A REPORT FROM THE NEW MEXICO DENTAL ASSOCIATION FOUNDATION

NEW MEXICO DENTAL ASSOCIATION
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...the heart of dentistry

SPECIAL SMILES SPECIAL CARE

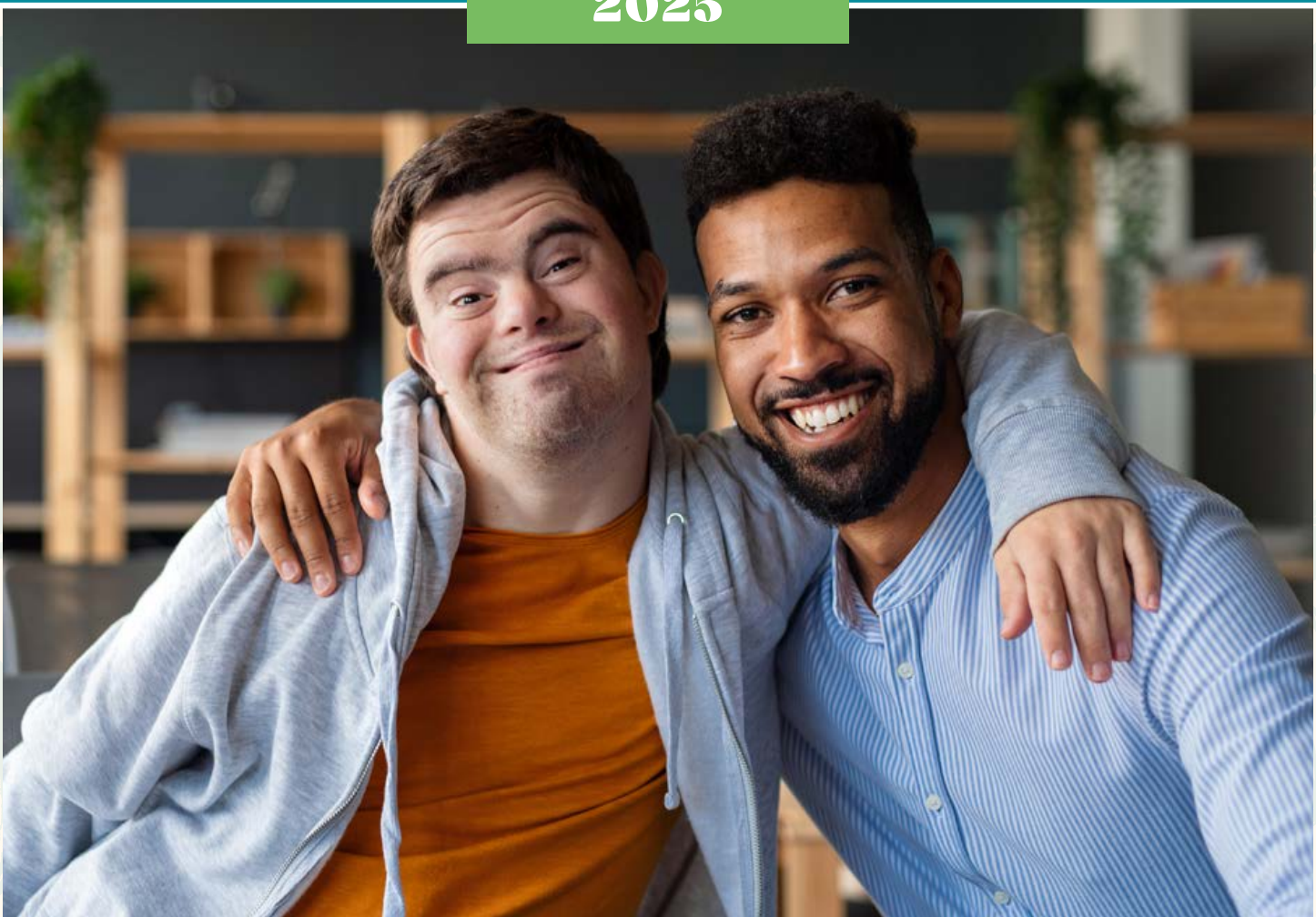
A Report on the State of Special Needs Dental Care in New Mexico

IN PARTNERSHIP WITH

New Mexico DENTAL ASSOCIATION

SCHOOL OF MEDICINE
DENTAL MEDICINE

2025



EXECUTIVE SUMMARY
Special Smiles, Special Care

FOCUSING ON ORAL HEALTH CARE FOR THOSE WITH SPECIAL NEEDS IN NEW MEXICO

» Recognizing the need for better dental care access for patients with special needs in New Mexico, the New Mexico Dental Association Foundation, the New Mexico Dental Association, and the University of New Mexico School of Dental Medicine collaborated to study needs and resources for care in the state.

» A taskforce was convened to guide research, analyze results and make recommendations concerning ways the state could improve dental care for those with special needs.

» The taskforce developed survey tools for practitioners, patients and caregivers, conducted focus groups, reviewed published research, and drew on personal experience to reach conclusions about the current state of care in the state.

» The taskforce noted there is almost no surveillance of need and resources going on and what limited data that is collected is mostly inaccessible and not usefully synthesized.

» Some challenges were noted in generating the number of responses to surveys of patient/caregivers, but the results of both surveys were deemed cross-sectional. This determination was made by comparing responses to known comparable data. The taskforce recognized that in many cases the data was not quantifiable to a level to demonstrate scientific significance while still being representative enough to suggest or confirm trends and observations.

» The results confirmed that there is widespread difficulty in patients with special needs receiving timely care, particularly in some parts of the state, but to a large degree in all locations. Not surprisingly, those patients with an established dental home fare better than those without. With or without a dental home, limits on coverage and financial resources may compromise care by limiting available services.

» Current resources for care are overwhelmed by demand, but recruitment of additional resources and expansion of capacity are limited by poor reimbursement in spite of a willingness by many providers to do more.

» In addition to financial limitations, providers cited inadequate training for themselves and staff and facility limitations as significant barriers to increasing special needs care.

» The taskforce noted that information resources for both patients and practitioners is lacking which leads to poor communications and isolation.

» People with special needs predominantly rely on Medicaid as a primary resource in funding care, but limitations on coverage and poor reimbursement for providers are factors in many of the barriers both people with special needs and practitioners face.

» Hospital access for treatment of those with special needs is limited by lack of resources and institutional bias against prioritization of dental cases.

» The taskforce made 23 recommendations focusing on:

- Information resources
- Medicaid reform
- Training
- Resource development
- Surveillance and responsiveness to patient need

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While technology has dramatically improved most people's healthcare in recent years, it has also created a tragic conundrum. With added cost has also come an increased focus on efficiency and standardization. This means that the further away from "the norm" a patient lies, the less likely "efficient care" is able to accommodate their needs. The system becomes adapted to those with routine needs and less able to address those with special needs. This leaves those with these special needs searching for care and with fewer resources to acquire it.

Recognizing the problem is important but understanding it and finding ways to address it are less apparent. As institutions, the New Mexico Dental Association Foundation, the New Mexico Dental Association, and the University of New Mexico School of Dental Medicine, each have a unique perspective on this issue. In 2023, discussions about how they might partner to understand and address challenges providing special needs care resulted in seeking a grant from the CareQuest Foundation to evaluate the need for special needs care and the availability of resources to facilitate it in New Mexico. That collaboration resulted in this report and a commitment to seek solutions together.

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UNDERSTANDING THE CHALLENGE

There are a rapidly increasing number of studies indicating the importance of oral health in the overall health and well-being of people. This underscores the importance of maintaining oral health for everyone and particularly those with disabilities that make routine care more difficult. The very fact that they may require modifications that are not routine presents many additional challenges including increased costs, time, and personnel with specialized competencies.

Many patients with disabilities do not require specialized treatment, but some do. The term “Special Needs” in dentistry can be applied to many kinds of conditions that require specialized equipment and techniques to facilitate care. Patients with these conditions may require accommodations ranging from minor adjustments in technique up to general anesthesia in hospital settings. Particular conditions might present with varying degrees of disability and need for adaptations therefore it is more useful to distinguish “special needs care” by the methods required to provide that care rather than the conditions requiring it. Moreover, needs can change with age and the progression of pathological conditions over time. While society sometimes labels people as “special needs” because of an identifiable condition or disability, it is more appropriate to focus on the types and levels of accommodation needed to treat these individuals.

Nonetheless, it is important to also note that some conditions do carry with them particular complications both to health and care. Comorbidities like respiratory, digestive, and mental illness are common. Intellectual, neurological, and physical disabilities may all complicate a person’s ability to care for themselves and maintain necessary levels of hygiene. Intellectual disabilities are almost always developmental and usually congenital. Neurologic disabilities are almost all acquired and include conditions like, traumatic brain injuries, stroke, multiple sclerosis, and Parkinson’s disease. It is also worth noting that individuals with special needs, particularly developmental disabilities, have more dental-related diseases than the population at large.

PREVALENCE OF DISABILITIES

» It is estimated that 13.4% of the U.S. population has an identified disability.

» The CDC estimates that 1 in 33 babies has a congenital disability.

» There are approximately seven million individuals in the U.S. with intellectual disabilities, which is a little more than 2% of the population.

» About 46% of those over age 75 have a disability.

While not all people with disabilities will require special needs care, it is helpful to understand what portion of our population has identified disabilities that may require accommodations of one level or another. The University of Montana assimilated data from the American Communities Survey on disabilities over a five-year period (2018–2022) from the entire United States. It reports an estimated 16.3% of New Mexicans have an identified disability. The U.S. Census data has determined that number to be 17.7%. Approximately 40% of those report cognitive difficulty, meaning "because of a physical, mental, or emotional problem, the respondent reports difficulty remembering, concentrating, or making decisions." Roughly 25% of those with identified disabilities in New Mexico live in poverty.

SPECIAL NEEDS RELATED TO DISABILITIES

Although the level of a person's disability can typically be placed higher or lower on a continuum of severity and therefore it is not helpful to make generalizations about disabling conditions, there are certain commonly observed challenges associated with different disabilities. For example, patients with congenital conditions caused by genetic abnormalities may present with multiple genetic-dependent conditions including heart and respiratory problems or dental problems like missing teeth, tooth malformations, or cleft palate/lip. Older patients suffering from aging dementia often have complex medical and prescription histories, as well as greater likelihood of edentulism, periodontal disease, and prosthetics. The oral hygiene regimen of disabled patients is often poor as a result of physical and cognitive limitations or caregivers lack of adequate skill. This can result in high rates of caries, more difficult restorative scenarios, and a poorer prognosis for care received. These challenges complicate treatment beyond the accommodations required to directly manage the disability.

Most of the accommodations needed to provide special needs care address physical restrictions, behavioral challenges, or limitations on communication. This can include behavior management techniques, devices that limit

movement, and medications that provide sedation. There may also be a need to adapt routine treatment procedures to manage an airway, make an injection, or accommodate a patient unable to move out of a wheelchair. In some cases, it might require that treatment be provided in other settings like a long-term care facility or hospital operating room. Caregivers may also be an essential part of the patient's care but introduce an additional layer of complication to communications.

Patients with physical disabilities or medical complications may be confined to their home or a care institution or present serious transportation challenges and onsite services are likely not available in their communities. New Mexico's sparse population and geographic barriers may add to transportation difficulties. This can be further complicated by the need to consult specialists which are typically limited in rural areas.

Another often overlooked need is the care of adults with special needs. In many cases, pediatric dentists whose training includes techniques to address special needs for children are no longer equipped to manage their care when they become adults. Suddenly a patient with special needs that has had a dental home and consistent care as a young person has difficulty connecting or accessing a dentist qualified and equipped to manage their care as an adult.

Often the challenges to providing care are practical issues secondary to the disabilities themselves. Most encounters with patients with special needs will require fairly standard accommodations. But, while not unique to those with disabilities, the additional time during a busy day needed to clean and disinfect a dental chair that was unintentionally contaminated by body fluids can be particularly disruptive. There is also a hazard of being bitten by a patient with limited control or the danger of needing to leave a patient unattended and having them wander into other areas of the office. The office routines and capacity to deal with these issues must be considered when accommodating patients with special needs.

TRAINING FOR SPECIAL NEEDS

All dentists receive some limited training in behavior management, sedation, and medical complexity. This may qualify them to provide care to patients with minimal special needs but may not prepare them adequately to fully assess the needs, manage the treatment, or recognize the need to refer even those with moderate levels of special needs care. Some General Practice Residencies (GPR) and Advanced Education in General Dentistry Residencies (AEGD) provide specialized training and experience in caring for special needs. Pediatric residencies also often include special needs training with a focus on children. Other specialty residencies, particularly those with advanced sedation programs, may provide skills to provide specialty care to those with special needs.

Training includes not only a better understanding of the requirements and limitations of patients with special needs, but also the utilization of specialized equipment and techniques to provide care. This involves communication skills, stabilization techniques, sedating medication, and sophisticated monitoring of vital functions. It generally means that having practical experience with treating patients exhibiting a variety of different disabilities and care requirements is needed to gain even the basic skills required to routinely deliver special needs care.

There is currently not a recognized specialty in special needs care, although some general practitioners who have received advanced training limit their practices to patients with special needs. While that might seem like a deficiency, it does leave the door open for more general practitioners to dedicate a portion of their time to treating special needs patients. Training can be received in continuing education settings, but training that allows practitioners to be comfortable providing care usually requires hands-on experience in a "mini residency" or mentoring environment. Programs of this type are usually taught by practicing dentists or faculty in clinical settings that include observation of patients being treated or participants providing supervised care. Generally, there is not a "certification" required to begin providing care. In New Mexico, Medicaid requires documented completion of a class to bill certain codes for special needs care.

Although this kind of training is often provided for little or no cost, practitioners may be reluctant to take the extended time away from their practice needed to complete training. Effective delivery of care may also require specialized training for hygienists and assistants which can add to the expense. Encouraging people to receive this training may require additional incentives to offset these costs and encourage practices to dedicate a portion of their time to treat patients with special needs.

Prior to the 1980's, few dentists other than specialists received residency training. Most patients with special needs received minimal or no dental care outside of institutional settings. Even there it was woefully inadequate. Even today, special needs care is not a required part of the advanced dental curriculum.

New Mexico has never had a dental school and has practitioners from many schools from across the country with a varied level of experience with patients having special needs. The University of New Mexico (UNM) added an AEGD residency in 2004 which eventually added a capability to treat special needs patients and train residents. They currently do not have a dedicated faculty person to provide special needs care or teach residents but do have some clinical facilities for that purpose. A search is currently underway to identify a new person to lead this program.

In the early 2000's, UNM began to provide a grant for Dr. Ray Lyons at the state hospital in Los Lunas to provide training to interested practitioners via a "mini residency." He later opened a dedicated outpatient clinic in Albuquerque under the auspices of the New Mexico Department of Health (DOH). He continued to provide training to NM dentists in that setting or at the UNM clinic with their faculty. As a result of Dr. Lyons retirement a few years ago and the temporary closure of the UNM clinic, there have been fewer training opportunities during the last several years. The NM Special Needs Clinic is currently the only facility in New Mexico dedicated to the treatment of patients with special needs. They do provide some training to allow dentists to be certified to use the Medicaid Behavior code. Individual private practices in Las Cruces and Roswell along with a few specialty, particularly pediatric, practices and community clinics currently offer some care for patients with moderate to more advanced needs but the coverage is spotty and nominal relative to the need.

TASK FORCE

The New Mexico Dental Association Foundation (NMDAF) was awarded a grant in November 2023 to conduct research and make recommendations toward improving the accessibility of care for patients with special needs in New Mexico. With their partners, the University of New Mexico (UNM) and the New Mexico Dental Association (NMDA), a taskforce was convened to design the project, conduct research, analyze the results, and make recommendations. The taskforce consisted of dentists from throughout NM with experience providing care to patients with special needs in different settings and with a variety of needs. Consideration was given to the scope of the types of special needs to be included, and it was determined that the research would include both acquired and congenital disabilities. It would also include any developmental, cognitive and physical disabilities that might present with special needs in providing dental care.

The taskforce consulted authorities in providing special needs care suggested by the Special Care Dentistry Association (SCDA) and reviewed reports and research conducted over the last few decades with perspectives on special needs. It used the resources to identify the following research questions:

01

What are the key state resources that promote and provide oral health care as it relates to New Mexicans with disabilities, including wellness and prevention services, and how effective are these efforts?

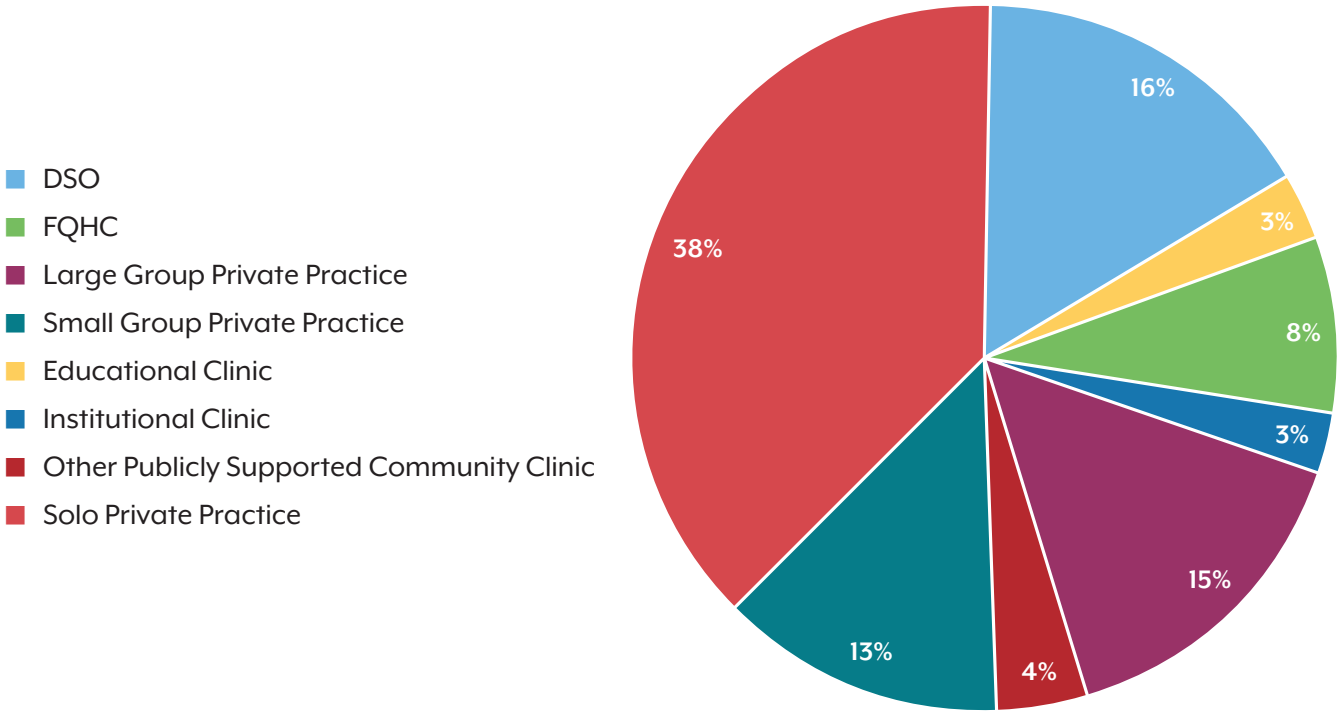
02

Are accurate oral health data available concerning New Mexicans with disabilities?

03

What are the access barriers to oral health care in New Mexico, including barriers to wellness and prevention services, for people with disabilities?

PRACTICE TYPE



“Yesterday I had embarked on some significant dental work, and I realized that the arms of the chair don’t go up enough for me to get into it easily and swing my legs onto the chair. So, I ended up sitting on the arm of the chair and the way the chair is designed it’s difficult to position myself and be in the position needed by the dentist to do the work.

04

What is the level of provider willingness and competence to provide oral health care to New Mexicans with disabilities?

05

What programs initiated by the public and private sectors have improved access to coverage and care for New Mexicans with disabilities? In other areas outside New Mexico?

06

What are key disparities and gaps in commercial and public third-party coverage of the types of programs and services most needed by New Mexicans with disabilities? (to include scope of coverage, reimbursement rates, scope of services)

07

Are accurate oral health data available concerning access to wellness and prevention services (including third-party coverage) and their relative long-term costs and benefits for New Mexicans with disabilities?

08

What are the educational capacities of New Mexico institutions to prepare providers to adequate competence to provide necessary oral health services to New Mexicans with disabilities?

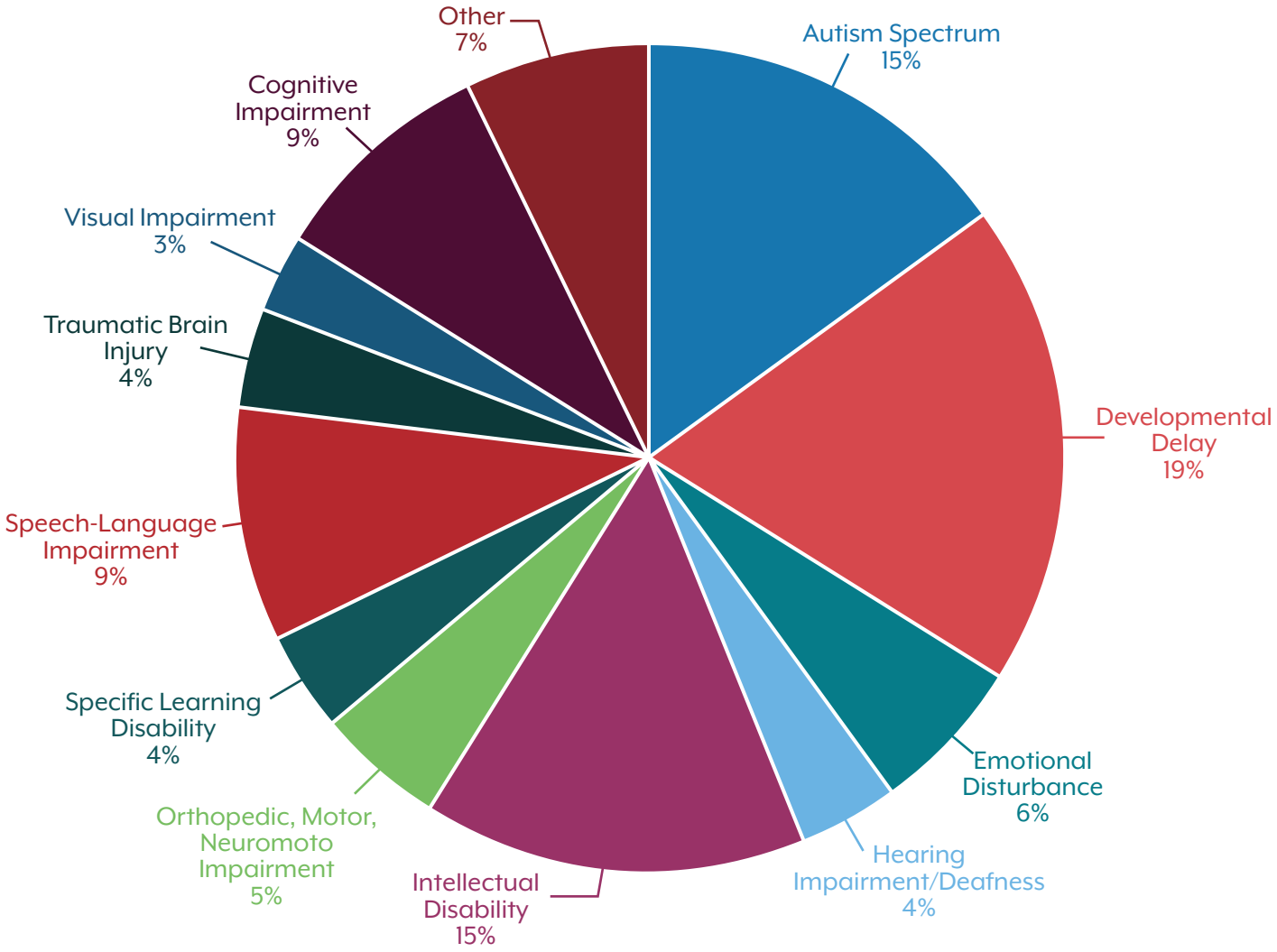
Various methods were employed to consider each question. Some questions or parts of questions were addressed through literature review, consultation with representatives from agencies and institutions, and first-hand experience of taskforce members. Others required the development of survey tools and focus groups.

The taskforce developed two surveys. The first was targeted toward patients with special needs and their caregivers. The second was developed for practitioners. Survey questions were based on fulfilling the goals of the research questions and selected by reviewing similar survey instruments as well as developing original questions. An expert in survey research was consulted to improve sensitivity, specificity, and usability of data gathered. The surveys were built on the REDCap platform for online presentation and then tested and refined by presenting it to sample audiences.

Participants for the patient survey were solicited by a variety of means. Most organizations and agencies were reluctant to share email lists, but several agreed to distribute it using their electronic communications. Flyers with links were distributed at several events including the state Special Olympics competition. On several occasions, participants at events were solicited to take the survey at booths or roaming survey-takers with tablets. Caregivers at assisted-living and group homes were also asked to participate on behalf of residents. The survey remained “open” for approximately three months. The taskforce found it challenging to acquire information resources to gather responses from this group with agencies and organizations citing privacy concerns about distributing the survey.

The practitioner survey was promoted through multiple direct emails to all dentists statewide and included both members and non-members of the New Mexico Dental Association. Links were also included in e-newsletters and solicited at dental gatherings using flyers with a scannable QR code link. Reports on the activities of the taskforce were given to several groups including the New Mexico Board of Dental Health Care and the New Mexico Primary Care Association which included requests to complete the survey.

NATURE OF CONDITIONS RESPONSES BY PERCENTAGE



"One thing that's really frustrating is that my dentist and her helpers do not understand what to do and I think that training would be so helpful. For example, I have trouble swallowing. All that water going down my throat is difficult for me, and one of the troubles with Parkinson's is that most people die of aspiration. I'm scared any time I'm in a dental chair.

Focus group research was conducted by S.D. Hughes Group, LLC. Participants in the patient/caregiver group were solicited from survey respondents and community advocates for special needs care. The participants in this focus group were offered a gift card for taking part in the group. The practitioners focus group was developed to include an appropriate mix of specialists and general dentists, statewide representation, and practices currently providing special needs care and those that are not. Participants in the practitioners' group did not receive compensation. A report on both groups was provided to the taskforce with analysis.

SIGNIFICANT RESULTS

Despite the challenges in receiving responses to the Patient/Caregiver survey, the results seemed to provide a reasonable cross-section of the special needs community statewide. The breakdown of urban and rural persons with varying disabilities while not definitive, did provide representative data on groups consistent with the known demographics. Approximately 75% of surveys were completed by a caregiver while 25% were completed by the patient. Sixty-seven percent of those that responded to the survey reported that their patient had a congenital disability versus 33% that had an

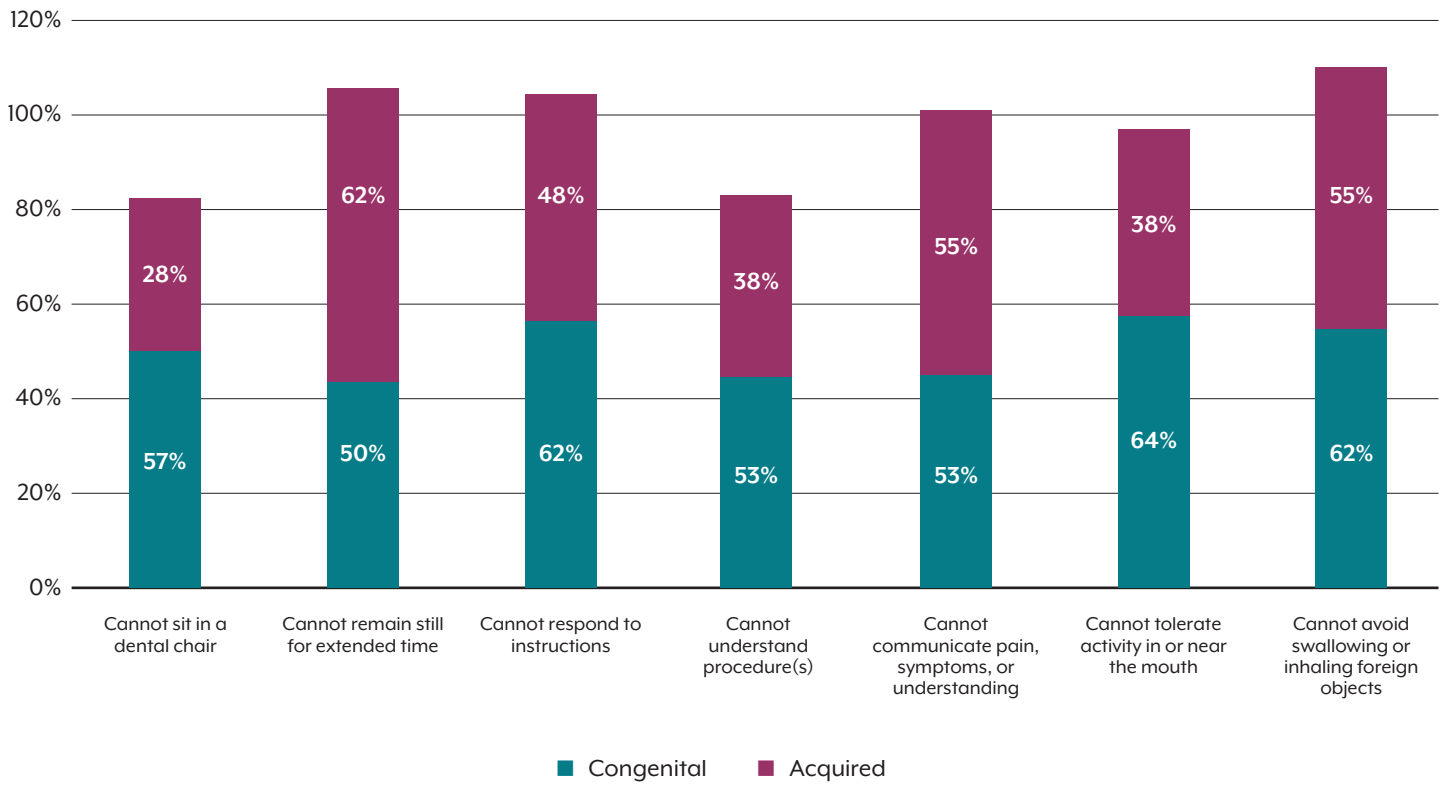
acquired disability. Living arrangements varied, with most (60%) being cared for at home, 13% living independently and about 27% living in group homes or care facilities. We noted that the survey may not have been representative of those living in long-term care facilities. There did not appear to be any correlation between living arrangements and either the oral or overall health level.

Nearly three-quarters of respondents reported having some type of dental home, defined as a dental practice from which they received regular care and maintained their records, with most of those reporting their dental home was a private practice general dentist. Forty-seven percent of respondents report having at least one untreated dental problem. Of those, respondents gave the following reasons for not receiving treatment they knew was necessary:

- 52% reported an inability to find a dentist or specialist
- 19% cited coverage or lack of funds
- 5% said that transportation was a problem
- 36% listed difficulties with the patient tolerating treatment
- 14% cited poor previous experiences
- 14% had a lack of interest in having the problems treated
- 19% require a hospital but had no availability
- 21% said it was something else

> "I would say it's staffing, it would be staffing for me in my office. To be perfectly honest, I've had most of my staff with me since I've opened my practices. And then, like what [redacted] was saying earlier with the staffing, we just need staff who are better trained on how to treat patients that are with special needs.

BARRIERS TO DENTAL TREATMENT



"For my little kids, I do all the scope of dentistry. For the adults, I'm limited in my training because of periodontal disease or adults with 40 years. That's beyond what I was trained for. But I don't know where to refer them, so I just keep them until the family is ready to move on, or they know where to go.

More than half of respondents with congenital disabilities reported one or more of the following problems receiving dental care:

» Cannot sit in a dental chair

» Cannot respond to instructions

» Cannot tolerate activity in or near the mouth

» Cannot avoid swallowing or inhaling foreign objects

Significantly more than half of respondents with acquired disabilities reported one or more of the following problems receiving dental care:

» Cannot remain still for extended time

» Cannot communicate pain, symptoms, or understanding

» Cannot avoid swallowing or inhaling foreign objects

Respondents to the patient survey with congenital disabilities cited multiple barriers to receiving care including:

» 44% Geography (distance to travel)

» 35% Transportation

» 51% Finances

» 72% Appointment availability

» 79% Behavior/anxiety

» 84% Communications

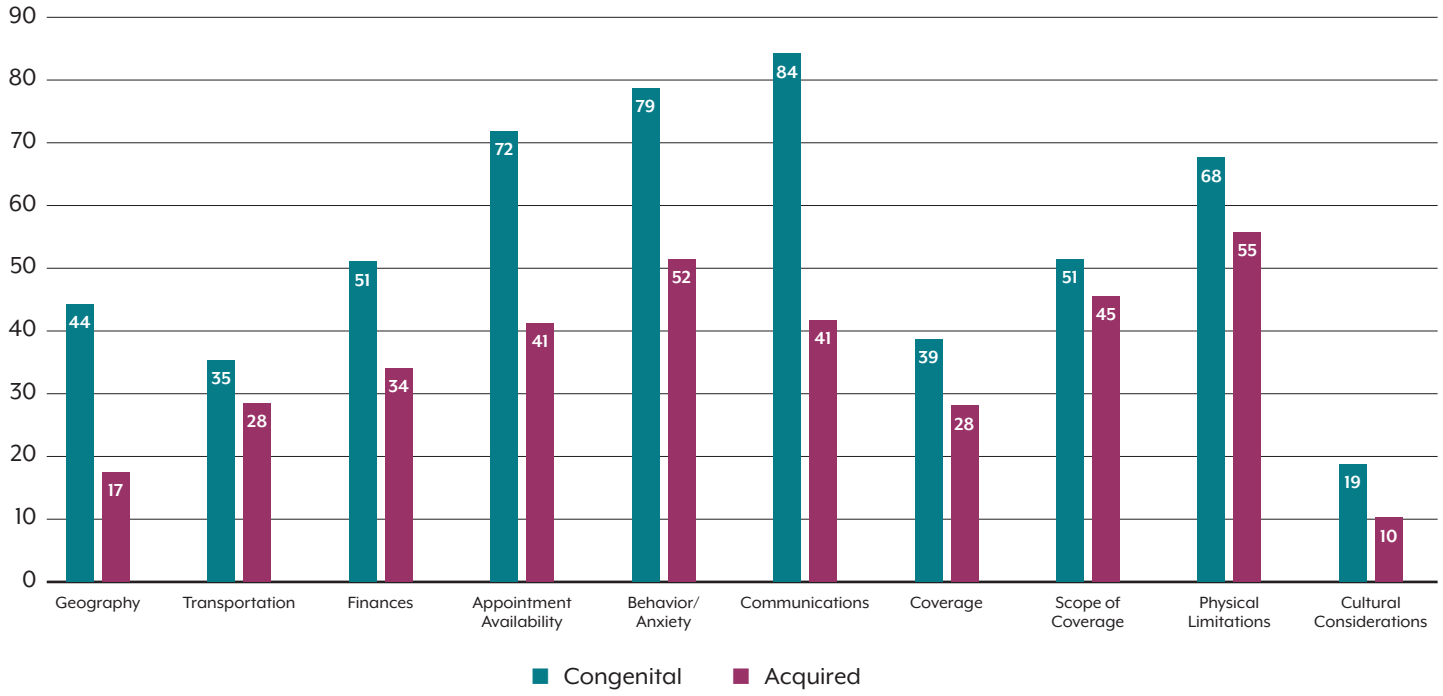
» 39% Coverage

» 51% Scope of coverage

» 68% Physical limitations of disability

» 19% Cultural considerations

BARRIERS TO CARE AS A PERCENTAGE



Generally, respondents to the patient survey with acquired disabilities cited multiple barriers to receiving care including:

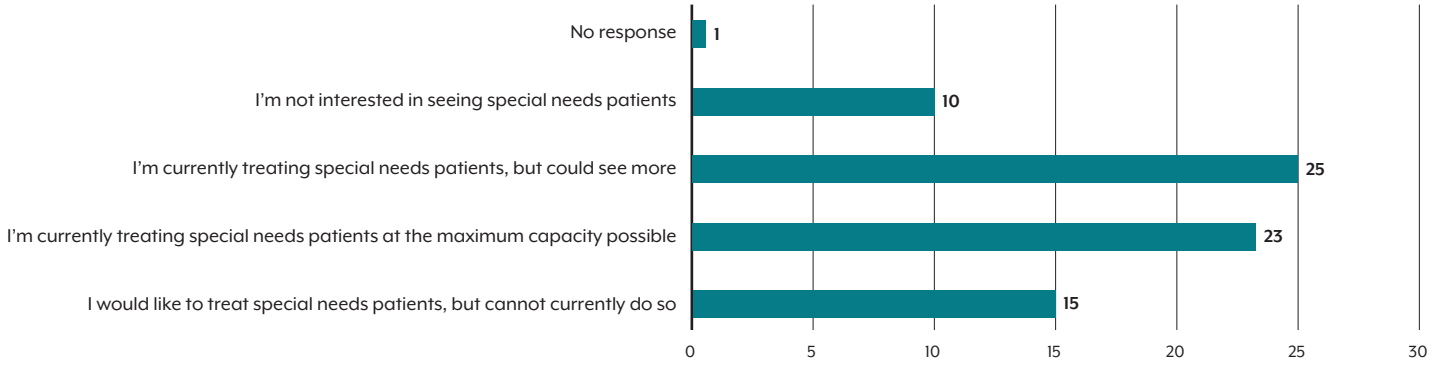
- 17% Geography (distance to travel)
- 28% Transportation
- 34% Finances
- 41% Appointment availability
- 52% Behavior/anxiety
- 41% Communications
- 28% Coverage
- 45% Scope of coverage
- 55% Physical limitations of disability
- 10% Cultural considerations

It should be noted that those with congenital disabilities reported having more barriers to care.

The taskforce noted that some of these barriers are consistent with the population at large, like geography, finances, and cultural considerations, while others are probably more unique to those with special needs, like communications and physical limitations. Several, like anxiety, transportation, and scope of coverage, are probably common to both those with and without disabilities but may be worse with those requiring special needs care.

> "She got there, I don't remember what time, but we waited, and we waited, and we waited, and we waited. Do we start saying something? But we're grateful that we're getting the surgery because there are a lot of people that don't even get it. Is there gonna be retaliation? I mean, as a parent, seeing your kid suffer that can't really understand why they can't eat, why they can't drink, why they're just sitting there in this room waiting. Because you don't want to leave in case they call you. That part was very, very, very rough.

ATTITUDE TOWARDS TREATING SPECIAL NEEDS PATIENTS



"I think a common theme [has been] resource[s], like somewhere we all could go to say, hey, there's a provider that's accepting people. Because you don't know what you don't know. You'll be talking to someone who'll [say], "Did you know about this?" And you're like, no, my case manager didn't tell me about this or that. So just having a resource we could plug into [that could tell us] the only dentist available is in Albuquerque. At least that gives us someone to talk to and someone to maybe go see.

PRACTITIONERS

Four out of five dentists that responded to the survey treat patients with disabilities that might be considered "special needs," but only one-third of those provide the kind of accommodations that we have considered to constitute "special needs care." This includes 25% that provide some kind of protective stabilization (specialized equipment) and almost 50% that utilize sedation. It is worth noting that more than half of those that provide protective stabilization are pediatric dentists that provide little or no care to adults with disabilities. It is also worth noting that about half of those that provide sedation for those with special needs are specialists that either do not provide comprehensive care (mostly oral-maxillofacial surgeons often limited to tooth removal) or treat only pediatric patients with sedation. In the survey, all of those that reported currently treating patients in the hospital operating room were pediatric dentists with both general practitioners and specialists currently utilizing sedation citing the extreme difficulty getting access to hospital operating rooms.

Approximately one-third of practices that are currently seeing patients with special needs reported that they could see more. The most often cited reason for not seeing more was the limitation of facility capacity (72%). Forty percent said that financial considerations and lack of training for themselves or their staff was preventing them from increasing the number of patients with special needs that they see.

For those that do not provide special needs care most cite lack of training as the reason. Half of dentists reported that they had not had any training for providing special needs care beyond undergraduate dental school and only one quarter reported having specific training in a post-graduate residency or specialty training program. Dental school curricula typically have minimal training and very little experience treating patients with special needs. The focus tends to be on behavior management techniques in pediatric settings. This makes it difficult to adequately diagnose, competently treatment plan, or appropriately refer those with special needs, so a significant number of practitioners simply choose not to see them.

Seventy-one percent of those that do not currently treat patients with special needs list financial considerations preventing them from providing special needs care. More than half indicate that they would consider doing so with more training for themselves and staff and if it was a financially viable option to justify improvements to facilities and incorporate them into their regular schedules. Nearly 60% of those that do not currently treat special needs patients indicated a desire to do so.

CONCLUSIONS

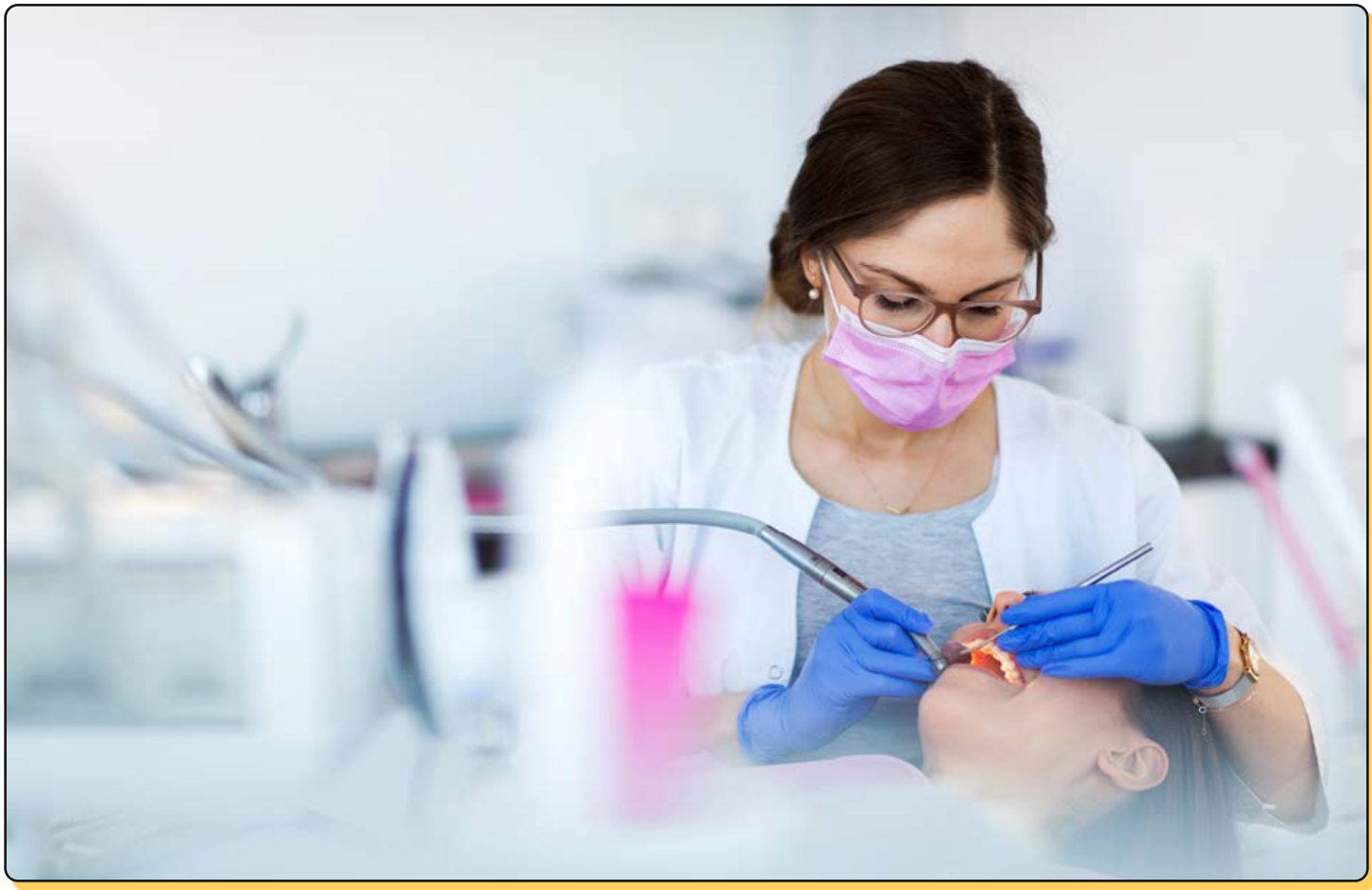
It is apparent from the surveys, focus groups, and interviews that there are many unmet dental needs among those that require special needs care. Patients and caregivers express difficulty getting appointments, challenges with cost, unavailability of specialty care, and the poor coverage as common barriers. At the same time practitioners expressed frustrations with coverage limitations, inadequate training, and lack of financial resources as barriers to their ability to provide care. The taskforce also noted that there is little data being collected and even less shared about how the special needs of people with disabilities are being met.

This study identified a number of questions to be considered. Here are some conclusions based on those questions:

CURRENT RESOURCES

The NM Health Care Authority operates a clinic in Albuquerque that exclusively treats patients with developmental disabilities. It is currently operating beyond capacity and has a long waitlist of those seeking regular care. It is fully equipped for special needs care and has a staff with extensive experience. They provide training to a limited extent for dentists of the community that wish to be certified to provide special needs care through Medicaid.

The University of New Mexico also has a clinic dedicated to special needs care. It only recently (2024) became operational again due to lack of staff. They are equipped to treat a wide range of disabilities. They will provide training to AEGD residents at UNM and to dental hygienists enrolled in UNM programs. They also hope to provide training programs to community members. UNM also has an outpatient ambulatory care facility that can provide general anesthesia and deep sedation.



> “Just have one frustration. It’s like nobody [has a master list of providers], whether it be Medicaid or whether it be the UNM autism center. Any time you try to ask somebody, well, do you know anybody? Do you? You know it would be nice if we called Medicaid, that they would have a list of those dentists that take special needs.

There are two private general practices in Roswell and Las Cruces that provide adult special needs care. Patients with special needs are seen regularly with limited availability subject to schedules that include non-special needs care. In-office sedation is offered but general anesthesia is severely limited by unavailability of hospital facilities for dental care throughout the state.

Most pediatric practices throughout the state provide special needs care for children but are not equipped to provide adult care as their patients “age-out” around age 18. They also cite difficulties providing care under general anesthesia for all their patients, both with and without special needs.

There are few resources providing preventive training or referring patients to appropriate places for treatment. One program that has been effective is the Special Olympic “Special Smiles” program which provides education and screenings to Special Olympians across the state. While this program has been an excellent resource, it is limited to addressing those with special needs that are able to participate in the programs offered through Special Olympics.

Many people with disabilities that require minimal accommodation for care are seen in private offices throughout the state. Usually, these patients do not require special equipment and respond well to routine behavioral accommodations. Perhaps the greatest limitation here is the number of offices that see Medicaid patients and the limits of Medicaid coverage itself.

The taskforce recognized that there are no centralized resources for patients and caregivers to have questions answered or to learn where care is available. There are no effective case management services related to dental care or information on where special needs might be met. This is also true of resources to assist dental practices in making referrals or having their questions answered.

> “I think that’s extremely important. I know we have a special needs code that we can add to our visits. But recognizing the fact that it takes not only extra time, but sometimes, special conditions, circumstances, equipment, in order to treat folks that need these services.

ORAL HEALTH DATA

As previously noted, the taskforce found that while some agencies might collect limited data about the care provided to patients with special needs, it is not in a form that is usable or accessible to researchers and advocates. Although privacy concerns must be accommodated, data could be processed to allow research and surveillance without compromising the patient’s privacy. Without some standardized data collection and synthesis, it is impossible for policymakers to make wise decisions or advocates to make informed recommendations.

There is currently no standardization of data collection and no meaningful infrastructure for reporting or analysis. Several state agencies may collect data related to special needs care but there is no means of aggregating this data that would allow integration and analysis. There is currently no entity tasked with surveillance, public or private. Lack of data or the limited availability of data creates a situation where needs are not only ignored but not even understood.

In most states, the state dental director would be tasked with establishing the methods and means to perform oral health surveillance. New Mexico lacks dental public health expertise in spite of a statute adopted in 2017 that requires the Department of Health to have a state dental director who is a qualified dental professional with public health expertise. The benefits of a fully qualified Department of Oral Health would not only allow the implementation of more effective public oral health measures but also enhance the ability of the state to gather useful oral health data to inform policies and utilize resources more effectively.

“I think transportation support matters a lot [as does] case managers. Because there’s so many with Parkinson’s, [and] so many interactions and elements that are unique … We lurch along doing our own case management. But having someone [serve that role] actually could be more efficient or help us do it for ourselves. Helping us help ourselves would be greatly appreciated!

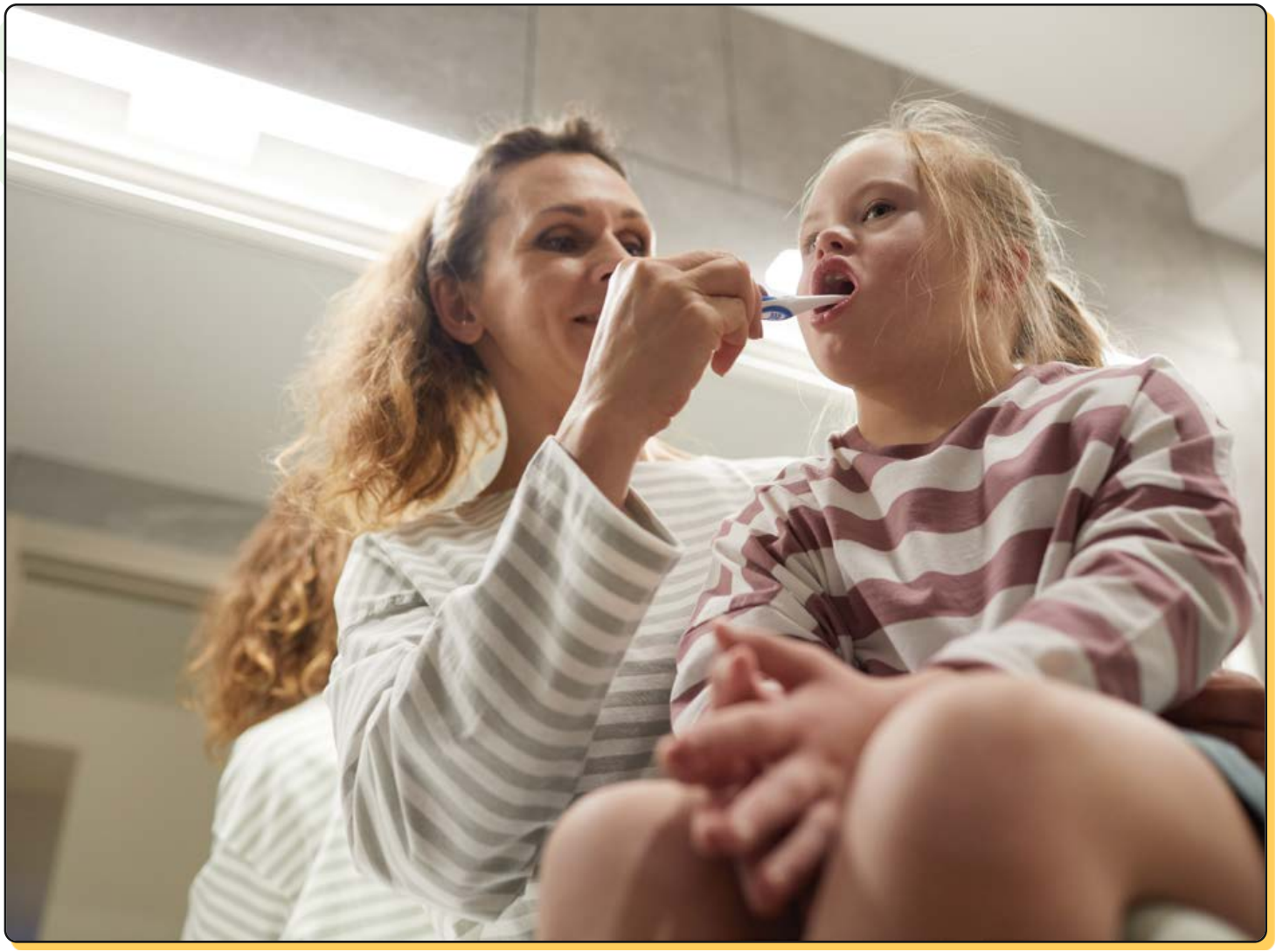
BARRIERS TO CARE

The two most significant barriers reported by respondents were anxiety about appointments and communications. These can also be barriers to patients without disabilities but were reported by twice as many in our special needs survey than are typically reported in surveys of all patients. Almost 70% cited the physical limitations of their disability as a barrier to receiving care. While there are never simple solutions to these problems, additional training and more effective case management will often reduce anxiety and improve communications. Training would also better equip practices to deal with physical limitations.

Almost three-quarters of respondents reported difficulty getting appointments. This can arise from a number of factors. For the general population, this is often a factor of finding someone that accepts the patient’s coverage. This is especially true of Medicaid where the number of practices participating is smaller and coverage is limited, particularly for adults. Since nearly 80% of our respondents reported Medicaid as their primary coverage, it is not surprising that this would be a significant barrier. Since an even smaller group of providers are equipped to provide the accommodations many of these patients need, this can be a difficult barrier to overcome. Clearly, the state needs more dentists trained and equipped to provide appropriate care. It will also be essential to find incentives for dentists to be trained and provide regular care.

More than half of respondents reported that the scope of coverage and finances are barriers while nearly 40% reported that inadequate coverage was a barrier. Again, since the overwhelming majority of respondents were covered by Medicaid, with limited coverage for adults, these were not surprising results. While Medicaid does provide for some preventive care and limited restorative care, the coverage for gum disease, infection and heavily damaged or lost teeth is only marginally better than palliative. Medicaid, rather than taking down barriers, can be a barrier in itself for patients with special needs. It is also worth noting that seniors requiring special care as a result of dementia or other disability may have no coverage if they rely on Medicare for health coverage since it does not have a dental benefit.

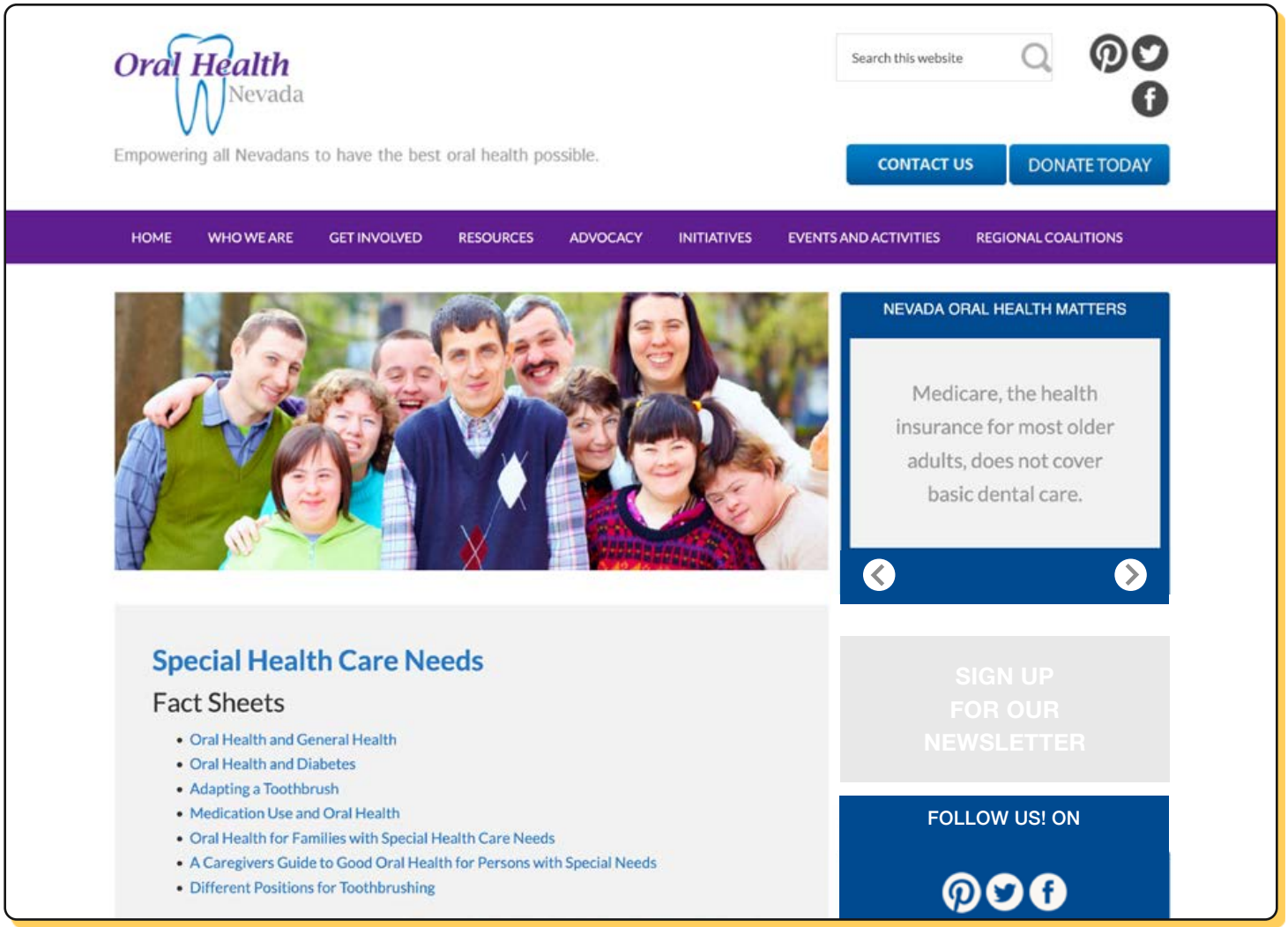
About 44% of respondents cited geography as a barrier. This can also be a barrier for the general population as there is a concentration of dental practices in urban areas and so many in New Mexico live in rural areas. This becomes an exaggerated barrier for those with special needs when there are so few practices offering special needs accommodations. Transportation was also a barrier for more than a third of respondents. This is a function of not only the need to travel a distance to get an appointment, but also the difficulty of transporting a patient with ambulatory limitations. While transportation services like the SunVan in Albuquerque are helpful, smaller communities may not have such a service and coordinating this service with limited appointment availability can be difficult. There are also cases where transport, while possible, is not practical. Residents of long-term care facilities might be strictly-speaking termed as ambulatory, but leaving the facility for routine appointments is difficult and unlikely. A more practical solution is bringing care to them. There are few such services in the state and almost none that can provide more than palliative care. Those that have tried to bring preventive and restorative care to confined patients have found it to be financially not viable. If Medicaid is inadequate in normal clinical settings, it is impossible with the additional expenses related to mobile services.



Interestingly, less than 20% cited cultural considerations as a barrier. This corresponds pretty well to the general population. While New Mexico should strive to provide culturally sensitive dental care, it is a barrier for fewer than might be expected in our culturally diverse state. As New Mexico considers how to train more of its students in the dental professions, it should prioritize programs that lead to a more culturally and geographically representative dental workforce, while continuing to demand more cultural sensitivity.

The barriers cited by patients and caregivers are both many and real. All can be reasonably overcome with a commitment of resources and the will to see these problems solved. An infrastructure to stimulate and monitor progress is needed, but in most cases the "raw materials" are present to make change. For example, despite the shortcomings of Medicaid, a coverage structure exists which could be reformed and improved. Also, training can occur by expanding programs that already exist. Making these changes is largely a matter of investment and commitment.

> "The only other thing I thought about was that maybe there is some sort of funding for hygiene products, specifically for low dexterity patients. Because a lot of special needs patients are low dexterity. But the new Samba toothbrush [a device from Curaprox, a Swiss company, manufactures], that's awesome, is like $300. My hygienist is a special needs parent and obviously she got one, but not every parent's gonna do that.



PROVIDER CAPACITY AND ATTITUDES

Sixty percent of dentists in the survey reported treating patients with special needs but only one-third of those reported providing accommodations typically associated with special needs care. Of the 40 people currently certified to use the special needs code under New Mexico Medicaid, only around 15 provide services regularly and only 5–6 of those are general practitioners. It is easy to understand why patients and caregivers report difficulty getting appointments and having unmet oral health needs.

Seventy percent of those reporting that they provide special needs care indicated a willingness to do more. This was true of both specialists and those in general practice and in both urban and rural locations. The most commonly cited barriers to expanding the volume of care for those with special needs were the need for additional training and inadequate financial resources. Nearly three-quarters cited a need to improve their facilities and level of staff training. Most indicated they would consider adding capacity if it were financially feasible.

It is noteworthy that even though demand is high, it is not translating as "demand" in the marketplace. Practitioners showed a willingness to increase capacity but were concerned that adding this capability would result in less than adequate financial compensation. This reinforces the dysfunction of the current Medicaid program and its ability to create demand in the marketplace by empowering those that require services to get them, despite the large number of people covered, especially among those have special needs.

There is also a great deal of ignorance in the care community around exactly what constitutes "special needs" and what resources are required. Patients with limiting disabilities may present to practitioners for care but are typically treated only to the extent of the practitioner's capabilities. Many practitioners are unaware of what methods and techniques would be most appropriate to accommodate the needs and do not know where to refer for the most appropriate care. Obviously, this becomes

SAMPLE PASSPORT (COURTESY ORAL HEALTH KANSAS)

My Dental Care Passport

For users: This passport is unique to you. Please fill out all information that you think is important.

For my dentist or healthcare provider: This is key reading for all staff working with me. It gives important information about how I can be supported when visiting your clinic. This passport should be kept visible and used when you talk to me or have a question about me.

Please check the box that applies:
☐ I completed this form myself ☐ I completed this form with help from someone else

This form was completed with help from:
Name:
Phone:
E-mail:

ABOUT ME

My name is:
I like to be called:
Nickname if you have one.

I am: ☐ Male ☐ Female ☐ Transgender Male ☐ Transgender Female ☐ Variant/Non-conforming ☐ Not listed_____

My preferred pronoun is:
☐ He ☐ She ☐ They ☐ Ze ☐ Not listed_____ ☐ No preference

Where I live right now:
For example: supported living; in my own home; in my family home.

What type of disability/ies I have:
Primary:

Secondary:

This is the best person to contact for more information about me or if I need help:
Name:
Role:
Contact phone number:

Other health professionals that might be helpful to contact:
Please list name, role, and contact phone number.

MEDICAL HISTORY

The dental team will ask you more about this when you visit them. It is important to know about your physical and mental health to take care of you safely. You will be asked about your health history every time you visit the dentist. This will include any changes in the medicines you take.

My brief medical history:
Include other conditions such as a seeing disability, hearing disability, diabetes, epilepsy, asthma, depression as well as past serious illnesses or operations, and other medical issues.

These are the medicines I take now and how they help me:
Please list all prescription and non-prescription medications.

DENTAL HISTORY

My last visit to a dental office was:
Check one.
Within the last ☐ 3 months ☐ 6 months ☐ 1 year ☐ Over a year ago ☐ Never

When I last visited the dentist, the dental team understood me as a person and my specific needs. ☐ YES ☐ NO
Please explain:

When I had dental care in the past, I needed help to stay calm?
☐ YES ☐ NO
Please explain:

Did this include being given medicine before or at the dental visit?
This is often called sedation. For example: nitrous oxide/gas, pills to help you stay calm, I.V. sedation, general anesthetic in a hospital. ☐ YES ☐ NO
If yes, describe what was used, if known.

This medicine made my dental visit easier. ☐ YES ☐ NO

How I react to dental or medical procedures:
For example: usual response to shots, IV's, examinations, x-rays

My best visit to the dental office was when:
Share things that DID work well.

My worst visit to the dental office was when:
Share things that DID NOT work well.

Here are the questions and/or worries I have about my teeth and mouth:

Taking care of my teeth and mouth:
I need help when cleaning my teeth ☐ YES ☐ NO
I clean my teeth ☐ 2 times a day ☐ 1 time a day ☐ every week ☐ less than every week

When I clean my teeth:
Please list all the things you/a helper do when cleaning your teeth.
For example: I use a power toothbrush with fluoride toothpaste for 2 minutes, we use floss one time a day.

I wear dentures. False teeth I put in and take out. ☐ YES ☐ NO

It is hard for me to care for my teeth. ☐ YES ☐ NO
If yes, please explain:

These are the things I need to be comfortable in a dental chair:
Please check all that apply.
Support for: ☐ neck ☐ back ☐ arms ☐ knees ☐ feet
☐ Sit up in dental chair (cannot tolerate a reclined position)
☐ Supportive stabilization security wrap
☐ A weighted blanket
☐ Stabilization support for spasms

I do better when dental staff provide my care:
☐ from behind me ☐ in front of me ☐ does not matter

If I start to choke, here is how you can help:

MOBILITY

I use these aids to help me move:

You can help me move by:
For example: assistance needed to get into dental chair, go to the restroom.

COMMUNICATION & BEHAVIOR

Ways that I prefer to communicate with people:
Check all that apply.
☐ Talk to me directly.
☐ Give me time to process the questions.
☐ I have a speech impairment and can be difficult to understand.
☐ It takes time to form my words so please be patient.
☐ Other:_____

I communicate using:
For example: speech, preferred language, sign language, communication devices or aids, pictures, non-verbal sounds. Also state if extra time/support is needed.

Here are visual or verbal cues that will be useful to know about me:

Here are the ways I communicate some things:
Worried; scared; angry:
Yes; Okay; I understand:
No; I do not understand:
Other:_____

On most days, I would describe myself as:
Check all that apply.
☐ Happy ☐ Quiet ☐ Nervous ☐ Other:
☐ Sleepy ☐ Loud ☐ Angry

These are the things I do sometimes that may be hard or dangerous:
For example: limb movements that may strike your hand when holding a dental tool

These are some things that can help me relax:
Check all that apply.
☐ Earphones to block out noise
☐ Eye covers to block light and activities
☐ An object that helps me feel relaxed/secure
For example: fidget spinner, security blanket
☐ Other:_____

SENSITIVITIES

These are some things that can upset me:
Check all that apply.
☐ Smell – office, perfume, cologne
☐ Sounds – music, drill, phones, voices, clock
☐ Sight – lights, overhead arm, mirrors, shiny tools
☐ Positions – chair height and tilt, being "still," lying flat
☐ Closeness – people, water, light, x-ray machine
☐ Touch/Temp –gloves, air, gauze, water, suction, room/water temperature, toothbrushing
☐ Texture – toothpaste, gauze, cotton, metal
☐ Pressure – seeking or aversion
☐ Taste – gloves, toothpaste, fluoride

OTHER THINGS YOU MIGHT NEED TO KNOW ABOUT ME

My hobbies and interests are:
Please list any hobbies or interests.

Please use this space for any further information.

impossible when adequate resources do not exist, or current resources are already overwhelmed. Even practices that are equipped and willing to provide care on a regular basis cite a lack of specialty referral resources as a barrier.

INFORMATION AND COMMUNICATION RESOURCES

Underlying nearly all barriers, there is a need for resources that make information available and allow communication. The lack of standardized communication tools adds to the cost and inefficiency of care, hampers efforts at surveillance, and squanders limited resources. Patients and caregivers have few sources of reliable information to locate care resources or inform practices that would prevent oral health problems. Ignorance of how pertinent systems work perpetuates their inadequacy and compounds problems.

Many of the resources that would help to solve these problems already exist in individual practices, organizations, or agencies, both inside and outside the state. They may not be accessible to others for a variety of reasons but mostly because there is not an entity or agency to curate and make them accessible. Making them available to patients, caregivers and practitioners would help efforts not only to improve individual oral health, but also to facilitate advocacy efforts to enhance resources for the community. While a single entity could serve as a convening agency, ultimately a network of advocates, public and private organizations, and professionals need to be assembled to make sure that resources are gathered and made available broadly. A website could be used to make them easily accessed and even promote communication within the network. While surveillance would best be accomplished by state agencies, making the results of those observations available to the public will allow a better understanding of what is currently happening and monitor changes for better or worse. The axiom that "information is power" is true and applying that power to the challenge of special needs care is imperative if we are to find solutions.

RECOMMENDATIONS

01

Medicaid improvements

Dental Medicaid needs to be overhauled to be even minimally functional. It would include:

- Reimbursement rates that assure broader participation and practitioner satisfaction
- Rules that encourage comprehensive and definitive care equivalent to that of the rest of the community
- Streamlined credentialling for practitioners
- Recognition and support of special needs accommodations
- Access to hospital resources

02

Central hub for information and resources

Creation and maintenance of a website to support patients with special needs and practitioners would allow the dissemination of important information for the oral health care of those with special needs. It should include:

- Patient educational resources like fact sheets, videos and brochures on home care and how and where to seek care
- Practitioner resources including forms, educational resources, referral and payment resources, and networking tools
- Reporting and surveillance tools

03

Practitioner Network

Create a network of interested practitioners to:

- Exchange best practice ideas
- Provide and support continuing education opportunities related to special needs
- Recognize those in the community providing special needs care
- Facilitate care teams of practitioners providing complementary services

This group could be facilitated and supported by the New Mexico Dental Association by providing CE credits, communication tools, and event support.

04

Investigate enhanced reimbursement for time-intensive special needs care by promoting the utilization of adjunctive code recognition, modifiers, and other third-party payer tools

- Setting-based
- Facility-based
- Time-based
- Behavior-based

This will require engaging the national dental provider community on coding and standards to improve coverage for those with special needs in both privately and publicly funded dental coverage.

05

Ensuring hospital or out-patient surgical center access and adequately equipping operating rooms for oral health procedures

Hospitals are generally reluctant to schedule time in operating rooms for oral health procedures under general anesthesia. This is largely a problem of inadequate reimbursement but there are also issues with providing necessary equipment for many dental procedures. A cooperative approach is needed to develop resources and provide a better understanding of all the challenges of providing care under general anesthesia in a hospital setting.

06

Create regional ambulatory surgical centers for oral health procedures, at UNM and dental hygiene schools

Many dental procedures could be provided using deep sedation and general anesthesia in ambulatory surgical centers. Creating facilities within existing clinical facilities operated by public dental educational institutions would provide regional resources for this care. This would benefit not only local patients and practitioners but could contribute to learning experiences of students in these institutions.

07

Recognize certification for dentists and staff who have had enhanced training

Providing a certification mechanism for those with enhanced training in providing care to those with special needs would add prestige and allow the community to identify those providing special needs care. This could be accomplished through existing organizations or agencies that recognize training, and the value promoted to the public and among the professional community.

08

Add satellites to existing special needs clinics or partner with existing practices in various locations

The NM Healthcare Authority (previously DOH) clinic in Albuquerque is effective but lacks capacity. There are a number of ways to build on this success by creating satellite practices in other locations or by creating partnerships with private practices in different communities. This would allow use of existing infrastructure to rapidly improve capacity.

09

Improve surveillance of needs, care provided, and resources

Lack of relevant data was identified as a problem in understanding what the needs and capacity of special needs care are. State agencies collect data from various sources but are not analyzing or making the data available for analysis. Creating protocols, identifying data sources, and synthesizing data into usable information is desperately needed to allow policymakers to react and support special needs care.

10

Encourage at least one treatment space that can accommodate special needs in new construction

While the cost of retrofitting all existing dental clinical facilities would be overwhelming, encouraging those that are building and remodeling spaces to create design accommodations to allow special needs care is reasonable, especially if reimbursement levels justify providing more care to those with special needs. Often these would be small enhancements that would allow better access to those requiring wheelchair access or greater privacy.

11

Create standardized forms and passport for care

Using some type of standardized reporting, whether electronic or other, would allow greater efficiency of care and referrals. A standardized form or "passport" to communicate patient needs and extenuating circumstances could facilitate the introduction of a patient to practitioners. This could also lead to better surveillance, care experiences, and cost-savings.

12

Expand or create mobile van and home health care options

For patients with ambulatory and transportation issues there is a need to bring oral health to their care locations. This could include assisted living and memory-care facilities, as well as those that are homebound. The added costs of providing this kind of care would have to be accommodated, but this would be far less expensive than creating dedicated spaces in these facilities to provide care and the advantage of providing preventive and preemptive care will be a savings.

13

Create a referral clearinghouse or matching service

Taking advantage of existing resources and utilizing them more efficiently would not only improve care but result in cost savings. Often it is simply a matter of not knowing what and where resources are. Structuring care teams with general practitioners and specialists or facilitating the creation of ad hoc teams through intelligent referral would improve care and save by reducing the duplication of efforts.

14

Encourage special needs curriculum in NM feeder schools

While New Mexico does not have its own dental school, there are a number of schools where we send our students and that send graduates to New Mexico more regularly. Encouraging these schools to provide dedicated training in special needs would potentially increase the number of those providing this care but more importantly improve the capability of dentists to make intelligent choices and referrals. Collectively raising the intelligence and sensitivity of the care community will improve experiences and quality of care.

15

Encourage the UNM and HCA clinic to provide training for post-doc dentists

This newly reopened UNM clinic is not only a resource to the special needs community but also a valuable educational resource for residents and community dentists. Creating educational opportunities for practicing dentists in the form of mini-residencies or continuing education classes would allow training to take place within established practices. The need for hands-on training would more effectively be provided by the practices that are already providing special needs care.

16

Provide grants for equipment or facility improvements

While the costs are actually relatively small, the availability of funding for practices to expand or enhance their special needs care will be an incentive to consider it. This could be in conjunction with taking a class or contingent on certification and would be an added reason for practitioners to consider it while providing them with the tools they have learned to use.

17

Use of teledentistry for initial consultation

Initial encounters typically involve a great deal of information gathering prior to physical examination. Much of this information can be collected via interview which can be done through online communications. Furthermore, much of the clinical data gathering can be done by assistants, hygienists, and community dental health coordinators (CDHC). Not having to be physically present can save time, money, and transportation costs for patients while allowing dentists to be more efficient and extend their reach beyond their clinic.

18

Expanded use of Community Dental Health Coordinators (CDHC)

CDHC's are specially trained dental team members that have case management skills. They can play a dual role of providing some services while facilitating care for those with particular needs. One role that has been underutilized is their ability to gather dental data for use in teledentistry. Current reimbursement mechanisms are a barrier to fuller implementation, but New Mexico does have a training program.

19

Grants for oral hygiene home care devices when needed

Many patients with special needs would benefit from using electric toothbrushes, oral irrigation devices, and other commercially available oral hygiene devices. Generally, purchase of these devices is not covered by dental benefits programs and with so many with special needs living in poverty, a program which provides affordable access to these devices would be beneficial.

20

Allow oral home care instruction for caregivers to be reimbursable

When a dentist or their staff need to visit a home to instruct patients or their caregivers in specialized home care procedures, there is no mechanism for reimbursement. These necessary activities should be included in the patient's coverage and the practitioner's time compensated.

21

Encourage a wholistic approach to care by integrating the dental-medical care team and being purposeful in promoting family-centered care

The advantages of integrating oral care with other healthcare is being recognized in many areas. There is a growing understanding of how poor oral health contributes to a variety of systemic conditions. Encouraging cooperation between various caregivers and recognizing how the experience of those that live and care for those with special needs can nurture better health will lead to better outcomes. Training for special needs care needs to include methods to encourage more wholistic care.

22

Create special needs "forum" to solicit regular feedback from the special needs community

Having a way for those with special needs to communicate what is working and not working will help to inform a continuous quality improvement in providing special needs care. Preventing those with special needs from being "forgotten" and empowering them with a stronger voice will allow advocates to bring down barriers and expand resources.

23

Develop the Office of Oral Health in the New Mexico Department of Health to be fully qualified to create the methods and means needed for all oral health surveillance

The current Office of Oral Health does not have the appropriate personnel or experience to conduct necessary oral health surveillance. This particularly impacts demographic groups with particular requirements, like the special needs community. Starting at the top, we need a state dental director that is a dental specialist in public health with experience developing surveillance programs and oral public health programs. This would be a small investment with the potential for many health benefits and cost savings.

FINAL OBSERVATIONS

While there will be many ideas about how to address the inadequacy of oral care for those with special needs, there should be agreement that it is a problem desperately in need of solutions. The taskforce in making these recommendations recognizes the solutions will be multi-faceted and require the cooperation and contributions of dental practitioners, the special needs community, policy makers, and the organizations that support them. We hope that this report and the recommendations that accompany it will serve as a "blueprint" for improving oral health outcomes for New Mexicans with special needs across the state.

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SPECIAL SMILES SPECIAL CARE

A Report on the State of Special Needs Dental Care in New Mexico

IN PARTNERSHIP WITH

New Mexico DENTAL ASSOCIATION

SCHOOL OF MEDICINE
DENTAL MEDICINE

2025