

Oral Health Forum for Children with Special Health Care Needs in Rhode Island



Final Report & Action Plan

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Acknowledgements

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Executive Summary

On November 9, 2006, the Family Voices program at the Rhode Island Parent Information Network (RIPIN) and the Oral Health Program at the Rhode Island Department of Health convened a statewide **Oral Health Forum for Children with Special Health Care Needs** to identify access barriers, propose solutions, and build support for improving the oral health status of children and youth with special health care needs (CYSHCN). The federal Maternal and Child Health Bureau sponsored the Forum through a cooperative agreement with the Association of State and Territorial Dental Directors. Additional federal support was received from the Centers for Disease Control and Prevention and local partners, including the Rhode Island Chapter of the American Academy of Pediatrics, United Healthcare, and Neighborhood Health Plan of Rhode Island.

Staff of RIPIN and the Oral Health Program, in consultation with professionals in the fields of oral health, medical care, and CYSHCN, planned and hosted the Forum. Jill Beckwith, MPH, Policy Analyst at Rhode Island KIDS COUNT, served as the meeting facilitator.

The Forum assembled a broad group of stakeholders who shared expertise, best practices and collaborative solutions to develop an *Oral Health Action Plan for Children and Youth with Special Health Care Needs in Rhode Island*. Over 60 participants attended the Forum, including representatives from oral health professional societies, primary care medical providers, hospital-based dental programs, community-based social service organizations that serve CYSHCN and their families (including RIPIN, the Paul V. Sherlock Center on Disabilities, and Comprehensive Evaluation, Diagnosis, Assessment, Referral, and Reassessment Family Centers – CEDARR Centers), child advocacy groups, dental and medical insurers, community health centers, Head Start agencies, and state agencies (including the Rhode Island Departments of Health, Human Services (State Medicaid agency), and Children, Youth and Families. A detailed list of Forum participants can be found in Appendix A.

The event opened with welcoming remarks from the host organizations and energizing comments from the Lieutenant Governor-elect and Rhode Island Oral Health Commission Chair Elizabeth Roberts. An interdisciplinary panel of speakers highlighted the context of CYSHCN in Rhode Island. The expert panel included 1) Deborah Garneau, MA, Program Director in the Office of Families Raising Children with Special Health Care Needs, RI Department of Health, 2) Susan Stuart, DO, MS, FAAP, South County Pediatric Group and mother of a child with special health care needs, 3) Daniel Kane, DMD, Dental Director, Pediatric Dental Center, St. Joseph Hospital, and 4) Shirley Spater, DMD, MPH, Dental Director, Samuels Sinclair Dental Center, Rhode Island Hospital. Speaker presentations provided an overview of CYSHCN in Rhode Island, including information on the particular medical and oral

health issues facing this population, and a description of the type of oral health services and treatment considerations that would best serve CYSHCN. The personal story of one Rhode Island child's oral health needs and the issues facing his family in accessing the oral health system was highlighted by Dawn Wardyga of Family Voices, with additional true experiences included in participant packets.

Forum participants formed interdisciplinary workgroups; each group included parents of CYSHCN, oral health professionals, parent consultants, state agency representatives, and other stakeholders. Workgroups were asked to consider six areas of discussion: screening, medical home inclusive of a dental home, organization of services, insurance issues, family roles and transition to adulthood. Groups were charged with the tasks of: 1) identifying a main goal that would benefit CYSHCN for each topic areas; 2) proposing steps that could be taken to accomplish each goal; 3) identifying progress that already has been accomplished in each topic area; 4) providing suggestions for progress; and 5) identifying resources/likely collaborators.

Following the workgroup session, a facilitated discussion encouraged each group to share their best ideas as well as the ideas that would be most difficult to accomplish. Subsequently, RIPIN and the Rhode Island Department of Health incorporated the issues and themes identified by Forum participants, along with feedback from the presenters and other key stakeholders, to develop the following *Oral Health Action Plan for Children and Youth with Special Health Care Needs in Rhode Island* and an associated logic model, which can be found in Appendix B.

Oral Health Action Plan for Children and Youth with Special Health Care Needs in Rhode Island

A. Screening

Over the past few years, opportunities have increased for oral health screening of children in Rhode Island, with many school-linked pediatric dental programs sponsored by hospitals and community health centers. As of June 2006, these programs were operating in 43 elementary schools, four middle schools and two high schools in Rhode Island and had collectively screened more than 10,000 children during the 2004-2005 school year. In September 2006, a consortium of three community health centers (Cranston Community Action Program, East Bay Community Action Program, and Thundermist Health Center) launched the Molar Express, a Ronald McDonald Care Mobile with two dental operatories. The Molar Express will be deployed to 22 of the 39 cities and towns in Rhode Island to provide oral health screenings and other oral health care services to children. Private dentists and dental safety net providers also have been increasingly involved in *Give Kids A Smile!*, a one-day event each February during which oral health providers donate their time and expertise to provide oral health services to children without dental homes. While progress in the area of screening has been impressive, additional strategies specifically tailored to ensure oral health screenings for CYSHCN are needed in the future.

Goal

- All CYSHCN will receive early and regular oral health screenings during well-child visits with their primary care providers.

Priority Strategies (Years 1-2)

- Train primary care providers (such as pediatricians, family practice physicians, obstetricians/gynecologists, nurse practitioners, nurse midwives, physician assistants, and other appropriate health professionals) to conduct oral health screenings of pregnant women and CYSHCN and refer patients appropriately for oral health care services.
- Include oral health activities and outcomes in Individualized Family Service Plans (IFSPs) through Early Intervention Programs and Family Care Plans at CEDARR (Comprehensive Evaluation, Diagnosis, Assessment, Referral, and Reassessment) Family Centers. IFSPs should be specifically designed to centralize and coordinate the complex medical and family support needs of children and youth with special needs and their families.
- Train Parent Consultants who work in the Pediatric Practice Enhancement Project (PPEP) in oral health promotion/disease prevention opportunities so that they can talk with parents, CYSHCN, physicians and dental providers about the oral health

needs of CYSHCN in their practices. Parent Consultants are parents of CYSHCN that are stationed in clinical settings to link families with community resources, assist physicians and families in accessing specialty services, and identify systems barriers to coordinated care.

- Expand the PPEP to additional pediatric practices and dental centers in Rhode Island.

Other Promising Strategies (Years 3-5)

- Include dental hygienists as part of the health care team in pediatric offices to conduct oral health screenings and provide anticipatory guidance to children and parents.
- Provide insurance reimbursement through medical and dental payors to primary care providers for oral health screenings.

Likely Partners (Alphabetical)

Central Rhode Island Area Health
Education Center
Dental insurers
Medical insurers
Rhode Island Academy of Family Physicians
Rhode Island Chapter of the American
Academy of Pediatrics
Rhode Island Dental Assistants Association

Rhode Island Dental Association
Rhode Island Dental Hygienists' Association
Rhode Island Department of Health
Samuels Sinclair General Practice Residency
Program, Rhode Island Hospital
St. Joseph Hospital Pediatric Dental
Residency Program

B. Medical Home Inclusive of Dental Home

Because overall health is inclusive of oral health, the concept of a dental/medical home was defined as “a single source of on-going health care and/or referrals in the community where providers work as partners to meet the needs of CYSHCN and their families.” Strengths noted in Rhode Island were numerous, and included: 1) a large number of children with health insurance (although significantly fewer have dental insurance); 2) the September 2006 launch of the RIte Smiles program (a dental benefits manager program for Medicaid-eligible children born on or after May 1, 2000); 3) an increased number of dental residency training programs that provide increased access to oral health services for the most vulnerable populations; 4) recent licensure changes at the state level that have made it easier for dentists from other states to practice in Rhode Island; and 5) an increasing number of school-based/school-linked and mobile dental programs that have provided thousands of children with dental homes.

Goals

- Reciprocal communication will be practiced by all providers of care (including primary care and oral health providers) for all CYSHCN. Primary care providers (medical home) will conduct oral health screenings and communicate findings with the child’s dentist (dental home) and the family of the child. In turn, the child’s dentist will provide early and regular oral health care for the child and communicate findings with the primary care provider and the family.
- All CYSHCN will visit a dentist by the age of one year and twice yearly thereafter (or more frequently, as recommended/needed).

Priority Strategies (Years 1-2)

- Provide cross-disciplinary training between medical and dental professionals to increase their respective knowledge, skills and resources necessary for the provision of high quality oral health and medical care to CYSHCN.
- Train primary care providers to conduct oral health screenings of CYSHCN and to refer appropriately for oral health care.
- Provide specialty training for primary care dentists (pediatric and general practice) and dental specialists regarding special treatment considerations for CYSHCN. Dentists who are participating providers in the RIte Smiles program will be the first providers offered this type of training.
- Ensure that the Molar Express regularly visits schools and community agencies that serve CYSHCN and that health professionals working in school-based/school-linked dental programs are trained to deliver high quality oral health services to CYSHCN.

- Educate expectant and current parents on the importance of oral health and its relationship with overall health through public health campaigns, communications with primary care providers, and partnerships with WIC agencies, Head Start/Early Head Start programs and other community agencies serving parents.

Other Promising Strategies (Years 3-5)

- Provide mentorship opportunities between experienced professionals and those seeking to improve their knowledge and skills in providing oral health and medical care to CYSHCN.
- Develop a "Center of Excellence" for the oral health care of CYSHCN, at which they can receive oral health care services from professionals with expertise in treating their unique needs.
- Collaborate with professional societies to identify oral health professionals with expertise in treating CYSHCN.
- Identify dentists and physicians participating in the networks of dental and medical insurers who specialize in treating CYSHCN. Families, primary care providers, community agencies and oral health professionals should be encouraged to contact insurers to obtain referral information that will assist families in locating primary or specialty oral health care.
- When appropriate, include oral health screening, education and referral to oral health providers in the Individualized Family Service Planning (IFSP) process for young children (birth to age three in RI) with special health care needs.
- Pass legislation to mandate oral health screenings for school entry, in addition to other screening regulations for school-age children already in place.

Likely Partners (Alphabetical)

CEDARR Family Centers	Rhode Island Dental Association
Community agencies that serve parents of CYSHCN	Rhode Island Dental Hygienists' Association
Dental insurers	Rhode Island Department of Education
Early Intervention	Rhode Island Department of Health
Family advocates	Rhode Island Department of Human Services/ Medicaid
Head Start/Early Head Start Programs	Rhode Island Parent Information Network
Legislators	Rhode Island School Districts & Schools
Medical insurers	Visiting Nurse Association (VNA) Home Visitors
Pediatric Practice Enhancement Project	WIC Program
Primary care providers	
Rhode Island Dental Assistants Association	

C. Organization of Services

Forum participants noted a strong dental safety net in Rhode Island, which is comprised of 12 community health centers with dental clinics, three hospital-based dental centers (Rhode Island Hospital’s Samuels Sinclair Dental Center and St. Joseph Hospital’s Pediatric Dental Centers in Providence and at the Fatima Health Center) and the dental hygiene clinic at the Community College of Rhode Island. It is estimated that these sites served over 16,500 children in their most recently completed reporting year (which varied according to the site). Also, there are approximately 550 dentists actively practicing in Rhode Island, including 20 pediatric dentists. While many private dentists and most of the safety net providers care for CYSHCN, few have specific expertise in special care dentistry, although the Samuels Sinclair Dental Center at Rhode Island Hospital focuses on serving children and adults with special health care needs.

Goals

- All CYSHCN will have access to affordable, high quality oral health services in a health care system that is easy to navigate.

Priority Strategies (Years 1-2)

- Identify dentists and physicians participating in the networks of dental and medical insurers who specialize in treating children and youth with special needs. Families, primary care providers, community agencies and oral health professionals should be encouraged to contact insurers to obtain referral information when seeking to assist families in locating primary or specialty oral health care.
- Encourage dental providers to implement open access policies, in which patients are seen on the day they call for an appointment regardless of the reason for their visit.

Other Promising Strategies (Years 3-5)

- Co-locate medical, oral (general and specialty) and behavioral health services.
- Integrate electronic health (medical, dental, behavioral) records among providers.
- Ensure access to specialized transportation for CYSHCN to obtain oral health services. Ensure access to enabling services, such as interpretation, as needed.
- Add oral health services to the Rhode Island Department of Health’s KIDSNET database to ensure the provision of timely and appropriate preventive health services and follow up.

Likely Partners (Alphabetical)

Dental, medical, & behavioral health providers
Dental insurers

Health insurers
KIDSNET, Rhode Island Department of Health
RIDE/RI Public Transit Authority

D. Insurance Coverage

While Rhode Island has long been a national leader in the number of children who have medical insurance (ranging from 90-95%), an insufficient number have dental insurance (per the Rhode Island Department of Health's 2004 Health Interview Survey, 76% of parents reported having dental insurance coverage for their children). In September 2006, the Rhode Island Medical Assistance Program (RIte Care/RIte Share/Medicaid) launched the RIte Smiles program for Medicaid-eligible children born on or after May 1, 2000. Through this program, the Rhode Island Department of Human Services has contracted with a specialized vendor (UnitedHealthcare Dental) that is responsible for ensuring access to comprehensive dental services for its members by establishing and maintaining a network of participating dentists, paying claims to dentists, and providing interpreter and transportation services to its members as needed. While this program will increase access to care for the state's youngest children, the program must be extended to all children under the age of 19 years. Dental providers participating in RIte Smiles must be trained to treat CYSHCN. Children and youth who have private dental insurance coverage sometimes have oral health needs beyond those which are covered by their policies; these children and youth need assistance in bridging that gap to full coverage.

Goals

- All CYSHCN will have access to affordable high quality medical and dental insurance.

Priority Strategies (Years 1-2)

- Expand the RIte Smiles program for all children eligible for Medical Assistance, regardless of age.
- In the absence of the expansion of the RIte Smiles dental benefits manager program, increase Medicaid fee-for-service reimbursement rates paid to dentists who serve the balance of the population ages 6-19 years.
- If neither of the above is possible, provide reimbursement incentives for dentists willing to treat CYSHCN, including enhanced reimbursement rates and/or loan repayment programs.
- Ensure that dental insurers (private and public) provide reimbursement for behavior management codes for oral health providers who treat CYSHCN.

Other Promising Strategies (Years 3-5)

- Close the insurance gap for children with private dental and/or medical insurance: Provide coverage for necessary dental services that are not covered by private insurance.
- Support efforts to ensure universal access to medical and dental insurance for all children and youth in Rhode Island.

Likely Partners (Alphabetical)

Dental insurers (public & private)
Legislature
Medical insurers (public & private)
Rhode Island Department of Health

Rhode Island Department of Human Services
Rhode Island Office of the Health Insurance
Commissioner

E. Family Roles

The premise of Forum discussion was the principle that families are the constants in children's lives and, therefore, are pivotal in assuring that CYSHCN access appropriate dental and medical services. Rhode Island is the home of the Pediatric Practice Enhancement Project (PPEP), which was developed to assist and support pediatric primary and specialty care practices in providing improved short- and long-term health outcomes for CYSHCN and their families within a medical home. A collaborative initiative between the Rhode Island Departments of Health and Human Services, Neighborhood Health Plan of Rhode Island, and RIPIN (including Family Voices), PPEP places and supports trained Parent Consultants in clinical settings to link families with community resources, assist physicians and families in accessing specialty services, and identify barriers to coordinated care. The primary role of the Parent Consultant is to create linkages between the family, pediatric practice, and the community as a whole.

Goal

- All family members of CYSHCN will have the knowledge, skills and resources necessary to ensure optimal oral health of the children in their care, including oral health self-care at home and access to oral health services.

Priority Strategies (Years 1-2)

- Include oral health in checklists and resources that Parent Consultants use with families.
- Train Early Intervention program staff to assist families in finding dentists if their child does not have an established dental home.
- Increase the oral health knowledge and improve oral disease prevention practices of CYSHCN and their families, including appropriate daily home care, regular dental visits, and healthy nutritional habits.
- Increase the knowledge of expectant and current parents regarding the importance of oral health and its relationship with overall health through public health campaigns, prenatal counseling, and communications with primary care providers.

Other Promising Strategies (Years 3-5)

- Increase the number of Parent Consultants available at schools.
- Ensure that CYSHCN and their families have the resources they need to access oral health services, including adequate insurance coverage, a dental provider with expertise treating CYSHCN, etc.
- Change child care licensing regulations to include oral health screenings.

Likely Partners (Alphabetical)

CEDARR Family Centers

Early Intervention

Family advocates

Head Start/Early Head Start Programs

Health plans

Rhode Island Department of Education

Rhode Island Parent Information Network

Rhode Island School Districts

Visiting Nurse Association (VNA) Home Visitors

F. Transition to Adulthood

Forum participants noted a strong family practice model in Rhode Island, which promotes a smooth transition between pediatric and adult care. For those CYSHCN in the care and custody of DCYF, transition planning begins at age 19, in advance of “aging out” of DCYF care at age 21. Forum participants noted that transition planning would be best accomplished if it began earlier in life and that oral health services should be included as one of the items to be considered in a transition plan for all CYSHCN.

Goals

- During the transition to adulthood and as adults, all individuals with special health care needs will have a medical home, a dental home, and the knowledge, skills and resources necessary to ensure optimal oral health.

Priority Strategies (Years 1-2)

- Train general practice dentists in RI to work with adults with special health care needs.
- Identify dentists and physicians participating in the networks of dental and medical insurers who specialize in treating children, youth, and adults with special needs. Families, primary care providers, community agencies, and oral health professionals should be encouraged to contact insurers to obtain referral information when assisting individuals and families in locating primary or specialty oral health care.

Other Promising Strategies (Years 3-5)

- Transition planning should start at age 14 and include oral health self-care and services by oral health professionals.
- Explore professional requirements/certifications for caregivers regarding oral health screening and oral health care.
- Ensure that group homes and other care facilities for children, youth and adults with special health care needs are providing adequate oral health care to the people in their care. In collaboration with the Department of Mental Health, Retardation and Hospitals, review existing regulations to assure that oral health prevention and promotion activities are included in child and adult residential/group home settings and residents’ oral health status is monitored by health professionals during the course of their behavioral treatment.

Likely Partners (Alphabetical)

Family practice physicians
Group homes
Paul V. Sherlock Center on Disabilities
Rhode Island Chapter of the American
Academy of Pediatrics
Rhode Island Department of Education

Rhode Island Department of Health--Office
of Families Raising CSHCN
Rhode Island Department of Mental Health
Retardation & Hospitals
Rhode Island Parent Information Network/
Family Voices Program

Next Steps

The *Oral Health Action Plan for Children and Youth with Special Health Care Needs in Rhode Island* will be shared with Forum participants and statewide stakeholders, including the professional dental associations of Rhode Island, the Community College of Rhode Island, and the Rhode Island Chapter of Pediatrics. Additionally, the *Action Plan* will be presented at upcoming meetings of the Oral Health Commission and the Leadership Roundtable for CYSHCN, as well as the Oral Health Professional Advisory Council and the Primary Care Providers Advisory Committee, which advise the Rhode Island Department of Health.

A steering committee will be convened to follow up and track implementation of the *Action Plan*. Discussions are progressing as to whether the committee will be associated with the Oral Health Commission or a separate entity; a decision will be made after the Lieutenant Governor-elect takes office in January 2007.

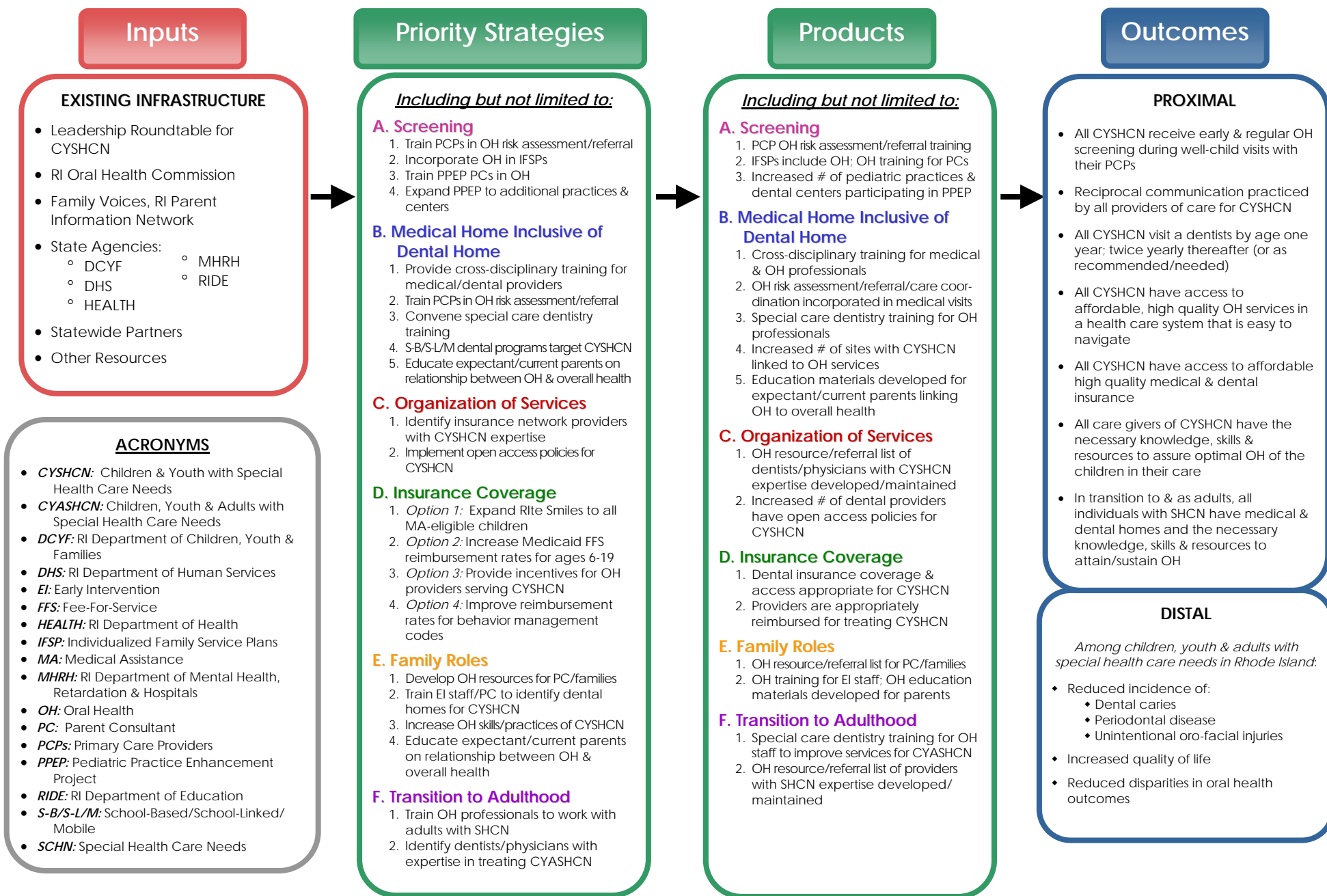
Additionally, the Family Voices program, RIPIN, Rhode Island Department of Health, and likely collaborators will seek legislative support, grants and other resources to support the strategies identified in the *Action Plan*. Implementation and timelines associated with each strategy will be dependent on the availability and successful leveraging of future funding opportunities in this topic over the next five years. Possible funding opportunities include continuation of a grant awarded by the Health Resources and Services Administration to the Rhode Island Department of Health to increase oral health workforce partnerships in the state. If funded, the focus of Year 2 will be children with special health care needs. The grant will partially fund a mini-residency training for oral health professionals in Rhode Island interested in increasing their special care dentistry knowledge and clinical/cultural competency skills to better serve individuals with special health care needs.

Appendix A: Forum Participant List

About Families CEDARR Center * Arrowhead Dental Associates * Bayside Family Healthcare, Inc. * Blackstone Valley Community Health Care * Cranston Child Development Center * CHILD, Inc. * Comprehensive Child Care Services * East Bay Community Action Program Head Start * Family Voices * Lifespan Community Health Services * M.I. Robertson School, Central Falls * Neighborhood Health Plan of Rhode Island * Northwest Community Healthcare Dental Clinic * Parents * Pediatric Dental Center, St. Joseph Hospital * Rhode Island Dental Hygienists' Association * Rhode Island Department of Children, Youth, and Families * Rhode Island Department of Education * Rhode Island Department of Health * Rhode Island Department of Human Services * Rhode Island Foster Parents Association * Rhode Island KIDS COUNT * Rhode Island Oral Health Commission * Rhode Island Parent Information Network * Salve Regina University * Samuels Sinclair Dental Center, Rhode Island Hospital * Sherlock Center on Disabilities * South County Pediatric Group, Inc. * State of Rhode Island Office of the Lieutenant Governor * Thundermist Health Center of South County * United Healthcare Dental

Appendix B: Action Plan Logic Model

Oral Health & Children/Youth with Special Health Care Needs (CYSHCN) in RI





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