

Dare to Dream

Youth Leadership Development Initiative

Location: Rhode Island

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Category: **Emerging Practice**

BACKGROUND

Data from the most recent RI High School Youth Risk Behavior Survey (YRBS) of about 4,000 9th-12th graders is disturbing and includes information that youth with disabilities in comparison to their typical peers as more likely to: start earlier and currently smoke cigarettes, drink alcohol, use marijuana; and more likely to be threatened.

Students participating in the Dare to Dream Initiative come from across the State of Rhode Island and are from all walks of life economically. In the state, 40% of the CYSHCN are living in poverty and in households under 200% of the Federal Poverty Level (FPL). Twenty one percent of the students that participated in the Dare to Dream Conference came from public schools in the core cities and communities where more than 15% of the children and youth live in poverty. Twenty -two percent of Rhode Island youth are estimated to have special health care needs. In 2007, HEALTH began to conduct youth risk behavior analyses for YSHCN. Data showed YSHCN in comparison to their typical peers are likely to engage in risky behaviors, have frequent school absenteeism, and maintain poor health habits. Data from RI Kids Count regarding graduation rates reports that RI's four-year graduation rate for the class of 2009 was 75% and the dropout rate was 14%. Only 5% of students completed their GED within four years of entering high school and 6% were still in school in the fall of 2009.

PROGRAM OBJECTIVES

The overall goal of the project is to promote youth leadership and development through a forum for youth investment to provide supports, services, and opportunities that help youth with disabilities to achieve positive outcomes. Specifically the proposed project will recruit, train and support young adults with disabilities to serve as mentors to other youth with special needs.

TITLE V/MCH BLOCK GRANT MEASURES ADDRESSED

#12: Percent of children with and without special health care needs who received services necessary to make transitions to adult health care.
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TARGET POPULATION SERVED

The project is administered by the Rhode Island Department of Health, Office of Special Health Care Needs (OSHCN) and is a statewide initiative. The sample size is 39,170 or 17.3% children and youth with special health care needs.

PROGRAM ACTIVITIES

The theoretical foundation for the project is evidenced-based research that supports the premise that all youth including those with disabilities need to participate in positive youth development activities and acquire leadership skills to be contributing members of society. Specifically for youth with disabilities, youth need to gain self-esteem and leadership skills, including self-determination and self-advocacy, for this to be effective. Unfortunately, the opportunities for youth with disabilities to access positive youth development and leadership activities are very limited. The Dare to Dream Youth Leadership Development Initiative was developed to provide these youth with an initial forum (statewide youth led conference) to bring the initiative to the forefront and provide a spring board for the development of positive youth programs in schools and the communities throughout RI.

The Dare to Dream Youth Leadership Development Initiative was implemented in 2008 with the receipt of technical assistance from the State of New Jersey for the convening of a state leadership advisory committee for the planning and facilitation of the first statewide student leadership conference. Like New Jersey, RI's project included a one day student leadership conference led by high school students with disabilities throughout the state to provide a forum for high school youth to explore transition from school to adult life and develop self determination and self advocacy skills to enhance their capability. The Dare to Dream conference has been held yearly beginning in 2009 and the initiative has grown to include youth development, leadership and mentorship activities in schools and communities statewide.

RI's model provided student led workshops and a motivational keynote speaker, with the topics and content were chosen by RI leadership. Since every state has their own unique service delivery model, student led workshops provided information relevant to the RI system. RI also provided assistance to students and school systems through the incorporation of theatre personnel to guide students in the development and facilitation of their workshop presentations.

PROGRAM OUTCOMES/EVALUATION DATA

The Dare to Dream Initiative evaluates the percentage of YSHCN who receive the services necessary to make transitions to all aspect of adult life including adult healthcare, work, and independence. This is accomplished through an evaluation that is conducted annually and includes process measures such as number of youth recruited, trained, supported, and outcome measures.

Rhode Island integrated the data collection for graduation and dropout rates for special education students with the state's student information system beginning in 2007. This system is utilized to measure the impacts of the expanded Dare to Dream Initiative on graduation outcomes for special education students. Rhode Island also uses the CDC's YRBS survey, which examines 30 health-risk indicators for RI public high school students (grades 9-12). The findings from the YRBS are used to inform policy and programs for YSHCN. RI will continue to utilize this tool to measure the impact of the expanded Youth Initiative activities.

The results of RI's project is that the state now has an increased number of YSHCN who have participated in the initiative over the past four years and as a result are now taking on leadership roles. State and community agencies have become partners in a collaborative effort to promote leadership development programs for YSHCN.

Beginning in 2009, in pursuit of building leadership among YSHCN, HEALTH held the first student leadership conference entitled Dare to Dream attended by almost 400 students. The goal of the event was to motivate and inspire YSHCN to follow their dreams, find their voice in self-advocacy, and take the necessary steps to accomplishment. In 2010, Dare to Dream was expanded to include a school-based curriculum for the development of student led leadership workshops for presentation at the annual conference. The 2011, the *Dare to Dream* Conference, attended by over six hundred (600) students, highlighted opportunities for continued local participation by rolling out the Dare to Dream Club Start-Up Kit in which students were provided with the tools, contacts and permissions to sponsor a YSHCN leadership program in their school/community. By 2012, school systems throughout the state were well informed about the growth of RI's youth initiative and the success of the Dare to Dream Conference and as a result,

the number of students attending the conference grew to over 700. School systems are required to register students and provide documentation for the school system's student led workshop presentation during the year prior to the conference.

PROGRAM COST

RI Department of Health Title V funds have been utilized for the initiative in support of youth with special health care needs and performance measure #6 which address the successful transition of all aspects of adult health care, work, and independence. The initiative has been administered by personnel from the RI Department of Health, OSHCN and supported by state and community partners to facilitate accomplishment of youth leadership and development programs. The Dare to Dream Initiative yearly cost is approximately \$50,000.

ASSETS & CHALLENGES

Assets

The OSHCN at the RI Department of Health conducted a survey of pediatric and adult primary care providers in RI during 2005-2006 to determine physician willingness/ability to either transition or accept YSHCN into their practices. Resulting from this survey, it was determined that there was no established transition policy and that transfer to an adult primary practice was subject to the physician's comfort level regarding the YSHCN's diagnosis and most adult physicians reported a lack of comfort with the majority of special needs diagnoses. Since RI was eager to begin impacting this system, we focused on the YSHCN and their empowerment. Rhode Island added a disability indicator to the YRBS, to allow a comparison of YSHCN and those without regarding risk behaviors. Resulting from the poor outcomes for YSHCN and the need to address the needs of this population-RI launched this project.

Challenges

The challenge has been implementation of the initiative into schools in view of the current climate regarding the increased academic focus to improve testing outcomes. As a result some schools have not embraced and taken advantage of all of the youth leadership programming that is available, although a good majority has.

Overcoming Challenges

The RI Department of Health, OSHCN has promoted the project by collaborating with partners at the state and community level who have partnered to champion the initiative. Thought this collaboration, partners are also able to highlight their programs to identify their role in project implementation.



LESSONS LEARNED

All youth including those with disabilities need to participate in positive youth development activities and acquire leadership skills to be contributing members of society. For this to be effective for youth with disabilities, youth need to gain self-esteem and leadership skills including self-determination and self-advocacy.

FUTURE STEPS

While, a long term sustainability project is not in place as of yet, continued funding of the project through Title V funds is the current plan to carry out the next steps of the project, which are in the process of being identified.

COLLABORATIONS

The Dare to Dream Initiative was a collaboration between the OSHCN at the RI Department of Health and other RI state agencies/ community leadership representing the following: Department of Education, Office of Rehabilitative Services, Transition Council, Transition Advisory Committee, Transition Academies, Regional Transition Centers, Regional Vocational Assessment Centers, Rhodes to Independence, RI Parent Information Network, Parent Support Network, Gamm Theatre, Serve RI and New Jersey Department of Education.

PEER REVIEW & REPLICATION

There has not been an expert/peer review process of the project to date, nor has it been replicated.

RESOURCES PROVIDED

The products/resources that resulted from the project include the following: RI Policy Brief, Youth Transition Workbook, Dare to Dream resources (Dare to Dream Club Kit, Community Building Curriculum, Dare to Dream Presentation Poster, Dare to Dream Documentary Videos) and Provider resources (Provider Action Checklist, Portable Medical Summary, Ready? Get Set, Go!).

More information about these products/resources can be found at:

<http://www.health.ri.gov/programs/adolescenthealthcaretransition/>

Key words: Youth Leadership, Family/Consumer Involvement, Service Coordination & Integration, Autism, Health Promotion, Health Inequity/Disparities, Chronic Disease, Emergency Preparedness, Primary/Preventive Health Care

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