services* reinforces the objectives established within the child's Individual Educational Plan (IEP) or Individualized Family Service Plan (IFSP). For example, a child with a significant communication disorder may receive home-based services from the paraprofessional worker to reinforce the clinical treatment recommendations of the child's Speech Pathologist. Specialized treatment services are not substitutes for the clinical therapy provided by a licensed therapist.

HBTS Treatment Support: The intent of treatment support is to facilitate the ability of a child or adolescent with moderate to severe developmental and/or neuro-medical conditions to remain in the family's home, carry out his or her activities of daily living, and successfully transition to adulthood. Treatment support must address the child or youth's ability to:

- Acquire and use information
- Complete tasks
- Interact with and relate to others
- Care for himself/herself
- Participate in community activities

Treatment support services can be provided by the same worker who provides HBTS specialized treatment or by another individual who meets the qualifications for a home-based treatment support worker. The clinical supervisor directs this set of activities. Treatment support services are not intended for the convenience of others nor are they to be provided when another more appropriate service is needed, such as childcare, respite care, or certified nursing assistance.

As of June of 2006, there are *fifteen (15) agencies certified* by the RI DHS to offer HBTS in Rhode Island. The names of the certified agencies are listed below.

1. ARC of Northern RI – Certified in October 2003
   One Cumberland Plaza, Fourth Floor
   Woonsocket, RI 02895

2. Adeline LaPlante Memorial Center – Certified in August of 2002
   1130 Ten Rod Road
   North Kingstown, RI 02852

3. Bradley Hospital – Certified in December of 2002
   1011 Veterans Memorial Parkway
   East Providence, RI 02915

4. Cranston ARC – Certified in December of 2003
   875 Centerville Road, Building 3, Suite 7
   Warwick, RI 02886

5. Family Services, Inc. – Certified in December of 2002
   55 Hope Street
   Providence, RI 02906

6. Frank Olean Center –Certified in July of 2003
   93 Airport Road
   Westerly, RI 02889

7. Groden Center – Certified in December of 2002
   86 Mount Hope Avenue
   Providence, RI 02906

8. John Hope Settlement – Certified in August of 2005
   7 Burgess Street
   Providence, RI 02903

9. The J. Arthur Trudeau Center of Kent County – Certified in March of 2003
   3445 Post Road
   Warwick, RI 02886

10. Looking Upwards – Certified in June of 2003
    438 East Main Street
    Middletown, RI 02842

11. Ocean State Community Resources – Certified in March of 2003
    1445 Wampanoag Trail, Suite 207
    East Providence, RI 02915

12. Perspectives – Certified in March of 2003
    1130 Ten Rod Road, Building C, Suite 201
    North Kingston, RI 02852

13. Spurwink – Certified in March of 2003
    One Spurwink Place
    Cranston, RI 02910

14. TIDES Family Service – Certified in March of 2003
    215 Washington, Street
    West Warwick, RI 02893

15. United Cerebral Palsy of RI – Certified in May of 2003
    200 Main Street
    Pawtucket, RI 02860

APPENDIX C

KIDS CONNECT (Formerly known as "Therapeutic Child & Youth Care")

Established in 2003, KIDS CONNECT provides therapeutic services to Medicaid enrolled children who have special health care needs within a DCYF-licensed child and youth care center. All services provided are based upon a "therapeutic integration plan" that is developed by a licensed health care professional in consultation with the child's family and with the licensed childcare program. This service is not intended to replace other services for which children with special health care needs are entitled to receive (including but not limited to those provided by Early Intervention, Special Education, and Head Start), but rather to allow the children to acquire skills in a more natural, age appropriate setting. The "therapeutic integration plan", which must be approved by the child's CEDARR Center, should document how the direct services of a therapeutic integration specialist will allow the child to participate with typically developing peers, resulting in an opportunity for increased social interaction.

As of June of 2006, there are *five (5) agencies certified* by the RI DHS to provide KIDS CONNECT throughout Rhode Island. These agencies are listed below.

1. Child Care Connection – Certified in 2003
   151 Hunt Street
   Central Falls, RI 02863

   Child Care Connection (Satellite)
   22 Cedarr Swamp Road
   Smithfield, RI 02917

   Child Care Connection (Satellite)
   197 Beverage Hill Avenue
   Pawtucket, RI 02860

   Child Care Connection (Satellite)
   42 Greco Lane
   Warwick, RI 02885

   Child Care Connection (Satellite)
   25 Blackstone Valley Place
   Lincoln, RI 02865

2. KIDS Klub, Inc. – Certified in December of 2005
   462 Smithfield Avenue
   Pawtucket, RI 02860

3. Meeting Street – Certified in December of 2005
   667 Waterman Avenue
   East Providence, RI 02914

4. Crayons Child Care and Family Services
   3445 Post Road
   Warwick, RI 02886

5. Child, Inc. – Certified in September of 2003
   160 Draper Avenue
   Warwick, RI 02889

   Child, Inc. (Satellite)
   849 Centerville Road
   Warwick, RI 02886

   Child, Inc. (Satellite)
   28 Payan Street
   West Warwick, RI 02893

   Child, Inc. (Satellite)
   23 Cady Street
   Coventry, RI 02816

APPENDIX D

Consumer Directed Providers of Personal Assistance Services and Supports (PASS)

The Personal Assistance Services and Supports Project (PASS) was established in 2004. The goal of PASS is to *facilitate independent community living* for children with special health care needs. PASS was designed to promote and strengthen the ability of children with special health care needs to achieve in the following domains:

- The accomplishment of essential activities of daily living within the family home
- The ability to make self-preserving decisions
- The capacity to participate more fully in social roles and settings

Through the PASS Program, a direct service worker is engaged through one of Rhode Island's three PASS certified agencies by a family to provide personal assistance to their child with special health care needs. PASS provides a *family-directed service option*, to reduce families' dependence on an agency-based model of care. As of June of 2006, there are three (3) agencies certified by the RI DHS to provide PASS throughout Rhode Island. These agencies are listed below.

The PASS direct service worker provides hands-on assistance and guidance to children with special health care needs. This interaction builds upon the goals mapped within the child's Individual Education Plan (IEP) or the Individualized Family Service Plan (IFSP). This plan is integrated through the CEDARR Family Center and the child's school (or Early Intervention Program, if the child is less than three years of age).

PASS agencies provide support to families so that the family may recruit, hire, and supervise a personal assistant to help their child accomplish essential activities of daily living within the family home and participate more fully in social activities. PASS provides a *family-directed service option*, to reduce families' dependence on an agency-based model of care.

The PASS direct service worker provides hands-on assistance and guidance to children with special health care needs. This interaction builds upon the goals mapped within the child's Individual Education Plan (IEP) or the Individualized Family Service Plan (IFSP). This plan is integrated through the CEDARR Family Center and the child's school (or Early Intervention Program, if the child is less than three years of age).

1. The ARC of Northern Rhode Island – Certified in April of 2005
   1 Cumberland Street, 4th Floor
   Woonsocket, RI 02895

2. The J. Arthur Trudeau Center – Certified in December of 2005
   3445 Post Road
   Warwick, RI 02886

3. United Cerebral Palsy of Rhode Island – Certified in December of 2005
   200 Main Street
   Pawtucket, RI 02860