

Consortium for the Development of Community Supports (CDCS) Dental Survey Report 2003

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Introduction

For years there have been anecdotal accounts about difficulties in finding dental care for people with Developmental Disabilities living in the community. The 2001 Human Services Research Institute report *Today's Choice: Tomorrow's Path* said "Dental Care in North Carolina remains the number one health care concern for people with developmental disabilities". During the April meeting of the Consortium for the Development of Community Supports, (CDCS), parents, providers and Area Programs all voiced that access to dental care is a major issue. The Collaborative Supports and Services Sub-committee of the CDCS chose to address this as their top priority. The NC Department of Public Health also identified dental services as a real problem for individuals with disabilities. They suggested that the first step towards creating new services and meeting that need was a better understanding of the problem. Many people from across the country who are actively involved in improving access to dental services were helpful as we planned to survey dental care needs for people with developmental disabilities in the Western Region* of North Carolina.

Methodology

The initial step was to identify the level of need and the scope of required services. Accordingly, we drafted a preliminary dental needs survey, based on surveys done by Henry Hood, DMD "Survey of ICF/MR Dental Clinics in the Southern Region of the United States" and "Dental Survey of Long Term Care Providers in One Hundred North Carolina Counties" by Tom Bell with input from Bob Ealy DDS, Christi Stockstad, DDS Nancy Ferguson Brown (Burke County Health Department), and a family member whose son is living at Western Carolina Center

The survey was also forwarded to Area Program DD Directors, and the multi-specialty collaborative sub committee of the CDCS for comments and refinement. The revised document was further forwarded to the entire membership of the Consortium for suggestions and comments.

Subsequently the dental survey was mailed to 668 different public and private residential providers, day programs and schools. Each survey was mailed with a self-addressed stamped envelope to facilitate response. (The Division of Facility Services was invaluable in helping us with their mailing list.) Each Area Program arranged to have their case-managers fill out the survey for folks on their caseload who are living with their families. One provider sent it to more than 400 families of people they provide with periodic services.

* The counties included are: Cherokee, Clay, Graham, Swain, Macon, Jackson, Heywood, Transylvania, Henderson, Rutherford, Polk, Gaston, Lincoln, Cleveland, Mecklenburg, Union, Cabarrus, Stanley, Rowan, Catawba, Alexander, Ashe, Allegheny, Avery, Watauga, Wilkes, Caldwell, Burke, McDowell, Buncombe, Madison, Yancey, and Mitchell.

Scope of Survey:

Three basic questions were asked of respondents.

I. Do the characteristics of the person requiring services effect access?

We determined which type of residence, what ages, and type of disability applied to people about whom we received responses.

II. Does the type of service requested/needed effect access?

We asked questions to determine:

- A. How many people needed what type of dental services?
 - Preventive Care (cleaning and X-Rays)
 - Teeth Filled or Pulled
 - Endodontal care
 - Other (Bridges, Dentures, Orthodontics etc.)
- B. How many people need extra personal support such as behavioral plans and therapeutic holds?
- C. How many people need what types of equipment support such as lifts, wraps and restraints?
- D. How many people need what types of sedation?

We asked questions to determine what difficulties people encountered in obtaining both routine and emergency services, including distance to travel and time waiting for an appointment.

III. We described possible service models and asked if people would use them.

We described two possible service delivery systems (Mobile ACCESS Unit and Center of Excellence) and asked if people would use each and how far they would travel to use them.

We also asked if people would like training in tooth brushing and preventive care techniques for use with people with Developmental Disabilities.

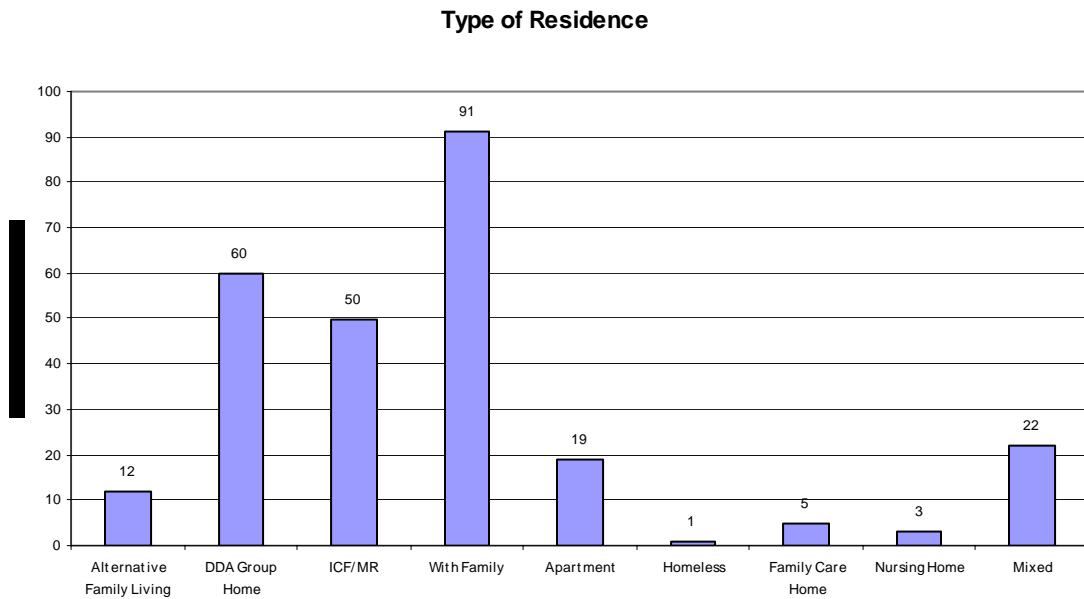
Responses:

We received 285 (39 %) responses reporting on behalf of 2595 people. The responses were distributed among the following categories.

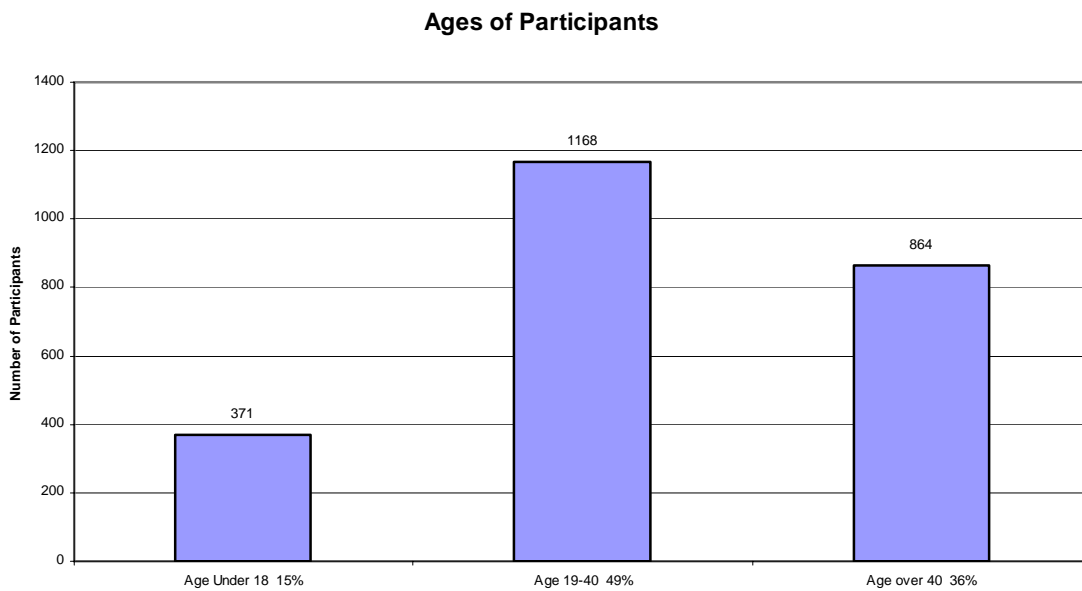
- 91 responses from families of people living at home
- 102 responses from Residential Providers
- 74 responses from Area Program staff
- 17 from Day Program/Periodic Service Providers
- 2 from Schools

Results:

Residential setting:



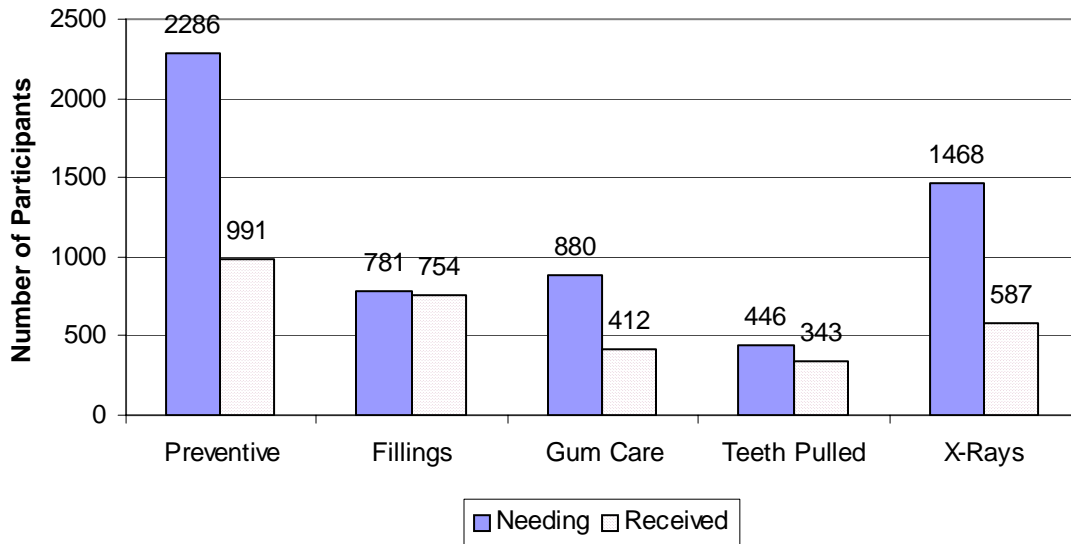
Ages of people with developmental disabilities in residence:



Types of dental services needed and/or received:

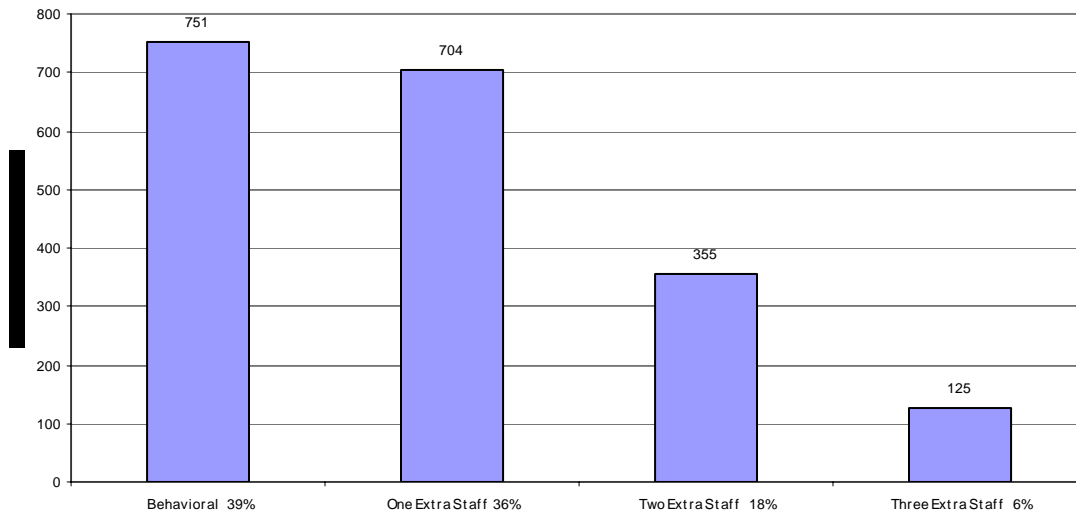
Eighty six percent (2226) out of 2595 actual responses were marked as needing preventive care on the returned surveys. We could posit that all people actually need preventive care, thus boosting the actual number to 2595 or 100 %. Evidently, people find it easier to have teeth pulled or filled than to get routine preventive care.

Types of Care Needed and Received



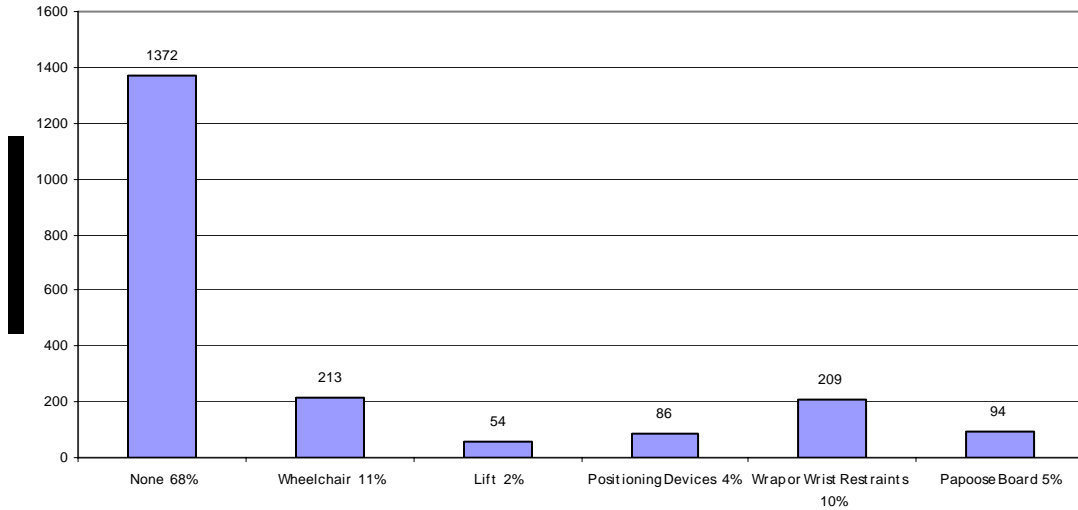
Personal support (behavior plans/therapeutic holds) needed to participate in dental care: Seventy five percent of all people responding (1935) needed some kind of special behavioral supports or holds.

Personal Support Needs



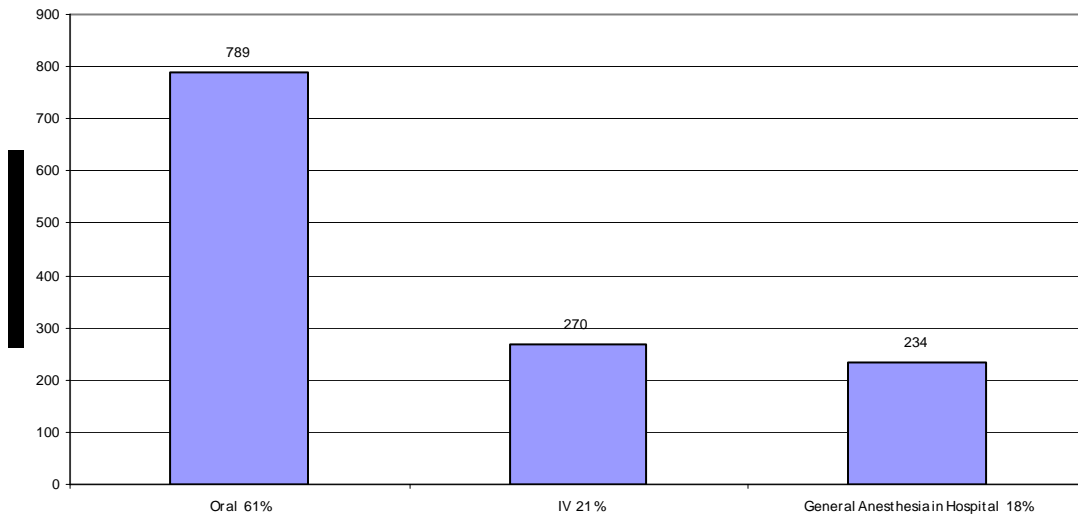
Level of equipment support needed: Twenty five percent (656) of all respondents routinely needed some kind of equipment support.

Equipment Support Needs

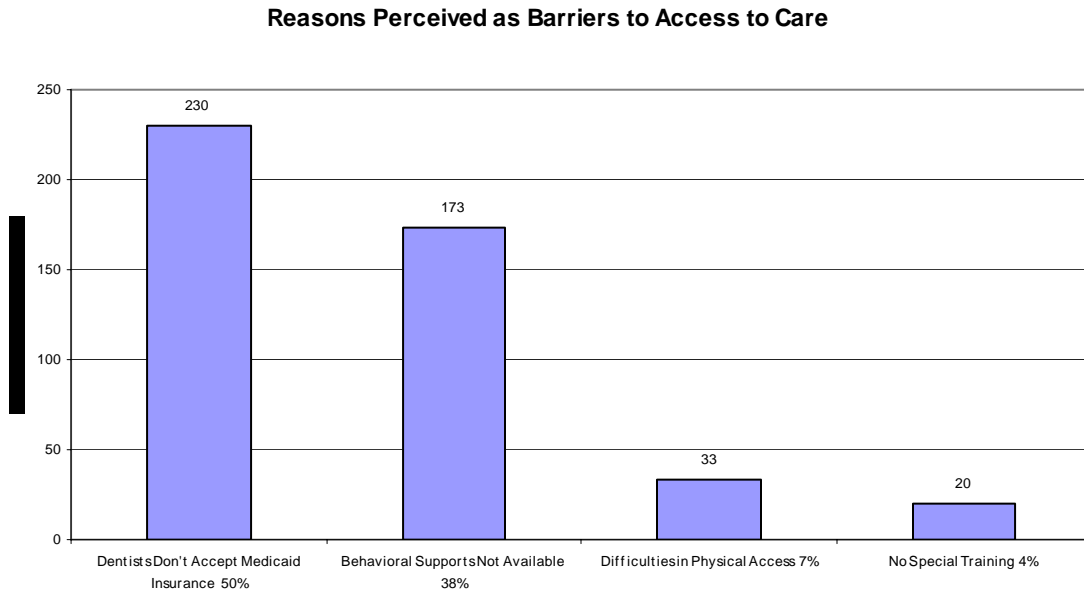


Sedation needed: Fifty percent (1293) of all respondents required some kind of sedation.

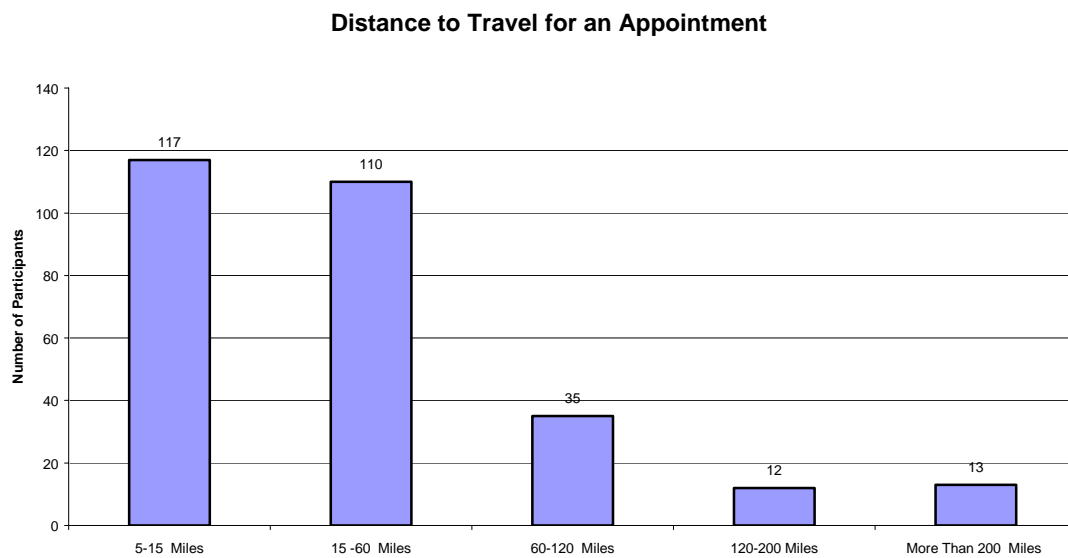
Sedation Support Needs



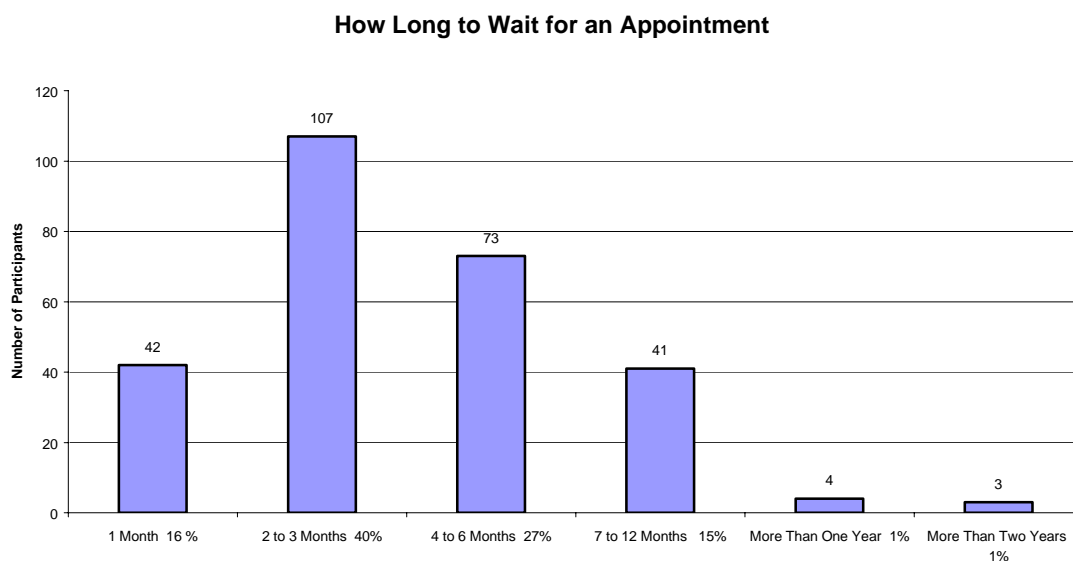
What difficulties do you encounter when trying to obtain routine dental care?



How far do you have to travel to obtain dental services?



On average, how long do you have to wait for an appointment?



What difficulties do you encounter when trying to obtain Emergency Dental Care?

Many anecdotal responses referred to the following issues:

1) *Long waits for emergency care.* Access to dentists for emergencies ranges from four weeks to as long as three months. As a result, clients often get taken to emergency rooms for toothaches, abscesses, etc. They receive pain medication orders and referral to their regular dentist (if one exists). Waits still exceed two to three weeks even after the emergency room visit and prescription for pain medications.

2) *Absence of willing providers.* There were a number of comments referring to unwillingness of dentists to accept clients with developmental disabilities. The Medicaid rate is not sufficient to cover the dentists' costs. The unique requirements, such as sedation, personal or mechanical supports needs of some clients make them a challenge to serve in a typical dental office. In other words, people without developmental disabilities will probably fill appointments with dentists who do take Medicaid before people without developmental disabilities.

3) *Distance.* Small numbers of dentists seeing individuals with developmental disabilities results in significant travel to access dental care. This is costly for the family or provider and difficult for the consumer. Within our region, clients travel up to several hours or even out of state.

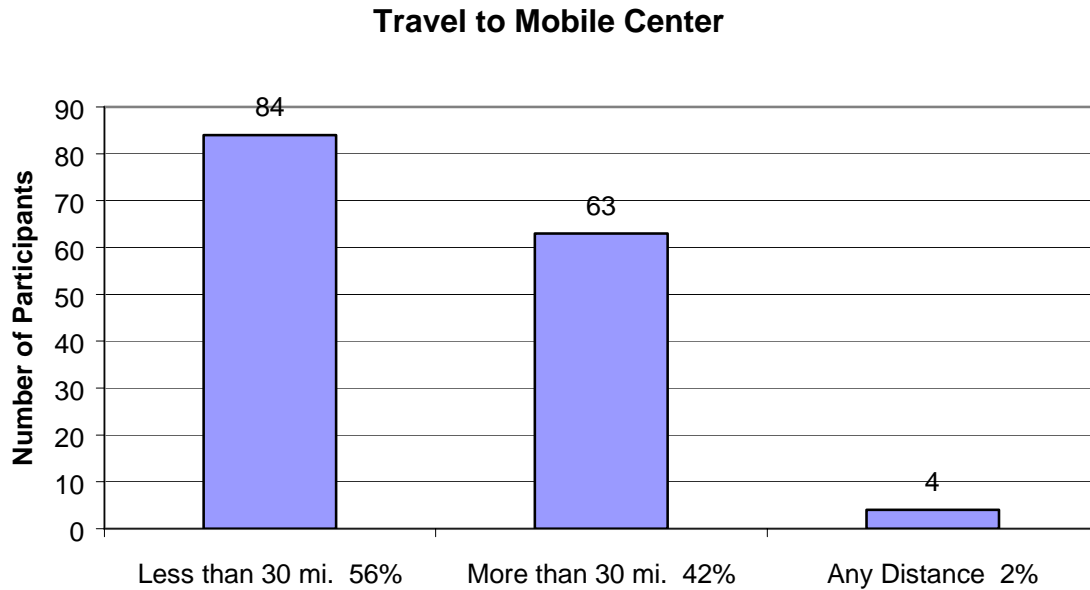
4) *Inexperience.* Dentists are often reluctant to serve medically fragile individuals because they do not have the proper training or experience. These results in clients referred to Carolinas Medical Center, Baptist Hospital, health departments and Western Carolina Center, who are not staffed to provide extensive and continuing services to outpatients.

Proposed Solutions:

A. Bringing dental care to areas lacking sufficient numbers of dentists and other professional staff to serve clients with developmental disabilities. People were asked if they would utilize a mobile clinic.

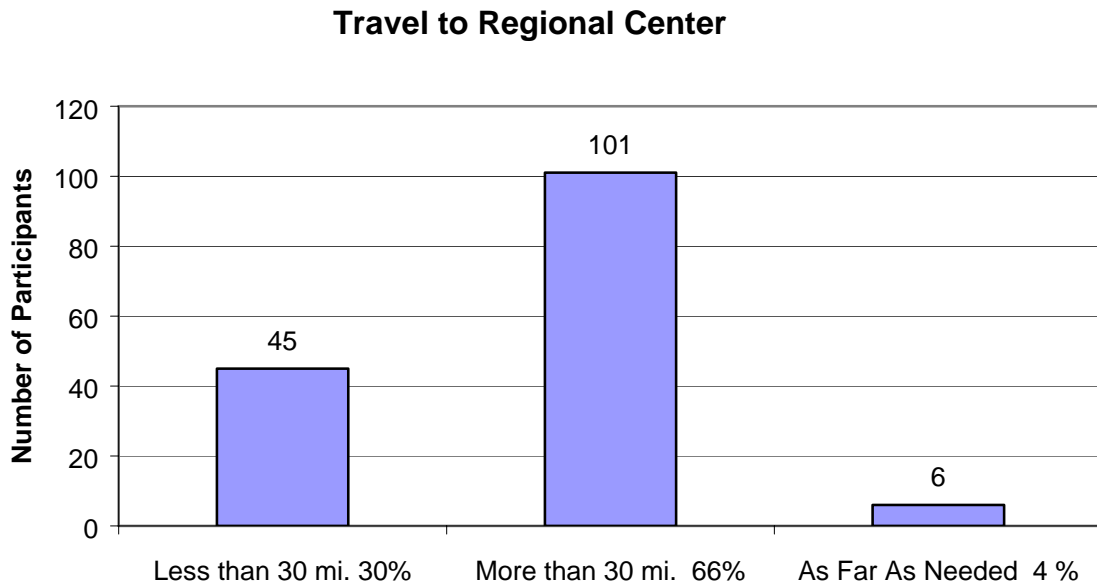
A mobile dental clinic can provide routine dental care on site by traveling to the community. Would you use one? How far would you be willing to travel?

Eighty Three percent (238 respondents) said they would use one.



B. Establishing a regional center of excellence. Some clients require sophisticated supports, sedation, etc. beyond what can be delivered through a mobile clinic. Western Carolina Center could establish an outpatient regional medical center.

A Regional Dental Center can provide more comprehensive, specialized services. Would you travel to utilize one? Eighty seven percent of respondents (247) said yes.



C. Helping maintain dental health. Since tooth brushing and preventive care are so important to maintain dental health, we asked if caregivers would like help learning effective prevention techniques.

Would you utilize *special* training for caregivers to learn how to use preventive dental care techniques? Eighty five percent (242) replied yes.

Conclusions

- Most people with developmental disabilities who are living in the community do not have dental insurance. They rely on Medicaid funding. They most often report that dentists in their community either 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.
- Private providers sometimes have relationships with community dentists who provide some care to some of their residents, but routinely travel 120-200 miles to obtain care for those who have complex needs, behavioral issues or are medically fragile. Many families and group homes have no dental care at all.
- There is virtually *no emergency care* available for any community residents with developmental disabilities who rely on Medicaid insurance. Emergency rooms may give 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.
- Eight five percent (242) of respondents said they would welcome training in preventive care and oral hygiene.

Recommendations:

- 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 in the Western Region of a mobile dental clinic that will treat people who have Medicaid insurance and insure that special populations will be served therein. (Work with Kate B. Reynolds Foundation, the already 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 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 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.