

INFORMING BEST PRACTICE FOR THE COMPREHENSIVE COMMUNITY DENTAL  
CARE OF ADULTS WITH DEVELOPMENTAL DISABILITIES: A GROUNDED THEORY  
STUDY

by

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A THESIS

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## ABSTRACT

**Background:** Dental care for the persons with Intellectual Disabilities/Developmental Disabilities (ID/DD) is an underdeveloped specialty within the field of Dental Healthcare. There are no consistent and agreed upon training or licensing guidelines. Patients with ID/DD are 13% less likely to receive a routine dental appointment one time per year compared to young adults without a disability. Further, patients' negative experiences with dental care can affect the overall success of dental appointments and likelihood that the patient will engage in continuing care. To address this gap in the literature, this study sought to, take the first steps toward establishing a set of core competencies for a patient centered dental care provision among patients with DDs utilizing a grounded theory approach

**Methods and procedures:** In 2020, semi-structured qualitative interviews were conducted with 13 dental care professionals including 8 Dentists and 5 Dental Hygienists. There were 6 female participants and 7 male participants. NVivo software was used to conduct thematic data analyses. A grounded theory research approach was utilized to integrate the findings into some preliminary theories.

**Outcomes and Results:** Three main themes emerged from the analyses: Perceptions of dental care providers regarding best practices for inclusive practice: Techniques and provider characteristics; Barriers to inclusive practice and Facilitators to inclusive practice. Many of the participants had personal relationships with at least one person with developmental disabilities which influenced their decision to specialize in that type of dentistry. Providers mentioned empathy and patience as key qualities among those conducting comprehensive dental care in the

community setting. Some of the significant barriers to comprehensive community care were the lack of formal education in patient centered ID/DD dental care provision, lack of practice preparation of dental providers, and a lack of dental funding.

Conclusions and implications: Most providers had no formal knowledge of PCC and the majority of the clinicians interviewed had no formal training on the dental care of persons with DDs. Dental programs should increase the availability of training that facilitates PC community care for this population (e.g. sedation methods). More structured educational programs are needed in order for both medical and dental providers to feel better prepared for comprehensive care of persons with DDs in the community setting. Further, future research should examine the perspectives of ID/DD patients and their caregivers with regard to dental care to better address their specific needs.

## DEDICATION

This thesis is dedicated to all of the family and friends who supported me through this process, and to my nephew Zachary who has been the primary inspiration for me to strive to improve health and dental care for persons with developmental disabilities. To my children, may you always aim to do your best wherever life takes you. Thank you also to my husband Patrick for endless support and encouragement. I love you all.

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## INTRODUCTION

Having an Intellectual or Developmental Disability (ID/DD) in the United States (US) has a significant association with poor oral health<sup>1</sup>. Dental care for the ID/DD population is an underdeveloped specialty within the field of Dental Healthcare; wherein there are no consistent and agreed upon training or licensing guidelines.<sup>2</sup> Patients with ID/DD are 13% less likely to receive a routine dental appointment one time per year compared to young adults without a disability<sup>2</sup>. Further, patients' negative experiences with dental care can have an effect on the overall success of dental appointments and likelihood that the patient will engage in continuing care.<sup>3</sup> Oral health is closely linked to overall health and wellbeing, therefore it is crucial that ID/DD patients have access to routine patient-centered dental care.<sup>4</sup>

Lack of insurance, high cost of treatment, and a lack of the provider's willingness to treat persons with ID/DD have been associated with lower likelihood of ongoing community based dental care among people with disabilities.<sup>2</sup> Additionally, most young adults age out of their Medicaid insurance benefits at age 21, which can present a cost barrier to care.<sup>2</sup> This, paired with the shift to community based dental care from the institutional models (i.e., people with DD who previously received care exclusively in an institutional setting began receiving care in community settings following the closure of many facilities), has caused disruptions in comprehensive consistent care among patients with disabilities.<sup>2</sup>

Developmentally disabled patients in Virginia are especially affected by this transition to community care, with approximately 800 patients having entered the community population after the closure of 4 out of 5 institutional health facilities between 2014 and June of 2020. This figure excludes an additional 2,000+ community DD patients who, although they did not reside at the facilities, were able to attend those facilities for dental, medical and behavioral health.<sup>5</sup>

### **Patient/Person Centered Care**

Patient/person centered care has gained traction in the field of Preventive Health Patient/person centered care posits that it is important to see the “person behind the patient” and to open the lines of communication and understanding to create a welcoming environment for both the practitioner and the patient.<sup>6</sup> Patient/person centered care can reduce anxiety in the patient and it can decrease stress and frustration in the practitioner because both parties are working together to attain a common goal of comprehensive care.<sup>6</sup> Patient/person centered dental care has been linked to success of dental appointments for patients with developmental disabilities.<sup>2</sup> However, there is no consensus in the literature on the best practices for patient/person centered dental care provision among persons with DD.

### **Historical Context and Problem**

As a result of the Olmstead act in 1999, medical and dental care for adults with intellectual and developmental disabilities transitioned from an institutionally based model, where the individual received medical, dental and behavioral support in one facility away from the general public, to community based practice where they now receive care in an integrated community setting (i.e., private and public dental practice settings).

In the community setting, the individual usually has several different practitioners in varying locations that they need to travel to for care. In Virginia, there were five institutions for persons with DD.<sup>7</sup> Out of the five institutions, four closed their doors permanently between 2014 and 2020, and one remains open.<sup>7</sup> When these individuals with DD began entering the community settings to reside in private homes, nursing care and group homes, few medical and dental providers accepted patients with DD into their practices.<sup>3,8</sup> Many providers lacked formal education on working with persons who have DD.<sup>9</sup> The lack of clear accreditation guidelines and consensus on core competencies for doing this work is likely one of the reasons for this. It was only 16 years ago when The American Dental Association added “special needs” to the requirements for school accreditation.<sup>10,11</sup> Specifically, they required that at least one of the programs’ learning objectives be directed at the ADA’s definition of “special needs”.<sup>10</sup> Krause et al. (2010) surveyed dental schools on their compliance of this ADA accreditation change. Out of the 22 schools which responded to the survey (originally sent to 65 accredited dental schools in the US and Canada), 91% of the respondents reported that they had written exams on special needs patients but only 18% had clinical examinations, and 9% had an actual patient care training experience.<sup>12</sup> Furthermore, only 42% of dental hygiene schools in the US offered clinical education on special needs patients.<sup>13</sup> The Joint Commission for Dental Examinations (the body that administers the board examinations for dental and dental hygiene graduates) does not have a written requirement that the prospective licensee be proficient in the ID/DD population prior to candidacy application.<sup>14</sup> Given this lack of consistency in training and licensing requirements, it is not surprising that many patients with DD are unable to access quality dental care.

Among the few providers who are trained in working with persons who have DD, the majority report having gained that training at the clinical/post licensure level (i.e., as the provider encounters patients in their community based practice or through optional continuing education courses).<sup>9,15</sup> Unfortunately, much of the training available refers to techniques such as restraints/supports or excessive sedation which are considered ethically and legally problematic, and do not focus on the patient centered approach and the reduction of anxiety.<sup>16</sup> For instance, the National Institutes of Health have an education series titled “Practical Oral Care” which is information about the special needs patient.<sup>17</sup> The material has not been updated since 2009 and although it gives examples on accepting special needs patients into an office it offers no way to establish whether the provider has adopted patient centered techniques and lends no detailed instruction on how to implement the suggestions in the literature.<sup>17</sup> There is a clear need for research to inform a set of core competencies for patient centered dental care provision among patients with DDs.

### **Patient Centered Care Model**

A person centered care model informed this study<sup>18</sup>. The person centered care model highlights the importance of dental health in the patient’s overall health and stresses that providers should understand the individual as a whole person including their health and behavioral concerns. When the provider learns more about health and behavioral concerns for each individual, they are able to espouse a more tailored, empathetic, and comprehensive approach to dentistry.<sup>18</sup> The person centered approach has the ability to improve the quality of health and dental care as well as overall health outcomes.

## **Thesis Statement**

The aim of this thesis study was to, through a grounded theory approach, take the first steps toward establishing a set of core competencies for a patient centered dental care provision among patients with DDs by examining:

- (1) Perceptions of dental care providers regarding best practices for inclusive practice:  
Techniques and Provider characteristics;
- (2) Barriers to inclusive practice
- (3) Facilitators to inclusive practice

Long term, I aim for this research to inform the establishment of measurable core competencies for the dental practitioners in community settings.

## **Significance**

The work is significant because it will address 2 public health needs: The need to inform core competencies for patient centered dental care provision for persons with DD and the need to identify barriers and facilitators to gaining necessary training, and implementing these inclusive practices.

## **Positionality Statement**

As a dental care professional, I have worked with persons who have developmental disabilities for the past 14 years. I also have a young family member who has a DD.

This personal experience informs this work because I understand the struggles that patients with DD face in finding consistent ongoing patient centered care in community settings. I currently work for the Virginia Department of Behavioral Health and Developmental services

where I have written the policy and procedures manuals for the community care of persons with DDs. I participate in collaborations with private organizations such as the Virginia Health Catalyst where I am on the Clinical Advisory Board. Additionally, I have presented topics on persons with DDs at 3 Special Dental Care Association Conferences. I believe that this background gives me a unique perspective in exploring this topic through a qualitative, grounded theory methodology. My hope is that this research will guide future progress in community based models and reduce the amount of barriers and misconceptions for this underserved population.

## **METHODS**

### **Recruitment**

For the purpose of the study, participants were eligible to participate if they were currently licensed in the Commonwealth of Virginia to either practice dental hygiene or dentistry and had at least 5 years of experience with the DD population. This time frame of experience was used with the assumption that if the practitioner spent at least 5 years in this specialty practice, they would have already decided if treating adults with developmental disabilities in the community setting is something they would continue long-term, throughout their career, and they would have developed their own techniques. I recruited participants from different parts of the Commonwealth, however stayed within Virginia as regulations and practice requirements are state-specific. The goal of the study was to identify current barriers, challenges, and successes in dental care provision for adults with ID/DD and to gather an understanding of what these practitioners perceived as a successful patient centered appointment in a community setting. I also wanted to determine what processes the dental providers were conducting in order to achieve a successful dental appointment with persons who have DDs. Informed consent was established in written form from the dental providers.

### **Data Collection**

To generate a list of potential participants, I used my own knowledge of the dentists and dental hygienists throughout the Commonwealth of Virginia who were already seeing patients with Developmental Disabilities in their community offices. As a dental care professional myself, I started with my own network of colleagues.

In September of 2020, I contacted potential participants via email and conducted a Qualtrics screening survey to identify participants who met my eligibility criteria.

After the sending the initial set of messages to 20 potential participants, I used a snowballing technique to identify additional potential candidates. Fourteen participants met the eligibility criteria and agreed to participate in semi-structured interviews pertaining to their current dental practice methods and techniques and their experience with the DD population. I conducted 13 semi-structured interviews (i.e., the participants were asked a series of open ended questions) through the secure video conferencing platform Zoom. The 14<sup>th</sup> participant completed the consent form, but did not complete the interview process due to schedule constraints. I attempted 4 different scheduled meetings but they were all cancelled by the participant. Interviews were transcribed verbatim by a professional transcription company.

### **Data Analysis.**

I conducted qualitative analyses concurrently with data collection. In weekly meetings with Dr. Morales-Alemán, we discussed emergent themes for each of my research questions. We determined that theme saturation for my main areas of inquiry was obtained around the 8<sup>th</sup> interview, however I continued with the scheduled interviews to ensure that no new information was overlooked or left out.<sup>19</sup> I used the Nvivo data analysis software version 12 to create nodes and to label common themes and subthemes among participants.<sup>20</sup> The topic guide for the interviews (see full topic guide in appendix) included questions such as “*Can you tell me how you understand person-centered dentistry?*”, “*Can you describe how you learned to treat the developmentally disabled patient in the dental setting?*”, and “*Are there any specific attributes that you feel are important for the provider to have when treating the developmentally disabled patient in the dental setting?*”.

I also used questions such as “*What barriers to care do you experience when treating the adult patient with developmental disabilities*”, to begin to understand how these participants are working towards expanding access to care across the Commonwealth of Virginia.

### **Grounded Theory**

After completing the content analysis, I also utilized a grounded theory research approach to integrate my findings into some preliminary theories.<sup>19</sup> Grounded theory is a methodology where the intent is to move beyond description and to generate or discover a theory.<sup>19</sup> I chose a grounded theory approach because there is a dearth of research on the community based dental care among developmentally disabled patients. The majority of the research is quantitative and identifies only the provider’s willingness to treat versus what skills are needed for practical application<sup>8,9,21,22</sup>.

## **RESULTS**

### **Demographic Characteristics**

Thirteen participants completed the semi-structured interviews. The participants ranged in age from early 30's to late 60's and had between 5-35 years of dental care provision experience. The participants reported seeing anywhere from 1-65 patients with Developmental Disabilities per month with 30 being the mean. The sample included 5 dental hygienists and 8 dentists (including 4 who also performed sedation dentistry). There were 6 female participants and 7 male participants. Two of the participants were from the Southwest region of Virginia, as defined by the Department of Behavioral Health and Developmental Services (DBHDS) Health Planning Region Map.<sup>5,7</sup> There was representation from both rural and urban settings based on the DBHDS Health Planning Region Map and the definition of a rural setting by Isserman et al. (2005) stating that "rural population density of less than 500 per square mile and 90% of the population is in a rural area or the county has no urban area with population of 10,000 or more" and the Zeng et al.'s (2015) analysis of the Commonwealth of Virginia where of 806 ZIP-code areas 190 are urban, and 616 are rural.<sup>23,24</sup>

### **Thematic Analysis**

The person centered care model highlights the importance of dental health in the patient's overall health and stresses that providers should understand the individual as a whole person including their health and behavioral concerns. One of the goals of this study was to understand how practicing dental providers perceived and performed person centered dentistry, and how they defined its role in dental care for developmentally disabled patients.

With the developmentally disabled population it is important to treat the patient holistically, because medical and behavioral histories influence the outcome of the appointment. The person centered approach has the ability to improve the quality of health and dental care as well as overall health outcomes.

I have organized my results around my 3 main areas of inquiry:

(1) Perceptions of dental care providers regarding best practices for inclusive practice:

Techniques and provider characteristics;

(2) Barriers to inclusive practice

(3) Facilitators to inclusive practice

I found 2 main themes within area 1, these were Defining patient centered care and Characteristics of dental providers. There were also 5 sub-themes in area 1 (see Table 1). There were 2 themes within area 2; Barriers for practice preparation and Barriers to community access to care, with 5 sub themes (see Table 1).

Area 3 included 3 themes, Establishing patient trust, Practice and Accessibility Modifications, and Collaborative care- referring to specialists or recognizing other medical needs, and 4 sub-themes (see Table 1). In the sections below I discuss the study findings and provide illustrative quotations for each theme and subtheme.

<p><b>Table 1. Outline of Results Section *</b></p> <p><b>(1) <u>Perceptions of dental care providers regarding best practices for inclusive practice: Techniques and provider characteristics</u></b></p> <p><b>Defining patient centered care</b></p> <p><b>Characteristics of dental care providers</b></p> <ul style="list-style-type: none"> <li>Empathy and personal affinity to treat persons with DDs</li> <li>Patience and Understanding</li> <li>Flexibility of the dental provider</li> <li>Having personal connections to persons with DDs</li> <li>Having remarkable clinical experiences during or after higher education</li> </ul> <p><b>(2) <u>Barriers to inclusive practice</u></b></p> <p><b>Barriers for practice preparation</b></p> <ul style="list-style-type: none"> <li>Lack of clinical exposure to patients with DDs</li> <li>Lack of sedation training</li> </ul> <p><b>Barriers in community access to care</b></p> <ul style="list-style-type: none"> <li>Lack of dental funding</li> <li>Geographical challenges</li> <li>Lack of health literacy</li> </ul> <p><b>(3) <u>Facilitators to inclusive practice</u></b></p> <p><b>Establishing patient trust</b></p> <p><b>Practice and accessibility modifications</b></p> <ul style="list-style-type: none"> <li>Defining your practice as family care or inclusive practice</li> <li>Creating unique treatment plans</li> <li>Incorporation of sensory activities</li> <li>Alternative methods for care planning</li> </ul> <p><b>Collaborative care- referring to specialists or recognizing other medical needs</b></p> <p><b>Integrating study findings using a grounded theory approach</b></p>
<p>* <b><u>Area of Inquiry, Theme, Subtheme</u></b></p>

## **1. Perceptions of dental care providers regarding best practices for inclusive practice: Techniques and provider characteristics**

As mentioned previously, this study aimed to understand dental care providers' perceptions of inclusive practices and patient centered care. Two main themes emerged under this area of inquiry (area one). These were Defining patient centered care and Characteristics of dental providers (see Table 1).

### **Defining patient centered care**

One of the goals of the study was to determine whether participants were familiar with the patient centered care model. I found that very few of the participants knew the definition of patient centered care “where individuals, in partnership with providers, identify life goals and interventions”.<sup>25</sup> However most of the providers were utilizing techniques in their offices that aligned with the definition of patient or person centered care.<sup>25</sup> When asked “*what is your current understanding of patient centered care*” one of the dental hygienists, who had been in practice over 30 years, stated it was creating and facilitating a care plan based on the individual’s needs.

A dentist who worked in the community dental health program tied in the importance of the health history with the overall dental health.

*“Patient centered dentistry would be creating a care plan and facilitating it for the individual patient based on their needs.”(104)*

One dentist who had some opportunity to work with persons who have DDs in and after school talked about the uniqueness of each patient being part of PCC.

*“Each patient is unique and they have their own background, their own health history, which is extremely important that that all plays into what could be going on orally and dentally.” (103)*

One hygienist who had previous experience in a hospital setting but who (at the time of the interview) worked in public health included the patient's abilities as part of PCC

*“[PCC] is considering the patient's needs and abilities to provide care that is specific to their needs.”(110)*

One provider with a sedation practice in the DC Metro area explained that he had heard about patient centered care before but he was not exactly sure what it meant. Upon answering, the answer was very similar to the participant who stated it was about patient needs.

*“I think it's dentistry that's tailored to the patient's needs. I've seen that before and I have to admit, I didn't feel like I knew exactly what it was.”(109)*

A hygienist who had been working in the community with persons who have DDs for over 30 years stated it should not be restricted to time.

*“[person centered care is] focused on patient care as a complete priority and not restricted to time”(106)*

Overall, despite differences in the degree to which providers had even heard the term Patient Centered Care, most provided a definition that closely aligned to how it is defined in the literature.

### **Characteristics of dental care providers**

Four subthemes emerged with regard to provider characteristics when I asked about providing patient centered care for persons with DDs: empathy and personal affinity to treat persons with a DD, flexibility of the dental provider, having personal connections to the developmentally disabled population, and having remarkable clinical experiences during or after higher education, patience.

## **Empathy and personal affinity to treat persons with DDs**

Dental hygienists who treated persons with DDs on a regular basis discussed their motivations as empathy and general desire to treat this under-served population. Most of the participants said they felt they had a passion or calling to this type of dentistry. Some mentioned that they had worked with other dental providers in the past that were not willing to provide care to the DD population at all, and the individuals would ultimately be referred out to other offices as part of their motivation for going into this type of practice.

Two of the participants also mentioned that most of their practice was reserved for persons with developmental disabilities:

*“I realized, that it was the most rewarding thing I’ve ever done in dentistry, to be honest with you. And I said, this is what I want to do.”(109)*

*“I’ve always had a compassion for individuals that needed help that couldn’t get it elsewhere.”(101)*

One hygienist who worked exclusively in community care discussed having a passion for this type of dentistry.

*“...passion is one thing that I think is very important. You got to kind of think, and what if this was would my child, you know, how would I want this child to be seen-- what kind of treatment, things like that.”(101)*

One of the dentists with over 30 years of experience talked about treating patients like family members.

*“ It’s a state of mind and personal attitude to looking on those individuals as a regular patient, just like your own family member, and then thinking about treating them in a way which will be the best possible in your scenario and circumstance that you can do for those patients. Once you have that kind of attitude, the things fall in order, and you can start putting things accordingly so they can be treated better.”(106)*

Finally, many of the study participants noted personal satisfaction as a result of the appreciation and happiness of the patient and family. Being able to help an underserved population was very rewarding to the professionals. Two of the providers worked with one of the state programs talked about how rewarding dentistry for persons with DDs can be.

*“ It’s just really rewarding to have somebody so thankful for what you do for them.” “ their [people with DDs] outlook on life is so uplifting. Some of these individuals, they’re just so positive and happy, it’s rewarding [for me] to see that.”(101)*

*“ they [persons with DDs] are some of the most grateful people in the entire world. I mean, so it’s, of course we like to think we’re doing dentistry and doing the right thing, but it certainly helps when somebody is appreciative. And sometimes the patient, but most often the family is just over the moon to have compassionate care. So it’s highly rewarding [for me] in that way.”(113)*

One hygienist who worked in a community based program talked about including the patient in celebrations of their care and the importance of continuity, and how working with patients in this way have made it so she has experienced important communication milestones with at least one individual

*“I think celebrating who they are [is an important part of making the patient comfortable]. I mean every person is different but sometimes it’s just the little things. At the group home I had been there probably ten years. And worked with a guy that I had been told could speak but I had never heard utter a word. And one day we were brushing his teeth and he looked at me and said teeth. And I was so excited I went running. I think I went running down the hallway. And yelled, so and so just said teeth. And all of the staff started laughing to me. But it was the first time he had acknowledged to me that he knew who I was. He knew who I was, what I did. And I heard him verbalize it. And that was just -- it was great.(104)*

Overall, the study participants agreed that in order to provide ongoing care to individuals with DDs, you need to possess empathy and a strong affinity to treat this underserved population.

## **Patience and understanding**

Several of the providers in the sample spoke directly about the need for patience when treating persons who have a DD. A couple of providers had approximately 7 years of experience treating persons with a DD in a public health setting, while a few others had over 30 years of experience each treating persons with a DD in a community setting. It is important to note this because despite the difference in time working with individuals with DD, the need for patience was something that was recognized by all of these providers.

*“ I think it's a mindset and that open attitude, patience, and being able to think outside of the box and not just be stuck in the paradigm of: Patient get in dental chair, be able to lean back, be able to open and stay open. Because that's not reality when working with patients with disabilities. (103)*

*“Patience and just a different way of looking at things. Just because it doesn't work, the way that you want it to work doesn't mean that it can't work kind of thing. Adaptability, so just adapting in the situation.”(108)*

One dentist who had over 30 years of clinical experience and who conducted sedation and non-sedation appointments talked about being flexible as a provider.

*“ It's different dentistry, you need a lot of patience to work with that, and you cannot sit on the doctor's stool and chair and sit down and work, it's not like that. You have to stand and you have to adjust yourself to find an appropriate position.”(106)*

One hygienist who had been working with persons who have disabilities since dental hygiene school talked about the importance of having patience and understanding.

*“ Patience is first and foremost. An understanding of the particular individual with disability's needs. Being flexible. Let's see what else. Being knowledgeable about the person's particular needs. And certainly, having a good knowledge base of dental care and dentistry in order to provide what that particular person needs.(104)*

*“it requires a ton of patience, is I guess the biggest thing, because it's not just you and your dentistry, it's a dance with your patient.”(113)*

The ability to exert patience and understanding was one of the most common qualities the providers felt was necessary when treating patients with DDs.

### **Flexibility of the dental provider**

The participants also discussed the importance of flexibility with the dental provider and the ability to change based on the level of cooperation and tolerance of the patient as an important provider characteristic. Recognizing that even the same patient could present differently at each appointment was also discussed. For instance, the concept of desensitizing appointments was discussed by one dentist who practiced in the Southwest portion of the state where access to mobile dentistry, telehealth providers, sedation services and other medical specialists were not as readily available.

*“I recommended to parents and caregivers, especially with patients with autism, to do the desensitization of: drive to the office. A couple days later, drive to the office and into the parking lot, and drive to the office and walk to the door. And then a couple days later, drive to the office and just come in the waiting room and sit and like build up. Because a lot of that is just the anxiety of coming in and all of a sudden, now you're in. Now you got to go back to this room that you've never seen, then you're going to meet people that you've never seen. But if you break it up and so then when they come, it's, "Oh, I've been here before. So it's not as scary." ... “I think you learn as you go with each individual patient, but you learn that, alright, we're beginning to lose them. [as in the patient's cooperation level is diminishing] I'd rather be able to see everything and if we have to go back and get a couple other radiographs next time, then okay. We'll get a couple other radiographs next time. Or if we need to split this cleaning into two appointments, then we'll split this cleaning into two appointments. I think it's better if they have a more positive de-sensitization kind of deal then leave here frustrated and crying or screaming or something because that's not good for any party involved... Once they've made up their mind, they're done. And we feel strongly that there's no reason to force on a non-sedation patient any treatment, if they're done, they're done we pick up where we left off.”(103)*

One dentist who saw patients with and without sedation noted the importance of finding out more about the patient to determine how best to approach treatment planning.

*“We've had a few where they come in for screening and they want to go ahead and get something done and we use that as like a little litmus test to see kind of where we are on the spectrum, but no, I don't ever have like this must be done at the appointment, there is times that you have to split it up” (113)*

The ability for the dental provider to be able to step out of their comfort zone emerged as an important part of being able to conduct care. Being able to recognize that their patients needed a little bit of extra consideration could make the difference between successful and unsuccessful appointments.

### **Having personal connections to the developmentally disabled population**

In addition to provider characteristics for dental care provision with DD populations, I aimed to understand what motivated providers to go into this field. When I asked what made practitioners begin the care and treatment of patients with developmental disabilities, a great majority noted a personal relationship with a friend or family member who had been diagnosed with developmental disabilities which either drew them to the specialty or encouraged them to specialize in it later on in their career. The remaining few had not necessarily anticipated the specialty, however once they landed upon it they saw a need and enjoyed the “helping” part of the practice.

One hygienist who had over 30 years of clinical experience and who also had significant training while in dental hygiene school said her desire to work with persons who had DDs began early in childhood.

*“Growing up, our next door neighbor had a child with Down syndrome. So, I had been, exposed [isn't a good word, but] from a child. And just always had an affinity for working with that particular population. So, it was something I enjoyed when I was in hygiene school.” (104)*

*“I think my first exposure that I remembered with a person with special needs was growing up. Our neighbor, their son had pretty severe autism. And just as a kid, seeing how they worked with him, being able to interact. I think that played a part.”(103)*

### **Having remarkable clinical experiences during or after higher education**

In addition to having personal relationships with a person who had developmental disabilities, many of the participants noted having a personal experience once they finished their professional school which resulted in them specializing in dentistry for the DD population in their community practices.

*“I think just all those exposures over time instilled in me that there's something bigger in life than this. And that I could make this a part of what I want to do. And I just had an interest and passion for being able to help this area of dentistry.”(103)*

*“I graduated from dental school, I started working with a group, dental group practice. And I always wanted to kind of help the population of disabled patients because it seemed like everybody was kind of pushing them out of their offices and didn't want them there.”(109)*

The majority of the participants who I interviewed had a personal connection to at least one person with a DD. The few that did not had some type of experience whether in school or shortly after entering community practice that led them to the specialty. Many of them felt like it was important to have those connections in order to be able to develop empathetic practice.

### **(2) Barriers to inclusive practice**

A second goal of this study was to identify barriers to inclusive dental healthcare provision in community settings. That is, what were the things that prohibited persons with DDs from obtaining comprehensive dental care in the community setting. We identified 2 themes; Barriers for practice preparation and Barriers to community access to care, with 5 sub themes (see Table

1)

## **Barriers for practice preparation**

An emergent theme in our data was the dearth of training for dental care professionals in working with the DD population. In our sample, only a couple of the interviewees had any formal training in school that included clinical competency graduation requirements on the treatment of patients with developmental disabilities.

*“ in my dental hygiene program we went through a community services program. And then after that I worked at a state run facility in Connecticut where I learned hands-on. And went on to get my master's degree and minored in community health.”(104)*

A dentist who worked in multiple public health settings had optional externship opportunities to choose from while in college.

*“The last year, they were different externships you could go to. For every other week, for two days, you could choose, and it was one externship. We didn't get rotated around. You had to do this externship. And I picked the developmental aspects... “It was a true developmental center where they actually brought the patients from group homes to that center because they had a problem with shortage of dentists who were willing to treat the patients. So they brought them there, and we had a full-time faculty who was specialized in developmental patients.”(102)*

The remaining participants had little to no formal school training, or the training that was offered at their particular school was not mandatory for all students and the curriculum could be chosen as an elective. However, despite these differences in pre-clinical education, and as mentioned previously, all of the participants were utilizing similar practice techniques (as defined as person centered) when treating individuals with developmental disabilities.

One hygienist who worked in public health but who did not see very many patients with DDs every month stated that her exposure in school was a program at The Virginia Home which was a source of exposure for dental hygiene students attending Virginia Commonwealth University at that time.

One of the school's clinical instructors worked at the Virginia Home and arranged for it to be part of a rotation schedule in which the students could see patients with disabilities. It was a short rotation and it was not known whether the program continued, or if that particular instructor was still an employee.

*"The only experience I had with any one prior to being in practice was through the Virginia home at VCU, we went to the Virginia home and that was my first experience with individuals with disabilities."(108)*

In a similar situation, one dentist who had previously noted having education in her dental program, went on to elaborate that the program was available at the time due to the efforts of a particular instructor who was now deceased and it was not known if the same opportunities were available for future students.

*"So we worked with the Special Olympics Mom Project every year, which I think was great experience. And I don't know if you're familiar with Dr. Jim Schroeder. He was in Richmond. He just recently passed away, but he worked at the school. He was in private practice for a while, but then he went to the school, but he was huge on special needs. So if you kind of made it known that that was an interest to you, he would help facilitate that."(103)*

One dentist who now has a child with a DD, could not really recall the specifications of their training but noted it was not exclusive to persons with DDs.

*"...during dental school, we did a rotation [for special needs] through. I don't even know what the [specifics were] just it was like a section of the school where we had to do a rotation through and treat people with different disabilities, whether it was developmental or physical. We didn't spend a lot of time there."(105)*

One dentist whose practiced was dedicated to persons with DDs did not have any hands on training in school and stated the lecture material was very limited.

*"Maybe we had 45 minutes seminar throughout the four years of dental school that discuss special needs dentistry."(109)*

The participants who did not have a substantial amount of training in school suggested that dentistry for patients with developmental disabilities may have been easier in the community setting had they learned by vetted techniques versus by trial and error.

One dental hygienist mentioned that some employer restrictions acted as a barrier- as the providers were required to not only adhere to time constraints but also to a certain amount of procedures or billable items. In other words, the participant had been forced in the past to complete a certain amount of things at each visit and faced reprimand if they were unable to do so.

*I think [the largest barrier] really was just the management, like how the care that they needed and the time that they needed for care wasn't prioritized in the schedule. I think that was my biggest thing is that I felt like they [patients with DDs] deserved more time for treatment than what they got.(110)*

One dental hygienist with 20 years of experience noted that although they were able to learn through observation techniques, a formal training in school would have been more efficient.

*“ We did shadowing and learning that way. But I think knowing what I know today, I think that it's better to have some formal education and at least a set training” (110)*

One hygienist who worked in a Federally Qualified Free Clinic (FQFC) and who oversaw volunteer dental staff, described her training methods as mostly observation techniques.

*“ here in our setting, it's probably going to be from watching... someone who has had experience with treating individuals with disabilities, and just kind of going with their comfort level on it, as far as how they progress in the future with it.(108)*

Overall, there was a clear lack of exposure to formal training among most of the providers in the sample and an identified need for it in dental schools. It also appeared that a few of the schools that offered the opportunity to treat patients with DDs did so through the concerted efforts of staff members who were there at the time the participants attended. This means it is not known whether or not the programs are still in existence.

## **Lack of clinical exposure to patients with DDs**

Another sub-theme for barriers to inclusive practice was a lack of clinical exposure [to persons with DDs]. One of the dentists who has worked in 4 different programs for persons with developmental disabilities suggested that earlier exposure to the DD population could encourage more providers to complete the dental care in community practice.

*“I don't think there's enough exposure to the dental as clinician dentists. I mean, practitioners, hygienists. I don't think the exposure is enough there in dental schools or in private practice. I feel if there was more exposure, we actually would have more dentists and more hygienists actually willing to do it.”(102)*

One hygienist who saw approximately 10 patients with a DD per month expressed a related concern that she was unsure how to approach dental care for some individuals with communication and behavior challenges. Due to this uncertainty, the facility at which she was employed had a policy to refer patients with challenges that impeded treatment to another office or sedation practice if initial attempts to treat were unsuccessful.

*“ Really, when they're [the patients] nonverbal, and they just don't want to open their mouth; like you don't really know where to go because you don't want to make things worse, you don't want to cause trauma, but you really don't know where to start because they don't trust you. They don't know you.(108)*

The lack of clinical exposure to individuals with DDs seemed to cause an uncertainty in how to treat them in the community clinical setting.

## **Lack of Sedation Capabilities or Training**

The need for sedation was also mentioned as a barrier to practice preparation. Not all dentists can perform sedation whether it be minimal sedation techniques (i.e., add here) or IV sedation (i.e., add here).

These procedures require special training and equipment as per the Virginia Board of Dentistry, and at the time of the study the regulations in Virginia made it difficult to expand sedation services in every office due to training and permitting requirements.<sup>26</sup> Currently, dentists have to have a special certification to do any sedative procedures and this is costly and time consuming.<sup>26</sup> This can impose limits on the amount of care for more challenging patients and an appropriate referral is not always available.

One dentist who worked in public health and who is trying to expand participation with different programs for persons with DD described a need for sedation technique in community care when asked about barriers to care.

*“ Sedation, I think. I personally [is a barrier to inclusive care], I'm not certified to do sedation, but I feel like a lot of these patients could benefit from any form of sedation because they're very apprehensive.”(102)*

One dentist who did use sedation techniques in his office recalled that when it was not an option for care, appointments took longer and that the time constraints had effects on the quality of care.

*“I've worked in different environments that there is just no time to do that kind of stuff. If you got three columns of hygiene and two in treatment and you're running around all day, you really can't give the attention to somebody that has different needs.”(113)*

Many of the dentists and hygienists talked about scenarios where it may have been helpful to have sedation options but also mentioned the difficulty in being able to implement it in their practices.

### **Barriers in community access to care**

Three barriers emerged with regard to access to community care (i.e., dental care in community settings like private or public practices as opposed to within institutions for DD patients). These were lack of dental funding, geographical challenges, and lack of health literacy.

## **Lack of Dental Funding**

Lack of funding and inaccessibility of a provider within a reasonable distance were two of the barriers that were mentioned especially with regard to parts of the state that were not as densely populated. The most common ways for persons with a DD to find a provider in Virginia was through their insurance company customer care, through word of mouth, and through programs such as the Department of Behavioral Health and Developmental Services (DBHDS) that offer community based referrals and treatment.<sup>5,7</sup> Also, just because a dental provider is on a list of participating dentists, does not mean they are accepting new patients or that they can see patients who have a DD.

I found that most of the participants in this study did not accept Medicaid and the other forms of insurance programs that a high percentage of DD individuals in Virginia rely on for access to care. However, most of the participants stated that they provided sliding scale fees schedules, and several participated with the community DBHDS community program, in an effort to accommodate as many persons who have a DD as possible.<sup>5,7</sup>

Two dental hygienists, one with over 30 years of experience in community dental care, and the second working exclusively in a public health setting brought up funding as a barrier to care.

*“...access to quality and appropriate care is a barrier, that is the number one issue [to accessing care] I think. Access to quality, appropriate affordable care for people with special needs.”(104)*

*“... the lack of dental funding comes up a lot when discussing treatment plans, it is a common barrier to care”(101)*

## **Geographical challenges**

In Virginia there are many barriers for DD patients that extend beyond the lack of finances. In the Eastern part of the state there are bridges and tunnels that can impede the ability to travel in a timely fashion due to consistent traffic congestion, bottlenecks and construction on primary and secondary roads. There is no way to get to the Hampton Roads area without crossing a major waterway, and this makes it difficult especially for people travelling to appointments in and around that area, for instance. In the Western part of the state there are geographical challenges such as mountain roads and roads that are inaccessible in the winter months due to snow and ice.

One hygienist who worked in a mobile clinical setting talked about location and transportation deficits.

*“location can be a hassle, we see people in the farthest corners of the state. And it might not be just a lack of a dentist, but a lack of, you know transportation to that dentist.(101)*

The same provider (who worked in a state run program which contracts community dentists to refer patients who need a dental home) also mentioned that it is difficult to find other resources for some of the patients depending on their location.

*“finding some contracting dentists in different areas to fit the patient’s needs, it has been a challenge. We are growing” (101)*

## **Lack of Health Literacy**

A lack of health literacy among the DD population and their caregivers also emerged as a barrier to community based dental care. In the quotation below the provider describes a scenario where the patient’s caregiver or guardian did not understand the potential ramifications of the patient losing a front tooth.

*“ I think the ones [people with DDs] that live in residential homes where maybe the... I don't know who's responsible but either the caregivers or the director of that home don't really... I don't wanna say they don't care about their oral health but when you tell them, look, they have this front tooth that needs – it has an abscess and they're like, “Take it out.” It's like, you can't just take out a front tooth. I mean, I told one person. I said, how would you like if I have to get your center or front tooth? How would you like that? “Well, I wouldn't like it.” So why do you think it's okay for him? Because he can't talk?”(109)*

One hygienist who worked in a FQFC discussed how some patients and caregivers may not be open to new techniques for dental care based on previous experiences. They somehow felt everything needed to continue the same as it had been in the past.

*“a lot of times, from the caregiver or parent, they know what has happened [for the patient] in the past. They go off what their previous experience was so you kind of have that barrier against you”(108)*

Overall, it seemed that the patients do not always have caregivers or guardians who understand the importance of overall health and its relationship to dental health.

### **(3) Facilitators to inclusive practice**

Finally, a third aim of this study was to identify facilitators to inclusive practice. We found 3 themes: Establishing patient trust, Practice and accessibility modifications, and Collaborative care- referring to specialists or recognizing other medical needs, with 4 sub-themes. (see Table 1). The participants in this study all expressed a desire to provide a service to a specific under-served population. They noted that even though there are increased efforts to eliminate barriers across the state, there are still a lack of dentists and hygienists who treat these individuals. When discussing how the providers could reduce these barriers in the field of dental care for the DD population there was a mention of the importance of the provider having a willingness to treat the patient the same as any other individual.

Each time they met with someone new whether they were developmentally disabled or not, these participants tried to work with each person to make it the best and most comprehensive visit that they could. The following sub-themes for this area of inquiry are described below:

### **Establishing patient trust**

When I asked about the most important attributes of the dental appointment most included establishing trust. Participants also mentioned that including the patient in the care plan regardless of their communication abilities plays an important role in the success of the appointment. Developing rapport and eliminating surprises in the appointments can increase the chances of completing steps in the dental appointment. Participants also noted that one of the sedation dentists that patients who have developmental disabilities value consistency from appointment to appointment.

*“the other thing I found is, there is a lot of times folks with these developmental disabilities can be very different visit to visit.”(113)*

One hygienist who had over 35 years of experience expressed the importance of getting to know the patient in order to achieve success.

*“: this is very personal for me. More time in the first appointment getting to know them and their caregiver, whether it's a parent or a caregiver. Find out where they're comfortable, where they're not comfortable.(107)*

Two of the dentists who treated persons with DD as part of the Commonwealth of Virginia community programs talked about making the patient feel included by speaking to them and creating a friendly environment.

*“ The facility has to be a little bit catered to their needs so when they come in the office, they don't feel like they are getting into the hospital or somewhere they will be given shot or some restraint, and some of them, they already have some experience of being restrained.”(106)*

*“I think it's very important that you speak to the patient, because they're ‘the patient’ if the patient is non-verbal or you want to know how long have they been experiencing pain and the patient can't tell you that; then sure, you have to ask caregiver. But I think that you've got to*

*direct the patient and speak to them. They're not just a warm body in the chair. So I think that's real important and that's going to help them know that you care. "(103)*

The majority of the participants talked about having ideals and goals for the appointments however they maintained flexibility and if the appointment could not be completed as planned they were willing to continue the next time and build on small successes. The small milestones are important to both the provider and the patient, as mentioned by one of the dentists working in a small practice in a rural southwest Virginia town.

*" Usually, if we don't get everything we planned that day done, I'll at least find something to say "We got this done. That's good." So they're not leaving thinking that they should be disappointed."(103)*

One dentist who had a son with Downs Syndrome reflected on experiences with him when discussing appointment successes.

*" I mean, for some patients, if they get in the chair, it's a success. That's how I feel about my son right now. If I can put a toothbrush close to his face, we're getting there if we build on each step of the way." (son has developmental disabilities)(105)*

One hygienist and a dentist with 20 years of experience who both worked in community programs with persons who have DD talked about small milestones equaling big successes.

*" I think it's a home run when a patient comes on the unit and allows me to take a look in their mouth, just, you know experience that, because it takes a lot of trust for an individual to lay you back, open your mouth and then put their fingers in your mouth looking around, moving your tongue, putting instruments in your mouth. Those are huge successes, even if all we did was count their teeth"(101)*

One of the dentists who participated with a community health program for persons with DDs noted that it is good to be flexible even with how you achieve set goals with the patient.

*" any time I can do something in their mouth, it's a success. Yeah, there is not a set goal. Well, there is a set goal, but if we don't get to finish the whole goal, that's still a success."(102)*

One hygienist with over 30 years of experience and who worked in a non-sedation setting was content even with accomplishing small tasks at each visit.

*“ if I have a patient with special needs in the chair and they are comfortable and all I get to do is look in their mouth and they come in happy and they leave happy, that's a successful appointment” (107)*

Overall, most of the participants discussed establishing patient trust as the main facilitator in being able to perform dental care on patients with DDs. Building the rapport helps the individual learn what to expect at each visit.

### **Practice and accessibility modifications**

There are ways that the provider can adjust their practice setting and/or techniques to better accommodate persons with DD. Most of the participants did not bring up ADA compliance or accessibility challenges, but all of them talked about the need to be willing to change the way that they performed dentistry with every patient that they saw.

*“I like that it's different, that it makes you look at things differently, so that is not the same routine. It's a little change, and you get to experience things that are just different. You change your ergonomics, and you have to adjust how you practice, so it's, keeps you on your toes.” (108)*  
One dentist who had multiple office locations and rotating staff members talked about making changes in set schedules to accommodate the patient.

*“ So we don't let patients to not be seen if they need to be seen, we get them even if we have to do some extra effort, maybe coming earlier or taking care of them during lunch break. Yeah, but generally speaking, they don't have any difficulty getting the appointment.” (106)*

There were 4 sub-themes under the theme Practice and accessibility modifications. They were Defining your practice as family care or inclusive practice, Creating unique treatment plans, Incorporation of sensory activities, and Alternative methods for care planning.

### **Defining your practice as family care or inclusive practice**

Several of the providers indicated that the integration of persons with DD into their practices was as simple as providing family dentistry and including all members of the family. Being able to treat all the members of a family may also be effective in reducing some anxiety.

For instance, if the parents and siblings of a person with DD are comfortable with a dental practice they can use positive reinforcement to make it a more relaxing and fun experience for everyone in the family.

*-“: I don't see there to be any barriers for my willingness to treat them, it's just part of my normal patient population. I just feel like if I'm seeing the mom, dad, and sibling, why would I not see the brother?”(105)*

One of the dentists who participated with the state dental program mentioned that his office sees all types of patient regardless of need or behavior challenges.

*“: In my current practice, we see all kind of patients in the same facility, regardless if they are noisy or they have behavioral problem, or they're on the wheelchair”(106)*

When talking about dental referrals one hygienist talked about providing ongoing care in a mobile setting.

*“Once we figure out where they need to go [patients who have DDs], that will be their dental home. In some instances that individual doesn't have a dental home because of their locale, we might not have a contracting dentist in that location. So we will continue to see them with a mobile unit to provide that gap service.(101)*

### **Creating unique treatment plans**

In the dental field, if a patient comes in for an appointment, most of them are articulating how they want the appointment to go without the provider realizing it (e.g. wear sunglasses to shield the light). With persons who have DD, they may be less likely to state these preferences, so the provider needs to be mindful of how the dentistry is approached. Instead of citing patient-centered care, or having a set model for care, a large portion of the participants described their methods of treatment planning as largely based on what the patient could tolerate and what seemed to be the most comfortable for them.

One dentist who had been working with persons who have DDs also included that as the dental professional you should try to make personal connections with the patient to learn more about them.

*“Well, I think there is a couple of parts, one would be that not, there is no two people that are the same, so you have to customize the approach to the person. And that could be anywhere from like behavior management, essentially just trying to connect with them personally and not just view them as a mouth” (113)*

One provider who worked in a FQFC discussed taking things that were taught in school and adapting them to patients with DDs.

*“...that you are trying to treat the person and not trying to make them fit into what is expected. As far as what you're taught in school. What exactly is supposed to happen at every appointment for every patient, but rather adapting these visits to the patient, and what they can tolerate.(108)*

### **Incorporation of sensory activities**

Introducing sensory activities and games to make the patient feel more at home in the dental office (e.g., weighted blankets, customized music and television programs) also came up as a subtheme. In addition, some of these items were relatively simple to incorporate into any office or space regardless of size.

A couple of the participants described the sensory waiting room that their dental office created. It offered a separate place for persons with or without DDs to relax before and after treatment.

*“There are sensory stuffed animals back there. There are different pictures on the walls and the room has been painted for soothing for when they come in, it's already soothing. It's not stark and startling.(107)*

*“We do turn on music, or certain patient we give them from the phone or tablet, we let them watch their own program.”(106)*

One dentist who had a sedation practice talked about ways patients relaxed themselves prior to appointments.

*“ We have a gentleman that brings something like a dozen shoelaces and that’s what relaxes him”(109)*

Another dentist explained that he did incorporate some appropriate activities in his waiting room but later explained that he does not typically have his patients with DDs wait in the waiting room for any length of time.

*“[In the waiting room] There's books. There's puzzles there, which they're not geared for kids specifically. They're geared more for adult patients with disabilities. (102)*

One hygienist who worked in a mobile dental setting talked about one individual and how they would try to find things for him ahead of time so during the appointment he was more comfortable.

*“If they have something they like to hold on to, they're more than welcome. We've had individuals that loved pamphlets and magazines. I remember one individual would love to look at little pictures of babies. So we would take all the magazines we could find and pull out pages of little babies and that particular individual sat in the chair and held a little add like a Gerber baby with food and would allow me, it just soothe, and it made him comfortable.”(101)*

*“ My team is all salt of the earth, and they all love to work with all different types of people, but we all have kind of soft spot for people with developmental disabilities.”(113)*

### **Alternative methods for care planning**

Sometimes, alternative methods are necessary when treating persons with DD. It is important for the provider to recognize when the patient is unable to complete the appointment or if sedation techniques are going to be necessary to provide comprehensive care. All of the participants recommended sedation techniques for difficult situations after multiple failed attempts at non-sedation appointments. Sedation techniques can help with the reduction of anxiety and can also be effective for behavior management.<sup>27</sup> The dentists who were using sedation in their offices talked about tailoring it to each individual in an effort to only use the minimum amount of sedation needed to complete care.

None of the participants advocated the use of physical restraints of any kind to conduct treatment. Three of the hygienists who were interviewed talked about the potential use of sedation as a facilitator to dental care provision if all other methods had been exhausted.

*“ if the individual is not cooperative, if they're combative, or they're just really nervous, really scared, and they really need some treatment, we would refer the individual to a contracting dentist that provides sedation.”(101)*

*“, if it was something that we had to just slow down and it was going to take longer, then I would do the extra appointment. If it's only if we didn't see a way that we were going to be able to treat the patient, we would schedule a sedation appointment.”(110)*

*“ After a couple of visits if it doesn't look like we're going to accomplish anything, then we would look at maybe referring for some sedation” “: If they're not cooperative, after trying X-rays, trying to clean, polish, toothbrush proceed, exam. Then we would just chair the appointment for the day”(104)*

Most of the providers were implementing small things into their practices in order to make the patients feel at home whether they had DDs or not. It was about making each person feel as if you had taken the time to learn a little about them in order to increase their level of comfort.

### **Collaborative care- referring to specialists or recognizing other medical needs**

A good number of the participants were not familiar with collaborative care or inter-professional care. That is, working with other medical and dental providers to create comprehensive care plans for the patient, or recognizing that the dental patient has other health care concerns that are not being met and facilitating the proper referrals. Dental providers collect detailed medical histories, and sometimes lab, test and cardiology results, yet it seems there is a lack of communication with those medical providers outside of the field of sedation dentistry. As a part of the patients care team the dentist should also be able to recognize where there may be underlying health conditions, behavioral needs or even durable medical equipment needs. Although many of the providers discussed collaborating with other dental professionals only one discussed a collaboration with medical or inter-professional teams. This suggests that there is

more work to be done in the field and training of collaborative practice whether initiated from the medical or dental side.

One hygienist talked about an appointment that they worked on where not only was the patient seen in their own home, but it was a collaborative case with medical professionals and dental professionals in order to complete a number of procedures at one time.

*“a patient we had not too terribly long ago, needed a transfusion, he needed to be put to sleep for his cleaning. That took a lot of coordination between anesthesiologists, dentist and a nurse that would give the transfusion for the medication this individual needed. So that's not just two doctors, that's quite a few of practitioners put together all in one place in the individual's home.(101)*

### **Integrating Study Findings Using a Grounded Theory Approach**

I used the following figures to illustrate my data and show a how the providers described the typical dental appointment and the characteristics and qualities necessary to ensure that comprehensive dentistry is achieved. Figure 1 outlines the qualities that the participants felt were the most important as well as the types of life experiences and training that encouraged them to begin the care and treatment of persons with DD and continue that care long term. Figure 2 frames the dental appointment and ongoing care in chronological order as if you were walking through a typical visit and lists the important characteristics identified by the participants at each step.

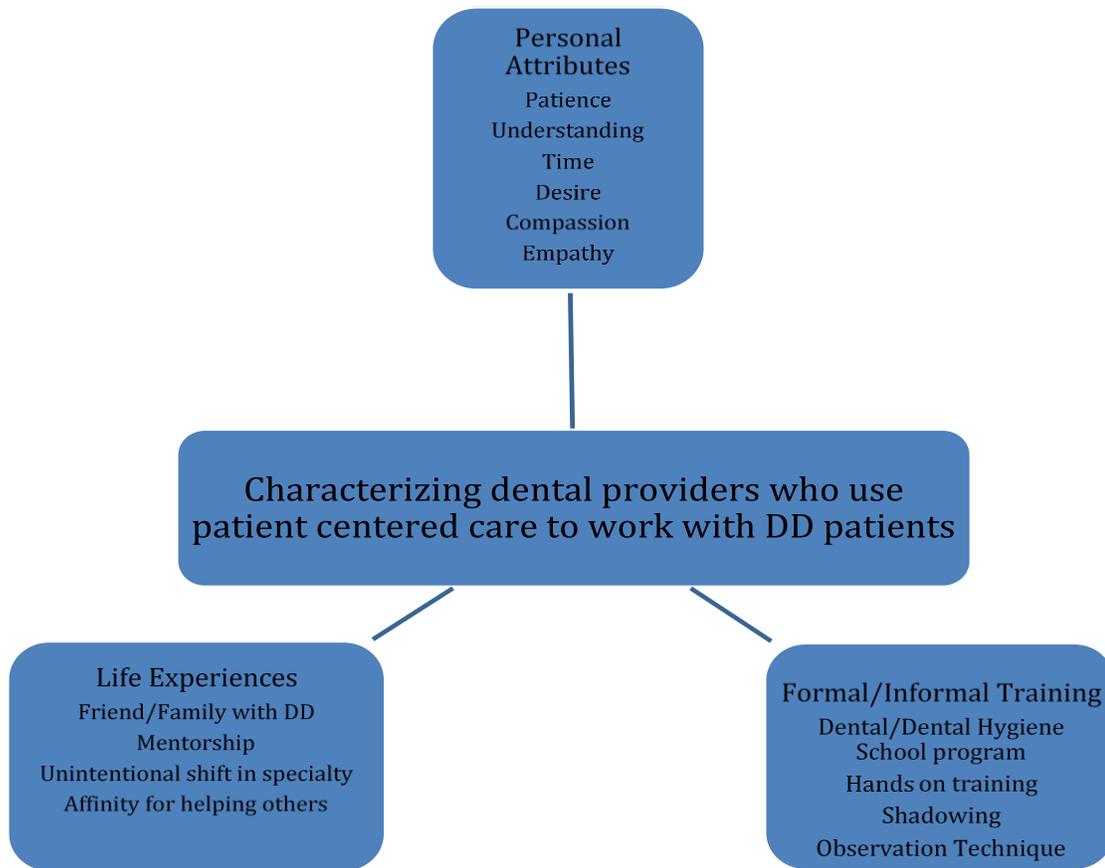


Figure 1: Characteristics of Dental Care Providers who care for Developmentally Disabled Individuals

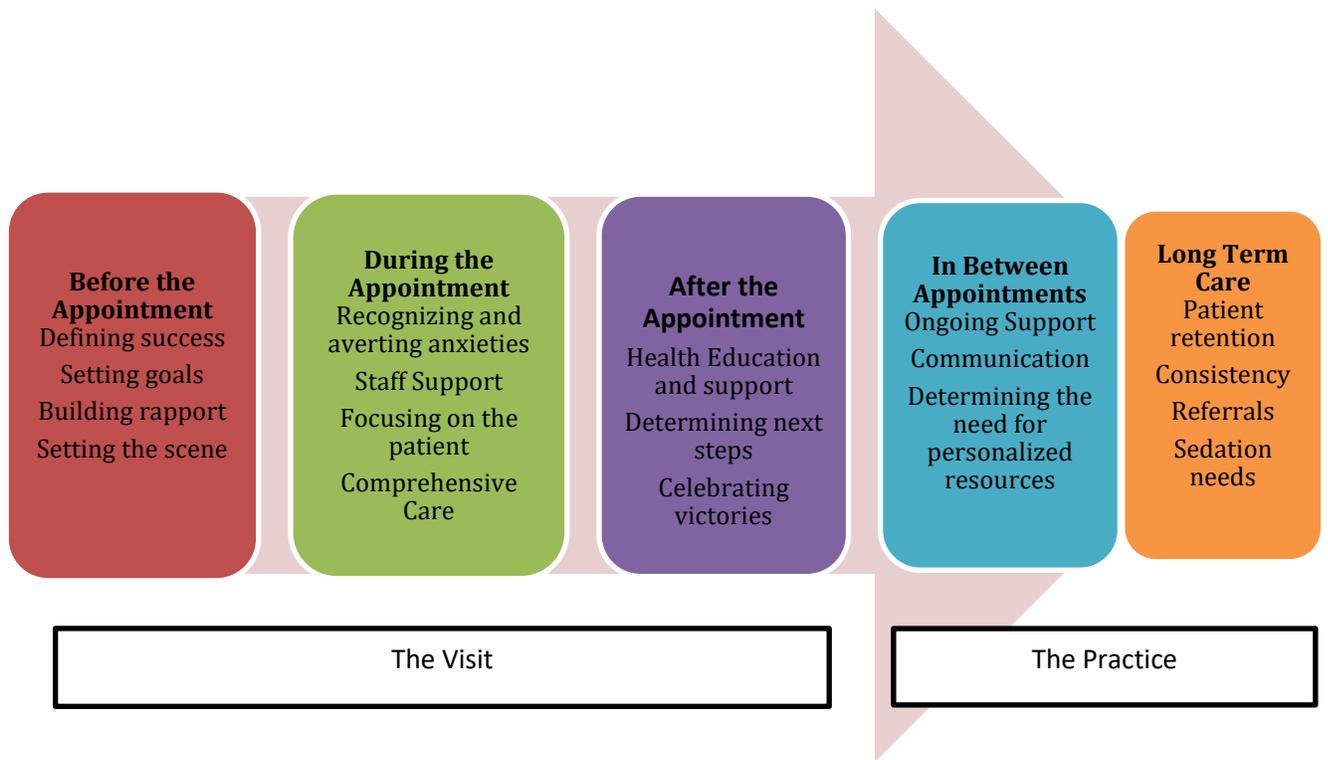


Figure 2: Steps of the appointment process and ongoing care

## **DISCUSSION**

The goal of this thesis study was to, through content analysis and a grounded theory approach, examine the current perceptions of practicing dental providers on the patient centered care model and the qualities or skills necessary to implement it in community practice as well as to determine how providers treating patients with DDs conduct comprehensive dental care. Through this analysis we aim to take the first steps toward establishing a set of core competencies for a patient centered dental care provision among patients with DDs. Overall, we found that a great number of providers had no formal knowledge of PCC and that the majority of the clinicians interviewed had no formal training on the dental care of persons with DDs. We also found that in addition to having a desire to treat and an empathetic approach to care there was some clinical training that was sometimes needed in order to achieve optimal care (i.e. sedation methods). The sections below provide an overview of the findings in light of the current literature.

### **Provider willingness to treat**

Through this study we collected and analyzed the perceptions of dental care providers who worked with DD populations regarding best practices for inclusive practice, as well as their identified barriers and facilitators to inclusive practice. Understanding the techniques and perspectives of the dental providers who have been successfully performing comprehensive dental care for persons with DDs in their community offices is an important step in developing guidance for those competencies.

Like other healthcare fields, there is a deficit of professionals who are willing to treat persons with DD in their offices, and as discussed in some nursing research, providers have a higher likelihood at becoming an advocate for those with developmental disabilities if they have a vested interest or personal connection.<sup>28</sup> One nursing study conducted as part of a doctoral dissertation at The University of Alabama, also talked about the concept “empathic awareness”, or being aware that a group of individuals needs advocacy and mentorship because of their close connection with them.<sup>28</sup> They found that the majority of nurses working with patients who had DDs or special circumstances, had some type of personal connection with that population and had a true desire to advocate on their behalf. Similar to my study, most of the study participants had a friend or close family member with a DD. In addition, those who did not have a friend or family member with a DD, but who were also advocating for inclusive practice, discovered along their career path that there was a deficit in the care and treatment of persons with DDs, and chose to make it their respective specialty. More training on empathetic care and patient centered practice earlier in the professional’s career such as, in dental school could increase the amount of providers willing to enter this branch of specialty care.

### **Improving the knowledge of the patient centered care model**

Person centered care has been an emerging field over the last several decades, and it can be defined as “where individuals, in partnership with providers, identify life goals and interventions”.<sup>25</sup> Although most of the participants in this study did not have an innate knowledge of what “person centered care” was, they were already utilizing some of the components of the field in their practice models.

In a study conducted in the UK on dentists' perceptions on communication and patient centered care, the researchers found that even though the dental providers had not been formally trained on how to conduct PCC, they [the dentists] felt that PCC was something they were able to do naturally.<sup>29</sup> More specific instruction and clinical practice on the patient centered care model could be introduced in dental schools and/or through interactive CE courses in order to facilitate common practice in the community setting.

### **Empathy and its relationship to dentistry for patients with DDs**

Many participants discussed their motivations as empathy and an affinity to treat people with DD in their community practices as they would any other patient. Many of them also used this opportunity to discuss personal relationships with individuals in their past and present lives which drove them to pursue this particular specialty. A few of the study participants also referred to this as having a passion for helping professions or a certain state of mind that they enter in which to complete comprehensive care. In a study by Michael, Dror, and Miller (2019) the researchers found a positive association between empathy attitudes and PCC attitudes among medical and dental students.<sup>30</sup> They also determined that the presence of empathy in the provider enhanced the patient's trust and willingness to participate during the appointment, because it allows the patient to see the genuine interest of the provider.<sup>30</sup> This was similar to the my study, where the participants used empathetic attitudes and experiences from their personal connections, and applied it to their patient appointments to provide a more personalized and meaningful visit.

Some of the participants noted how difficult the care of persons with DDs could be, and described instances where they needed to continue their flexibility and willingness to change the way they conduct dentistry with every patient and sometimes even between appointments with one patient. Similarly, a few of the participants went on to elaborate on the importance of “seeing the patient” and their individual needs. These findings are aligned with previous research on community care techniques.<sup>6</sup> For instance Stenman, Wennstrom and Abrahamsson (2010) discuss a direct relationship with the communication skills of the dental hygienist to the reduction of anxiety and overall improved oral health of the patient.<sup>6</sup> As with the PCC model, empathy education and training could be introduced in dental programs and through CE courses where the professional could learn more effective communication methods and empathetic practice modalities in order to help facilitate more successful comprehensive dental care.

### **Improving training for dental providers of patients with DDs**

As discussed earlier, at the time of this research, the definition for special needs put forth by the American Dental Association does not discuss developmental disabilities as its own subset and many colleges and institutions do not have specific clinical requirements on patients with DDs in order for students to complete their training.<sup>10</sup> Existing research also shows that many health care providers who treat persons with DD have a general lack of education and training.<sup>9</sup> As a result, we expected the majority of the participants to have received experience in the dental care of persons who have DD to have occurred outside of the formal setting and as a voluntary specialty. Only a few of the participants had any formal college training on the care and treatment of individuals with DD and the remainder gained their experience in the community or public health setting.

Yet, despite these differences, the providers were all conducting care in relatively the same manner as described around patient centered care and empathetic treatment. Some noted that they taught themselves through trial and error and that it would have been more efficient to learn earlier, and with a formal program, but that they felt confident in how they acquired the skills. In a similar grounded theory study, 22 physicians were interviewed on their current practice for patients with developmental disabilities, and they reported having little to no training in their respective educational programs.<sup>31</sup> Some also described the experience of treating patients with disabilities like “operating without a map” which was very comparable to this study’s participants learning through trial and error methods.<sup>31</sup> The difference in the study, perhaps due to the nature of care, medicine versus dentistry, at least one of the physician study participants felt as if not having specific training for individuals with disabilities had resulted in at least one death.<sup>31</sup> More structured educational programs are needed in order for both medical and dental providers to feel better prepared for comprehensive care of persons with DDs in the community setting.

### **The need for the expansion of sedation dentistry in the Commonwealth of Virginia**

In Virginia, the move from institutionally based medical and dental services to community based services also introduced the need for improved care models.<sup>5,7</sup> In the past, providers had used physical restraints to conduct care on patients who had behavior challenges instead of the aforementioned patient centered care and/or sedation methods.<sup>5,7,16</sup> In this thesis study, providers mentioned sedation techniques as both barriers (lack of training in them) and facilitators (can be used with challenging patient situations, when trained personnel are available to community based care).

At the time of this study, Virginia Board of Dentistry regulations state that dental providers must go through special training and permitting in order to be able to conduct even minimal sedation techniques in their community practices (i.e. nitrous oxide and pre-medications/oral medications).<sup>26</sup> The initial training is anywhere from several weeks to several months depending where the dentist is taking the clinical course (typically offered yearly at a few locations across the country).<sup>32</sup> The admission is based on an availability, and many have to travel out of state, leaving their dental jobs or practices unattended while they are gone. This poses additional challenges for single dentist practices or for dentists who manage the majority of the patient loads within their community office. This training and certification is also costly, so it may not be possible for dentists who are not yet well established in the business aspect of their practice (typically from \$3,000 to \$12,000 not including travel expenses).<sup>32</sup> The permitting process is one through the state and the dentist applies and goes through inspections to ensure compliance with all of the specifications put forth by the oversight agency, typically their Board of Dentistry.<sup>26</sup> Once all of this is complete there are continuing education requirements for both the dentist and all auxiliary members of the sedation team that are done bi-annually.<sup>26</sup> Furthermore, if the dental provider has an individual under their care that would benefit from sedation techniques and they do not have these certifications they are forced to refer the individual to another appropriate office. In some areas of Virginia in particular, rural and urban, there are not sedation providers within a reasonable distance (50 miles or 1 hour as defined by Virginia DBHDS) so the patient may have to wait until services are available.<sup>33</sup> Among the providers who discussed sedation as a facilitator, their opinion was that dentists who are able to conduct sedation have more treatment options and they are able to further tailor the appointment to the individual.

In a study by Faulks et al (2007) the researchers were able to show how outpatient sedation with nitrous oxide facilitated successful dental appointments for over 300 patients who had been previously unable to receive dental services or whose behaviors prohibited dental services from being conducted.<sup>34</sup> The increased availability of this type of sedation practice could potentially lead to the increase of integrated care for DD populations, meaning more patients could be seen in the community setting.

Four of the participants held Virginia sedation certificates and noted that they were able to see a great varied number of patients with DDs because of their flexibility in care. All four of the sedation dentists were able to conduct the care in an outpatient setting meaning that the individuals did not have to have the services completed in a hospital setting and the visits could be as short or as long as they needed to be in order to achieve comprehensive care. The sedation providers felt that the ability to conduct these services had a positive effect on the patient's overall behaviors and that they could provide more comprehensive care in a safe setting. Similar to the insights of this study's participants, a study by Ferrary et al (2019) also made mention to the fact that conscious moderate sedation using the drug midazolam in an opt-patient setting was effective in the reduction of anxiety and due to the amnesic effects of the drugs patients had reduced anxiety and higher cooperation for subsequent visits.<sup>35</sup> It may be more efficient to implement sedation practice in an outpatient setting if the providers had more access to the necessary courses whilst in dental school in order to offset some of the time and financial constraints. Additionally, the respective Board of Dentistry could work more closely with the Board of Anesthesia in order to develop overlapping protocols to make out-patient sedation services more available possibly through collaborations with medical anesthesia providers.

## **Contributions to the Literature**

This study contributes to the literature on patient centered care among DD populations by examining the perspectives of a group of professionals who are currently active in the care and treatment of persons with DDs and evaluating their perspectives and techniques on how they conduct comprehensive community dental care. It successfully identifies a deficit in professional education and a need for earlier exposure and formal instruction as a means to increase access to care for an underserved population. The research looks at specific barriers and facilitators, but also how the participants adjust their practices to work with or around those challenges and positive aspects of dental care.

## **Further Research and Implications**

As previously mentioned, there is a dearth of literature on the patient- dentist relationship and the PCC model is not specifically taught in dental and dental hygiene schools.<sup>29</sup> Additionally, there are not specific requirements for the preparation and training for the treatment and care of persons with DDs within the American Dental Association or the Virginia Board of Dentistry.<sup>10,26</sup> Our study found that only a small percentage of the participants had any formal education on the care and treatment of individuals with DDs and some of those programs were in place specifically because of the influence of the staff that was working in those institutions at the time, and it is not known if those modules are a permanent part of their respective curriculums. A great number of the participants in this study referred to their method of training as through trial and error or self-taught over long periods of time. More research should be conducted on the type of training that is needed for the care and treatment of persons with DDs, and to establish the best time for implementation (i.e 3<sup>rd</sup> or 4<sup>th</sup> year dental students). It could also be determined whether clinical methods should be considered

including the use of simulations and mock scenarios such as the “point of view” method used by Levett-Jones et al (2017) where students experience simulations that allow them to see through the eyes of the patient, or if the training should be throughout the educational time period in a classroom using case study methods.<sup>36,37</sup>

In our study we found that only one of the participants knew about collaborative care or integrated health models. More research is needed to determine if collaborative care instruction could help facilitate a more holistic approach for the dental and health care of persons with DDs.

Patients and caregivers should be included in a future research studies in this topic to better understand their perspectives. It would be helpful as well to gain insight on how persons with DD and their caregivers interpret these same appointments and their effectiveness. Due to its relationship with the PCC model more research can also be conducted on the pre-appointment process and how the providers learn about each individual prior to care in an effort to build rapport and reduce anxiety. Documents such as the “My hospital passport” allow the patients and caregivers to fill out all of the individual’s health dental and behavioral concerns and they can bring it with them to every medical or dental appointment.<sup>38</sup>

## **Limitations**

Like all studies, this study had limitations. As is typical of qualitative research, the sample size was small, and although there was diversity in age race and gender of the participants, the study findings are not generalizable.

A lack of clinical diversity among providers is also a potential limitation to the research (i.e. a significant difference in educational background or community experience). I tried to mitigate this by drawing participants from different areas of the state or region with the aim of ensuring

varied perspectives of practitioners with regard to experience, and higher educational backgrounds as this can have effects on their treatment perspectives.<sup>39</sup> Due to COVID restrictions, in person interviews with the practitioners, patients and direct service providers were not possible, and were conducted remotely. There is a possibility it did not yield the same candid responses as one would if conducting a visit in person.

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