

Oral Health Disparities:
Children With Intellectual and Developmental Disabilities

By

Elizabeth S. Galenti

Thesis

Submitted to the Faculty of the
Graduate School of Vanderbilt University
in partial fulfillment of the requirements

for the degree of

MASTER OF ARTS

in

Medicine, Health, and Society

May, 2016

Nashville, Tennessee

Approved:

Aimi Hamraie, Ph.D.

Laura Stark, Ph.D

Table of Contents

Introduction Narrative	1
Introduction.....	3
Methods.....	6
Theoretical Orientation.....	8
Results.....	9
Health Policy Literature.....	9
SSI and Medicaid Literature	12
Special Education Literature	14
Discussion	16
Conclusions and Future Research	21
References	24

Introduction Narrative

While volunteering at interfaith dental clinic, I witnessed firsthand the disproportionate oral health disparities that exist for children of low SES families with intellectual and developmental disabilities (ID/DD). After spending many hours interacting with patients while working the front desk, I realized that specialized oral health resources for patients with ID/DD are not easily accessible. Caregivers of children with disabilities would call the clinic desperate to find practitioners willing to treat their children because they were not covered by private insurance plans. It was incredibly hard for me to repeatedly turn away caregivers and explain that the clinic only treats patients with special healthcare needs one day each month. After spending time talking with mothers and caregivers, I realized that they often did not realize their children were eligible to enroll in TennCare dental coverage which provides preventative dental care for children until age eighteen. Other caregivers of children with disabilities receiving Medicaid coverage reported low provider participation. Caregivers explained that dental offices would often claim that they were not taking new patients once the caregivers revealed their children were enrolled in Medicaid dental plans. As a result, I became extremely frustrated with the apparent disconnect between Medicaid coverage and actual dental health outcomes for patients with disabilities. Why were so many caregivers calling Interfaith Dental Clinic desperately trying to get dental care for their children if they had Medicaid coverage?

One day I got home after a long shift at Interfaith Dental Clinic and started reading about Medicaid dental coverage for children with disabilities. I hoped that when parents called the clinic, I would be more helpful in my ability to give them accurate information. Even as a white, non-disabled, educated woman with access to the internet at home, I was nevertheless unable to

navigate the website. I took a break to make coffee and reflect on my experience teasing apart all the complicated information regarding dental coverage. It was astonishing to me that I had a college degree from Vanderbilt University yet I could not comprehend the different plan choices and eligibility information listed on the Medicaid website. How were caregivers, who did not speak English as their primary language or did not have a high school education, expected to understand and apply this information?

The next day I went to the Department of Health Policy at the Vanderbilt School of Medicine where I am a Graduate Assistant. I was determined to ask the faculty specializing in Medicaid research to help me better understand dental coverage for patients with special healthcare needs. The faculty members had endless information about healthcare for ID/DD children but were not familiar with dental coverage. After working at the Health Policy Department for several months I had come to view the faculty members as walking textbooks, they had endless degrees and award winning publications. If faculty members at the Department of Health Policy were not familiar with dental coverage for the population of patients with disabilities, where was I going to find this information?

I began cold calling dental clinics specializing in treating patients with special healthcare needs and learned that other people shared my confusion and frustration with Medicaid dental coverage. Several administrative staff members shared stories about breakdowns in coverage and resulting disproportionate out-of-pocket oral healthcare fees experienced by families of children with disabilities. The more I heard, the more frustrated I became. Dental offices pointed to poor Medicaid coverage while caregivers on the other hand, reported low provider participation.

There appeared to be some sort of breakdown happening and I wanted to learn what was causing the disconnect.

As a result, I decided to use my Masters thesis as the vehicle to learn more about the disproportionate oral health disparities I witnessed while volunteering at Interfaith Dental Clinic. I wanted to perform a literature review in order to see who is talking about this issue and what they have to say about dental care for children with disabilities. I hope to be able to use this information in practice at Interfaith Dental Clinic to help patients access dental coverage and improve oral health outcomes. First, I provide background information about barriers to oral healthcare experienced by children with disabilities. Then, I turn to available published literature by Health Policy, Medicaid and Special Education disciplines, to reveal not only how to describe what people should research but how they should approach improving oral health for children with special healthcare needs. Although Health Policy, Medicaid and Special ed literatures utilize the medical model of disability, I argue that adopting the social model of disability will improve oral health outcomes for children with intellectual and developmental disabilities by identifying ableism as a cause of oral health disparities.

Introduction

In the last forty years there has been a dramatic increase in oral health disparities for patients with intellectual and developmental disabilities (ID/DD) despite dramatic technological advances in the dental field (Lee 1). There are several important reasons why addressing oral health disparities for ID/DD children is more important than ever. First, The number of people with ID/DD is increasing because of population growth, better reporting and methods of diagno-

sis, as well as increased longevity and aging of this population (Fisher 2). Therefore, the population of patients with disabilities requiring specialized dental care is dramatically increasing. In addition, the transition from people with ID/DD living in institutionalized settings where preventative dental care programs were easily accessible, to living in family residences has resulted in poor oral health outcomes for this marginalized population of patients (Pediatric Dentistry 102). Patients with ID/DD have higher rates of dental caries but experience significant unmet dental care needs (Fisher 2) . ID/DD patients require specialized treatment that combines interdisciplinary, generic care, treatment, and coordinated services (Fisher 1) . .

ID/DD children require specialized care that often requires anesthetic and is therefore incredibly expensive (Kancherla 9). Dental procedures performed in a specialized environment, such as the hospital, are not covered by Medicare. Therefore, specialized care leaves caregivers of ID/DD patients with disproportional healthcare costs. As a result, patients with ID/DD are often not able to receive even basic dental procedures depending on the severity of their disability. When procedures are moved to hospital settings, families of ID/DD children must pay large out of pocket costs for treatment. It is estimated that lifetime medical costs for a child with ID is close to one million dollars (Kancherla 13). Healthcare costs over a patient's lifetime are significantly reduced if preventative dental care is easily accessible.

Existing literature on the social studies of socioeconomic status (SES) and oral health does not address patients with intellectual and developmental disabilities. Medicaid and health policy literature does not talk about SES for patients with ID/DD, but instead operates on the assumption that children with ID/DD receive health insurance. However, Medicaid and health policy literature do not take into account psychobiological and other determinants of oral health

for low SES patients (Boyce 8). For example, barriers to care such as transportation and continuity of care go unnoticed when overlooking SES for this population of dental patients. The assumptions these studies are making about race and class appear to create a conceptual problem that I hope to analyze and use my thesis project.

While health policy, Medicaid and special education literatures need to move past assumptions about SES, they also need a better understanding of intellectual and developmental disabilities in order to address issues of health disparity. For example, disability is defined using the medical model as, “interruptions or departures from a standard script of human form, function, behavior, or perception that in contemporary thought we call normal” (Garland 343). On the other hand, utilizing a critical disability perspective would offer views of disability acceptance and neurodiversity. Disability acceptance claims, “the ‘problem’ is not the person with disabilities, the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person” (Davis 2). Therefore, literature based on a medicalized definition of disability seeks a way to cure disability in order to preserve the ideal form of the body, or what is considered to be ‘normal.’ As a result, neurodiversity, a type of counter-eugenic logic, makes a case for conserving disability. One major consequence of eliminating neurodiversity would be its effect on the population distributions around the norm which leads to a normalizing society (Foucault 141). Ableism, the need to conserve normal or able bodied people, is a major cause of health disparities for children with ID/DD. In this paper I will propose what people should research regarding oral health for children with disabilities and how they should approach this research using critical disability perspectives.

The purpose of my literature review is to study dental health disparities and barriers to care for children with intellectual and developmental disabilities using a critical disability theoretical framework to in order to determine the factors limiting the continuity/quality of care patients receive and to improve access to comprehensive and preventative dental care.

Methods

For my thesis project, I conducted a literature review in order to engage and analyze conceptual problems in existing literature discussing dental health disparities for children with ID/DD. In order to examine health disparities I analyzed three bodies of literature. First, I began by reading health policy literature. I wanted to learn about the methods health policy literature used to study oral health disparities. Literature frequently discusses individual barriers to care such as education, SES, diet, age and living in rural areas (Ahn 31) but disability is often overlooked. Next, I examined literature discussing Medicaid and oral health disparities. There is endless information in Medicaid literature on disabilities and health disparities but little information on disability and dental care. When oral health is addressed, Medicaid literature cites plan choice as a barrier to care. Children often do not receive Medicaid coverage as a result of lack of information and caregiver confusion when selecting a Medicaid plan. For example, many caregivers believe they must be on Welfare to get Medicaid coverage or that Medicaid information is not available in the patients' primary language (Kim 441). Lastly, I began reading Special Education and Disability Literature to see what disability advocates say about dental care for ID/DD children. I was able to find a plethora of Special Education literature discussing oral health however, I was surprised to find that literature utilized the medicalized model of disability rather than a

critical disability lens, according to which emphasizes a politics of appearance to combat ‘the stare’ that pathologies physical impairment (Blum 19).

This literature review includes analysis of thirty articles discussing oral health disparities. Of the thirty articles, 11 discuss Health Policy, 10 articles focus on Medicaid coverage, and 9 articles discuss special education. When conducting my literature review I used several main search terms that evolved as I continued to read more articles and look at new journals. I have included my the PubMed MeSH terms with brief explanations of the significance of each term used in my literature review.

- **Dental care:** Most articles I found by searching “dental care” did not talk about patients with intellectual and developmental disabilities. There are many articles that discuss technological discoveries in the dental field but not dental health disparities for underserved populations.
- **Oral health:** After struggling to find articles concerned with treating patients with special healthcare needs, I had success using “oral health” instead of “dental care.” However, most articles did not focus on ID/DD patients. Often there would be one sentence stating that some patients require specialized care in specialized environments.
- **Health Disparities:** Initially I had a difficult time finding information using “dental disparities.” However, I was able to find more information once I broadened the scope of search to “health disparities.”
- **Medicaid:** This term helped narrow my search to articles concerned with providing care to underserved populations but often did not include dental care. There are many articles discussing the need for policy reform but they do not mention coverage for children with special health-care needs.

- **Disability:** I was not able to find many articles on PubMed discussing disability and dental care. My initial PubMed search resulted in articles describing plan choice for people enrolled in SSI (Supplemental Security Income). However, “disability” was useful once I began searching disability EJournals.

Theoretical Orientation

Applying the critical disability theory lens shifts my thesis project from a broad literature review to an analysis utilizing a critical framework addressing oral health disparities and disabilities. Disability is often oversimplified and viewed as a monolithic condition or deviation from the norm. For example, Garland-Thomson expands on the cultural association between disability and impairment when she claims, “what counts as disability legally ranges across a broad spectrum of physical, motor, mental, sensory, behavioral, medical, and appearance conditions that restrict function and full participation and are understood as stigmatized and exclusionary ways of being” (341). The medical model of disability focuses on the need to find a cure while the social model of disability utilized by the critical disability theory models emphasizes disability acceptance, rights, and diversity. For this paper I will use the social definition of disability, which says that disability is a condition created by culture based on ideal forms of the body (Davis 3) rather than a deviation from the norm. Using the critical disability perspectives of acceptance, neurodiversity, ableism and counter- eugenic arguments for conserving disability, I will not only describe what people should research but how they should approach improving oral health for children with intellectual and developmental disabilities as well as providing a cost-effective solution.

Results

Health Policy Literature

Health Policy literature examines the structural barriers to dental care for children but does not take disability into account. When disability is mentioned, it is frequently discussed in one sentence and grouped with other marginalized populations experiencing unmet dental needs. For example, one article claimed, “oral health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their social and economic position, racial or ethnic group, religion, gender, age, mental health, cognitive, sensory, or physical disability, sexual orientation, gender identity, geographic location, or other characteristics historically linked to discrimination or exclusion (Lee 225). The brief mention of disability as a social group experiencing systematic barriers to dental care is consistent across the literature I came across when reviewing Health policy articles.

One of the commonly cited barriers to care in this literature is the uneven distribution of dentists around the country (Ahn 30). As a result, patients living in rural areas often reported difficulties accessing preventative dental care as well as continuity of care. Patients in rural areas, “experience greater health disparities significantly associated with delaying dental care (Ahn 5). Therefore, this literature claims that rural patients cannot easily access preventative dental care and are unable to maintain continuity of care. Clinic hours were also considered a barrier to care because rural patients have to travel to neighboring communities for dental appointments, often requiring taking time off from work (Kim 4). Interestingly, environmental barriers to care for children with special healthcare needs are not highlighted by health policy literature.

In order to improve access and continuity of preventative dental care, health policy literature advocates for creating a mid-level workforce. Health Policy literature cites dental education curriculum as a barrier to care that needs to be reformed. Historically, dental schools did not train future dentists to provide specialized care unless dentists enrolled in a post doctorate program to learn how to treat patients with special healthcare needs. In addition to curriculum changes in which specialized training would allow dentists to provide specialty care, structural changes to dental school must be implemented to eliminate the student debt barrier to care for treating children with special healthcare needs (Casamassimo 6). However, health policy literature claims that improving provider availability may be difficult. Dentists often pushback and disagree with the initiative to create a midlevel workforce, such as the advanced dental hygiene practitioner and dental therapist, because of self interest and self-preservation (Castaneda 8). Dentists want to limit the midlevel workforce due to a large financial incentive. Dental professionals believe that they will lose patients if providers with less education are able to perform and charge less for routine procedures. Health policy literature acknowledges that there is a shortage of dentists in rural areas but does not address the shortage of pediatric specialists trained to provide oral care for children with special healthcare needs.

Health policy literature examines SES as a factor contributing to oral health disparities (Sabbah 301) but does not mention disability. In a pamphlet discussing children's health issues, the NIH claims that, "low-income children, especially those from racial or ethnic minority groups are especially at risk for untreated tooth decay" and but does not include ID/DD children (NIH 102). The pamphlet goes on to discuss healthcare for Autism Spectrum Disorder in an entirely different section. Surprisingly, this literature claims that non-financial factors are the pri-

mary determinate of oral health disparities for children with special healthcare needs because, “monetary costs are negligible for children enrolled in Medicaid (Mitchell 5). While most children with ID/DD receive SSI or Medicaid coverage, other factors associated with SES such as social inequalities contribute to oral health disparities. For example, patients with low SES account for higher levels of cariogenic oral bacteria (Boyce 3). The psychobiological and social influences on biological processes that contribute to long-term dental disparities are not examined in health policy literature. The assumptions health policy literature is making about race and class appear to create a conceptual problem because many structural barriers to care for this population of patients are not frequently discussed by Health Policy literature.

By assuming that SES is not a barrier to care for ID/DD patients, health policy literature overlooks individual factors contributing to oral health disparities. For example, health policy literature will often overlook other predisposing factors such as ID/DD caregivers’ education and other oral-health-related behaviors such as skipping breakfast (Ahn 11). The importance of the caregiver in promoting good oral health is unique to children with intellectual and developmental disabilities. Health policy literature cites oral literacy, or the caregiver's ability to access and utilize oral health information and services as a barrier to care (Lee 227). However, after reading several blogs and blog comments discussing the struggles mothers face when trying to comprehend Health policy information, I was surprised to find that the mothers focused on sensory processing as the biggest barrier to care for their children (Vacha 1). It appears that health policy literature underestimates the importance of individual barriers to care related to the role of the caregiver. The blog posts often state that dental appointments were stressful for not only the child but the caregiver as well. Children’s fears of healthcare environments were frequently cited as

the reason for not bringing children with special healthcare needs to the dentist for preventative care.

SSI and Medicaid Literature

SSI (Supplemental Security Income) and Medicaid literature address special healthcare needs of children with intellectual and developmental disabilities but does not address dental care as well as label SES as a barrier to care. This body of literature discusses coverage for people with disabilities at or below the poverty line (Snowbeck 1). Therefore, the assumption is made that all children with ID/DD have healthcare coverage, and children that cannot access care are not enrolled in healthcare plans (Lewis 1). However, many children that are eligible for Medicaid or State Children's Health Insurance Programs (SCHIP) are not enrolled (Journal of Health Care for the Poor and Underserved). This study found that misconceptions about Medicaid qualification resulted from parents not enrolling their children if their primary doctors did not take Medicaid or the belief that they must be on welfare to get Medicaid coverage (Journal of Health Care for the Poor and Underserved).

Medicaid literature does not often talk about disability and oral healthcare, however, the few articles I did find discussed the confusion caregivers face when selecting a healthcare plan for their children with special healthcare needs (Mitchell 4). I often became frustrated when reading articles about plan choice because the information is overwhelming and very confusing. As a result, I began to question how patients with low oral health literacy as well as language barriers, are able to make sense of the plan choices for children with disabilities. From Medicaid literature I was able to identify three main plan choices. For low SES families, caregivers must

select either managed care (MC) coverage or the free-for-service (FFS) system. However, legislative and regulatory action over the last two decades have moved low SES children from fee-for-service (FFS) systems to Medicaid and SCHIP programs. Children with family incomes too high to qualify for Medicaid but too low for private insurance are eligible for SCHIP coverage. This shift in policy occurred because CSHCN account for a large share of healthcare costs and the continuity of care could be improved by coordination of health care services (Huffman 7). Children enrolled in the capitated MC plan were more likely to see a regular doctor because the plan utilizes case managers to work with families to coordinate care. Having caseworkers facilitate appointments was found to ensure that the child was consistently seeing the same physician (Mitchell 9). Coordinating appointments between several specialist as well as dental appointments improves continuity of care for children with special healthcare needs. On the other hand, caregivers with children enrolled in FFS plans reported fewer provider options (Mitchell 2). Doctors received low reimbursement rates for FFS plans therefore most doctors do not want to treat patients with this plan.

Dental coverage is not frequently discussed in this body of literature but often articles discuss the administrative and financial barriers to care that leads to low provider participation in Medicaid plans (Valet 37). Dental Medicaid programs are historically underfunded and have low reimbursement rates which leads to low provider participation and in turn a shortage of dentists treating Medicaid patients or underserved communities (Castaneda 9). Providers would rather perform charity or volunteer care to avoid the Medicaid paperwork and get reimbursed 30% their normal rate (Castaneda 1). The underfunding of public insurance programs as well as a shortage of dentists in some communities contributes and perpetuates oral health disparities for children

with special healthcare needs (Bisgaier 5). Therefore, the, “impulses of exclusion and generosity, which, although seemingly paradoxical, together “drive the engine of American health care” (Hoffman 237). Dentists deviate between not wanting to treat patients covered by Medicare and the desire to perform charity care for the same population of patients due to low reimbursement rates.

Low reimbursement rates create a conceptual problem because younger dentists reported not treating children with special healthcare needs due to low reimbursement rates and large educational debt. Financially secure, older dentists reported providing care to CSHCN even though dental education has only recently implemented curriculum training dental students to provide specialized care (Casamassimo 1). As a result, providers without appropriate training end up treating children with special healthcare needs contributing to poor quality of care for ID/DD children.

Special Education/Disability Literature

There are many articles in Special Education journals discussing oral health for children with special healthcare needs. Interestingly, oral health is considered to be, “the most prevalent unmet healthcare need among children and adolescents with special healthcare needs” (Bertness 5). However, this differed from health policy and Medicaid literature which do not talk about the severity of the need to address unmet dental care needs for this population of patients. Special Education literature goes one step further and discusses the unique barriers to care for children with special healthcare needs such as, “frequent use of medicine high in sugar, dependence on a caregiver for regular oral hygiene, reduced clearance of foods from the oral cavity, impaired sali-

vary function, preference for carbohydrate-rich foods, a liquid or puréed diet, and oral aversions” (Norwood 615). Special ed literature also acknowledges that often parents do not perceive a disability the same way as medical professionals and how this impacts healthcare (Raver 22). These factors are unique to ID/DD patients but were rarely mentioned in health policy and Medicaid literature. Similarly, the severity of the disabilities and the implication on oral health care is unique to special ed literature (A Special Needs Guide to Dental Hygiene). Disability scholars highlights that, “poor oral health has a serious impact on quality of life, everyday functioning, social inclusion and self-esteem” (Khokhar 1) for patients with ID/DD. Interestingly, the unique impact of oral health outcomes for this population is not included in other literature.

Special Education literature not only claims that SES is the primary barrier to care for children with special healthcare needs but also acknowledges that not all disabilities experience dental care the same way. Authors in this discipline acknowledge that, “children with more severe conditions and from low-income families are particularly at risk with high dental needs and poor access to care” (Norwood 614). Health policy and Medicaid literature on the other hand, do not mention that low SES children with severe conditions often require more dental care covered by Medicaid. Therefore, Special ed scholars unpack the assumptions that health policy and Medicaid literature are making about class and oral health in order to combat disproportional out-of-pocket healthcare costs disability studies advocates for policy reform. Health policies must expand coverage for this population to decrease the higher financial expenditure of healthcare (Newacheck 5). Therefore, Special education literature acknowledges that families of ID/DD

children experience disproportional out-of-pocket costs and proposes the solution of expanding coverage.

Special ed literature also discussed limited provider availability as a barrier to care and proposed the solution of utilizing interprofessional education (IPE) to improve access and quality of dental care for people with ID/DD. Education in oral health during medical school is very limited. In a survey of pediatricians, “only 36% said they had received previous training in oral health, with 13% reporting training during medical school” (Norwood 617). Implementing IPE as an educational model requires a modification of attitudes, values, and behaviors in both faculty and student in order to address the oral health needs of an underserved population while experiencing clinical and didactic education in a school-based public health setting (Mabry 848).

Training dental hygiene students and elementary school nurses to assess oral health improved the comprehensive care of patients with special healthcare needs. Under the Individuals with Disabilities Act, all children with disabilities between the ages of 3 and 21 are entitled to free, appropriate public education (Thomas 226). Therefore, providing oral health screenings in elementary schools is a cost effective way to improve continuity and quality of oral healthcare for children enrolled in public education.

Discussion

While special education literature fills gaps left by the Medicare and health policy literatures such as acknowledging SES as the primary barrier to care and discussing factors unique to CSHSN that impact oral health, it would benefit greatly from a critical disability framework. In what follows, I analyze the challenges children with ID/DD face in the dental healthcare system

through a critical disability lens. The works I have cited in this paper support my argument that Medicaid and health policy literature drastically oversimplifies issues, making incorrect assumptions regarding race and class, thus creating a conceptual problem. Health policy, Medicaid and Special Education literature not only make assumptions about disability but also do not address crucial critical disability theories such as neurodiversity, disability acceptance, and ableism. If these fields were to incorporate critical disability theories, the outcome would be reducing barriers to care by changing the way researchers define disability in order to improve the relationship between members of the disability community and healthcare system.

After reading health policy literature, I was surprised to find how little health policy has looked at disability, as well as use the language of disability in discussing oral health disparities. Instead, there is a focus on the healthcare needs of able-bodied patients rather than the much smaller group of disabled patients that deviate from the norm. Most articles in this discipline address structural and individual barriers to care for underserved populations, but often overlook disability. However, I argue that the lack of access to economic resources and healthcare experienced by patients with special healthcare needs, “contributes to the creation and proliferation of disability” (Erevelles 17) because this reaffirms disability as a deviation from the norm. Therefore, this is an issue that deserves attention as there is a considerable financial incentive to address the oral healthcare needs of this population. While only 15.6% of children have special healthcare needs, this population accounts for 33.6% of healthcare costs (Newacheck 15). Implementing dental education curriculum changes and training a mid-level workforce are the core efforts this literature is citing as the solution to improving specialized care for this population of patients. However, policy expansion and curriculum changes are not cost effective and time sen-

sitive solutions to improving oral health disparities for children with ID/DD. Accessing preventative care early in life significantly reduces lifetime costs associated with intellectual and developmental disabilities (Kancherla 13). Therefore, there is a sizable financial incentive for policy makers to create changes in health care coverage that would improve oral health for children with special healthcare needs. Policy changes improving coverage for children with special healthcare needs will ultimately help decrease the disproportional health care costs endured by families of children with intellectual and developmental disabilities. However, health policy literature needs to acknowledge and address the disproportionate oral healthcare disparities experienced by ID/DD children because of assumptions made regarding Medicaid coverage and SES.

Much like health policy literature, Medicaid literature oversimplifies Medicaid and SSI coverage for children with special healthcare needs. Articles concerned with Medicaid discuss healthcare but rarely mention dental care and the special oral health needs of ID/DD patients. As a result, patients with ID/DD are not able to access specialized comprehensive dental care. The underfunding and low reimbursement rates cause limited provider participation which contributes to a limited number of providers and ultimately to poor continuity of care for patients with Medicaid coverage. Plan choice is another structural problem patients experience when enrolling in Medicaid coverage. Caregivers “become ensnared in a bewildering and endless maze of paper, policies and uninsured telephone calls (Blum 43). Changes must be made to streamline the overly complicated enrollment process in order to ensure people that qualify for coverage, are able to enroll in Medicaid coverage. I was most surprised to learn about the issues that arise when patients require procedures using anesthesia. Medicaid does not cover procedures performed in a hospital setting. As a result, patients do not receive necessary treatment. Without preventative

care, patients experience higher incidences of childhood caries which often leads to chronic adult diseases (Boyce 6). Medicaid and SSI coverage are not adequate in ensuring children with special healthcare needs receive preventive and comprehensive dental care. Expanding Medicaid coverage is not an adequate solution to improving oral healthcare for ID/DD children. Medicaid literature must acknowledge and address SES of patients as a primary barrier to care in order to improve access, continuity, and quality of dental care.

Special education literature addresses this problem and provides solutions in the form of policy changes as well as addressing individual factors. Implementing interprofessional education by training elementary schools nurses to perform oral health screenings is one of the initiatives suggested by special ed literature. IPE goes beyond creating a mid-level workforce by establishing a presence in healthcare provided to all children enrolled in school. Providing oral screenings in elementary school drastically improves access to care for children with special healthcare needs that are experiencing barriers to care, such as transportation issues and other factors associated with SES. Changing education curriculum and training health professionals to screen for oral health is a cost effective solution to improving dental health disparities.

While Special Education literature proposes unique solutions to improving oral health outcomes, disability literature is too fringe in that other disciplines are not communicating with this body of literature. In order to improve oral health disparities for children with intellectual and developmental disabilities, changes must be made in order to encourage dialog between disciplines. When I began my initial research I thought that there must be a gap in literature because health policy and Medicaid literature rarely discuss disabilities and SES. However, after searching disability EJournals I was able to find information regarding oral health and children with

special healthcare needs. Health policy and education curriculum reforms supplemented with IPE are all necessary in order to begin the process of improving dental health disparities for children with disabilities.

While Special education literature stresses the importance of addressing oral healthcare needs of ID/DD children, this literature approaches disability in an ableist way by favoring able-bodied people as the normative. Disability is not only medicalized by this literature but also characterized as a condition that overburdens schools and healthcare systems (Blum 4). Therefore, disability is viewed as a problem that needs a cure or solution rather than a deviation from what society views as the norm. The idea of the majority of the population lying within the curves of the bell curve and the outliers that deviate from the norm will be thought of as deviants (Davis 6) has perpetuated the medicalized definition of disability. Therefore, a critical lens on disability helps identify ableism as a cause of oral health disparities for children with special healthcare needs. Research analyzing dental healthcare for ID/DD children should not be executed using ableist ideas about disability. When discussing disability we need to use critical disability concepts such as neurodiversity and disability acceptance. Instead of viewing disability as a deviation needing a cure, we must frame our thinking around the question, “if disability is inherent in the human, how can it at the same time disqualify us from full membership in the human community?” (Garland- Thomson 339). When researching oral healthcare for children with disabilities, literature must evolve to adopt an individual rather than a medicalized definition of disability in order for critical disability theory to gain ground in health policy, Medicaid and Special Education literature. The assumption literature makes about disability as a monolithic category of patients will continue to perpetuate the disproportional oral health disparities and out of pocket

expenses experienced by families of children with special healthcare needs. A shift in thinking must occur in order to adopt the individual definition of disability as a condition created by culture based on ideal forms of the body rather than a deviation from the norm. Changing the way researchers define disability will greatly improve the relationship between members of the disability community and healthcare system. This is the first step in the long process of improving oral health disparities for children with intellectual and developmental disabilities.

Conclusions and Future Research

Special Education literature addresses the needs of an underserved population and proposes IPE as a simple and inexpensive solution to dental health barriers for children with disabilities (Mabry 6). However, in Health policy and Medicaid literature, these simple solutions were not suggested. Initiating dialogue among disciplines is necessary in order to improve oral health outcomes for children with special healthcare needs. The need to implement policy reform and interprofessional education will become even more crucial as this population transitions to adult dental care and no longer have TennCare coverage (Pediatric Dentistry 2). For this reason, correcting this educational deficit in providing specialized oral healthcare is not only critical to the improvement of care for this population, but also is likely to help alleviate the monetary burden caused by insufficient health care coverage. Initiating dialog between disciplines would be a step in the right direction only if the medicalized definition of disability is shifted to the social model of disability. The “othering” of children with disabilities in the healthcare system has resulted in the acceptance of an ableist approach to disability research in the healthcare field. However, utilizing a disability acceptance framework and embracing neurodiversity will help facilitate a new

approach for studying disability. There is a shortage of literature concerned with dental health disparities for children with special healthcare needs which must be addressed with a critical disability approach when performing future research. This new approach is crucial in that it pushes past the rigid boundaries of ableism and views disability as something that should be celebrated rather than eradicated.

In the future I hope to use inductive methods such as participant observation and unstructured in-depth interviews to further develop my research project. Utilizing an ethnographic approach will allow me to include qualitative data in the form of interviews. I would like to include data collected from interviewing dentists and children with special healthcare needs. I want to learn more about the ways dentists view systematic barriers to care as well as the role of critical disability studies in improving oral health outcomes and how dentists define disability. After reading Special Education and disability literature, I was surprised to find that individual barriers to care were often positioned around caregiver experiences rather than the child. In addition to interviewing dentist and patients, I would like to include information collected from participant observation in the Interfaith Dental Clinic waiting room. My goal is to compare and contrast what literature is saying about oral health care disparities for children with special healthcare needs, and the data I collect from participant observation and unstructured in-depth interviews. I predict that the medicalized definition of disability widely accepted by scholars across disciplines will be inconsistent with what ID/DD patients actually experience. I hope this project will help dental health professionals and policy makers move past ableism and towards disability acceptance in oral healthcare.

References

“A Special Needs Guide to Dental Hygiene.” N.p., n.d. Web. 15 Nov. 2015.

Ahn, SangNam et al. “Residential Rurality and Oral Health Disparities: Influences of Contextual and Individual Factors.” *The Journal of Primary Prevention* 32.1 (2011): 29–41. ProQuest. Web.

Bertness J, Holt K, eds. 2011. *Oral Health Services for Children and Adolescents with Special Health Care Needs: A Resource Guide* (2nd ed.). Washington, DC: National Maternal and Child Oral Health Resource Center.

Bisgaier, Joanna. “Provider Barriers to Specialty Medical and Oral Health Care Access for Children.” ProQuest, Ann Arbor MI, 2012. ProQuest. Web. 17 Sept. 2015.

Blum, Linda M. *Raising Generation Rx: Mothering Kids with Invisible Disabilities in an Age of Inequality*. New York: New York UP, 2015. Print.

Boyce, W. Thomas et al. “Social Inequalities in Childhood Dental Caries: The Convergent Roles of Stress, Bacteria and Disadvantage.” *Social Science & Medicine* 71.9 (2010): 1644–1652. ProQuest. Web.

Casamassimo, P. S., N. S. Seale, and K. Ruehs. “General Dentists’ Perceptions of Educational and Treatment Issues Affecting Access to Care for Children with Special Health Care Needs.” *Journal of Dental Education* 68.1 (2004): 23–28. Print.

Castaneda, Heide et al. “False Hope: Effects of Social Class and Health Policy on Oral Health Inequalities for Migrant Farmworker Families.” *Social Science & Medicine* 71.11 (2010): 2028–2037. ProQuest. Web.

Davis, Lennard . “Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century,” *Disability Studies Reader* (2010), 3-16.

Erevelles, Nirmala. *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic*. New York: Palgrave Macmillan, 2011. Print.

Fisher, Kathleen. “Is There Anything to Smile about? A Review of Oral Care for Individuals with Intellectual and Developmental Disabilities.” *Nursing Research and Practice* 2012 (2012): 860692. PubMed. Web.

Foucault, Michel. “Part Five: The Right of Death and Power Over Life,” *History of Sexuality*, v. 1 (1990): 135-145

Garland-Thomson, “The Case for Conserving Disability,” *Journal of Bioethical Inquiry* (2012): 339-355.

Hoffman, B. (2006). Sympathy and exclusion: Access to health care for undocumented immigrants in the United States. In K. Wailoo, J. Livingston, & P. Guarnaccia (Eds.), *A death retold: Jessica Santillan, the Bungled Transplant, and Paradoxes in Medical Citizenship*. Chapel Hill: University of North Carolina Press.

Huffman, Lynne C. et al. “Impact of Managed Care on Publicly Insured Children with Special Health Care Needs.” *Academic Pediatrics* 10.1 (2010): 48–55. ScienceDirect. Web.

Kancherla, Vijaya, Kim Van Naarden Braun, and Marshalyn Yeargin-Allsopp. “Dental Care among Young Adults with Intellectual Disability.” *Research in developmental disabilities* 34.5 (2013): 1630–1641. PubMed Central. Web.

Kenneth W. Norwood Jr, Rebecca L. Slayton, COUNCIL ON CHILDREN WITH DISABILITIES and SECTION ON ORAL HEALTH *Pediatrics* 2013;131;614; originally published online February 25, 2013; DOI: 10.1542/peds.2012-3650

Khokhar WA, Clifton A, Jones H, Tosh G. Oral health advice for people with serious mental illness. *Cochrane Database of Systematic Reviews* 2011, Issue 11. Art. No.: CD008802. DOI: 10.1002/14651858.CD008802.pub2.

Kim, Young O. Rhee. “Reducing Disparities in Dental Care for Low-Income Hispanic Children.” *Journal of Health Care for the Poor and Underserved* 16.3 (2005): 431–443. Print.

Lee, J. Y., and K. Divaris. “The Ethical Imperative of Addressing Oral Health Disparities: A Unifying Framework.” *Journal of Dental Research* 93.3 (2014): 224–230. PubMed. Web.

Lewis, Charlotte, Andrea S. Robertson, and Suzanne Phelps. “Unmet Dental Care Needs among Children with Special Health Care Needs: Implications for the Medical Home.” *Pediatrics* 116.3 (2005): e426–431. PubMed. Web.

Mabry, Charlotte Connick, and Nicholas G. Mosca. “Interprofessional Educational Partnerships in School Health for Children with Special Oral Health Needs.” *Journal of Dental Education* 70.8 (2006): 844–850. Print.

Mitchell, Jean M., and Darrell J. Gaskin. “Do Children Receiving Supplemental Security Income Who Are Enrolled in Medicaid Fare Better Under a Fee-for-Service or Comprehensive Capitation Model?” *Pediatrics* 114.1 (2004): 196–204. pediatrics.aappublications.org. Web.

Mitchell, Jean M, and Darrell J Gaskin. "Factors Affecting Plan Choice and Unmet Need among Supplemental Security Income Eligible Children with Disabilities." *Health Services Research* 40.5 Pt 1 (2005): 1379–1399. PubMed Central. Web.

"National Institutes of Health (NIH) | Turning Discovery Into Health." U.S National Library of Medicine. U.S. National Library of Medicine. Web. 12 Feb. 2016. Intellectual and Developmental Disabilities (IDDs): Condition Information

Newacheck, Paul W., and Sue E. Kim. "A National Profile of Health Care Utilization and Expenditures for Children with Special Health Care Needs." *Archives of Pediatrics & Adolescent Medicine* 159.1 (2005): 10–17. PubMed. Web.

Pediatric Dentistry; 2012 Reference Manual, Vol. 34 Issue 6, p96. "Policy on Transitioning from a Pediatric-centered to an Adult-centered Dental Home for Individuals with Special Health Care Needs"

Raver, Sharon A. et al. "Comparison of Quality of Life Perceptions of Caregivers of Individuals with Intellectual Disabilities in the United States and the Czech Republic." *Journal of the International Association of Special Education* 11.1 (2010): 22–30. Print.

Sabbah, Wael et al. "The Role of Health-Related Behaviors in the Socioeconomic Disparities in Oral Health." *Social Science & Medicine* 68.2 (2009): 298–303. ProQuest. Web.

Snowbeck, Christopher "Community Groups Fear Loss of UCare from State Health Plans." *Star Tribune*. N.p., n.d. Web. 12 Nov. 2015.

Thomas, Stephen B., and Constance Hawke. "Health-Care Services for Children with Disabilities: Emerging Standards and Implications." *Journal of Special Education* 32.4 (1999): 226–237. *EBSCOhost*. Web.

Vacha, Michelle "The Need for Oral Health Care at Safety Net Clinics | Disability.Blog." N.p., n.d. Web. 15 Nov. 2015. <https://usodep.blogs.govdelivery.com/page/24/?s=disability+benefits>

Valet, Robert S. et al. "Family Reports of Care Denials for Children Enrolled in TennCare." *Pediatrics* 114.1 (2004): e37–e42. pediatrics.aappublications.org. Web.