



Dental Public Health Activities & Practices

Practice Number: 36004
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SECTION I: PRACTICE OVERVIEW		
Name of the Dental Public Health Activity: Survey on Dental Access for People with Mental Retardation and Other Developmental Disabilities in the Western Region of North Carolina		
Public Health Functions: Assessment – Acquiring Data Assessment – Use of Data Assurance – Access to Care and Health System Interventions		
Healthy People 2010 Objectives: 21-1 Reduce dental caries experience in children 21-2 Reduce untreated dental decay in children and adults 21-3 Increase adults with teeth who have never lost a tooth 21-4 Reduce adults who have lost all their teeth 21-5a Reduce gingivitis among adults 21-5b Reduce periodontal disease among adults 21-6 Increase detection Stage I oral cancer lesions 21-7 Increase number of oral cancer examinations 21-8 Increase sealants for 8 year-olds' first molars & 14 year-olds' first & second molars 21-12 Increase preventive dental services for low-income children and adolescents		
State: North Carolina	Federal Region: South Region IV	Key Words for Searches: Assessment, dental survey, developmental disabilities, mental retardation, special needs, special health care needs, access to dental care
Abstract: In North Carolina, anecdotal information have for many years accounted difficulties in obtaining dental care for people with mental retardation and other developmental disabilities (MR/DD) who live in the community. The 2001 Human Services Research Institute report, <i>Today's Choice: Tomorrow's Path</i> , concluded that "dental care in North Carolina remains the number one health care concern for people with developmental disabilities". Additionally, the 2005 North Carolina Oral Health Summit and the 2006 Special Care Dentistry Workgroup identified access to dental care for people with MR/DD as an important statewide health issue. To obtain regional data about access to dental care in the western part of the state, a survey was conducted in 2003 by the Consortium for the Development of Community Supports. A survey questionnaire was mailed to 668 public and private residential providers, day programs, schools, and families to provide information on the oral health and dental needs of individuals with MR/DD living in the community. The survey findings showed high unmet needs among the people with MR/DD living in the community and documented barriers to accessing dental care for this special needs population. The survey findings also guided the development of recommendations to improve access to care. Based on the survey's findings and recommendations, J. Iverson Riddle Developmental Center, a residential facility for people with MM/DD with an existing dental program serving its residents, established a new outpatient dental clinic to treat persons with MR/DD living in the community. The new outpatient dental clinic began treating patients in January 2006.		
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SECTION II: PRACTICE DESCRIPTION

History of the Practice:

The J. Iverson Riddle Developmental Center, formerly known as the Western Carolina Center, is a residential facility for people with mental retardation and other developmental disabilities (MR/DD) about 50 miles east of Asheville, North Carolina. The facility has about 340 residents and serves 35 counties in the western part of the state. Riddle is one of [five institutions in North Carolina providing dental care services to persons with MR/DD](#).

The mission of Riddle's dental program is to provide care to the residents its facility; an on-site dental clinic is part of the Center. The dental clinic provides limited dental services to people with MR/DD living in the community who have difficulty obtaining care from local dentists, such as individuals who formerly resided at Riddle.

With the trend towards deinstitutionalization of people with MR/DD in the 1980s and 1990s, there has been an increasing number of North Carolinians with MR/DD who experienced difficulty obtaining dental care from community dentists. This problem is more acute in rural areas of the state that includes the western region of the state. This problem in accessing dental care led families, professionals and advocates to look more closely at the problem and to develop solutions. In 2003, the Consortium for the Development of Community Supports (CDCS) decided to conduct a survey on dental access for people with MR/DD in the western region of North Carolina. The survey aimed to document the barriers to dental care for persons with disability who lived in the community and to recommend solutions.

Justification of the Practice:

Reasons for undertaking the survey to assess dental access for people with MR/DD in the western region of North Carolina include:

- ***The need to better understand the local problem and potential solutions*** – A 2001 report commissioned by the North Carolina Department of Health and Human Services (Today's Choice: Tomorrow's Path prepared by the Human Services Research Institute of Cambridge, Massachusetts) concluded that "dental care in North Carolina remains the number one health care concern for people with developmental disabilities." The Department of Public Health identified dental services as a serious problem for individuals with disabilities. However, the need for additional dental resources in the western part of the state had never been documented.
- ***The need to involve the MR/DD community in addressing the problem*** – To address the access to dental care problem for people with disabilities living in the community, the MR/DD community needs to be involved in developing solutions. The survey collected information from caregivers, case managers, and others who are part of the community-wide MR/DD system for the needs assessment.
- ***The need to follow good public health practice*** – Community needs assessments are an integral part of public health practice and oral health needs assessments are indicated when addressing community health problems. The ASTDD Guidelines for State and Territorial Oral Health Programs describes the use of oral health surveys to assess oral health status and disparities of special needs populations (<http://www.astdd.org/docs/ASTDDGuidelines.pdf>).

Inputs, Activities, Outputs and Outcomes of the Practice:

Inputs:

The survey focused on dental access for people with mental retardation and other developmental disabilities in the western region of North Carolina. The survey aimed to understand: how the need for dental care varied across the different MR/DD sub-populations, such as those living at home, in group homes, and in Intermediate Care Facilities for the Mentally Retarded (ICFs/MR); the need for different types of dental services such as preventive

care vs. emergency care; and the distance that patients were willing to travel to obtain dental care. The survey aimed to provide information to identify solutions such as the development of fixed or mobile dental clinics.

The investigators were two individuals affiliated with Riddle, Tosh Sims, MPH and Art Robarge, PhD. In developing the survey, the investigators borrowed from similar surveys that were conducted by researchers, including Dr. Henry Hood (*Survey of ICF/MR Dental Clinics in the Southern Region of the United States*) and Tom Bell (*Dental Survey of Long Term Care Providers in One Hundred North Carolina Counties*).

Numerous partners in the MR/DD community made significant contributions to the project by helping to review early drafts of the survey, distributing the survey to respondents, and following up with respondents to improve the response rate. For example, Area Program DD Directors, and the multi-specialty collaborative subcommittee of the CDCS reviewed the early drafts of the survey tool and forwarded the revised tool to the entire membership of the Consortium for comment. In addition, each of the Area Programs arranged to have their case managers fill out the survey for their clients with MR/DD who were living with their families.

Activities:

The survey followed the key steps of a community assessment:

- Identify community partners
- Conduct a self-assessment to determine the scope of the survey and available resources
- Plan the survey in conjunction with community partners
- Collect data
- Organize and analyze data
- Utilize data for program planning

The dental survey was mailed to 668 public and private residential providers, day programs, and schools to capture information on individuals MR/DD and from their service providers in congregate settings. In addition, information on individuals with MR/DD living at home was captured with the help of their case managers who distributed the survey questionnaires and worked with their families to complete the questionnaires. Each survey questionnaire was mailed with a self-addressed stamped envelope to improve response rate.

The survey aimed to answer the following broad questions:

- Do the characteristics of individuals, such as the severity of their condition or their living arrangement, affect their access to care?
- Does the type of dental service requested/needed affect their access to care?
- What model of service delivery (mobile or fixed clinic) was preferred?

The survey achieved a 39% response rate. A total of 286 responses were completed, which represented feedback representing 2,595 individuals with MR/DD in the western region of the state. For example, a response from a group home manager incorporates information from all individuals with MR/DD living in the home setting. The survey responses were categorized as follow:

- 91 responses from families of people living at home
- 102 responses from residential providers
- 74 responses from area program staff
- 17 from day program/periodic service providers
- 2 from schools

Outputs:

Survey findings showed that:

- 86% of individuals require preventive services
- 75% of individuals require some kind of special behavioral supports or holds
- 25% of individuals routinely need some kind of equipment support.
- 50% of individuals require some level of sedation; 18% require general anesthesia
- 50% of individuals perceived their major barrier is dentist unwillingness to accept Medicaid
- 40% of individuals had to wait 2-3 months for a dental appointment
- Top barriers reported for obtaining emergency dental care include:
 - Long wait time for dental appointments (1-3 months)
 - Absence of willing providers

- Long travel distance to a dental office or clinic
- Dentist's inexperience with serving people with MR/DD

Conclusions of the survey included:

- Most people with developmental disabilities who are living in the community do not have dental insurance. They rely on Medicaid funding. Dentists in the community will not accept Medicaid payment or are not accepting new patients if they do accept Medicaid. The dentists who will accept Medicaid frequently do not provide preventive care.
- For people with developmental disabilities who have complex needs, behavioral issues or are medically fragile, they routinely travel 120-200 miles to obtain dental care. Many families and group homes have no sources for dental care.
- There is virtually no emergency care available for any community residents with developmental disabilities who rely on Medicaid insurance. Emergency rooms usually offer pain medication.
- Eighty three percent (238) of respondents said they would use a mobile clinic for routine care. Eighty seven percent of respondents (247) said they would use a regional center and sixty six percent (101) indicated they would travel thirty or more miles and further ("whatever it takes") to a regional dental center.
- Eighty five percent (242) of respondents said they would welcome training in preventive care and oral hygiene.

Recommendations based on the survey findings:

- Use the present staff of dental departments in institutions as resources to train direct caregivers and parents in meeting the daily oral hygiene needs of persons with special needs.
- Pursue establishment of a mobile dental clinic in the Western Region of the state that will treat people who have Medicaid insurance including special populations. (Work with Kate B. Reynolds Foundation, the established ACCESS dental program, the Burke County Dental Task Force, and other community leaders.)
- Expand the mission of the present dental clinic at Western Carolina Center (Riddle) to include both inpatient and outpatient services.
- Enlist the support of schools of dentistry to expand the provider base and to offer the training and technical assistance to educate, train and encourage current practitioners to serve individuals with disabilities.
- Work with the dental society, practicing dentists, families, and consumers to persuade the NC Department of Health and Human Services and Division of Medical Assistance to conduct cost finding leading to the establishment of rates that fully compensate dentists for services rendered.

Outcomes:

One outcome of the survey was implementing the recommendation "to expand the mission of the present dental clinic at Western Carolina Center (Riddle) to include both inpatient and outpatient services" into action. As a result, a new outpatient dental clinic was established at J. Iverson Riddle Developmental Center in 2006. This new dental clinic is devoted to serve people with MR/DD living in the community. This clinic is staffed by one full time dentist and one dental assistant/receptionist and is located in the same building as the existing dental program that serves the residents of the facility. For more information about this new practice at Riddle, see [North Carolina Institution-based Dental Services for Persons with Disability Living in the Community](#).

Another recommendation of the study – "use the present staff of dental departments in institutions as resources to train direct caregivers and parents in meeting the daily oral hygiene needs of persons with special needs" – is also being implemented by the Riddle Center.

Budget Estimates and Formulas of the Practice:

For the survey, there were no additional expenses to compensate the two investigators since they were salaried employees of Riddle. The costs associated with printing and mailing the survey were assumed by Riddle. In-kind services were contributed by the MR/DD community to implement the survey.

Lessons Learned and/or Plans for Improvement:

Lessons learned:

- The dental survey provided documentation that convinced the Riddle's administration to create a new clinic for people with MR/DD living in the community. It is unlikely that the decision would have been made in the absence of the survey findings and recommendations.
- Even though the dental survey did not include a clinical assessment of the oral health status of individuals with MR/DD (e.g., a screening or dental examination), it had value by focusing on important access to care issues that affect quality of life.
- Since the survey involved only a mail questionnaire, it was inexpensive to implement.
- Individuals with MR/DD, their families, and others in their support system appreciated being involved in the survey. Their participation in the survey helped to increase their awareness of oral health as an important issue, and made them strong advocates to creating the new outpatient dental clinic at J. Iverson Riddle Developmental Center.

Plans for improvement:

- There is no current plan to repeat the dental survey. The survey was developed as a one-time endeavor to provide critical information for decision-making. The survey was not part of an ongoing oral health surveillance system.

Available Information Resources:

Resources related to J. Iverson Riddle Developmental Center:

- Tosh Sims, MPH and Art Robarge, PhD. [Consortium for the Development of Community Supports – Dental Survey Report 2003](#) (final report of the 2003 dental survey on dental access for people with mental retardation and other developmental disabilities in the western region of North Carolina).
- Bradley V, Smith G, Taylor M, Taub S., Heaviland M. Simon S. Today's Choice: Tomorrow's Path, An Evaluation of the System for People with Developmental Disabilities in North Carolina. Human Services Research Institute, Cambridge, MA. November 2001.
- North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services <http://www.dhhs.state.nc.us/mhddsas/divisioninfo.htm>
- J. Iverson Riddle Developmental Center <http://www.jirdc.org/>
- Dental services at J. Iverson Riddle Developmental Center <http://www.jirdc.org/dentistry.html>
- J. Iverson Riddle Developmental Center, Outpatient Dental Clinic <http://members.agd.org/members/Outpatient.html>

ASTDD tools for conducting community oral health assessments:

- ASTDD Basic Screening Survey – Manual; See access to care questionnaire, p 4-6 http://www.astdd.org/docs/BSS_Manual_9-25-03.pdf
- ASTDD Basic Screening Survey – Manual, planning guide, and examiner training <http://www.astdd.org/index.php?template=surveybss.html>
- ASTDD Seven-Step Model http://www.astdd.org/index.php?template=seven_steps.html

Resources related to the 2005 North Carolina Oral Health Summit on access to care:

- North Carolina Oral Health Summit - Building a Collaborative for Action. 2005 http://www.communityhealth.dhhs.state.nc.us/dental/oral_health_summit.htm#workgroups
- Background Paper by F. Thomas McIver; Training dental professionals to treat special needs patients and designing programs to expand access to dental services http://www.communityhealth.dhhs.state.nc.us/dental/images/summit/Background_McIver.pdf
- Background Paper by Allen Samuelson; Training dental professionals to treat special needs patients and designing programs to expand access to dental services http://www.communityhealth.dhhs.state.nc.us/dental/images/summit/Background_Samuelson.pdf
- 2005 NC Oral Health Summit; Access to Dental Care - Summit Proceedings and Action Plan – see p. 33-38; Training dental professionals to treat special needs patients and designing programs to expand access to dental services. <http://www.nciom.org/projects/dental/2005dentalupdate.pdf>
- NC Institute of Medicine; Task Force on Dental Care Access - Final Report. See page 9; Training dental professionals to treat special needs patients and designing programs to expand access to dental services. <http://www.nciom.org/pubs/dental.html> (follow link to "final report")

Other resources related to needs assessment/access to care for people with MR/DD:

- Strauss RP, Hairfield WM and George MC. Disabled adults in sheltered employment: an assessment of dental needs and costs. *Am J Public Health*. 1985 June; 75(6): 661–663.
- White Paper - Access to Oral Health Care for Florida's Citizens with Developmental Disabilities; Prepared by: The University of Florida College of Dentistry and Nova Southeastern School of Dental Medicine. January 2002. (<http://www.fddc.org/LINKS/pdf/AOHCfull.pdf>)
- Chambless CE, and Aldous S. Study of Dental Access by People with Developmental Disabilities in Utah, Part I: Consumer Survey, Utah Governor's Council for People with Disabilities and Division of Community and Family Health Services, Utah Department of Health, February 1999.
- Burtner AP, Jones JS, McNeal DR, and Low DW. A Survey of the Availability of Dental Services to Developmentally Disabled Persons Residing in the Community. *Special Care in Dentistry* 10(6): 182-184, 1990.
- Burtner AP, Dicks JL. Providing Oral Health Care to Individuals with Severe Disabilities Residing in the Community: Alternative Care Delivery Systems. *Special Care Dentistry* 14(5): 188-93, 1994.
- Tesini DA, Fenton SJ. Oral Health Needs of Persons with Physical or Mental Disabilities. *Dental Clinics of North America* 38(3): 483-98, 1994.

SECTION III: PRACTICE EVALUATION INFORMATION

Impact/Effectiveness

How has the practice demonstrated impact, applicability, and benefits to the oral health care and well-being of certain populations or communities (i.e., reference scientific evidence, outcomes of the practice and/or evaluation results)?

The survey documented the unmet dental needs of people with MR/DD living in the community for the western region of North Carolina. The survey also identified barriers to access to care and provided information needed to develop recommendations to reduce barriers. Survey findings provided information that was needed by decision-makers; these decision-makers then implemented selected recommendations. An outcome of the survey was the establishment of a new outpatient dental clinic at J. Iverson Riddle Developmental Center.

Efficiency

How has the practice demonstrated cost and resource efficiency where expenses are appropriate to benefits? How has the practice demonstrated realistic and reasonable staffing and time requirements? Provide unit cost analysis or cost-benefit analysis if appropriate.

The survey was accomplished efficiently by leveraging resources of the MR/DD community and asking community partners to share the work in implementing the survey. For example, J. Iverson Riddle Developmental Center provided in-kind support with two employees serving as investigators who designed the survey. Area DD managers and caseworkers helped by distributing the survey to group homes and families and by encouraging providers and families to respond to the survey. If these community partners were not available, additional project staff would have required more funding.

Demonstrated Sustainability

How has the practice showed sustainable benefits and/or how has the practice been sustainable within populations/communities and between states/territories? What mechanisms have been built into the practice to assure sustainability?

There is no current plan to repeat the survey on a regular and periodic basis as part of surveillance. However, a future follow-up survey may be possible to evaluate improvement in accessing dental care for people with MR/DD living in the community. More time will be needed to determine and demonstrate the sustainability of the benefits of the survey.

Collaboration/Integration

How has the practice built effective partnerships/collaborations among various organizations and integrated oral health with other health projects and issues? What are the traditional, non-traditional, public and private partnerships/collaborations established by the practice for integration, effectiveness, efficiency and sustainability?

To reach diverse constituencies, collaboration helped distribute the survey and to encourage providers and families to respond to the survey. Numerous partners in the MR/DD community made significant contributions. Area Program DD Directors and the Consortium for the Development of Community Supports helped reviewed and finalized the survey questionnaire. Each of the Area Programs arranged to have their case managers to distribute the survey to families of their MR/DD clients.

Objectives/Rationale

How has the practice addressed HP 2010 objectives, met the call to action by the Surgeon General's Report on Oral Health, and/or built basic infrastructure and capacity for state/territorial oral health programs?

The survey helped support efforts in advancing Healthy People 2010 oral health objectives and in responding to the Surgeon General's Call to Action to promote oral health (e.g., develop systems of care for underserved people).

Extent of Use Among States

Describe the extent of the practice or aspects of the practice used in other states?

It is not known how many states or communities have conducted a survey on access to care for people with MR/DD living in the community.