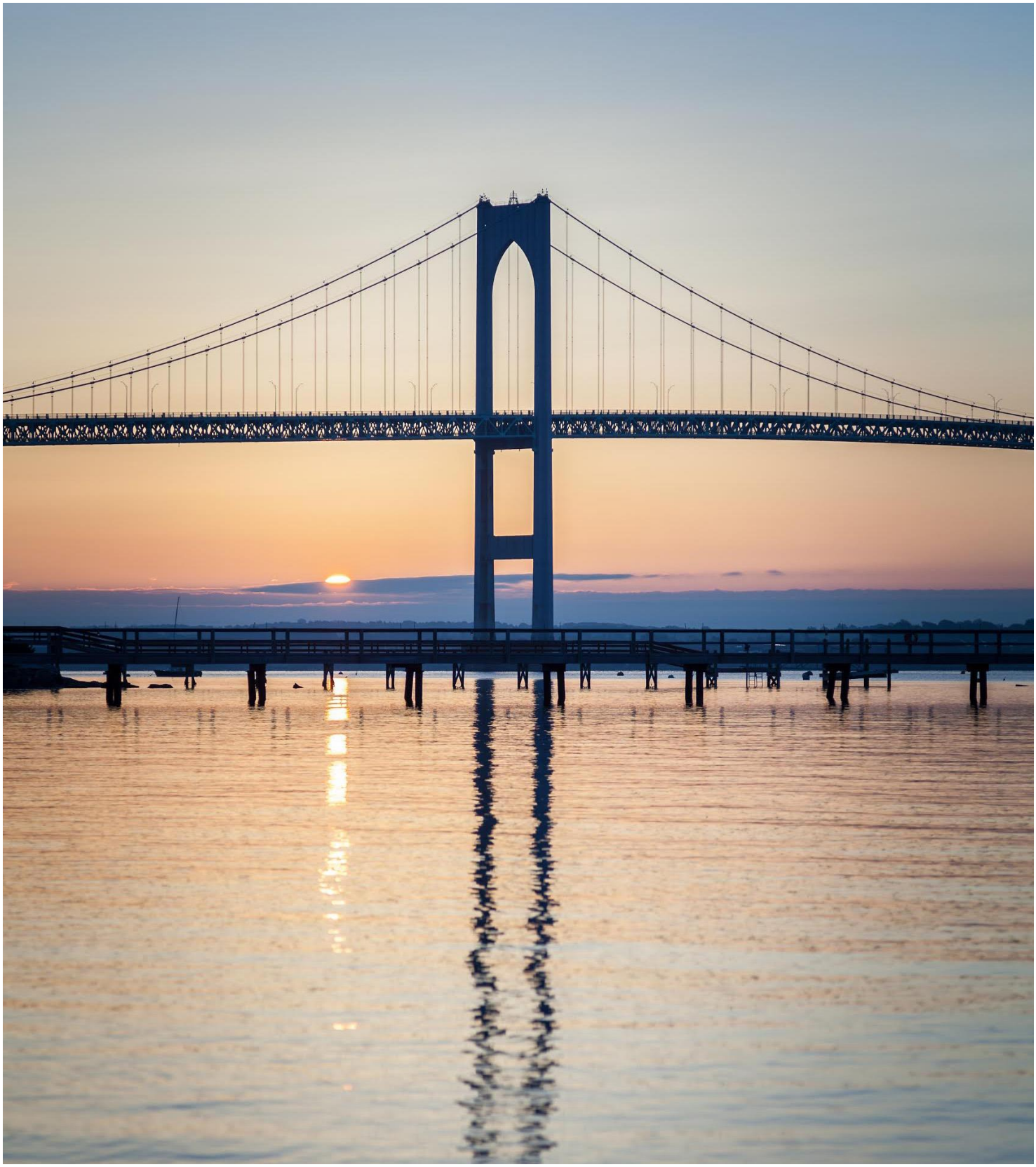

SUPPORTING CHILDREN AND YOUTH WITH SPECIAL NEEDS

Rhode Island State Plan 2015 - 2020

RHODE ISLAND DEPARTMENT OF HEALTH

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Rhode Island Department of Health
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March 2015

To Our Integrated Systems Partners:

We are pleased to present the Rhode Island State Plan for Children and Youth with Special Needs, developed by our community partners and HEALTH's Office of Special Needs. Population-based data and targeted feedback from a cross-section of state and community leaders were used to craft the recommendations in this plan.

As the Maternal and Child Health administrators in Rhode Island, we are charged to ensure family-centered, community-based, integrated systems of services for Rhode Islanders with special needs, through infrastructure building, training, technical assistance, and collaboration with consumers, other state agencies, and community agencies. We encourage you to use this plan to direct your efforts of integrating Rhode Island's system of care for children and youth with special needs and their families, and to collaborate with us in that process.

Thank you for partnering with HEALTH in achieving an integrated system. Please contact Deborah Garneau at 401-222-5929 if you have any questions or comments regarding the Office of Special Needs.

Sincerely,

Ana Novais, MA
Executive Director

Deborah Garneau, MA
Special Needs Director

EXECUTIVE SUMMARY

In public health terms, children and youth with special health care needs are considered a particularly vulnerable population since they are often isolated from appropriate support and may also have, or be at an increased risk for, a chronic physical, developmental, behavioral, or emotional condition.

The Office of Special Needs (OSN) within the Rhode Island Department of Health (HEALTH) developed this State Plan to ensure that children and youth with special needs, and their families, receive high-quality and community-based support and services from birth through adulthood within a high-quality, integrated system of care.

OSN assures access to care through systems improvement guided by consumer input, the Healthy People 2020 objectives, and the Title V – Maternal and Child Health Services Block Grant.

DEVELOPING AN INTEGRATED SYSTEM OF CARE

The OSN State Plan is funded through the Health Resource Service Administration Maternal and Child Health Bureau as part of an initiative to help states increase the proportion of children and youth with special needs who receive integrated care through a patient-centered, medical-home approach by 20% (from 44% to 64%) by August 30, 2017. The complete Request for Proposal and requirements for this plan can be found in Appendix A.

The goals for the State Plan, which covers the federal fiscal year 2015 through 2020, are:

- Develop a more integrated system of services for children and youth with special needs with the goal to increase Rhode Island's capacity to coordinate policy, communications, training, data, program development/analysis, and collaborative partnerships across agencies, organizations, and programs at the state and local level.
- Identify the role of OSN in maintaining a coordinated system of services and delineate the roles of other state agencies that support children and youth with special needs.
- Partner with state agencies, community stakeholders, health professionals, family organizations, and families of children and youth with special needs.
- Highlight the role of other state agencies and family support organizations. (See Appendix B for a full list.)
- Include measurable, state-specific strategies, goals, and objectives developed through stakeholder engagement.
- Provide a mechanism for effective coordination, collaboration, data sharing, and integration among stakeholders for State Plan priorities (to include integration of project activities with the Title V Block Grant and existing state activities focused on systems improvement).

STAKEHOLDER ENGAGEMENT AND METHODOLOGY

OSN recognizes the importance of working collaboratively with a wide range of stakeholders and community organizations to continuously inform and enhance efforts in all aspects of quality improvement related to their mission.

To further engage key stakeholders through a third-party perspective, OSN partnered with (add)ventures, a Rhode Island-based multidisciplinary brand culture and communications firm, to conduct a comprehensive research study on the current state of the system of care.

(add)ventures conducted a series of interviews with 25 partners, including non-profit and community organizations, hospitals, state agencies, and others (see Appendix B for a full list), to better understand their experience with special needs children/youth, their parents, and providers, as well as identify critical gaps and opportunities to help inform the planning process.

Participants were asked a series of questions about:

- Types of services provided through the system of care
- Current partnerships and involvement
- Communications approaches
- Family/child/youth experience and segments
- Opportunities for improvement
- The role of HEALTH/OSN

In December 2014, the stakeholders met to review the key findings from the initial interviews and develop the vision for the State Plan. Key findings identified that OSN, through HEALTH:

- is not a direct service provider
- assists people by supporting partner organizations
- is both a governing/regulatory office and a thought leader for the state

"More than 20.6% of Rhode Island's 218,241 children and more than 75 organizations comprise the current system of care in Rhode Island."

SUMMARY OF OPPORTUNITIES

This plan outlines four main opportunities that were identified as ways to help achieve OSN's goal of increasing the proportion of children and youth with special needs who receive integrated care.

1 **Build Connections**
A key role of OSN is to build connections between organizations and provide support in expanding access for children and youth within the special needs community.

2 **Share Information**
By sharing data and best practices with dozens of partner organizations, OSN can help guide programming, resource allocation, and more from a global perspective. It is appropriate for OSN to share and discuss upcoming policy initiatives with stakeholders to maintain its position as a thought leader.

3 **Educate Families**
OSN should uphold the responsibility to broadly educate the community at large about public health-related issues specifically in the area of special needs.

4 **Support Programs**
OSN has the opportunity to provide staff and funding to assist with programs coordinated or led by other organizations.

ABOUT THE OFFICE OF SPECIAL NEEDS

OSN strives to continuously improve the state's system of care to ensure that children and youth with special needs, and their families, receive high-quality and community-based support and services from birth through the transition from adolescent to adulthood.

In collaboration with families, other state agencies, heath providers, and community organizations, OSN is dedicated to six core components that comprise a system of services needed to support children and youth with special needs:

1. Family/professional partnership at all levels of decision-making
2. Access to comprehensive health and related services through the medical home
3. Early and continuous screening, evaluation, and diagnosis
4. Adequate public and/or private financing of needed services
5. Organization of community services that are family-friendly
6. Successful transition to all aspects of adult health care, work, and independence

MISSION STATEMENT
OSN's role is to support the children and youth with special needs, and their families, by supporting the organizations that provide direct services to this population. The following mission statement has guided OSN since 2004:

OSN ensures family-centered, community-based systems of services for children and youth with special health care needs through infrastructure building, training and technical assistance, and collaboration with families, other state agencies, heath plans, and community agencies. OSN assures access to care through systems improvement as guided by consumer input, Healthy People 2020 Objectives and Title V federal legislation. OSN is specifically charged with developing and implementing a plan to achieve appropriate community-based systems of services for children and youth with special health care needs and their families.

OSN Staff

OSN employs eight full-time staff members managing an annual budget of $1 million.

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OSN is part of the Health Equity team, which assures equitable systems, reduces health disparities, empowers communities, and builds capacity to promote access to comprehensive, high-quality services that are responsive to

CURRENT INITIATIVES

OSN is tasked with oversight of the system of care in Rhode Island under the Title V – Maternal and Child Health Services Block Grant and the Healthy People 2020 initiative. The following is a list of current programs and efforts managed by OSN.

Programs and Initiatives:
OSN works with a multitude of state and local partners to streamline and encourage critical programs to promote health and wellness for children and youth special needs populations. OSN provides support for these programs in the form of consultation, funding, and staffing.

OSN Programs	Description
Disability & Health Program	Promotes the health and wellness of people with special needs through inclusive self-management evidence-based programs; provides professional development for practitioners working with people with special needs, including training, targeted technical assistance, and access to assistive technology; addresses special needs of people with special needs in health promotion programs, health strategic planning, emergency preparedness, preventive health screening programs, and health care facility access; and increases access to quality of health-related data of people with special needs in Rhode Island and utilizes epidemiological methods and evaluation analysis to monitor the health disparities.
Adolescent Health Care Transition Program	Assists youth with chronic health conditions and disabilities to transition to the adult systems of primary and specialty care, education, employment, and insurance. Makes resources available for physicians, parents, and youth regarding the timeline and necessary components of transition that support self-determination.
Pediatric Practice Enhancement Project (PPEP)	A medical-home initiative that ensures a coordinated system of care for children and youth with special needs, and their families, by placing trained Parent Consultants in pediatric primary and specialty-care practices to assist families in accessing community resources, to assist physicians and families in accessing specialty services, and to identify barriers to coordinated care.
Family/Peer Resource Specialist Program	Brings the perspective of parents, youth, and consumers into policy development and medical home implementation. Resource Specialists strengthen the Division of Community, Family Health, and Equity's (CFHE) capacity to deliver effective services, to address critical health issues, and to involve the community in the discussion that leads to effective program planning for the State's special needs and culturally diverse populations. In addition, the program assists consumers in accessing community resources such as specialty care, independent living, education, employment, and vocational training.
Pediatric Specialty Services	Monitors and coordinates specialty care for children and youth with special health care needs (CYSHCN) and their families through contract management activities, providing technical assistance and family engagement. Coordination of pediatric specialists is accomplished through specific projects and initiatives including: interdepartmental collaboration for Rhode Island's care coordination system-CEDARR, Family Voices Leadership Team, and the Office of Health and Human Services (OHHS) Partnership Taskforce.

Healthy Lifestyles for Youth with Special Needs	Healthy Lifestyles is an evidence-based, 16-hour interactive workshop for youth with disabilities or special needs to develop confidence and skills to sustain a healthy life. Participants learn how to manage stress and maintain healthy relationships, and how health impacts their goals.
Dare to Dream Youth Leadership Program	Rhode Island's Dare to Dream includes ongoing leadership development opportunities, youth-development materials, youth advisory council, youth speakers bureau, and intensive leadership training.

OSN Initiatives	Description
Dare To Dream Student Leadership Conference	A one-day leadership event for students and young adults in Rhode Island with special needs. Includes workshops on leadership strategies, life skills, healthy living tips, and personal expression through art, poetry, and drama. Also includes keynote speeches from nationally-recognized leaders whose inspirational stories and messages help to inspire students and teachers.
Youth Advisory Council	OSN's Youth Advisory Council brings together youth or young adults to advise and collaborate on activities, programs, policies, and resources affecting the health, wellness, and transition of youth in our state. This Advisory Council is available to assist programs within HEALTH or other state agencies with youth-engagement strategies.
Youth with Special Health Care Needs Internship Program	OSN offers an Internship Program for Rhode Island's high school students to assist in office-based and entry-level work throughout the Department. Previous interns placed at HEALTH have helped with tasks including mailings, filing, data entry, meeting preparation, outreach assistance, organizing, preparing health fair materials, and providing youth input.

"The Office of Special Needs works with a multitude of state and local partners to streamline and encourage critical programs to promote health and wellness…"

Committee Involvement

OSN regularly attends the meetings of committees and councils throughout the state to maintain communications with other state and local partners and represents the state in discussions around best practices, legislative topics, and consumer needs. OSN participates in:

- **AmeriCorps Inclusion Advisory Committee:** to ensure children and youth with special needs are included in AmeriCorps programs throughout Rhode Island.
- **Association of Maternal and Child Health Programs (AMCHP):** to provide legislative and programmatic leadership to state Title V Programs.
- **Asthma Control Coalition:** to bring best practices to Rhode Island's community partners in the diagnosis and treatment of asthma, the most prevalent childhood chronic illness.
- **CEDARR Interdepartmental Team:** to administer the Comprehensive Evaluation, Diagnosis, Assessment, Referral and Re-evaluation (CEDARR) program – the state's care coordination for children and youth with special needs.
- **Children's Behavioral Health Coalition:** to help plan an annual parent professional conference to address a coordinated system of care for children/youth with mental/behavioral health disorders.
- **Collaborative for Health Equity and Wellness:** to bring together state and community organizations to reduce health disparities and promote equity in all policies.
- **Community Health Network:** to promote a coalition of evidence-based, chronic-condition self-management courses available to Rhode Islanders with special needs.
- **Community Health Worker Association of Rhode Island:** to organize Rhode Island's community health workers and to promote core-competency training.
- **Cross-Disabilities Coalition:** to convene a group of people with special needs.
- **Dare to Dream Advisory Committee:** to gather youth and youth organizations, transition staff, and state leaders to plan the annual Dare to Dream Conference.
- **RI Developmental Disabilities Council:** to advise the Developmental Disabilities Division of the Department of Behavioral Healthcare, Developmental Disabilities, and Hospitals (BHDDH) on policy and practice.
- **Disability Community Planning Group:** to advise policy and program implementation concerning integrating people with special needs in public health programs.
- **Emergency Management Advisory Committee (EMAC):** to prepare the state for all emergencies and disasters, and to attend to the needs of vulnerable populations, including people with special needs and disabilities.
- **Employment First Advisory Committee:** to convene stakeholders and state agencies to ensure that people with special needs have opportunities for integrated employment.
- **Family Voices Leadership Team:** to create a forum for stakeholders and families to ensure a coordinated system of care in Rhode Island for children and youth with special needs.
- **Executive Office of Health and Human Services (EOHHS) Partnership Taskforce:** to oversee the implementation of Rhode Island's 1115 Global Demonstration Medicaid Waiver.

- **Governor's Commission on Behavioral Health:** to advise the Departments of Behavioral Health, Developmental Disabilities, and Hospitals (BHDDH) and Children, Youth and Families (DCYF) on implementing the behavioral health, mental health, and substance abuse systems in Rhode Island.

- **Governor's Commission on Disabilities:** to address legislation, ensure accessibility, and monitor disability concerns in Rhode Island.

- **Interagency Coordinating Council:** to provide advice and oversight to the Early Intervention system and to EOHHS.

- **Joint Legislative Commission Addressing the Quality of Life of People Living with Autism in Rhode Island:** to hear testimony of and oversee Rhode Island's system of care for people with an autism-spectrum disorder.

- **Leadership Institute of CYSHCN Directors:** to implement standards of care for children and youth with special needs in individual state efforts.

- **Neighborhood Health Plan of Rhode Island (NHPRI) Children and Youth with Special Needs Advisory Committee:** to advise Rhode Island's managed-care providers regarding service delivery to children and youth with special needs and their families.

- **Preconception Health Advisory Committee:** to ensure that preconception health is systematically addressed in public health, health policies, and consumer awareness.

- **Region 1 Maternal and Child Health Network:** to maintain communication with New England colleagues on initiatives affecting children and youth with special needs and their families.

- **Rhode Island Council for Assistive Technology:** to provide advice to the Rhode Island Assistive Technology Access Partnership to help people get information about assistive technology.

- **Rhode Island Special Education Advisory Committee:** to advise the Rhode Island Department of Education (RIDE) on implementation of Individuals with Disabilities Education Act (IDEA) at the state and district level.

- **Rhode Island Transition Council:** to advise and orchestrate programs of transition for students, ages 14-21, receiving special education services or 504 services.

- **Statewide Family and Community Advisory Board (FCAB):** to advise and guide the four regional FCABs to promote continuity of planning and communication to ensure a statewide, integrated system.

- **Youth Act:** to provide youth who have special needs with opportunities to build advocacy and leadership skills to benefit their community.

- **Youth Advisory Committee:** to advise, assist, and collaborate with HEALTH on programs within the Department.

- **Youth Suicide Prevention Committee:** to represent diverse stakeholders from government agencies, community-based organizations, private entities, and individuals affected by injury.

OSN AND OTHER STATE AGENCIES

OSN works collaboratively with many other state agencies and it is important to delineate the unique partnerships:

Rhode Island Department of Education (RIDE): The primary responsibility of RIDE is to ensure the full implementation of the Rhode Island Comprehensive Education Strategy by developing and implementing a standards-based approach for each element of the Basic Education Program. Currently, there are 142,854 students in Rhode Island public elementary, middle, and high schools. The Office of Student, Community, and Academic Supports has a long and proud history of ensuring that students with exceptionalities receive support and intervention to meet high expectations and exit public education as productive citizens, life-long learners, and contributing members of the workforce. The goals of the Office of Student, Community, and Academic Supports ensure that children with diverse learning needs and children receiving special education services are given equal access to a public education and that schools develop effective strategies for meeting the needs of these unique learners.

The Office of Student, Community, and Academic Supports is responsible for advancing the education of: children and youth with special needs who require special education; children and youth who are English language learners or limited English proficient/Non-English speaking; children and youth who are disadvantaged and/or participate in Title I; who are experiencing homelessness, neglect, delinquency or are at-risk; children and youth who are learning beyond grade level; children and youth with expanded learning opportunities, such as after-school or summer programs, which support learning opportunities for students outside of the regular school day or school year. OSN works with RIDE on secondary transition, family engagement, special education services at the state and local level, and strategic-planning and advisory committees.

Rhode Island Executive Office of Health and Human Services (EOHHS): Responsible for managing the Departments of Health; Human Services (DHS); Children, Youth and Families (DCYF); and Behavioral Health, Developmental Disabilities, and Hospitals (BHDDH). Its mission is to assure access to high-quality and cost-effective services that foster the health, safety, and independence of all Rhode Islanders. OSN works with EOHHS on issues related to Medicaid, managed care, patient-centered medical homes, eligibility, Early Intervention, CEDARR, and direct-service provision to CYSHCN and their families.

Rhode Island Department of Behavioral Healthcare, Developmental Disabilities, and Hospitals (BHDDH): Ensures access to quality services and supports Rhode Islanders with developmental disabilities, mental health, and substance abuse issues, and chronic, long-term medical and psychiatric conditions. Its mission includes working to eliminate the stigma attached to these disabilities as well as planning for the development of new services and prevention activities. OSN works with BHDDH on issues related to behavioral health, developmental disabilities, and transition.

Rhode Island Department of Children, Youth, and Families (DCYF): Partners with families and communities to raise safe and healthy children and youth in a caring environment. All children in the DCYF system have special needs due to their unique family backgrounds. DCYF's Family Care and Community Partnerships Programs (FCCPs) provide children and families with needed supports and guidance as a way of assisting and promoting healthy family development. The state established four regional FCCPs for the state, and each FCCP is a collaboration of agencies within every community. The partner agencies are Community Action Programs (CAPs), mental health, health centers, and others that provide multiple points of access to assist families when needed. OSN serves in an advisory capacity to the FCCPs and works with DCYF on secondary transition, Early Intervention, family visiting, special needs services, youth empowerment, and children's behavioral health.

The Rhode Island Department of Human Services (DHS): Works hand-in-hand with other organizations in Rhode Island to offer a full continuum of services for families, adults, children, elders, individuals with special needs and veterans. OSN collaborates with DHS to ensure families with children and youth with special needs receive essential benefits, such as food and child care.

OSN AND FAMILY SUPPORT AGENCIES

In addition to collaborating with a number of state agencies, OSN also partners with several family-support agencies.

Rhode Island Parent Information Network (RIPIN): The Rhode Island Parent Information Network (RIPIN) is a statewide, non-profit organization with a mission to assist individuals, parents, families, and children to achieve their goals for health, educational, and socio-economic well-being by providing information, education, training, support, and advocacy for person/family-centered care and systems change. RIPIN is a member agency of The Fund for Community Progress and, along with 24 other grassroots agencies, they work to promote social change and family-centered policies in Rhode Island.

Parent Support Network of Rhode Island (PSN): The Parent Support Network (PSN) is an organization of families supporting families with children, youth, and young adults who experience or are at risk for serious behavioral, emotional, and/or mental health challenges. PSN seeks to strengthen and preserve families and reduce family isolation by promoting positive mental health and well-being, and building a culturally and linguistically competent system of care, through advocacy, education, training, and increased public awareness.

The Paul V. Sherlock Center on Disabilities: The Paul V. Sherlock Center on Disabilities is a University Center on Excellence in Developmental Disabilities Education, Research, & Service (UCEDD). Areas of emphasis include: early intervention & education transition; employment of people with developmental disabilities; independent living for adults with disabilities; leadership development; and higher education. UCEDDs have worked towards a shared vision that individuals with disabilities participate fully in their communities. Independence, productivity, and community inclusion are key components of this vision. There are 67 UCEDDs in the country and at least one UCEDD in each state.

KEY DEFINITIONS

The vision for this State Plan is centered on three core principles as defined by various stakeholders. OSN promotes these definitions and strives to expand the statewide system of care around these tenets.

Defining Children and Youth with Special Health Care Needs (CYSHCN):
As defined by the Maternal Child Health Bureau (MCHB) and adopted by the American Academy of Pediatrics (AAP) in 1998, children and youth with special health care needs (CYSHCN):

"Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

OSN's framework centers around the child, with the surrounding areas of need identified to provide a holistic and integrated system of support. **(FIGURE 1)**

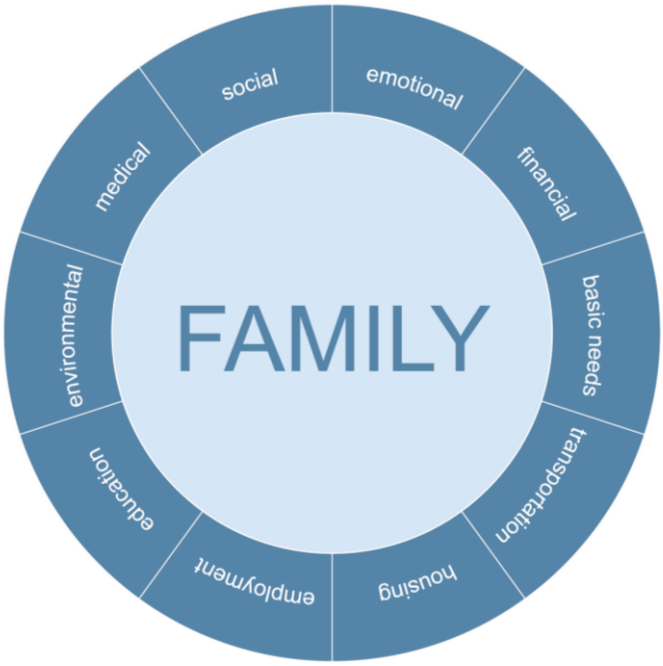

FIGURE 1. OSN FRAMEWORK

To this extent, "health care" is a misnomer as it may be interpreted as pertaining only to the medical aspects, excluding other features that impact health outcomes and are in the scope of the broader MCHB definition.

Integrated System of Care:
An integrated system of care is a streamlined and coordinated concept that aligns the delivery and management of systems and services related to an individual's care plan. The goal is to provide a seamless experience so the individual may receive quality care that is efficient, effective, and comprehensive.

As it relates to OSN, an integrated system of care also ensures that state and community systems of services and supports are aligned to promote and assure that children and youth with special needs receive a high-quality and coordinated, family-centered, medical-home approach.

OSN strives to offer a system of services with little overlap for children, youth and their families, along with easy access to resources and information, plus a strong referral process for partnering community organizations.

Patient-Centered Medical Home (PCMH):
According to the American Academy of Family Physicians (AAFP), the American Academy of Pediatrics (AAP), the American College of Physicians (ACP) and the American Osteopathic Association (AOA), the PCMH is an approach to providing comprehensive primary care for children, youth, and adults. The PCMH is a healthcare setting that facilitates partnerships between individual patients and their personal physicians, and when appropriate, the patient's family.

The AAFP, AAP, ACP, and AOA, representing approximately 333,000 physicians, have developed the following joint principles to describe the characteristics of the PCMH:

- **Personal physician** – each patient has an ongoing relationship with a personal physician trained to provide first contact, continuous, and comprehensive care.
- **Physician-directed medical practice** – the personal physician leads a team of individuals at the practice level who collectively take responsibility for the ongoing care of patients.
- **Whole-person orientation** – the personal physician is responsible for providing all of the patient's healthcare needs or taking responsibility for appropriately arranging care with other qualified professionals. This includes care for all stages of life: acute care, chronic care, preventive services, and end-of-life care.
- **Care is coordinated and/or integrated across all elements of the complex healthcare system** (e.g. sub-specialty care, hospitals, home health agencies, nursing homes) and the patient's community (e.g. family, public, and private community-based services). Care is facilitated by registries, information technology, health information exchange, and other means to assure that patients get the necessary care when and where they need and want it in a culturally and linguistically-appropriate manner.
- **Quality and safety**
  - Practices advocate for their patients to support the attainment of optimal, patient-centered outcomes that are defined by a care-planning process and are driven by a compassionate, robust partnership between physicians, patients, and patients' families.
  - Evidence-based medicine and clinical-support tools guide decision-making.
  - Physicians in the practice accept accountability for continuous quality improvement through voluntary engagement in performance measurement and improvement.
  - Patients actively participate in decision-making and feedback is sought to ensure patients' expectations are being met.
  - Information technology is utilized appropriately to support optimal patient care, performance measurement, patient education, and enhanced communication.
  - Enhanced access to care is available through systems such as open scheduling, expanded hours, and new options for communication between patients, their personal physician, and practice staff.

STATE LANDSCAPE

In Rhode Island, and throughout the United States, there is a need for comprehensive, coordinated, integrated state and community systems of services and supports to improve the quality of life for children and youth with special needs and their families.

More than 20.6% of Rhode Island's 218,241 children and more than 75 organizations comprise the current system of care in Rhode Island.

Indicators of Care Coordination and Medical Home for Rhode Island's Children and Youth with Special Health Care Needs[1] and Non-CYSHCN

Measure Description	CYSHCN (%)	Non-CYSHCN (%)
Prevalence		
Overall prevalence	20.6%	79.4%
Population estimate	44,872	173,369
Access to Mental Health		
Needed but did not get mental health services	31.0	49.6
Needed and received mental health services	69.0	50.4
Access to Support Services		
Had problems getting referrals when needed	2.9	1.9
Received no help with coordination of care among different doctors or services	78.1	85.1
Dissatisfied with communication among child's doctors and other healthcare providers*	**7.3**	**2.2**
Dissatisfied with communication of doctors and school, child-care providers, special education program, etc.	21.9	8.4
Quality of Healthcare		
Doctors never spend enough time with child	3.0	6.7
Doctors never listen carefully to parents	1.0	3.7
Parents never feel like partners in child's care	3.4	4.3
Had a visit with a health professional during past 12 months, but did not get asked about concerns (ages 0-5)*	**26.1**	**46.8**
Never got needed specific information from doctor or health care provider	7.9	3.5
Did not receive family-centered care	32.6	27.3
Did not receive one or more elements of effective care coordination*	**35.2**	**10.4**
Medical Home		
Child does NOT have an established source for care	3.7	6.9
Care does not meet criteria for having a medical home*	**49.6**	**37.6**

*indicates statistical significance

[1]Child and Adolescent Health Measurement Initiative (2013): "2011/12 National Survey of Children's Health: List of Common Chronic Conditions Asked About." Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at www.childhealthdata.org. Revised 3/14/13. http://nschdata.org/browse/titlev/state-title-v-survey-results

OPPORTUNITIES

For more than 15 years, OSN has addressed issues related to quality of healthcare, access to services, disparities in health outcomes, access to information, availability of positive youth-development initiatives, peer workforce development, and the quality of life for children and youth with special needs and their families and has led the charge to integrate a range of stakeholders in all aspects of systems and quality improvement.

As part of the development of this plan, these stakeholders, including non-profit and community organizations, hospitals, state agencies, and others (see Appendix B for a full list), were consulted to provide input about the role of HEALTH, and specifically OSN. The stakeholders helped provide a better understanding of their experience with special needs youth, their parents and providers, as well as identify critical gaps and opportunities to help inform the planning process.

This plan outlines four main opportunities that were identified to help achieve OSN's goal of increasing the proportion of children and youth with special needs who receive integrated care:

- Build Connections
- Share Information
- Educate Families
- Support Programs

Build Connections
A key role of OSN is to build connections between organizations and provide support to expand relationships for children and youth within the special health care needs community. This role is critical in helping to reduce overlap of organizations' efforts and ensuring the whole state is moving, in unison, toward serving the areas of greatest need at any given time.

OSN should continue or expand in the following areas:

Community Engagement
Key methods for this will include continued participation in committees and coordination of events that bring together constituents throughout Rhode Island to facilitate important conversations on special needs topics and to develop the overall knowledge base in the state.

Key Partnerships
As one of the only entities with connections to most support organizations in the state, OSN can initiate partnerships to expand the system of care in new ways. This includes exploring opportunities to build awareness among community organizations and services either involved or not directly involved in the system of care to increase coordination of Rhode Island's system of care, such as transportation, housing, employment, translation services, and community networks.

Successful Transitions
OSN can continue to build meaningful connections between youth and adult systems before, during, and after periods of transitions. OSN can help streamline communications between audiences and organizations to better prepare youth and families for transitions and to help clarify what resources are available at each life stage.

Share Information
OSN can share data and best practices with partner organizations because it is one of the only entities in the state with access to the Behavioral Risk Factor Surveillance System (BRFSS), Youth Risk Behavior Survey (YRBS), and National Survey of Children's Health data that help track and identify trends within the children and youth with special needs population. In addition, OSN keeps current with national advocates who are shaping the industry and building best practices, such as the Association of Maternal and Child Health Programs, National Association of Public Health Programs, Family Voices, Leadership Institute for CYSHCN Directors, and National Improvement Partnership Network.

By identifying data and best practices at the local, regional, and national level and sharing this information with other organizations in Rhode Island, OSN can help guide programming and resource allocation from a global perspective.

OSN can also help clarify and establish standards for what falls under the scope of work for special needs in Rhode Island and can further communicate these definitions to partner organizations and agencies.

Educate Families
HEALTH works to prevent disease and protect and promote the health and safety of the people of Rhode Island. Although OSN does not provide direct services to family members, OSN should uphold the responsibility to broadly educate the community-at-large about public health-related issues specific to the area of special needs as it relates to children and youth.

This can be accomplished through a variety of tactics, including the continued use of transition guides, a statewide integrated marketing awareness campaign, a web-portal resource guide, increased communications to ethnic populations, and inclusion of people with special needs as decision makers.

Support Programs
Many stakeholders interviewed were unaware of OSN's current program involvement. It's recommended that OSN continue funding and supporting existing programs and develop a strategic communications plan to broaden awareness among key stakeholders and other community organizations.

An opportunity for OSN is to provide staff and funding to assist with programs coordinated or led by other organizations. This partnership approach will allow OSN to remain flexible and maximize its impact by contributing to programs and events that are targeted at the greatest areas of need at a given time. A program may be selected to receive OSN support based on the population it serves, the magnitude of the impact, and alignment to the HEALTH mission.

ROADMAP

Framework for Five-Year Plan

In the next several years, OSN will focus its efforts on strengthening the system of care by enhancing and educating the community on the personal, professional, and public levels; empowering stakeholders and families with the tools they need to succeed; and extending the overall capabilities and access to care in the state. In the coming years, OSN will adopt an iterative process to ensure learning and continuous improvement within each phase.

2015: Education

Focus: Introduce OSN within the special needs community and define its role.

The focus of year one will be to introduce OSN and build awareness of OSN's role and responsibilities within the special needs community. To achieve this, OSN will focus on becoming more visible within the professional community and positioning itself as a resource for stakeholders in state agencies, community organizations, and providers who may not be as familiar with the programs, information, and best practices that OSN supports.

2016: Engagement

Focus: Bring together stakeholders and organizations and streamline communications.

The year-two objective is focused on developing the infrastructure in Rhode Island by strengthening communications and partnerships among agencies and organizations. During this year, OSN will work to unify professionals and families around the resources available in the state by creating valuable, innovative tools and resources. The tactical approach will include developing an inventory of data sources and exploring new communications vehicles for disseminating critical news and information through the system. This could include implementation of a comprehensive self-service web portal, or an in-depth training program for volunteers and peer mentors.

2017: Empowerment

Focus: Provide tools and increased support for existing stakeholder initiatives/programs.

The focus in 2017 will be on creating efficiencies and optimizing outreach efforts by building critical tools for the special needs community (including families and professionals). This will include building on 2016 initiatives and driving new features and mechanisms for the state communications infrastructure.

2018: Expansion

Focus: Innovate and expand program involvement to increase breadth of services in the state.

After the foundation is set, OSN will shift its focus to supporting the system as it grows and changes to provide expanded access to care. This may include support of new programs, expanded standards and best practices, or identification of new funding sources and partners.

2019 & Beyond: Extension

Focus: Reach new audiences and raise the profile of Rhode Island as a national leader.

As OSN becomes an established thought leader in the state, the focus in 2019 and beyond will be to increase visibility and engagement of the public. This will also include positioning Rhode Island as a leader and sharing best practices on a national scale through publications, and committee involvement.

Highlighted Tactics

	2015 Educate	2016 Engage	2017 Empower	2018 Expand	2019 & Beyond Extend
Build Connections	• Continue committee participation • Delegate/ collaborate on authoring of new content pieces	• Annual state summit • Bi-annual check-ins with each organization • Strengthen relationships with health plans, hospitals, and community-based providers	• Establish shared resources for tracking the pathways of children and families through the system (e.g. common benefits applications)	• Explore new partnerships with indirect, but related, services (e.g. RIPTA, culture brokers, translation services)	• Engage other states and national organizations to enhance Rhode Island's system of care
Share Information	• Continue publishing fact sheets/reports • Update OSN website and collateral • OSN annual report • Disseminate best practices and innovative approaches	• Universal and targeted listservs • Phase 1 of web portal as a resource guide	• Quarterly newsletter and e-News • Social media • Phase 2 of web portal as a communication vehicle	• Quarterly newsletter/e-News for professionals in Rhode Island • Social media	• Quarterly newsletter and e-News for professionals and public in Rhode Island and beyond
Educate Families	• Continue transition guides • Develop glossary of terms for those new to the system	• Statewide awareness campaign phase 1 • Family volunteer training • Develop inventory/index of organizations and resources	• Integrate CYSHCN in Rhode Island's No Wrong Door Initiative • Community-based events	• Establish family outreach-specific programs, task force	• Statewide awareness campaign phase 2 • Community-based events • Social media
Support Programs	• Continue funding/resources for ongoing programs • Develop system for prioritizing/ allocating monetary support from HEALTH to outside programs	• Training of mentors/ volunteers with no formal background • Transition support team	• Collaborate with corporations to direct in-state philanthropy efforts	• Collaborate with corporations to direct in-state philanthropy efforts • Department of Labor and Training teen employment program	• Promote universal design innovation in planning and community development

APPENDIX A: STATE REQUEST FOR PROPOSALS

Department of Health

Three Capitol Hill
Providence, RI 02908-5097

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State Plan for an Integrated System of Care for CYSHCN

The Rhode Island Department of Health, Office of Special Needs intends to develop a comprehensive state plan for CYSHCN in Rhode Island that involves a wide range of stakeholders including all CYSHCN state agencies, families, family organizations, health and social service providers. The plan should identify the role of HEALTH's OSN in maintaining a coordinated system of services and delineate the roles of other CYSHCN state agencies including Rhode Island Department of Education; Department of Behavioral Health, Developmental Disabilities and Hospitals; Executive Office of Health and Human Services, Department of Children Youth and Families; and Department of Human Services. The plan should highlight the role of family support organizations such as Rhode Island Parent Information Network, Parent Support Network and Sherlock Center
for Disabilities.

Access to quality, comprehensive, coordinated community-based systems of services that are family-centered, community-based, and culturally competent is essential for CYSHCN and their families and underpin the following six core components of a system of services for CYSHCN: Family/professional partnership at all levels of decision-making; Access to comprehensive health and related services through a medical home; Early and continuous screening, evaluation and diagnosis; Adequate public and/or private financing of needed services; Organization of community services so that families can use them easily; Successful transition to all aspects of adult health care, work, and independence.

***Need & Experience**:* There is a need in Rhode Island, as elsewhere in the nation, for comprehensive, coordinated, integrated state and community systems of services and supports to improve the quality of life for CYSHCN and their families. As Rhode Island's Title V CSHCN Agency, HEALTH through OSN has the responsibility to promote and assure that CYSHCN receive a patient/family-centered medical/health home approach to services and supports through statewide systems integration. HEALTH through OSN has addressed issues related to quality of health care, access to services, disparities in health outcomes, access to information, availability of positive youth development initiatives, peer workforce development, and the quality of life for CYSHCN and their families for decades and leads the charge to integrate a wide range of stakeholders in all aspects of CYSHCN quality improvement. It is the intent of the state planning process to build on OSN's best practice initiatives of the Pediatric Practice Enhancement Project and Dare to Dream Youth Initiative.

State Plan Activities:

- ☐ Identify with OSN key state and local partners who represent the components of the comprehensive CYSHCN system for participation on the CYSHCN State Plan Team.
- ☐ Key partners will include representative of the following state agencies -- Rhode Island Department of Education; Department of Behavioral Health, Developmental Disabilities and Hospital; Executive Office of Health and Human Services, Department of Children Youth and Families; and Department of Human Services -- community stakeholders, health professionals, family organizations, and families of CYSHCN.
- ☐ The plan should highlight the role of HEALTH's OSN in addition to the role of other state agencies and family support organizations such as Rhode Island Parent Information Network, Parent Support Network and Sherlock Center for Disabilities.
- ☐ Develop a comprehensive state plan to ensure an integrated system of services for CYSHCN with the goal to increase Rhode Island's capacity to coordinate policy, communication, training, data, program development/analysis, and collaborative partnerships across CYSHCN agencies, organizations, and programs at the state and local level.
- ☐ The state plan should include measurable state-specific strategies, goals and objectives developed through stakeholder engagement.
- ☐ The state plan should include a mechanism for effective coordination, collaboration, data sharing, and integration among stakeholders for activity priorities under the state plan. This mechanism will include integration of project activities with the Title V Block grant as well as existing state activities focused on systems improvement.
- ☐ The CYSHCN Needs Assessment and State Plan will be disseminated to Rhode Island's stakeholders.

Funding:

RI's CYSHCN State Plan development is funded through Health Resource Service Administration Maternal and Child Health Bureau to states with the goal of increasing the proportion of CYSHCN who receive integrated care through a patient / family-centered medical / health home approach by 20% (from 44% to 64%) by August 30, 2017. $25,000 is available for state plan development.

Products:

State Plan for CYSHCN that includes:

- ☐ State specific strategies, goals and objectives developed through stakeholder engagement.
- ☐ A mechanism for effective coordination, collaboration, data sharing, evaluation, and integration among CYSHCN stakeholders.
- ☐ Development of a shared resource of CYSHCN information and referral.
- ☐ A plan for measuring, evaluating and sustaining integrated system improvement.

Strategic partnerships among CYSHCN stakeholders reflected in written agreements.

Timeline:

September 2014- February 2015

Programmatic Contacts:

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APPENDIX B: STAKEHOLDER ORGANIZATIONS INTERVIEWED

About Families CEDARR[1] Center
American Academy of Pediatrics, Rhode Island Chapter
The Autism Project
Bradley Hospital
Children's Neurodevelopment Center at Rhode Island Hospital
Executive Office of Health and Human Services (EOHHS) Taskforce
Executive Office of Health and Human Services (EOHHS)
Family-Centered Care Initiative at Hasbro Children's Hospital
Family Voices of Rhode Island
Governor's Council on Disabilities
KIDS COUNT
Neighborhood Health Plan of Rhode Island
Parent Support Network of Rhode Island
Patient Centered Medical Home-Kids
Paul V. Sherlock Center on Disabilities at Rhode Island College
Rhode Island Department of Behavioral Healthcare, Developmental Disabilities, and Hospitals (BHDDH)
Rhode Island Department of Education (RIDE)
Rhode Island Department of Health (HEALTH)
Rhode Island Department of Human Services (DHS)
Rhode Island Office of Rehabilitation Services
Rhode Island Parent Information Network (RIPIN)
UnitedHealthcare
Women & Infants Hospital

[1] Comprehensive Evaluation, Diagnosis, Assessment, Referral, and Re-Evaluation

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