Oral Health Advocacy for People with Special Health Care Needs

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KEYWORDS

• Advocacy • Cultural humility • Special care dentistry • Social determinants of health

KEY POINTS

- Oral health care providers can engage in critical self-reflection as a starting point for developing cultural humility in the care of people with disabilities.
- Power imbalances between health care providers and patients with disabilities can be addressed using collaborative approaches that support autonomy, and by addressing power imbalances based on ableism hierarchies.
- Cultural humility also includes advocating to improve the social determinants of health that contribute to health inequities, including access to quality health care, economic stability and educational attainment, and social and environmental contexts.

Abbreviations

PSHCNs	people with special healthcare needs
CSHCNs	children with special healthcare needs
SDH	social determinants of health
ADLs	activities of daily living

INTRODUCTION

Advocacy work within the field of Special Care Dentistry is needed to help reduce oral health inequities for people with special health care needs (PSHCNs). This population has high rates of untreated dental decay and periodontal disease, as well as more difficulty accessing dental care.[1–3] Disabled individuals also report more difficulty finding care that meets their needs, including care that is culturally appropriate.[4]

By definition, Special Care Dentistry entails oral health care for "people with physical, medical, developmental, or cognitive conditions which limit their ability to receive routine dental care"[5] (**Box 1**). When referencing limitations to routine dental care, a medical model of disability would have the clinician focusing on the impairments of

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Box 1
Defining special care dentistry populations

People with special health care needs (PSHCNs): People "who have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and also require health and related services of a type or amount beyond that required by [individuals] generally." A special health care need (SHCN) may or may not lead to a disability.[7]

People with disability: The World Health Organization defines disability as impairments of body functions and structures, activity limitations, and participation restrictions that result from interactions between health conditions, personal factors, and environmental factors. A person with a disability may have special health care needs, but an association is not always present.[8]

Special care dentistry population: Special Care Dentistry involves care for "people with physical, medical, developmental, or cognitive conditions which limit their ability to receive routine dental care." People with special health care needs, as with disabled individuals, are more likely to have limitations in their ability to receive routine dental care. However, not all individuals with special health care needs and/or disability will experience such limitations.[5]

individuals with disability. In advocating for PSHCNs, a change in focus is indicated. The social model of disability posits that limitations are created by the environment.[6] This article reviews the environmental limitations to oral health often encountered by these populations. Furthermore, the article outlines advocacy pathways for the oral health professional with a cultural humility focus.

Developing cultural humility in the care of patients with disability is a good start in efforts to advocate for this population's oral health. Cultural humility in health care is characterized by the following 4 main concepts[9]:

1. Critical self-reflection
2. Addressing power imbalances in health care relationships
3. Advocacy for change to improve the social determinants of health (SDH)
4. A lifelong process of ongoing learning and action

This article explores these concepts and gives the oral health professional related recommendations for disability advocacy.

CRITICAL SELF-REFLECTION

Critical self-reflection is a process by which individuals become more self-aware. This is done through analysis of one's own assumptions about self, including one's own identities, experiences, skills, beliefs, actions, and biases.[9,10] For example, a health care provider engaging in critical self-reflection might humbly consider what they know versus what they do not know when it comes to the experiences of patients with disability. A provider might also consider their own relationship and experiences with disability and how their beliefs and experiences might enhance or limit their ability to take the perspectives of their disabled patients.

Critical self-reflection also involves an examination of how one is influenced by interpersonal, situational, and societal contexts.[10] For example, a provider might examine how their beliefs and actions related to disability are influenced by the larger context of an ableist society, or the smaller contexts of the health care setting in which they work, or specific individual interactions.

Self-critique, another element of critical self-reflection, involves examining those areas where the provider might seek transformation.[10] For example, a provider might

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recognize an area where one needs more education related to a disability concept, such as the social model of disability. Another example would be recognizing when a change in one's course of action or way of thinking is indicated, such as to avoid unintentionally stigmatizing language. Although it is important to practice self-critique in developing cultural humility, these skills will be counterproductive if self-critique is overdone and prevents the individual from achieving their transformative goals. Having a growth mindset in this area, knowing that cultural humility can be improved with learning and practice, will aid the practitioner in engaging in critical self-reflection and self-critique in a productive way.[11]

CLINICS ADVOCACY POINTS

- Engage in critical self-reflection related to knowledge about disability, experience with disability, and potential biases related to disability.
- Assess clinical skills, including skills in patient communication and facilitation techniques for supporting patients with disability.
- Assess the state of the dental practice in terms of accessibility and ability to deliver meaningful care to disabled individuals.
- Seek resources for education without imposing on individual disabled individuals. Examples include content published by disabled people, classes on disability studies, continuing education courses, and research articles.
- Maintain a growth mindset and seek solutions to gaps in accessibility, skills, comfort, and knowledge.

ADDRESSING POWER IMBALANCES

Power imbalances in health care relationships occur on multiple levels. Two significant types of power imbalances are those which are positional in nature as well as those associated with social identity groups.

Positional Power Imbalances

Positional power imbalances involve power differentials in positions of authority, where one individual holds more power over another, owing to the setting and nature of their position.[9] Examples of power imbalances in this area include those between employer and employee, between dentist and dental assistant, and between provider and patient. Addressing these power imbalances requires the person in the position of authority to moderate appropriate use of their power. Health care providers typically hold great influence over patients during the course of their care. The health care provider is the expert in their field and decides which care options to present to the patient. Similarly, the dental team should recognize that the patient is the expert in their own experiences, values, and needs.

Fully ascertaining the patient's area of expertise, and understanding their treatment wishes, is more challenging in certain situations. For example, when there are impairments in expressive or receptive communication, more attention is required in supporting communication needs. For some individuals, such as those with advanced dementia or significant intellectual disability, decision making may be delegated to a surrogate decision maker, such as a legal guardian. In these cases, the health care team should work to determine how best to support patient autonomy within this context. Additional discussion of informed consent for patients with disability is given in **Box 2**.

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Box 2
Considerations in obtaining informed consent for patients with disabilities

Presumed competence: Providers should assume that disabled individuals can make their own decisions.

Legal competency to consent: People who have been assigned a legal guardian for medical decision making no longer have the legal right to make their own health care decisions. This is determined by the court system. Guardianship is restrictive because it takes away the rights of the person with a disability and gives these rights to someone else (a legal guardian).[12] Guardianship is meant to be limited to cases where there is no safe alternative.

Decision-making capacity: Capacity relates to whether an individual has the ability to understand their health care conditions, and the risks, benefits, and alternatives to care. To give consent that is truly informed, an individual must not only understand what's at stake but also appreciate how these stakes affect them personally, and reason through the options to come to a decision.[13] Decision-making capacity is procedure specific. For example, an individual may have the capacity to consent to dental prophylaxis, but not to general anesthesia. Decision-making capacity cannot be based on diagnosis alone, nor provider perceptions about the quality of choices patients make.

Discrepancies between competency and capacity: The terms competency and capacity are often used interchangeably; however, it is important to be able to differentiate between these concepts, regardless of the terminology used. Discrepancies between capacity and competency can create legal and ethical dilemmas. One example is if a patient legally can make their own decisions but does not have the capacity to understand the proposed treatment in order to give informed consent. Supported decision making may be needed in these cases.

Assent to care: Minors, as well as adults with a legal guardian, are generally not able to provide informed consent for health care procedures. Providers should assess if the individual in such a situation assents, or agrees, to the proposed care. Ethical dilemmas can present when consent is given from a parent or guardian, but assent is not given from the patient.

Supported decision making: Supported decision making focuses on supporting patients in understanding and considering their treatment options in order to make their own decisions. This can be as simple as talking to a friend about one's health care options, or more coordinated, such as creating a supported decision-making agreement between the individual wanting support and the person they have chosen to support them. Advocacy groups are calling for more access to supported decision making for disabled individuals in order to avoid more restrictive alternatives, such as guardianship.[14]

Using techniques designed to support autonomy during patient-provider communication can also help address positional power imbalances. Three such techniques are reviewed here:

- *Person-centered interviewing* is an interviewing model that assures patient comfort and readiness for care, elicits all of the concerns a patient would like to discuss, and elicits the patient's symptom story, including the personal and emotional contexts, before moving on to provider-centric questions.[15]
- *Shared decision-making* is a collaborative decision-making model between provider and patient. Providers elicit and support patients' goals, preferences, and values and work together with patients to support their engagement in the decision-making process.[16]
- *Motivational interviewing* is a technique for supporting patient behavior change, founded on the spirit of collaboration, autonomy, and evocation.[17] Providers support patients where they are, in terms of their readiness to change, and help patients elicit their own solutions for moving toward desired behavior change.

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Beyond the need to support patient autonomy during patient-provider discussions, dentistry is procedural in nature. Patients are vulnerable to whether the practitioner attends to their needs throughout each encounter. Patients are also vulnerable because of the closeness of dentistry to sensitive areas. Tolerating touch to the head and neck, including inside the mouth, is difficult for many. Tolerating water from dental handpieces, ultrasonic scalers, or the air-water syringe is another common challenge. This is especially true for individuals with oropharyngeal dysphagia or oral sensitivities, which are commonly experienced by people with developmental or neurologic disabilities.[18,19] Attention to the needs of patients, including their verbal and nonverbal cues during procedures, can affect power dynamics in the patient-provider relationship.

CLINICS ADVOCACY POINTS

- Practice active listening and a collaborative style in patient interactions, recognizing the patient's own areas of expertise.
- Presume competence for patients with disabilities and learn more about surrogate decision making and supported decision making for people who have difficulty understanding their health conditions and treatment options.
- Use interviewing techniques designed to promote patient autonomy, such as person-centered interviewing, shared decision making, and motivational interviewing.
- Find ways to assure comfort and give power back to patients during clinical care, such as seeking assent for procedures, giving breaks during treatment, and seeking alternatives to enhance patient comfort.

Social Identity Group Power Imbalances

The next category of power imbalances are those related to social identity groups. The ADDRESSING Influences framework, from the field of psychology, identifies a list of social identity groups where power imbalances are common in society, including in health care interactions.[20] These include the following:

- Age and generational influences
- Developmental disability
- Disability acquired later in life
- Religion and spiritual orientation
- Ethnicity and race
- Socioeconomic status
- Sexual orientation
- Indigenous heritage
- National origin
- Gender and gender identity

Inequities and systems of oppression

Social group power imbalances are tied to health inequities, which are unjust differences in health outcomes between populations.[21] Systems of oppression contribute to inequities via power hierarchies where one group of people have dominant status in society and another group of people have nondominant status in society. *Ableism*, for example, is the system of oppression that maintains power imbalances between disabled individuals and those without disabilities.[22] This does not imply that disabled people cannot experience empowerment or success, but that they are more likely to

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experience societal barriers, and more risk to their health, on the basis of their ability status than their nondisabled peers.

Within each element of the ADDRESSING Influences there is not always a clear-cut binary. Disabled individuals may experience marginalization differently based on personal and environmental factors, as well as the functional impact of their condition. In addition, the experience of marginalization may vary depending on whether the disability is more visible or less visible, and how their experience of disability interacts with their other identities.[20,23]

Ableism and society

Ableism, as with other systems of oppression, occurs on multiple interacting levels.[22] At the societal level, ableism includes those laws, societal norms, and structural factors, such as the health care system, which disadvantage disabled people. An example at this level would be a health care insurance system largely based on employment, when disabled individuals are more likely to be unemployed or underemployed.

Ableism and organizations

At the institutional level, ableism includes organizational practices and norms that disadvantage disabled people. In terms of oral health, policies related to dental school accreditation, dental school curricula, dental practice, and the culture of the dental profession may have the unintentional outcome of disadvantage to disabled people. An example might include past predoctoral accreditation standards, which until 2020, only required graduates to be competent in assesssing the needs of PSHCNs as opposed to managing their care.[24]

Ableism at the Individual Level

At the individual level, ableism includes individual beliefs, attitudes, and behaviors that harm disabled people. An example is thinking disabled people are inferior to nondisabled people, which results in discrimination. Although ableism can be intentional, much of what sustains these systems of oppression is unintentional.[22] An example of an unintentional interaction is assuming a disabled person must be treated in a special care dentistry clinic simply because of their disability. This can have the negative effect of inappropriately segregating disabled individuals from people without disability. Although some individuals with disability may benefit from the advanced services offered in a special care dentistry clinic, referral should be an individualized assessment and not based on diagnosis alone.

CLINICS ADVOCACY POINTS

- Actively seek ways to include disabled individuals into the dental practice; if there are very few patients with disabilities in the practice, actively address accessibility barriers and promote access.
- Address ways that ableism may manifest in the clinic setting, such as via unconscious biases from providers and staff.
- Train the entire health care team on appropriate disability language, including the nuances of person-first (e.g. “person with a disability” / “person with an intellectual disability”) and identity-first (e.g. “disabled person” / “autistic person”) language, and how to avoid ableist language, both spoken and in the health care record.[25]

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- Avoid segregating disabled individuals into special care dentistry clinics or special hours within a practice; assess each individual's needs before considering referral and attempt to integrate care as much as possible.

ADVOCACY FOR CHANGE

The concept of cultural humility extends beyond self-work and addressing power imbalances in practice. It also includes advocacy for improving the SDH, which are environmental factors that affect health beyond the individual level.[26] The following are examples of SDH:

- Health care access and quality
- Economic stability
- Education access and quality
- Neighborhood and built environment
- Social and community context

Health Care Access and Quality

Health care access

Limited access to oral health care is a common concern among PSHCNs. For children with special health care needs (CSHCNs), dental care is the number one unmet need.[27,28] Adults similarly face difficulty accessing dental care.[2] This problem is multifactorial. Some of the reasons for limited access to oral health care are difficulty finding a dentist willing to treat, limited training for oral health professionals, and financial barriers.

Willingness to treat. Parents of CSHCNs report it is often difficult to find a dentist willing to treat their child.[29] Many People SHCNs have to travel long distances to find care, not being able to find care within the community in which they live.[30] Dentists are often hesitant to treat this population and concerned about their level of training and their staff level of training in treating PSHCNs.[31] Other causes of dentist hesitancy include perceived complexity of care, fear of emergencies, and financial concerns.[31]

Training and education. Dentists have historically felt ill prepared to treat PSHCNs. Hands-on training has been limited in many areas of special care dentistry, particularly in the care of patients with developmental disabilities.[31] The Commission on Dental Accreditation (CODA) enacted standards in 2004 that required dental graduates to be able to "*assess* the needs of patients with special needs," but did not include a requirement for competency in *treating* this population. Unfortunately, dental school administrators often feel pressures of a cramped curricula, which may contribute to educational deficiencies in this area. In one study, 50% of dental school deans reported the care of patients with special needs not to be a high priority in the curriculum.[32] In another study, less than 60% of administrators thought their dental schools were fully in compliance with the CODA standard, and 80% thought the school should spend more time teaching in this area.[33] In 2020, the CODA standard was enhanced to include *managing* the care of patients with special needs.[24] The aim is that future dental school graduates will have more training with these vulnerable populations and be more likely to provide treatment to these populations beyond graduation.

Similarly, opportunities for advanced training in the care of PSHCNs are limited. Although pediatric dentistry programs provide training in the management of CSHCNs, accreditation pathways for advanced education in adult special care dentistry and geriatric dentistry have not yet been developed.[34] Although residencies

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in general practice dentistry hold promise for advanced training in some areas of special care dentistry, training in this area is not consistent across programs.

Financial barriers. Health care access is also influenced by the cost of health care and how health care is financed. Disabled individuals have higher rates of work-related disability and are more likely to be unemployed or underemployed.[35] This results in this population having less access to work-funded health insurance, including dental insurance. Medicaid eligibility is high in this population. Among CSHCNs, 47% are Medicaid recipients, and among nonelderly adults with disabilities, 30% are Medicaid recipients.[36,37] The proportion of adults with developmental disabilities with Medicaid coverage is even higher.

Although states are mandated to include children's dental care under Medicaid, there is no such stipulation for adults. Coverage varies by states; Medicaid reimbursement rates are often low, and many providers opt not to enroll in the Medicaid program.[38] The result is that it is often difficult for Medicaid recipients to locate Medicaid providers for adult dental care services.

Health care quality

Another SDH is health care quality. Health care quality is defined by care that is not only equitable but also timely, efficient, person-centered, safe, and effective.[39]

Timely and efficient care. Delays in dental care can result in increased burden of disease, risk for complications, increased pain, and decreased quality of life. Compared to people without disability, individuals with limitations in physical functioning, cognitive limitations, and difficulty seeing or hearing are more likely to experience delays in care.[40] Delays in care are also more common among people who receive assistance with activities of daily living (ADLs), among people who receive assistance with instrumental ADLs, or those who experience participation restrictions, such as restrictions in ability to work or participate in social activities.[40]

Difficulty finding a dentist, long waiting lists, and the concentration of special care dentistry programs in urban areas all contribute to treatment delays. Many PSHCNs travel hours to receive dental care.[30] Long waiting lists for general anesthesia services are a common problem. Children with active dental pain who need care under general anesthesia typically wait almost a month for care.[41] Access to general anesthesia services for adults may be even more limited.[30,42] Barriers to general anesthesia services include limited access to hospital operating room block time for dentists, lower hospital reimbursement for dental procedures compared with medical procedures, and disruptions to the health care system attributable to COVID-19.[43] Treatment delays can also result from onerous processes for preauthorization approvals, justifications of medical necessity, and the limited numbers of hospital dentistry programs and providers.[43]

Beyond treatment delays, care efficiency is affected by the preparation of dental practices to meet the needs of their PSHCNs, who are more likely to need procedures rescheduled, need longer appointments, or have procedures completed over multiple visits. Practices need to be responsive to both the expected and the emerging needs experienced by PSHCNs during dental care.

Person-centered care. A key area of health care quality is person-centered care, which is care that "defines success not just by the resolution of clinical symptoms but also by whether patients achieve their desired outcomes."[44] This includes care that respects patient values, preferences, and needs, including emotional needs and physical comfort. Person-centered care also includes care that meets patient

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expectations regarding coordination of care and ease of navigation of the healthcare system.

One area of person-centered care that is particularly relevant for many disabled individuals is the assurance of needs related to autonomy. Disabled individuals often experience stigma from health care providers who make assumptions about the individual's ability to make their own decisions.[45] In addition, disabled individuals often report not feeling listened to by their provider, especially when communicating their own expectations and needs regarding the delivery of care.[45,46]

Another component of person-centered care for disabled individuals includes appropriate involvement of family members and caregivers. Disabled individuals often report that health care providers inappropriately defer to their family members or caregivers when discussing treatment options or plans of care, essentially "talking over" the individual with disability. Disabled individuals involve family members and caregivers in their care for different reasons, and the role of the family member or caregiver will vary depending on the individual patient's needs and preferences.

Safe and effective care. Safe and effective care is an essential component of quality in health care. People want care not only that is going to have good outcomes but also that will be done safely. Unfortunately, people with disabilities often report receiving care that is unsafe. For example, there are numerous reports of disabled patients being injured during transfers, such as from a wheelchair to another surface, or when the healthcare provider did not listen to their instructions.[46]

In addition to safety issues, care that is ineffective is also problematic. Effective care is defined as care that is evidence based and appropriately matched to patient need.[39] What constitutes effective care, including preventive care, interventions, and care facilitation techniques, is not always clear.[47] Unfortunately, the lack of effective care contributes to the oral health inequities for disabled individuals. As noted by the National Council on Disability, "…a lack of understanding of disability issues among health professionals can minimize the effectiveness of the services provided, thus creating another roadblock for those claiming their health care rights."[48]

Economic Stability and Educational Access/Quality

Disabled individuals are more likely to experience low income and have less access to employment.[35] Economic instability is one area that adversely affects health. It does this directly via limited access to pay for health care services, as well as indirectly, such as affecting educational opportunities.

Inequities persist in educational attainment for disabled individuals. For example, people with physical and cognitive disabilities report lower educational attainment than people without physical or cognitive disabilities.[49] There are numerous pathways by which educational attainment can affect health outcomes. A major pathway is economic, including higher paying and more stable jobs, more income, and more resources, such as employer-sponsored insurance, that can support health and access to health care.[50] Educational attainment is also tied to health behaviors, health literacy, stress levels, coping skills, and available social supports.[50]

In addition, education impacts health via the environments in which one lives. For example, the relationship between low educational attainment and disability varies significantly between states.[51] Reasons proposed for these interstate differences include variations in safety net resources for people with lower income, and contextual characteristics, such as the concentration of poverty, transportation systems, and the accessibility of the built environment.[51]

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Neighborhood, Built Environment, and Social/Community Context

Health is strongly tied to the environments within which one lives, varying not only by ZIP code, but also even down to the census tract level.[52,53] In addition, the built environment has significant impact on disabled individuals. For example, lack of accessible sidewalks, wheelchair ramps, and elevators can limit the ability of people with a mobility disability to access community resources and move about safely in their communities. Similarly, small operatories in dental clinics, tight spaces for obtaining radiographs, and narrow hallways can contribute to access barriers. Although the Americans with Disabilities Act mandates certain accessibility features in places of public accommodation, including dental offices, many dental offices still remain inaccessible.[48]

Another factor affecting the environments within which disabled individuals live, particularly those with developmental disabilities, is congregate living arrangements. Historically, people with developmental disabilities often lived in large institutions, and some still live in such institutions today. Concerns about segregation, quality of life, and abuse and neglect led to the nationwide process of deinstitutionalization, where most of such institutions have closed, moving their residents into community settings. Although institutional settings often had access to dental care with a dentist on site at the facility, the dental community was generally ill prepared for the closing of these institutions, furthering have a big impact on health for those void in access to dental care.[54]

Today, many adults with developmental disabilities live in smaller group settings, such as adult family homes, with the support of paid caregivers. Other people with developmental disabilities live independently, or with family members and friends. The availability and quality of caregiving support can have a big impact on health for those needing such services. Caregivers can help people perform oral hygiene care at home, drive individuals to appointments, schedule appointments, and advocate for their loved ones within the healthcare system. Family members and caregivers can be a great resource and part of the healthcare team. Unfortunately, people with developmental disabilities experience high rates of abuse and neglect, often from trusted individuals.[55] This betrayal of trust not only directly impacts health via the harm that it causes but also indirectly impacts health through a history of trauma that affects one's ability to trust those in positions of power, such as health care providers.[56]

Finally, dental providers and their practices make up part of the local social and community context. Whether people are able to access care in the communities in which they live and whether they have good relationships with their health care providers have important impacts on health.

CLINICS ADVOCACY POINTS

- Advocate within the culture of dentistry to promote care for disabled individuals.
- Promote programs and policies that enhance access to care, such as enhanced general anesthesia care, Medicaid reform, and provider loan repayment programs.
- Promote enhanced reimbursement programs for populations particularly vulnerable to access barriers, such as for individuals with intellectual and developmental disabilities.
- Promote education in special care dentistry, including supporting educational institutions, strong educational standards, and the creation of advanced education programs.

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- Prepare for the need for increased services in the community in areas where state institutions for people with developmental disabilities are still active and at risk of closure.
- Assess for signs of abuse and neglect and deliver trauma-informed care.
- Follow the lead of disability organizations who are working to improve the social determinants of health for disabled individuals.

LIFELONG PROCESS OF ONGOING LEARNING AND ACTION

The term cultural humility is used as an alternative to the term cultural competence.[9] "Competence" problematically implies that one can become a cultural expert, including expertise in cultures that are not one's own. Cultural humility rejects this notion and instead focuses on the humble nature of recognizing one's own limitations and areas needed for growth in the vast context of human diversity. Cultural humility in healthcare involves continually exploring what one knows and does not know, striving to do better, and seeking solutions for the stubborn and unjust nature of health inequities.[9]

DISCUSSION

The access to care barriers and oral health inequities faced by PSHCNs can seem insurmountable. However, there are always ways that healthcare providers can serve as advocates. Reducing oral health inequities requires a multipronged approach. Advocacy efforts can be particularly effective within the areas where one has the most influence, such as one's own dental practices and communities. In addition, effective advocacy efforts can be sought by partnering with community organizations already engaged in this work.[9] Advocacy efforts are most likely to be effective when they are nonpaternalistic and are responsive to the expressed needs of the communities served, particularly the individuals who experience the inequities themselves.[9,57]

SUMMARY

Special Care Dentistry focuses on oral healthcare for people with limitations to receiving routine dental care. These limitations are largely created by an environment that does not sufficiently meet the needs of these populations. Advocacy work within the field of Special Care Dentistry can help address these inequities and includes critical self-reflection, addressing both positional and social group power imbalances in healthcare, and advocacy for change to improve the SDH. Finally, developing cultural humility in this area requires a lifelong commitment to learning and action.

DISCLOSURE

The author has nothing to disclose.

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