

Rhode Island Department of Health Strategic Plan for Health and Wellness of Rhode Islanders with Disabilities and Chronic Illnesses 2007-2012

INTRODUCTION

"In Rhode Island, similar to the rest of the nation, one in five (20.2%) residents have disabilities. Rhode Islanders with disabilities demonstrate lower levels of employment, income, education, utilization of preventive health care, health and wellness, and greater participation in health risk behaviors compared to people without disabilities and chronic illnesses. There are also higher rates of disabilities among racial and ethnic minorities."¹ These data reflect responses from non-institutionalized persons with disabilities and/or their families,² and little is known about the health, secondary conditions, and disparities that may exist for Rhode Islanders with disabilities living in long-term care facilities, correctional facilities, or group homes. In order to realize its vision--"all people in Rhode Island will have the opportunity to live a safe and healthy life in a safe and healthy community"³ --the Rhode Island Department of Health ("HEALTH") desired to engage in a structured approach to improve the health and reduce secondary conditions of persons with disabilities and chronic illnesses and eliminate health disparities between and among Rhode Islanders.

HEALTH, like health departments throughout the country, is being guided by the goals and objectives found within *Healthy People 2010*, the federal government's plan for the health of all Americans. HEALTH has produced *Healthier Rhode Islanders by 2010: A Plan for Action*, its own version of *Healthy People 2010*. HEALTH reports on the status of Rhode Islanders with disabilities and chronic illnesses on ten leading health indicators and corresponding objectives of *Healthy People 2010* in its *Health Disparities and People with Disabilities and Chronic Illnesses Mid-course Review ("Review")*.

HEALTH's Disability and Health Program (DHP), based within the Division of Family Health, has been charged with facilitating the promotion of health and wellness of Rhode Islanders with disabilities and chronic illnesses and the reduction

¹ Rhode Island Department of Health, *Health Disparities and People with Disabilities and Chronic Illnesses Mid-course Review*, May, 2006, p.2

² Ibid, p. 20

³ Rhode Island Department of Health, *Health RI Strategic Plan 2004-2010*, December, 2003, p.1

of health disparities between Rhode Islanders with and without disabilities and chronic illnesses. With a grant from the federal Centers for Disease Control and Prevention ("CDC") and with Title V, Maternal and Child Health funds from the federal Department of Health and Human Services, the DHP has initiated several efforts under its charge. The DHP wishes to continue its efforts in accordance with a comprehensive work plan for the next five years. With this intent, the assistance of an outside consultant, and the DHP's Advisory Committee⁴, the DHP and the Office of Special Health Care Needs ("Office") undertook a strategic planning process to address four core priority areas: data and surveillance; health care transition: pediatric to adult; health promotion; and emergency preparedness.⁵ This *Strategic Plan for Health and Wellness of Rhode Islanders with Disabilities and Chronic Illnesses: 2007-2012* ("*Plan*") is the result of this process. The *Plan* provides a road map for the DHP and others in HEALTH to assure that the health and wellness of Rhode Islanders with disabilities and chronic illnesses are promoted and health disparities are reduced.

The *Plan* is organized around the four core priority areas identified by the DHP and the Office: data and surveillance; emergency preparedness; health care transition: pediatric to adult; and health promotion. For each core priority area, the *Plan* includes a subgoal, objectives, and outcomes established by the DHP and the Office and action steps identified by Advisory-Work Groups convened to discuss each subgoal.

In order to be included in the *Plan*, action steps had to meet certain criteria. First and foremost, the action steps had to be within HEALTH's areas of responsibility. The action steps also needed to coincide with one or more essential public health services as identified by HEALTH in its *HEALTH RI Strategic Plan 2004-2010* or with guidance provided by the CDC.

The DHP will implement the *Plan* over the 2007-2012 calendar years through measurable objectives to be set forth in annual work plans. In establishing annual work plans, the DHP will consult with the Office, the DHP Advisory Committee, and others in HEALTH, as appropriate, and will consider available resources and other factors, such as information obtained from prior years' activities. The DHP Advisory Committee will monitor the DHP's implementation of the *Plan*.

⁴ Appendix I describes the DHP Advisory Committee

⁵ Appendix II describes the strategic planning process

The *Plan's* effectiveness will be measured in several ways.

* Positive changes in health indicators for Rhode Islanders with disabilities and chronic illnesses and a reduction in disparities on health indicators between Rhode Islanders with and without disabilities and chronic illnesses will provide a measure of the effectiveness of the health care transition and health promotion action steps.

*A reduction in the number of Rhode Islanders with disabilities and chronic illnesses receiving health care from pediatricians beyond an appropriate age for pediatric services will indicate the effectiveness of the health care transition action steps and will be measured via follow-up to HEALTH's survey on pediatric to adult health care transitions.

*The degree to which health care transition activities are modeled after, consistent with, and reflect recognized authoritative guidance for such transition (e.g. A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs of the American Academy of Pediatrics, American Academy of Family Physicians; American College of Physicians-American Society of Internal Medicine and the American Medical Association's Guidelines for Adolescent Preventive Services) will offer another measure of health care transition efforts.

*Available, timely, and relevant data about the health and wellness of Rhode Islanders with disabilities and chronic illnesses will indicate the effectiveness of the data and surveillance action steps.

*The impact of emergency preparedness action steps will be measured by positive changes in the number of Rhode Islanders with disabilities and chronic illnesses using local or state registries and participating in other emergency preparedness efforts.

There are a few caveats for reading and understanding the *Plan* and its impact. First, effective implementation of action steps that involve information and education requires the use of alternative formats (meaning for example, written materials in large print, closed caption options and/or sign language interpreters for information or education sessions, etc.). Second, all materials, and other activities as relevant, are to be sensitive to Rhode Island's rich cultural and linguistic diversity. Third, efforts to obtain data about Rhode Islanders with disabilities and chronic illnesses

are to include race and ethnicity as feasible. Finally, there is no definition of "disabilities" or of "chronic illnesses" in the *Plan*; annual work plans, however, may include operational definitions as appropriate to effective and feasible implementation of the tasks to be undertaken.

The *Plan* reflects the collaborative and creative efforts of all who participated. The DHP and the Office thank each participant for the time and effort extended.

The PLAN

Goal: Promote the health and wellness of Rhode Islanders with disabilities and chronic illnesses, prevent secondary conditions, and eliminate health disparities between Rhode Islanders with and without disabilities and chronic illnesses.

Section I: Data and Surveillance

Subgoal: Widely available, accurate, and timely data on health and secondary conditions of, and access to health care by, Rhode Islanders with disabilities and chronic illnesses

RATIONALE:

HEALTH collects, analyzes, and makes available data on Rhode Islanders' health status using national and state-specific tools. Even so, information about the health and wellness of Rhode Islanders with disabilities and chronic illnesses may not identify secondary conditions associated with specific disabilities or chronic illnesses and is not available on all persons with disabilities and chronic illnesses (e.g. persons in congregate living facilities may be excluded from surveys). Without adequate and timely data and information, policy makers and public and private entities may be less effective in fostering improved health and wellness among Rhode Islanders with disabilities and chronic illnesses.

OBJECTIVE 1: To assure, maintain, and improve the quality of data and information about the health and wellness of Rhode Islanders with disabilities and chronic illnesses

ACTION STEPS:

- *Assess current sources of data and information relative to Rhode Islanders with disabilities and chronic illnesses.
- *Develop new tools or recommend modification of existing state and national data collection tools to enhance the ability to monitor and to track disparities in health indicators between Rhode Islanders with and without disabilities and chronic illnesses.
- *Facilitate integration of disability specific questions with current data collection efforts of state agencies (e.g. HEALTH, Office of Rehabilitation Services, Department of Education, and Department of Human Services) and sharing of data and analyses between and among these agencies.
- *Investigate processes to obtain demographic information on Rhode Islanders with specific disabilities and chronic illnesses and associated secondary conditions.
- *Facilitate the use of best practices for data collection.
- *Obtain qualitative and quantitative information on the impact of disabilities and chronic illnesses on Rhode Islanders.

OUTCOMES:

- * More accurate and relevant data about the number of Rhode Islanders with disabilities and chronic illnesses.
- *Better information about the secondary conditions associated with specific disabilities and chronic illnesses.
- *Timely and relevant data on health indicators for Rhode Islanders with disabilities and chronic illnesses and the disparities in these indicators between Rhode Islanders with and without disabilities and chronic illnesses.
- *Enhanced collaboration within HEALTH and between and among HEALTH and other agencies and organizations.

OBJECTIVE 2: To improve distribution to, and to encourage use by, policy makers and public and private entities of data and information on health and wellness of Rhode Islanders with disabilities and chronic illnesses

ACTION STEPS:

*Inventory and assess current efforts to inform policy makers, public and private entities, and the public of the availability of data and information on health and wellness of Rhode Islanders with disabilities and chronic illnesses.

* Increase reporting on, distribution of, and access to data and information on health and wellness of Rhode Islanders with disabilities and chronic illnesses.

OUTCOMES:

*Public and private efforts to address the health and wellness needs of Rhode Islanders with disabilities and chronic illnesses more adequately reflect the actual needs and concerns of Rhode Islanders with disabilities and chronic illnesses.

Section II: Emergency Preparedness

Subgoal: A statewide, coordinated emergency preparedness system addressing concerns of Rhode Islanders with disabilities and chronic illnesses in all phases of emergency preparedness: planning, mitigation, response, and recovery

RATIONALE:

In an emergency, the concerns shared by all Rhode Islanders are heightened for Rhode Islanders with disabilities and chronic illnesses. Through the four phases of emergency preparedness -- planning, mitigation, response, and recovery-- efforts are undertaken to address these concerns in a variety of situations (hurricanes, bio and other terrorism, pandemic flu, etc.). HEALTH's involvement in emergency preparedness focuses on the health and medical issues that may arise. Other public and private entities, including the Rhode Island Emergency Management Agency, the Domestic Preparedness Subcommittee under the Lt. Governor's Emergency Management Advisory Council, the Red Cross of Rhode Island, and the Rhode

Island Public Transit Authority, among others, are involved in emergency preparedness efforts throughout the state. Each group has initiated efforts to assure that emergencies do not have disproportionate adverse consequences for Rhode Islanders with disabilities and chronic illnesses. These efforts, however, can be undertaken more consistently and comprehensively. To do so, state and local responders need (a) to include persons with disabilities and chronic illnesses in all phases of emergency preparedness, (b) to be able to locate persons with disabilities and chronic illnesses, and (c) to better understand the specific needs of Rhode Islanders with disabilities and chronic illnesses that may require approaches that are different from those for other Rhode Islanders. Even best efforts, however, cannot foresee and address the needs of all persons with disabilities or chronic illnesses. Rhode Islanders with disabilities and chronic illnesses need to plan for their own health and well-being in case of an emergency and be assisted with such planning.

OBJECTIVE 1: To foster state policy that reduces adverse effects of emergencies on the health and wellness of Rhode Islanders with disabilities and chronic illnesses

ACTION STEPS:

*Identify, in consultation with health insurers and others, policies/regulations related to the ability of persons with disabilities and chronic illnesses to obtain necessary supplies and equipment (e.g. medications, medically necessary diets, and durable medical equipment) throughout all phases of emergency preparedness and recommend changes that allow individuals access to needed items.

*Review existing guidance for state, city, and town emergency preparedness plans and recommend changes to assure plans are adopted and Rhode Islanders with disabilities and chronic illnesses are included in all phases of emergency preparedness.

*Collaborate with public and private entities to coordinate and improve the state registry of persons with disabilities or chronic illnesses.

* Create opportunities for Rhode Islanders with disabilities and chronic illnesses to register with local/state entities for adequate emergency preparedness.

*Make available Standard Operating Procedure templates for use by the state, cities, and towns that address the health and wellbeing of persons with disabilities and chronic illnesses during all phases of emergency preparedness.

OUTCOMES:

* Increased registration of Rhode Islanders with disabilities and chronic illnesses.

*State policies support efforts to assure the health and wellness of all Rhode Islanders particularly Rhode Islanders with disabilities and chronic illnesses before, during and immediately after an emergency.

*Increased number of adopted emergency preparedness plans that include Rhode Islanders with disabilities and chronic illnesses in all phases of emergency preparedness and that address the needs of Rhode Islanders with disabilities and chronic illnesses within the plans' jurisdictions.

OBJECTIVE 2: To establish a centralized process for developing, sharing, and coordinating information and efforts to address the health needs of Rhode Islanders with disabilities and chronic illnesses through all phases of emergency preparedness

ACTION STEPS:

*Identify and assess statewide emergency response capacity to serve Rhode Islanders with disabilities and chronic illnesses before, during, and after an emergency.

*Assure coordinated planning and communication on emergency preparedness and the needs of Rhode Islanders with disabilities and chronic illnesses between and among various entities involved in emergency preparedness.

*Widely distribute to appropriate audiences information resulting from coordinated planning and communication efforts.

*Create opportunities for Rhode Islanders with disabilities and chronic illnesses to participate in emergency preparedness efforts (as committee members, drill participants, etc.) throughout the state.

OUTCOMES:

*Increased involvement of Rhode Islanders with disabilities and chronic illnesses in all phases of emergency preparedness.

*Increased cooperation and collaboration between and among public and private entities related to addressing the needs of Rhode Islanders with disabilities and chronic illnesses in all phases of emergency preparedness.

*Decreased duplication of efforts between and among public and private entities related to addressing the needs of Rhode Islanders with disabilities and chronic illnesses in all phases of emergency preparedness.

OBJECTIVE 3: To foster individual responsibility and capacity for emergency planning by Rhode Islanders with disabilities and chronic illnesses

ACTION STEPS:

*Distribute, to public and private entities and to individuals, tools (registry forms, information packets, etc.) that assist individuals to prioritize and take responsibility for their physical, emotional, and behavioral needs before, during and after an emergency.

*Offer information and training on promoting individual responsibility to plan for and respond to an emergency to professionals throughout the state working with Rhode Islanders with disabilities and chronic illnesses.

*Increase community/neighborhood awareness of needs of Rhode Islanders with disabilities and chronic illnesses before, during, and after an emergency.

OUTCOMES:

*Increased availability of information for Rhode Islanders with disabilities and chronic illnesses to plan for emergencies and to manage their needs before, during, and after an emergency.

* Increased number of Rhode Islanders with disabilities and chronic illnesses participating in the state registry.

*Increased public understanding of the specialized needs and resource requirements of Rhode Islanders with disabilities and chronic illnesses during emergency planning, mitigation, response, and recovery.

Section III: Health Care Transition

Subgoal: A coordinated pediatric-to-adult health care transition system designed to foster physical, mental, and social health improvements, increase independence, reduce risk factors for disease, and prevent secondary conditions among youth and young adults with disabilities and chronic illnesses

RATIONALE:

Rhode Island provides a coordinated, comprehensive pediatric health care system with primary care and specialty practitioners serving children with disabilities and chronic illnesses. This system is not duplicated in the adult health care system. One result is that some persons remain in the pediatric health care system beyond an appropriate age for pediatric services: 33% of pediatricians surveyed reported having patients over the age of 22 while 44% reported recommending transfer to the adult health care system at age 18.⁶ Other persons either are not being served or are being served in the adult health care system by a variety of specialists with little or no coordination. Although families receive assistance in navigating the pediatric health care system, adults are left to understand and to navigate the adult system alone or with families and friends with little or no assistance from the health care community.

OBJECTIVE 1: To foster system level reforms that promote transition from the pediatric to the adult health care systems for Rhode Island youth and young adults with disabilities and chronic illnesses

⁶ Burke, Robert T., Spoerri, Michael, et als, "Transition and Transfer of Adolescents to Adult Health Care" survey of Rhode Island pediatricians.

ACTION STEPS:

- *Identify successful models and best practices for transitioning youth and young adults with disabilities and chronic illnesses from the pediatric to adult health care systems.
- *Implement one or more pilot projects (e.g. medical home model, centrally located technical support transition team available to all practitioners, etc.) for transitioning youth and young adults with disabilities and chronic illnesses from the pediatric to adult health care systems.
- *Develop and promote use of transition tools such as transition guidelines, checklists, and summaries by and between pediatric and adult practitioners.
- *Identify adult health care providers serving persons with disabilities and chronic illnesses.
- * Assess adult health care providers' needs relative to accepting and serving youth and young adults with disabilities and chronic illnesses.
- * Build the capacity of adult health care providers to serve adults with disabilities and chronic illnesses.
- * Design methods to incorporate health care transition into education transition planning (i.e. through Special Education Individual Education Plans, 504 Plans, etc.) with youth and young adults.
- * Identify components of successful transitioning from pediatric to adult health care systems and available funding sources (e.g. funding for family and peer consultants, transition appointments, transition planning, etc.).
- *Identify and develop mechanisms (e.g. enhanced reimbursement levels) that support health care practitioners in their efforts to assist youth and young adults to transition from the pediatric to adult health care systems.
- * Establish functional goals (e.g. persons with chronic illnesses assume management of their own medical care, etc.) of successful transition.
- *Provide mechanisms by which adult health care providers serving young adults with disabilities and chronic illnesses obtain/maintain cultural and linguistic competencies.

OUTCOMES:

- * Clearer definition of the operational and funding barriers to successful transitioning from the pediatric to adult health care systems.
- * Successful transfer of information between pediatric and adult practitioners working with youth and young adults transitioning between systems.
- * Increased involvement of pediatric practitioners in transitioning youth and young adults with disabilities and chronic illnesses to the adult health care system.
- * Fewer adults with disabilities and chronic illnesses receiving health care through the pediatric system.

OBJECTIVE 2: To empower youth and young adults⁷ with disabilities and chronic illnesses to participate actively in transitioning from the pediatric to adult health care systems

ACTION STEPS:

- * Obtain from youth and young adults their perspectives on transitioning from the pediatric to adult health care system.
- * Develop a communication strategy for use by youth and young adults with disabilities and chronic illnesses with questions to ask and other guidance on transitioning from the pediatric to adult healthcare systems.
- * Identify adults with disabilities and chronic illnesses who have transitioned from the pediatric to adult systems and who could serve as coaches/mentors to individuals through transitioning activities.
- * Build the capacity of youth and young adults with disabilities or chronic illnesses to provide leadership and advocacy for transitioning from the pediatric to adult health care systems, through, for example, one or more of the following:

-mentoring-coaching programs

⁷ Efforts to empower youth and young adults incorporate corresponding efforts for their families as appropriate
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- intense transition camp or academy
- ongoing transition programming
- young adult consultants in pediatric and specialty practices modeled after the pediatric family consultant program.

OUTCOMES:

- *Youth and young adults have tools with which to transition from the pediatric to adult health care systems.
- *Fewer adults with disabilities and chronic illnesses receive services through the pediatric health care system.
- *Increase in youth and young adults with disabilities or chronic illnesses who are in leadership roles relating to transitioning from the pediatric to adult health care systems.

OBJECTIVE 3 : To educate and train pediatric and adult health care providers on the issue of health care transition of youth and young adults with disabilities and chronic illnesses, current recommendations, and successful models and tools

ACTION STEPS:

- *Collaborate with general and specialty professional and educational groups to identify opportunities to incorporate transition information and tools into educational efforts.
- *Develop competencies in transition planning, including psychosocial and behavioral issues, for pediatric and adult practitioners.
- *Develop capacity for technical assistance to practitioners as transition issues arise.

OUTCOMES:

- * Increased knowledge and expertise of adult and pediatric practitioners on issues relating to transitioning and serving youth and young adults with disabilities and chronic illnesses.

*Fewer adults with disabilities and chronic illnesses being served by the pediatric health care system.

IV: Health Promotion

Subgoal: Health promotion activities include Rhode Islanders with disabilities and chronic illnesses and reflect their health-related concerns

RATIONALE:

Health promotion entails encouraging individual healthy lifestyle behaviors and affecting policy changes that support healthy lifestyles and healthy environments. Many leading health indicators continue to show a discrepancy between Rhode Islanders with disabilities and chronic illnesses and those without disabilities and chronic illnesses. There is a need, therefore, to ascertain specific health concerns and barriers to healthy lifestyles among persons with disabilities and chronic illnesses and to assure these are addressed in health promotion efforts. Persons with disabilities and chronic illnesses need to be involved in the identification of needs and barriers. Health promotion materials must provide a current and accurate representation of persons with disabilities and chronic illnesses in order for health promotion efforts to be meaningful.

OBJECTIVE 1: To foster health promotion materials⁸ that address health related concerns of, and appropriately depict, Rhode Islanders with disabilities and chronic illnesses

ACTION STEPS:

* Make available existing health promotion intervention materials on topics relevant to the health and wellness of persons with disabilities and chronic illnesses, including on healthy eating, weight, smoking cessation, substance use, exercise, mental health, et als.

* Recruit individuals with disabilities and chronic illnesses and/or groups consisting of a majority of persons with disabilities and chronic illnesses to

⁸ "health promotion materials" include pamphlets, posters, billboards, etc. in alternative formats
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review and comment on existing health promotion materials for accessible format and content relative to persons with disabilities and chronic illnesses, including appropriate representation of persons with disabilities and chronic illnesses within the materials.

*Collaborate with HEALTH's health promotion staff to modify existing health promotion materials and/or develop new materials based on comments from Rhode Islanders with disabilities and chronic illnesses.

* Distribute disability-sensitive health promotion materials to individuals through health care providers and organizations, such as physicians' offices, Office of Rehabilitation Services, centers for independent living, schools, rehabilitation services, group homes, work-site wellness programs, etc.

OUTCOMES:

* Increased access by Rhode Islanders with disabilities and chronic illnesses to health promotion materials that address their concerns and provide user-friendly information.

* Positive and affirming health promotion messages about Rhode Islanders with disabilities and chronic illnesses.

*Progress towards targets for leading health indicators set out in *Review* for Rhode Islanders with disabilities and chronic illnesses.

OBJECTIVE 2: To encourage available and accessible health and wellness activities throughout Rhode Island

ACTION STEPS:

* Identify public and private recreational and fitness facilities⁹ in Rhode Island for accessibility to, and inclusion of, persons with disabilities and chronic illnesses.

⁹ "recreational and fitness facilities include, for example, Boys & Girls clubs, Ys, parks, gyms, yoga/meditation centers, golf courses, tennis facilities, hiking trails, etc

- *Assess primary and specialty health care facilities in Rhode Island for accessibility to persons with disabilities and chronic illnesses.
- *Inventory available sources of funding for Rhode Islanders with disabilities and chronic illnesses to participate in health promotion/healthy lifestyle activities.
- *Develop and distribute a resource guide of available, accessible public and private recreational and fitness facilities and health promotion activities.
- *Assess whether licensing and other regulations and/or policies may pose barriers to access of Rhode Islanders with disabilities and chronic illnesses to health promotion programs and recreational facilities and recommend changes when warranted.
- * Make available to Rhode Islanders with disabilities and chronic illnesses a comprehensive health promotion curriculum.
- *Promote disability awareness and accessibility training for fitness and recreational service providers.
- *Promote information and education programs for professionals (e.g. school nurses, vocational rehabilitation counselors, case managers, etc) on promoting healthy lifestyles for persons with disabilities and chronic illnesses.
- *Collaborate with the Rhode Island Department of Education and others (school districts and relevant local committees and advisory groups) to identify and expand health promotion activities and physical education in schools to include students with disabilities and chronic illnesses.

OUTCOMES:

- * Enhanced ability of Rhode Islanders with disabilities and chronic illnesses to make and implement healthy lifestyle choices.
- *Reduction of health care dollars spent on injuries and secondary conditions.
- *Expansion of number and type of professionals able to assist Rhode Islanders with disabilities and chronic illnesses to adopt healthy lifestyles.

*Increase in healthy behaviors modeled in schools, work places, and throughout state agencies.

* Progress towards targets for leading health indicators set out in *Review* for Rhode Islanders with disabilities and chronic illnesses.

OBJECTIVE 3: To reduce stigma associated with being a person with a disability or chronic illness and to effect attitudinal change in persons without disabilities and chronic illnesses

ACTION STEPS:

*Investigate media advocacy opportunities, including print and television stories, that foster positive and affirming images of persons with disabilities and chronic illnesses and challenge negative stereotypes.

* Integrate disability awareness with ongoing diversity efforts.

*Identify existing speakers' bureaus related to disability issues and collaborate to develop a coordinated, comprehensive, and active speakers' system.

OUTCOMES:

* Reduction of negative attitudes towards Rhode Islanders with disabilities and chronic illnesses.

SUMMARY

This *Strategic Plan for Health and Wellness of Rhode Islanders with Disabilities and Chronic Illnesses 2007-2012* establishes a multi-year roadmap for the DHP. It also can serve as a guide to other public and private entities within Rhode Island. The DHP looks forward to working with these entities and with persons with disabilities and chronic illnesses to implement the Plan and to realize each of the subgoals within it. As with any roadmap, the *Plan* sets out a clear course of action, but must remain flexible to account for unforeseen challenges. The DHP's intent is to confront each challenge with commitment to the *Plan* and to assure that Rhode Islanders with disabilities and chronic illnesses are positively affected by its efforts.

Appendix I

Disability and Health Program Advisory Committee Description

The Disability and Health Program's ("DHP") Advisory Committee is made up of twelve individuals, half of whom are individuals with disabilities and chronic illnesses. Another 25% are parents of children, adolescents, or young adults with disabilities and chronic illnesses. The remaining members include health and human services providers, university faculty, and representatives of advocacy organizations. The DHP Advisory Committee's functions include provision of general guidance and direction for the DHP, including identification of program priorities, provision of input and recommendations on program policy and planning, assistance in the development of annual program plan, participation in the development of and responsibility for approving the state plan for health promotion and the prevention of secondary conditions for Rhode Islanders with disabilities and chronic illnesses.

The DHP program staff and the Advisory Committee developed a state plan for health promotion and the prevention of secondary conditions of persons with disabilities and chronic illnesses ("State Plan") in 2004. The DHP Advisory Committee approved the planning process (refer to Appendix II) to develop a strategic plan (*Plan*) for the period 2007-2012 that includes RI's goals for disability

and health as well as objectives and action steps. The DHP Advisory Committee will monitor the DHP's implementation of the *Plan*.

Appendix II

Strategic Planning Process for Health and Wellness of Rhode Islanders with Disabilities and Chronic Illnesses

In order to update and expand the 2004 state plan for health promotion and the prevention of secondary conditions of persons with disabilities and chronic illnesses ("State Plan"), the Disability and Health Program ("DHP") within the Rhode Island Department of Health ("HEALTH") issued a request for proposals for a strategic planning process facilitator. With approval from the Advisory Committee, the strategic planning process got underway in early 2007.

With the State Plan goal-- *promote the health and wellness of Rhode Islanders with disabilities and chronic illnesses, prevent secondary conditions, and eliminate health disparities between Rhode Islanders with and without disabilities and chronic illnesses*--the DHP and HEALTH's Office of Special Health Care Needs ("Office") identified four core priority areas (data and surveillance, emergency preparedness, health care transition: pediatric to adult, and health promotion). The DHP and Office next formulated a subgoal for each priority area and invited representatives from within HEALTH and from other collaborators (refer to Attachment A) to participate on one or more Advisory-Work Groups convened to address each priority area.

Each Advisory-Work Group was asked to discuss specific questions (refer to Attachment B) related to the subgoal and to recommend specific action steps to be taken by HEALTH in order to make progress towards the subgoal. Invited participants were able to have input into the process by attending meetings¹⁰ and/or by responding electronically to the questions presented to each group and by commenting on drafts of the *Plan*. Consumer input also was solicited via electronic posting¹¹ of the questions for each core priority area and additional questions addressing (a) what Rhode Islanders with disabilities and chronic illnesses needed in order to make positive lifestyle changes and (b) how the current delivery systems could better meet the needs of persons with disabilities or chronic illnesses. Input from two consumer groups was obtained at separate meetings and will be helpful to DHP in development of work plans. A draft *Plan* was available for public comment via HEALTH's web site.

¹⁰ Meeting minutes will be available for future reference from the DHP when the *Plan* is final.

¹¹ Questions were available on websites for HEALTH; the Office of Rehabilitation Services of the Rhode Island Department of Vocational Rehabilitation; the Rhode Island Statewide Independent Council; and the Rhode Island Council for Community Mental Health Organizations

Appendix II: Attachment A

Advisory-Work Group Invited Participants and Organizations Represented

Data and Surveillance:

Leo Canuel, MA: PARI

Bob Cooper: Governor's Commission on Disabilities

Deborah Garneau, MA: HEALTH/Office of Special Health Care Needs

Kat Grygiel Burrell: Office of Rehabilitation Services

Jana Hesser, PhD: HEALTH/Center for Health Data & Analysis

Dianne Kayala, MS: Rhode Island Department of Human Services, Division of
Health Care Quality, Financing and Purchasing

Hanna Kim, PhD: HEALTH/ Family Health Data and Evaluation

Ken Pariseau, MSW, MS: Neighborhood Health Plan of Rhode Island

Don Perry, MPA: HEALTH/Center for Health Data & Analysis

Corinne Calise Russo: Rhode Island Department of Elderly Affairs

Susan Shepardson, MA: HEALTH/Disability and Health

Sam Viner-Brown, MS: HEALTH/Family Health Data and Evaluation

Emergency Preparedness

Carrie Bridges, MPH: HEALTH/Community Health and Equity

Rilwan Feyisitan: HEALTH/Community Health and Equity

Deborah Garneau, MA: HEALTH/Office of Special Health Care Needs

Roberta Greene: Office of Rehabilitation Services

Carol Kent: Rhode Island Department of Mental Health, Retardation and Hospitals

Anne LeClerc: Rhode Island Transportation Authority

James Litvak: PARI

Nick Logethets: Rhode Island Red Cross

Kate McCarthy-Barnett, Ed.D: HEALTH/Disability and Health Program;
Governor's Commission on Disabilities

Kim McLeod: Rhode Island Emergency Management Agency

Alysia Mihalakos, MPH: HEALTH/Center for Emergency Preparedness &
Response

Ana Novais: HEALTH/Community Health and Equity

Lorna Ricci, BA: OSCIL

Corinne Calise Russo: Rhode Island Department of Elderly Affairs
Susan Shepardson, MA: HEALTH/Disability and Health

Health Care Transition

Julia Bass, MEd, BCBA: The Empowered Families-CEDARR Center
Robert T. Burke, MD, MPH: Chair, Committee for Children with Special
Needs, Rhode Island Chapter of the American Academy of Pediatrics
Paul Choquette: Rhode Island Department of Human Services, Center for Child and
Family Health
Robert Crausman, MD: HEALTH/Health Services Regulations
Deborah Garneau, MA: HEALTH/Office of Special Health Care Needs
Deborah Golding: RIPIN
Alexandra Gonzalez: access2adventure, Disability & Health Intern
Mark Gunning: Statewide Transition Coordinator, Paul V. Sherlock Center
Dianne Kayala, MS: Rhode Island Department of Human Services, Division of
Health Care Quality, Financing and Purchasing
Phanida Khamsomphou: HEALTH/Family, Youth and School Success
Diana Kriner: RIPIN
Cheryl LeClair: HEALTH/Family, Youth and School Success
Gary Maslow, MD: Rhode Island Hospital
Kate McCarthy-Barnett, Ed.D: HEALTH/Disability and Health Program;
Governor's Commission on Disabilities
Ken Pariseau, MSW, MS: Neighborhood Health Plan of Rhode Island
Colleen Polselli: HEALTH/Office of Special Health Care Needs
Rosemary Reilly Chammat: HEALTH/Family, Youth and School Success
Pat Ryherd, M.Ed.: Office of Rehabilitation Services
Corinne Calise Russo: Rhode Island Department of Elderly Affairs
Susan Shepardson, MA: HEALTH/Disability and Health
David Sienko: Rhode Island Department of Education
Matt Sullivan: PARI
Dawn Wardyga: RIPIN

Health Promotion

Ana Braz; ICSW: The Empowered Families-CEDARR Center
Carrie Bridges, MPH: HEALTH/Community Health and Equity
Bob Cooper: Governor's Commission on Disabilities
Kathleen Cullinen, Phd, RD, LDN: HEALTH/Healthy Weight

Aleatha M. Dickerson, MS: Office of Rehabilitation Services
Seema Dixit: HEALTH/Tobacco
Monica Dzialo, M.Ed., CRC: Office of Rehabilitation Services
Deborah Garneau, MA: HEALTH/Office of Special Health Care Needs
Betty Harvey: HEALTH/Health Promotion and Wellness Team
Chris Hopkins: Special Olympics Rhode Island
Patrick McCabe: The Empowered Families-CEDARR Center
Kate McCarthy-Barnett, Ed.D: HEALTH/Disability and Health Program;
Governor's Commission on Disabilities
Jerry McCole: National Disability Sports Alliance
Patricia Rajotte: HEALTH/Arthritis
Corinne Calise Russo: Rhode Island Department of Elderly Affairs
Susan Shepardson, MA: HEALTH/Disability and Health
Brian Skeels: access2adventure
Sarah Everhart Skeels, MPH: access2adventure
Heather Sprague, MA: PARI
Bill Waters, PhD: HEALTH

Appendix II: Attachment B

Advisory-Work Group Questions

Data and Surveillance

In order to reach the following subgoal-- *widely available, accurate and timely data on health and secondary conditions of Rhode Islanders with disabilities and chronic illnesses and access to health care by Rhode Islanders with disabilities and chronic illnesses*-- in your opinion,

- (1) what do we need to know about Rhode Islanders with disabilities and chronic illnesses that we do not know,
- (2) what, if any, current obstacles prevent us from having this knowledge, and
- (3) what *specific* actions are necessary to remove these obstacles?

Emergency Preparedness

In order to reach the following subgoal-- *a statewide, coordinated emergency preparedness system addressing concerns of Rhode Islanders with disabilities and chronic illnesses at all levels of emergency preparedness: planning, response, and recovery*--in your opinion,

- (1) what are the emergency preparedness concerns specific to Rhode Islanders with disabilities and chronic illnesses at each level of emergency preparedness,
- (2) what obstacles prevent these concerns from being addressed and what current activities are designed to address them, and
- (3) what *specific* actions are necessary to attain this subgoal?

Health Care Transition

In order to reach the following subgoal--*a coordinated pediatric-to-adult health care transition system designed to foster physical, mental, and social health improvements, reduce risk factors for dependency and disease, and prevent*

secondary conditions among youth and young adults with disabilities and chronic illnesses--in your opinion,

- (1) what is necessary to an efficient and effective transition from pediatric to adult health care,
- (2) what are the current obstacles to and facilitators of such a transition, and
- (3) what *specific* actions are necessary to remove these obstacles and to support these facilitators?

Health Promotion

In order to promote the following subgoal-- *health promotion activities include Rhode Islanders with disabilities and chronic illnesses and reflect their health-related concerns--in your opinion,*

- (1) what are the health concerns of Rhode Islanders with disabilities and chronic illnesses,
- (2) how can health promotion efforts better serve persons with disabilities and chronic illnesses, and
- (3) what *specific* actions are necessary to attain this subgoal?