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Transitioning from Individualized Pediatric Dental Care of Children with Autism Spectrum Disorder at the Mailman Segal Dental Clinic to Traditional Dental Settings

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TRANSITIONING FROM INDIVIDUALIZED PEDIATRIC DENTAL CARE OF
CHILDREN WITH AUTISM SPECTRUM DISORDER AT THE MAILMAN SEGAL
DENTAL CLINIC TO TRADITIONAL DENTAL SETTINGS

Toni-Marie Small, D.D.S.

A Thesis Presented to the Faculty of the College of Dental Medicine of Nova
Southeastern University in Partial Fulfillment of the Requirements for the Degree of
MASTER OF SCIENCE

June 2020

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By

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A thesis submitted to the College of Dental Medicine of Nova Southeastern
University in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

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June 2020

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I certify that I am the sole author of this thesis, and that any assistance I received in its preparation has been fully acknowledged and disclosed in the thesis. I have cited any sources from which I used ideas, data, or words, and labeled as quotations any directly quoted phrases or passages, as well as providing proper documentation and citations. This thesis was prepared by me, specifically for the M.S. degree and for this assignment.

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Abstract

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DEGREE DATE: June 2020

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NOVA SOUTHEASTERN UNIVERSITY COLLEGE OF DENTAL MEDICINE

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ABSTRACT

Background

Children with special healthcare needs (SHCN) such as Autism Spectrum Disorder (ASD) usually develop strong bonds with their pediatric dental care provider. However, as they mature, transitioning to other services or providers is necessary. Low rates of successful transition of children with SHCN have gained national attention especially since their lifelong conditions require continuous care. It is important to facilitate a smooth transition among providers; dental care providers specifically. These transitions are imperative to prevent these children from losing access to dental care as they mature. This pilot study seeks to describe the proportion of children with ASD seen at the Mailman Segal Center for Human Development Dental Clinic (MSD) that were required to transition to other dental providers and determine characteristics that influenced the decision to remain at Nova Southeastern University (NSU) dental clinics. **Objective:** Although children with Autism Spectrum Disorder (ASD) develop strong bonds with

their pediatric dental provider, as they age, a transition to other providers is necessary. Low rates of successful transition, coupled with the need for long-term care, highlight the importance of understanding the transition process. The objective of this study is to examine characteristics associated with the retention of patients at NSU dental clinics.

Methods: A retrospective chart review of patients with an ASD diagnosis was conducted. Data such as demographics, insurance status, and household income were collected. A logistic regression analysis was conducted to examine patient factors associated with the transition to an NSU clinic. **Results:** Data were collected for 101 children (89.1% male & 10.9% female) required to transition between 2015-2019; Medicaid was the most frequently reported insurance type (68%). In terms of transitions, 42% of patients transitioned to an NSU clinic, 5.9% sought care privately, 19% are still active patients, and the remaining 33% were lost to follow up. Regression analysis indicated that insurance type was significantly associated with transition to NSU. Children with Medicaid were seven times more likely to transition to an NSU clinic than to seek private care (OR= 7.156; [CI: 2.931, 17.472]; p=0.000). **Conclusion:** Results demonstrate that insurance may play a major role in a family's decision to seek care at a facility. Since many studies have shown that Medicaid acceptance is low among private dental care providers, these findings suggest that this may be a major barrier to finding facilities to transition children with ASD.

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CHAPTER 1: INTRODUCTION

1.1 Special Healthcare Needs

Special healthcare needs (SHCN) are defined as “chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount that is generally required”.¹ As a result of the advancements of modern medicine, the life expectancy of persons with SHCN has vastly increased with many surviving into adulthood. Children with SHCN usually develop strong bonds and comfort with their pediatric medical and dental care providers.¹ However, as the children mature, transitioning them to more appropriate services for their age or stage of development becomes critical to optimize their healthcare.² This transition should be smooth and uninterrupted to ensure that access to preventive care is continuous and minimize the tendency of this population to fall into symptom-driven care seekers.^{1, 2} Establishing and maintaining a dental home has proven to result in the continuous provision of comprehensive care and optimizes dental health throughout adulthood.²

1.2 Dental Home

The American Academy of Pediatric Dentistry (AAPD) defines a dental home as an ongoing relationship between a dentist and patient that is continuous and encompasses all aspects of dental care required to achieve optimal oral health.³ When a dental home is established with a pediatric dentist, the child and dentist establish a relationship that is sometimes difficult to break.⁴ The dental home model includes a dentist that leads the team of dental care professionals that are personally responsible for providing comprehensive dental care to the patient.⁵ It has been established with strong clinical evidence that preventive care promotes oral health and is the most cost-effective way to maintain optimal

dental health.⁵ Therefore, early establishment and maintenance of a dental home is strongly encouraged.

1.3 Transitions

Facilitating healthcare transitions has become a national concern for children with SHCN because only 40% of patients with SCHNs have been found to be receiving the care they need following a transition.⁶ Although most of the literature centered on healthcare transitions of people with SHCN is from a medical perspective, the AAPD considers these principles can be directly applicable to oral health care.² The AAPD believes that with proper handoff procedures, with clear communication between the family and providers, transitions can be smooth and effective.² The AAPD describes 6 critical steps in order to ensure a successful transition, as follows:²

1. A healthcare provider should be identified who takes specific responsibility for the transition.
2. Core competencies to provide appropriate care for children with SHCN should be taught to providers and should be a part of their certification process.
3. An accessible and portable summary of the child's history should be available to all the providers involved.
4. A detailed, written transition plan should be made in collaboration with the family.
5. The same standards of care should be applied to children with SHCN as their peers.
6. Affordable, continuous insurance should be available to these children through adolescence into adulthood.

The AAPD stresses that it is important to educate and prepare the family for the transition as early as possible to allow for smooth transition.² This will include a defined plan agreed upon by the dentist and family for the transfer of care to take place.² However, there are many cases in which this is not possible. According to some pediatric dentists, dental transitions can be very disruptive to the established routine especially considering how sensitive children with SHCN can be to their environment.⁶ The pediatric dentist plays a key role in establishing a successful transition. Though parents recognize the importance of transitions, parents of children with ASD have expressed their willingness to have the child remain with their pediatric dentist through adulthood.¹

1.4 Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a broad group of life-long, neuro-developmental conditions for which diagnosis entails three criteria: social impairments, communication impairments, and deficits in developing and maintaining relationships.⁷ ASD is considered a spectrum due to the wide variation of manifestations and severities the disorder can present in each affected individual. Being a life-long condition, children with ASD require long-term healthcare.

1.4.1 Prevalence

The Centers for Disease Control and Prevention (CDC) reports that ASD affects 1 in 54 children with boys being diagnosed four times as frequently as girls.⁸ Boys are affected 4.3 times more frequently than girls by the disorder.⁸ ASD touches all racial, ethnic and socioeconomic groups; however, minority groups tend to be diagnosed less often and later in life.

1.4.2 Etiology

The exact etiology of ASD is uncertain. It is agreed that the spectrum is multifactorial and may have a strong genetic component.⁹ Other biologic and environmental factors have also been implicated.⁹ The period before, during and immediately following birth has been found to be the most critical period for disorder development. Children born to older parents are also at greater risk.¹⁰

1.4.3 Diagnosis

Most children are diagnosed after age four. However, studies have shown that the disorder can be reliably diagnosed at age two.⁹ Diagnosing ASD involves developmental screening and a comprehensive diagnostic evaluation. The developmental screening involves assessment of the child's stage of learning, speech and behavior. If there are delays in any of these elements, this can be a sign of a problem, requiring additional screening.⁹ The second diagnostic step, comprehensive diagnostic evaluation, may be performed by the child's pediatrician, a neurologist or child psychologist. It involves a more thorough review of the child's development regarding behavior, speech and learning but may also include genetic, neurologic and or hearing and vision testing.¹¹

1.4.4 Comorbidities

Autism Spectrum Disorder is a SHCN that requires a wide array of specialists to provide care and support. These children require services that meet their individual needs as they mature. Frequently cited comorbidities include Attention Deficit Hyperactivity Disorder (ADHD), chronic sleep problems, chronic gastrointestinal disorders, seizure disorders and schizophrenia.⁹ As a result of these comorbidities, children with ASD often

participate in a number of support services and therapies. Children with SHCN such as ASD have many unmet health needs with dental care being the most commonly unmet.¹

1.5 Healthcare Transitions for Individuals with Special Healthcare Needs

1.5.1 Autism Spectrum Disorder

“Autism spectrum disorder is a lifelong neurodevelopmental disability and a major psychiatric pathology in children and adolescents”.¹¹ Behavioral intervention is considered to be a well established approach to treat this disorder. Many studies have demonstrated the effectiveness of applied behavior analysis (ABA) and therapies based on ABA as the most successful treatment modalities for children with ASD.¹¹ Basic principles of ABA are based on research done by B. F. Skinner called operant conditioning. According to Skinner’s theory, “In a given environment context, behaviors that produce favorable outcomes will continue to occur through the process of reinforcement and those behaviors that do not produce favorable consequences will decrease over time or extinguish.”¹² Skinner demonstrated that behavior response can be developed or changed over time by providing reinforcing consequences for the target behavior response referred to as behavior shaping.¹² Applied behavior analytic therapies target several areas of development including cognition, communication, physical, motor, social and adaptive skills. These skills are taught through breaking the complex task into multiple simple tasks while using a system of reward as an encouragement for desired behavior.¹³ These methods are conventionally conducted by trained ABA therapists in one-on-one sessions.¹¹

Several studies have examined variables affecting the course of treatment using ABA. The majority of the studies have found that children with higher cognitive function

and early age of initial therapy are associated with better prognosis.¹¹ Some studies have also identified long treatment hours, severity of ASD-related symptoms, and language skills to be major predictors of treatment outcomes.¹³

Applied behavior analysis dictates that combinations of therapies should focus on creating positive dental interactions among the dental team and patient with ASD. In this approach, dental care is combined with progressive desensitization with individual reinforcement such as praise and going to the treasure box. During desensitization office visits, the patient is gradually engaged and exposed to the dental environment and equipment that produces anxiety.¹⁴ In multiple visits, the patient is expected to be desensitized to the “seemingly new” equipment, office and dental/auxiliary staff.^{15, 16} Studies have shown that children with mild-moderate forms of ASD are good candidates for desensitization techniques.¹⁴ It is crucial that a dentist be cognizant about severity of ASD before considering dental desensitization for patients. The following section will describe the Mailman Segal Center Dental Clinic, the setting for this study, and will specifically include the techniques utilized there for treatment and transition processes.

1.5.2 Autism Spectrum Disorder and Medicaid

Children with an ASD diagnosis are eligible for benefits under the federal Medicaid program in the state of Florida. In order to qualify, children must have the diagnosis by the age of 8, and services are covered until the age of 18.¹⁷ This coverage includes screenings and behavior therapy with an annual cap of \$18,000 and a lifetime cap of \$200,000.¹⁸ State funding also provides care for children with ASD in other avenues such as the Florida Early Steps program for children with ASD from birth to age three, special education services for three year olds and older through the Department of

Education and vocational training for adults with special needs through the Florida Division of Vocational Rehabilitation.¹⁸

1.6 Mailman Segal Center for Human Development

Nova Southeastern University (NSU) houses a specialized dental clinic in the Mailman Segal Center for Human Development (MSC). The MSC was founded in 1973 and is one of the fifteen schools, centers and colleges that encompass NSU. The Center aims to foster the development of children, families, and educators in order to strengthen families and optimize the development of the children it serves. This is achieved through community advocacy, family support, direct service programs and professional training. Through the employment of many professionals in a wide array of fields, MSC provides support and services to children with ASD.

1.6.1 Baudhuin Preschool

The Baudhuin Preschool (Baudhuin) located at the MSC provides prekindergarten education to children with autism spectrum disorder. The program partners with the School Board of Broward County and is accredited by the National Association for the Education of Young Children. Baudhuin aims to provide an environment that encourages children to develop in all areas by utilizing the principles of ABA. The Baudhuin curriculum incorporates occupational, speech/language and behavioral services.

1.6.2 Kapila Family Foundation Starting Right

The Starting Right program is available to children at the MSC 18-36 months who exhibit delays in language and social skills. In this program, children along with their parents are provided twice a week with a curriculum that aims to improve their

communication, social and school readiness skills. Individual visual schedules are tailored to each child to enable them to traverse a full classroom day smoothly.

1.6.3 Pediatric Dentistry Residency Program

1.6.3.1 Program

The NSU Pediatric Dentistry Residency program is a two-year postdoctoral dental program designed to prepare general dentists to fulfill specialty certification with the American Board of Pediatric Dentistry. The university-based program consists of didactic, clinical and research aspects. Residents are trained to complete comprehensive pediatric dental care inclusive of preventive and restorative dentistry as well as advanced behavior management techniques.

1.6.3.2 Clinics

Joe DiMaggio Dental Clinic

The clinic located at the Joe DiMaggio Children's hospital is staffed by residents and faculty of the NSU Pediatric Residency Program and well as NSU predoctoral dental students. Children at this clinic are able to receive preventive, restorative and emergency dental treatment including adjunctive nitrous oxide, oral conscious sedation and general anesthesia where necessary.

a. KID Dental Clinic

The KID dental clinic is located at the Kids in Distress campus in Wilton Manors, Florida. This clinic is also served by NSU pediatric dental residents, faculty and predoctoral students. As with the Joe DiMaggio clinic, comprehensive dental services are provided except oral conscious sedation and general anesthesia. Patients in need of these additional services are referred to the Joe DiMaggio facility. Unique to the KID clinic is

the Nasoalveolar moulding (NAM) clinic at which newborns with cleft lip and or palate are able to receive a prosthesis aimed to improve corrective surgery outcomes.

1.6.4 Health Resources & Services Administration (HRSA)

HRSA is an agency of the U.S. Department of Health and Human Services. Their mission is to provide healthcare to those who are vulnerable, be it medically, economically or geographically. As a part of this mission, HRSA supports the training of healthcare professionals to provide quality healthcare for their target population through facilitating further education and funding education programs.

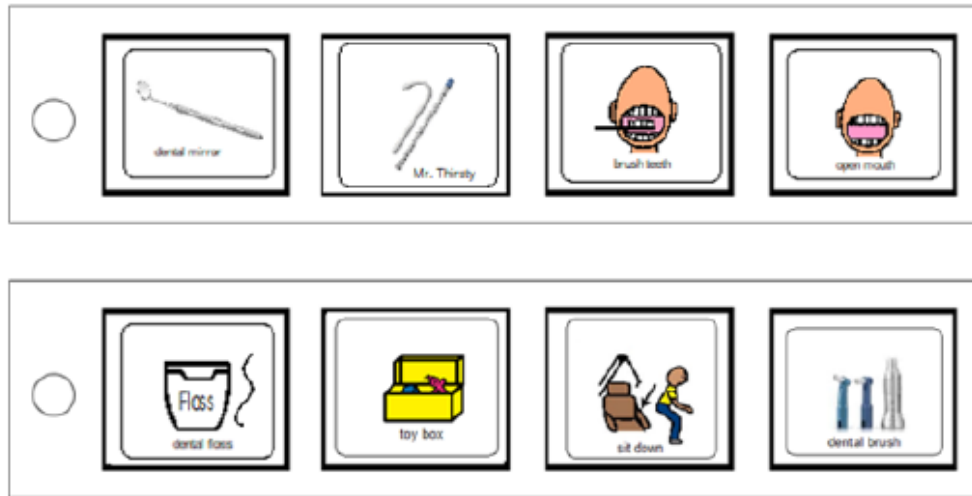
1.6.5 Mailman Segal Dental Clinic

The 2010-2020 HRSA-funded Pediatric Dental Residency Program provides dental services free of cost to individuals with ASD at the Mailman Segal Dental Clinic (MSD). The team providing care at this one-chair-dental clinic consists of a full-time pediatric dentistry faculty, a pediatric dentistry postgraduate student (resident), a dental assistant, a patient navigator and a behavior support specialist.¹⁹ Children with an ASD diagnosis who attend MSC educational programs are eligible to be seen at the MSD. At the Clinic, they can receive frequent and personalized care inclusive of desensitization visits, preventive and restorative care inclusive of advanced behavior management techniques such as inhalation and oral conscious sedation. Individualized visits are provided to the patients with the aim of allowing them to become comfortable in the dental environment and foster their ability to become familiar with stimuli within it that reduce their ability to adapt.¹⁹ The monthly visits the children are able to receive as a result of grant funding allows them to develop a long-standing relationship with the pediatric dental team that becomes familiar and comfortable.

1.6.6 Progressive Desensitization at the Mailman Segal Dental Center

The ability to receive dental care by children with ASD requires life skills that can be learned. Progressive desensitization visits have been proven to allow children with ASD to be able to become comfortable in the dental environment and accept treatment.^{19, 20} In these visits, the child is brought to the same clinic and different elements of a standard dental visit (e.g., sit in chair, open mouth, examine with a mirror, floss, radiographs) are gradually introduced in conjunction with the assistance of an applied behavior analyst. Acceptance of these aspects is encouraged with positive reinforcement and rewards. Children scheduled at the MSD for monthly recare visits. Within the MSC, children with ASD may be enrolled in the specialized preschool program, early intervention program, challenging behavior or feeding clinics, and/or receive speech-language therapy. In the dental setting, skills acquired in the other settings at MSC are scaffolded on and used to help the patient acclimate to the MSD. For example, visual supports are used in the progressive desensitization protocol. Visual supports are a series of pictures that describe to the child the dental steps to provide a procedure timeline that cues the patient to what will follow after each phase.²¹ Figure 2 provides an example of a visual support that is used in the dental setting at the MSD. A study in 2010 showed that children who were exposed to progressive desensitization were able to increase the completion of oral examination and treatment after repeated sessions.²⁰ Dental visits are also important for teaching children with ASD good preventive habits and reduce the burdens of oral disease.⁴

Figure 1. Visual supports used in the dental setting.



The aim of progressive desensitization visits at the MSD is to facilitate the child being able to acquire the necessary skills for them to function in any dental setting.

1.6.7 Transitions from the MSD

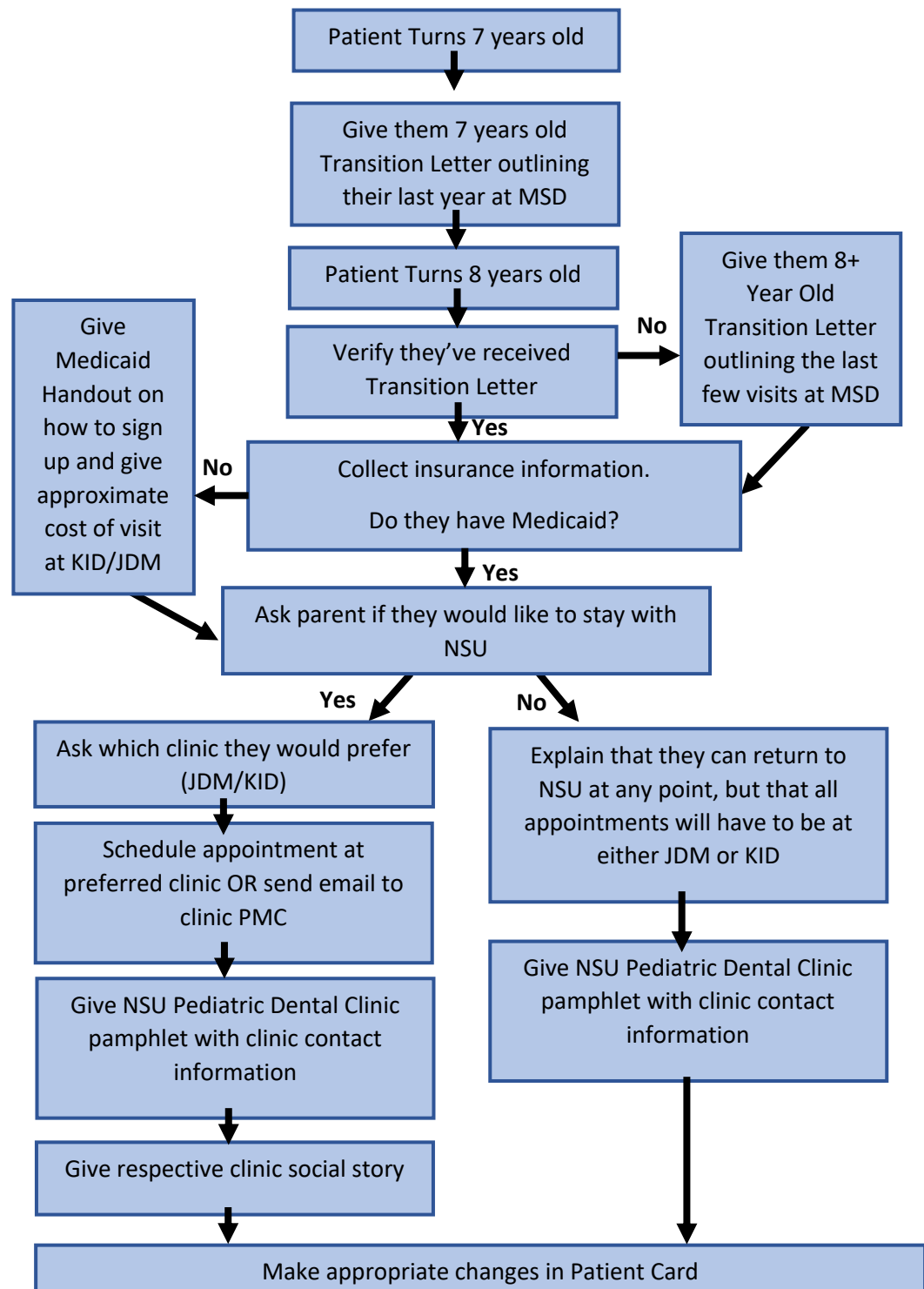
The 2010-2020 HRSA-funded Pediatric Dental Residency Program provides progressive desensitization services to children enrolled in the clinic until the age of eight years. When the child turns eight, they are required to transition to another NSU clinic or private provider to receive ongoing dental care. During the first visit, the transition process at the MSD is discussed with the family. Parents are informed that children seen at the MSD will need to transition to another clinic at eight years old. The parent also fills out a Pre-treatment Assessment form (Appendix A) in order to document information about the child's diagnosis as well as services and supports they receive. This form was adapted from Autism Speaks, which is an organization dedicated to promoting solutions through research for the needs of persons with ASD and their families.

At their first appointment at the clinic after the child turns seven years old, a Transition Letter (Appendix B) is given to the child's parents reminding them about the

upcoming transition when the child turns eight years old and the transition process used. The letter also discusses financial responsibility should the parent choose to be transitioned to an NSU dental clinic. The NSU pediatric dentistry clinic located at Joe DiMaggio Children's Hospital also sees children with SHCN and some children referred to this clinic continue their care and behavior protocols. As such, children transitioned from MSD can continue to receive the extra support they may need. However, a few children who have reached eight years old but are still in the process of completing their treatment plan, are retained until treatment is complete.

The NSU pediatric dentistry clinics accept Medicaid insurance as well as cash payments. Grant coverage for children available at the MSD does not extend to other clinics. The implications of making a transition to an outside setting on parental financial responsibility are presented in person by the patient navigator. Insurance information is discussed with and given to the patient navigator who can also direct the parent towards the process of signing up for Medicaid should they be interested in doing so. At this visit, the faculty and pediatric dentistry resident are responsible for discussing the goals of care in the remaining MSD visits prior to transitioning. Parents are then given the opportunity to ask any questions or voice any concerns they may have. On the last visit at MSD prior to transitioning, the patient navigator documents within the child's electronic health record (EHR) and contact notes in axiUm that it is the last visit and where the child's next visit will be, whether it be at an NSU clinic or if the parent has chosen to seek private care. This transition process is summarized in Figure 2.

Figure 2. Steps of transition process implemented at MSD.



1.7 Current Study

1.7.1 Purpose

Since it is reported that only 40% of patients with SHCN transition and continue care, it is important to understand aspects of a successful transition.² Dental care is the most common unmet health need for children with SHCN.²² The AAPD policy statement on transitioning pediatric patients with SHCN is directly focused on allowing them continue care in adult dental practices.² One of the aims of MSD is to teach the necessary skills and behavior children with ASD need to be comfortable in the dental environment and accept treatment. Acquisition of these skills at MSD should ideally allow the child to be seen at any dental office. Children at MSD are transitioned from the clinic to another dental provider at the age of eight years old. Continued care is essential for the child to maintain optimal oral health. To the author's knowledge, no study has been published that discusses the transitioning of children with ASD from highly specialized pediatric dental care to more traditional dental settings.

The study seeks to investigate the transition of patients at MSD who have reached the age of eight years old required to seek care in another NSU dental environment or privately. This pilot study gave insight to the proportion of the MSD patient population that has transitioned to NSU clinics or chose to see other providers to compare patient characteristics such as insurance type and age that desensitization visits began that affect that decision. This allowed for a greater understanding of the most effective aspects of the current MSD transition process over the last four years and examination of patient characteristics that predict patient retention at NSU or the decision to see other providers.

CHAPTER 2: METHODS

2.1 Study Design

This retrospective study analyzed 101 patient charts from Nova Southeastern University's Pediatric Dental Clinic at the MSC. Data was collected from axiUm dental charting software that included information from pre-treatment assessment forms (demographics and co-morbidities) and the MSD task analysis form (TAS). Convenience non-probability sampling was used to assess the patient chart. Convenience sampling is a type of non-probability sampling in which a population is selected based on accessibility and proximity.²³ This sampling method is necessary in this project due to the uniqueness of the target population as well as the small population size.

2.1.1 Institutional Review Board (IRB) Approval

IRB approval was granted on December 13, 2019 for this study. Approved IRB number: 2019-583. Approval was in compliance with the requirements for the protection of human subjects prescribed in Part 46 of Title 45 of the code of Federal Regulations (45 CFR 46) revised June 18, 1991.

2.1.2 Ethical Issues

All Protected Health Information (PHI) identifiers were removed to comply with IRB and the Health Insurance Portability and Accountability Act (HIPAA) regulations. This study was not conducted on human subjects and no ethical issues were identified as part of this study.

2.1.3 Grant

This research was awarded funding by the Health Professional Division Research Committee at Nova Southeastern University (HPD Grant No: 334584) and by Health Resource and Service Administration (HRSA) Grant # D88HP20126.

2.1.4 Sample Size

There are currently approximately 19 active patients with ASD receiving treatment at the Mailman Segal Center Dental Clinic. All active patients' charts were screened applying the study inclusion and exclusion criteria. The electronic health records (EHR) of patients ages eight years and above that attended MSD from 2015 to 2019 were accessed and reviewed. Patients who transitioned to active status at a NSU dental clinic were identified by review of the EHR. After applying the eligibility criteria, 101 patients qualified for the study.

2.1.5. Sample Description

The contact notes and chart notes from axiUm dental charting software were utilized to determine whether the child had transitioned from MSD.

2.2 Sample Population

Data was collected from the charts of a total sample of 101 patients at the MSC dental clinic located in Broward County, Florida. This clinic is a single chair dental clinic that is specialized for the dental treatment of children with ASD. All the treatment provided by the dental clinic is fully funded by a HRSA grant. The clinic has a dedicated Board Certified Behavior Analyst (BCBA) on staff that provides their expertise and guidance for behavior management during the dental treatment. Pediatric dental residents are part of a collaborative team and learn different techniques and skills utilized by the

onsite faculty pediatric dentist, clinic staff including the BCBA on the grant, and the Baudhuin Preschool employees. The MSC dental clinic is part of Nova Southeastern University and is located in the same building as the Baudhuin Preschool. The Baudhuin Preschool is a special school that serves as a model program for young children with ASD. This school program utilizes principles of ABA, which focuses primarily on the development of cognitive, social, adaptive, behavioral, motor, and communication skills with these children. Since all patients enrolled in the MSC dental clinic are students at this school, they are regularly exposed to ABA techniques and the Picture Exchange Communication System as part of their daily routine.

Information regarding demographics including age, gender and race/ethnicity (Hispanic or non-Hispanic) were collected from the pre-treatment assessment form (Appendix A). Data regarding co-morbidities including speech delay, developmental delay, and intellectual delay as reported by parents were also collected from the pre-treatment assessment form. Patients that did not qualify per inclusion criteria were excluded from the study.

2.2.1 Inclusion criteria and exclusion criteria

Inclusion criteria:

Patients of record at the MSD clinic with a diagnosis of ASD, who attended the MSD clinic from 2015 to 2019 and were eight years of age or older at that time.

Exclusion criteria:

None

2.2.2 Dependent variable

Transition type (i.e., transitioning to an NSU clinic or into another dental care

setting).

2.2.3 Independent Variables

Patient characteristics such as:

- i. Demographics (gender, race, ethnicity, city in which family lives)
- ii. Age at which progressive desensitization began
- iii. Number of progressive desensitization visits
- iv. Frequently utilized advanced behavior techniques (e.g., tell-show-do, nitrous oxide, oral conscious sedation) as measured by the chart notes from each visit
- v. Insurance status (i.e., Medicaid, private insurance, no insurance)
- vi. Annual household income
- vii. Number of siblings
- viii. Number of sessions spent with the BCBA
- ix. Number of additional services children receive based on MSD pretreatment assessment form (Appendix A)

2.2.4 Covariates

A covariate of this study may be that transitioning to an NSU clinic would result in the ability to see the same provider and thereby influence transition type; however, this could not be accounted for in this study.

2.2.5 Limitations

A limitation of the study is that children whose parents chose to see a private dentist are no longer followed up by MSD and, as such, it is not possible to determine via this study design if their transition was successful.

2.2.6 Confounders

Patient charts were completed by different providers and exposure to different resident providers for patient visits. The pretreatment assessment form had also changed throughout the years of the study and did not consistently include all the variables being studied. As such, there is missing data for some patients.

2.3 Design and Procedure

After receiving IRB approval, the patient navigator generated an axiUm report to identify the patients of MSD who were aged eight years and older. These patient's records were accessed via the pretreatment forms and the contact and chart notes from axiUm dental charting software to determine whether the child had transitioned from MSD. The following characteristics of each patient were recorded:

- i. Demographics (gender, race, city in which family lives)
- ii. Age at which progressive desensitization began
- iii. Number of progressive desensitization visits
- iv. Frequently utilized advanced behavior techniques (e.g., tell-show-do, nitrous oxide, oral conscious sedation) as measured by the chart notes from each visit
- v. Insurance status (i.e., Medicaid, private insurance, no insurance)
- vi. Annual household income
- vii. Number of siblings
- viii. Number of additional services children receive based on MSD pretreatment assessment form (Appendix A)

If the chart note indicated that the child no longer attended MSD, the transition to continued care at NSU or private provider was recorded. Attendance of the scheduled

appointment at an NSU clinic was noted if the parent chose to continue care at an NSU clinic. This data was de-identified by the principal investigator.

During data collection, compliance with all HIPAA requirements was upheld to protect patient information. In order to maintain compliance with this, the person accessing the patient charts (principal investigator), is the one who normally has access to medical record information by virtue of his patient care responsibilities. All collected data was de-identified prior to being entered into a password-protected database. Patients were assigned a unique number that was used to identify them in the database. All patient information was entered into the password protected, de-identified database.

2.4 Data Storage

All collected data was de-identified prior to being entered into a password-protected database. Patients were assigned a unique number that was used to identify them in the database. These numbers were randomly assigned as the charts were accessed and were not linked in such a way that would allow for the patient to be identified again in the future. All patient information was entered into the password protected, de-identified database. The software utilized for this study was Microsoft Excel, REDcap, and SPSS.

2.5 Statistical Analysis

Data was entered into a password-protected database in Excel. Descriptive statistics were used to summarize patient characteristics. Statistical analysis was conducted with the help of Maria Levi-Minzi, Ph.D. She is an Assistant Research Scientist at NSU's Center for Applied Research on Substance Use and Health Disparities. Dr. Levi-Minzi exported this data into SPSS version 25 for analysis. Frequencies,

percentages, and means and standard deviations were assessed to describe patient characteristics including demographics (e.g., age, ethnicity, gender), age at which progressive desensitization began, number of progressive desensitization visits, frequently utilized advanced behavior techniques (e.g., tell-show-do, nitrous oxide, oral conscious sedation), insurance status, family income, number of siblings and number of additional services child receives.

Count data was also reported in regard to the findings:

1. Number of children from MSD eight years and older who may have or not transitioned from 2015 to 2019,
2. Number of children whose parents opted to transition to a private practitioner,
3. Number of children whose parents opted to remain at a NSU pediatric dental clinic, and
4. Number of children whose parents opted to remain at a NSU pediatric dental clinic that attended the first appointment.

Regression was used to examine the factors significantly associated with the primary outcome variable of interest: transition to an NSU clinic (dichotomized by transition to NSU clinic/not remaining within NSU). Bivariate logistic regression models were constructed and analyzed to assess transition to NSU by select patient demographics and dental visit characteristics. Significance level was set at $p < 0.05$ for all comparisons. Variables that were significant in the bivariate logistic regression analyses ($p < 0.05$) were added simultaneously to a multiple logistic regression model. Independent variables included in the regression model were selected by the authors based on prior researchers' findings related to continuity in oral care.^{1, 4}

2.6 Quality Control and Data Management

During data collection, compliance with all HIPAA requirements was upheld to protect patient information. In order to maintain compliance with this, the person accessing the patient charts in axiUm EHR (i.e., the principal investigator), was one who normally has access to medical record information by virtue of his patient care responsibilities. All collected data was de-identified prior to being entered into a password-protected database. Patients were assigned a unique number that was used to identify them in the database. These numbers were randomly assigned as the charts were accessed and were not linked in such a way that would allow for the patient to be identified again in the future. All patient information was entered into the password protected, de-identified database.

CHAPTER 3: RESULTS

3.1 Descriptive Statistics

A search of the axiUm chart software with the inclusion criteria of patients of record at the MSD clinic with a diagnosis of ASD, who attended the MSD clinic from 2015 to 2019 and were eight years of age or older yielded 101 patients. Descriptive statistics summarizing demographics of the sample are summarized in Table 1. The majority of the patients were male (89%). Whites were the most represented racial group (26%) with Hispanic ethnicity reported by 23%.

Table 1. Descriptive statistics: Demographic data

| Demographics | N | % |
|---------------------------------------|----|-----|
| Gender | | |
| Male | 90 | 89% |
| Female | 11 | 11% |
| Race¹ | | |
| African American | 5 | 5% |
| American Indian | 1 | 1% |
| Mixed race | 1 | 1% |
| More than 1 race | 5 | 5% |
| White | 26 | 26% |
| Hispanic Ethnicity¹ | 23 | 23% |

¹Data missing for 63 participants

Patient characteristics being assessed in this study are summarized in Table 2 and show that Medicaid was the most common insurance type, with 40% of patients being insured by this method. Regarding behavior management techniques used, 100% of patients received Tell-Show-Do, and a similar number of patients received the advanced technique of nitrous oxide, oral conscious sedation and a papoose (36%, 35% and 37% respectively). Only 10% of patients required treatment under general anesthesia.

Table 2. Patient characteristics

| Patient characteristics | N | % |
|---|-----|------|
| Insurance type² | | |
| Medicaid | 40 | 40% |
| Private | 19 | 19% |
| None | 1 | 1% |
| Behavior management techniques used | | |
| Tell-Show-Do | 101 | 100% |
| Nitrous oxide | 36 | 36% |
| Oral conscious sedation | 35 | 35% |
| Papoose | 37 | 37% |
| General anesthesia | 10 | 10% |
| Transition type | | |
| NSU clinic | 43 | 43% |
| Private dentist | 6 | 6% |
| Active MSD patient ³ | 19 | 19% |
| Inactive patient ⁴ | 33 | 32% |
| Number of additional behavior therapies child receives^{5,6} | | |
| No additional services | 7 | 7% |
| 1 service | 13 | 13% |
| 2 services | 9 | 9% |
| 3 services | 19 | 19% |
| 4 services | 6 | 6% |
| 5 services | 3 | 3% |
| 6 services | 1 | 1% |

²Data missing for 41 participants

³Patient still attending MSD though transition period has passed

⁴Patient who has stopped attending MSD prior to transition period

⁵Examples of behavior therapies include feeding therapy, occupational therapy, behavior therapy

⁶Data missing for 43 participants

Only 7% of patients were receiving no additional behavior therapies, and the most frequently reported number of additional services was 3, with 19% of patients receiving 3 other behavior therapies. Regarding transition type, 43% of parents chose to transition to an NSU clinic and 6% decided to seek care at private offices. 19% of children who were

supposed to transition in the time period of 2015-2019 are still active patients at MSD, while 33% became inactive prior to the time at which transition was required.

3.2 Regression Models

3.2.1 Bivariate logistic regression

Bivariate logistic regression was used to examine the determinants of transition to an NSU clinic as shown in Table 3. The model included independent variables outlined in section 2.2.3. The only variable that proved to be significantly associated with transition to NSU was insurance: Those with Medicaid as their insurance were more than 7 times more likely to transition to NSU (OR= 7.156; [CI: 2.931, 17.472]; p=0.000).

Table 3. Bivariate analysis

| | Bivariate Results | | |
|--------------------------------|-------------------|---------------|-------|
| Variable | Odds ratio | 95% CI | p |
| Demographics | | | |
| Male gender | 2.625 | 0.716, 9.621 | 0.145 |
| White race | 0.653 | 0.273, 1.564 | 0.339 |
| Hispanic ethnicity | 0.832 | 0.322, 2.150 | 0.704 |
| Patient Characteristics | | | |
| Insurance type: Medicaid | 7.156 | 2.931, 17.472 | 0.000 |
| Oral conscious sedation | 1.216 | 0.532, 2.780 | 0.642 |
| Nitrous oxide | 1.600 | 0.703, 3.642 | 0.263 |
| Papoose | 1.242 | 0.549, 2.811 | 0.603 |
| General Anesthesia | 1.395 | 0.377, 5.157 | 0.618 |

3.2.2 Multivariate logistic regression

Multivariate analysis was not conducted because only one independent variable proved to be significant.

CHAPTER 4: DISCUSSION

4.1 Summary

The results of this study demonstrate that insurance types accepted by a clinic may play a major role in a family's decision to seek care at that facility. Many studies have shown that Medicaid acceptance is low among private dental care providers.^{24, 25} Parents with children who are insured with Medicaid were more likely to transition to an NSU clinic than seek care at a private dentist. Nova Southeastern University pediatric dental clinics accept Medicaid insurance and, therefore, having this type of insurance would not be a barrier to transitioning to one of the university clinics. Results suggest that acceptance of Medicaid may be more likely to influence a parent's decision to transition to another facility. Other characteristics such as behavior management techniques that need to be available to perform dental treatment on their child or the amount of additional support their child with autism needs did not appear to have the same influence.

4.2 Transition

Healthcare transitions of children with SHCN are a lifelong process and require individualized consideration as part of normal and healthy development.^{2, 22} The aim of transitions is to maximize the patient's ability to receive care that is optimal and appropriate for their stage of development.²² Across many healthcare specialties, improvements are needed to facilitate transitions and transition readiness. Smooth dental care transitions are required to maintain optimal oral health. Though there is a great difference between transition eligibility and transition readiness, transitions are often required based on eligibility criteria such as age, insurance type and stage of development.²⁶

Many families build strong and trusting relationships with their pediatric primary medical and dental care providers and are hesitant about the need to transfer.²⁶ To present transition as a normal event, studies have shown that written policies regarding transition should be presented to families far before the transition is required.²⁶ This process is upheld at the MSD clinic when the transition letter is presented to families when the child turns seven to open the door for parents to ask questions and prepare for the upcoming transition at the age of eight. Even with optimal preparation, there are many patient specific factors that may prevent these transitions from occurring successfully.

4.3 Predictors of Transition

4.3.1 Barriers to dental care for children with ASD

Children with ASD experience barriers to dental care that may affect their ability to transition. These barriers may include patient characteristics such as finances, culture, behavior, language barriers, lack of appropriately trained dentists, and insurance systems.^{27, 28} A study conducted by Brickhouse et al. in 2009 examined the severity of ASD-related symptoms and the ability of the child to receive regular dental care.²⁹ The characteristics assessed in the study by Brickhouse et al. were diagnosis, age, race, sex, household income, insurance and history of behavior at the dental office.²⁹ The patient characteristics assessed in this study were similar and include demographics, insurance status, behavior management techniques utilized, and number of additional services the child receives.

Other characteristics that were to be studied but were unsuccessful due to inconsistencies in the evolving pretreatment assessment form and electronic health record include number of siblings, family income, and number of sessions spent with the applied

behavior analyst. The findings of this study show that the majority of patients who transitioned did so to an NSU clinic (43%). This finding was associated with the patient having Medicaid insurance. A patient with Medicaid was 7 times more likely to transition to an NSU clinic (OR= 7.156; [CI: 2.931, 17.472]; p=0.000).

Medicaid is one of the primary sources of insurance for children with SHCN. Low Medicaid reimbursement rates reduce the incentive for many primary care providers to accept this type of insurance. As such, this is a barrier to access of routine preventative and primary care from dentists and other providers for the segment of the population that needs to utilize these benefits.²⁴ According to a survey by the American Dental Association (ADA) in 2015, only 38% of US dentists participate in the Medicaid or Child Health Insurance Program (CHIP).²⁵ This number of providers cannot meet the demands of the 54% of the pediatric population (42 million) in the US currently being served by these programs.²⁵ Medicaid and CHIP are only accepted by 28.9% of dental providers and 34.6% of pediatricians in Florida.²⁵ Medicaid insurance is accepted by all NSU pediatric dental clinics. The finding in this study of an association between insurance type and likelihood to transition to a facility that accepts it is consistent with other studies.²⁴

In this study there was no association found between behavior management techniques used and number of additional services the child receives related to transition type. A study by Barry et al. in 2013 showed that though the behavior of children with ASD was a perceived barrier to accessing dental care, there were no differences in the attendance of children with more behavior issues than those without.²⁷ They indicated that the study group with poor behavior was accessing care just as much as the control group. This supports the finding of our study. Assuming that number of additional

services received by the child was a direct reflection of the child's behavior, those receiving several additional services would be expected to have poor behavior in comparison to those who received none or very few. A lack of association between number of additional services received and transition type could imply that behavior had no influence on a parent's decision on where to transition.

It should be noted that the faculty providers and residents treating patients at MSD are the same providers available at the other NSU clinics. Therefore, though transition to another clinic is necessary and the physical environment changes, the providers that the child is familiar with remain the same as well as their abilities to treat them. This fact can be considered as a confounding variable as comfort and familiarity with the primary care provider has been frequently cited as a reason for resistance to transitioning; however, in the setting of this study, transition did not cause a change of provider. For the 32% of patients who became inactive before the transition became necessary, it could be as a result of children in the earlier clinic groups becoming desensitized before the transition period came and families may have withdrawn from the clinic before the child turned eight.

4.3.2 Patient Demographics

A convenience sample of patients attending the MSD clinic was used. In order to be accepted as a patient of this clinic, a child must be receiving services at the Mailman Segal Center for Human Development and have an autism diagnosis or educational eligibility. 89% of the patients were male, which is to be expected as ASD is known to affect boys four times more frequently than girls. 26% of those who reported race were

Caucasian.⁹ ASD is reported to affect all races and ethnic groups; therefore, this finding may be a reflection of the population of the school used in this convenience sample.

4.4 Limitations

The MSD clinic poses a unique situation that is not common to the general pediatric dental environment. HRSA-grant funding allows the clinic to provide dental treatment free of charge. As such, patients are able to receive regular dental treatment and frequent desensitization visits. The pediatric dental faculty and residents are also able to provide advanced behavior management techniques inclusive of oral conscious sedation and treatment under general anesthesia to manage the individual needs of each child. Many children attending the clinic also receive other behavior services in house at MSC, and attendance at dental visits is very convenient for the families as many of them are already present at the facility for other reasons and schedule their appointments surrounding these visits. This creates a more favorable environment for attendance regardless of the usual barriers parents of children with SHCN may face in honoring dental appointments. This may not be the case in all dental settings and thereby influence the external validity of the study.

Another limitation of this study was inconsistencies in the pretreatment assessment form used over the study period. The pretreatment assessment form was heavily relied upon to gain the data for some of the characteristics being examined. These included number of siblings, family income, and number of additional services the child receives. With several changes being made to the pretreatment assessment form used between 2015 and 2019, data on these characteristics was inconsistently available.

Therefore, there was missing data for some study participants, which may have reflected on the results and thereby failed to show other possible associations.

Lastly, the faculty at MSD are the same providers at the other NSU clinics. Several studies have shown that familiarity between families and their pediatric dental care providers is a reason for hesitation of parents to transition. However, in the MSD setting, the ability to continue with the same provider at another NSU clinic may have some influence on transition type. This was not accounted for in the results. This fact may also influence the external validity of this study.

4.5 Suggestions for Future Research

Future studies can include investigating the perspective of parents of children with autism on barriers they face to transitioning to traditional dental settings from specialized dental care centers. In addition, familiarity with the providers at MSD and the ability to transition with them can also be examined. The relationship between transition type and provider relationship would be interesting to study. Since the patients develop strong bonds with the MSD providers during their monthly visits for a few years, this may have influence on a family's desire to stay with these providers at NSU pediatric clinics.

In regards to the present study, separating and analyzing the data by transition year can be done to determine the differences in patient decisions by year. It has recently been noted that the severity of ASD of children who qualify to attend Baudhuin has been increasing throughout the years and this may influence the amount of desensitization the children may need before they acquire the skills for transition readiness. This factor could influence transition decision and may be studied further. Lastly, a relationship between

patient zip code and clinic choice could have been assessed because proximity to a facility could also influence transition decision.

CHAPTER 5: CONCLUSION

5.1 Conclusion

Dental care remains one of the most common unmet needs of patients in this population. Dental care transitions of children with SHCN such as ASD are important for maintenance of optimal oral health. It is clear from national surveys that these transitions are not occurring efficiently and these children are often being lost to follow up. Our findings suggest that insurance type and the ability to find a provider who accepts it may have a strong influence on transition choice. This study provides a foundation for assessment of barriers parents may face when transitioning their child with ASD to other dental providers becomes necessary.

Appendix A: Pre-Treatment Assessment Form

Parent and/or Guardian must be present for first dental visit.

Parent/Guardian Name: _____ Date: _____
 Parent/ Guardian Telephone: _____ Parent/Guardian Email Address: _____

PRE-TREATMENT ASSESSMENT FORM

(to be completed by Parent or Guardian)

Relation to Patient? ☐ Parent ☐ Guardian ☐ Caregiver

CHILD'S INFORMATION

Name: _____ Birthdate: _____

Sex: ☐ Male ☐ Female Race: ☐ White ☐ African American ☐ American Indian
 Ethnicity: Hispanic/Latino ☐ Yes ☐ No ☐ Asian ☐ More than one race

Family Income: ☐ 0-\$15,000 ☐ \$30,000-\$49,000 ☐ \$70,000 or more
☐ \$16,000-\$29,000 ☐ \$50,000-\$69,000 ☐ Prefer not to answer

Does the child have any siblings? ☐ Yes ☐ No If yes, how many? _____

Was your child diagnosed with Autism Spectrum Disorder (ASD)? ☐ Yes ☐ No

If yes, how would you describe your child's ASD: ☐ Mild ☐ Moderate ☐ Severe ☐ Other

If applicable, what age was your child diagnosed with ASD? _____

From what sources have you received information about your child's ASD diagnosis? (check all that apply)

☐ Pediatrician ☐ Psychologist ☐ Neurologist ☐ School ☐ Internet ☐ Other

What program is your child currently enrolled in?: ☐ Baudhuin Preschool ☐ The Academy
☐ Starting Right ☐ Other: _____

What other services is your child receiving?
☐ Occupational Therapy; How often? _____ ☐ Speech; How often? _____ ☐ Music; How often? _____
☐ Physical Therapy; How often? _____ ☐ ABA; How often? _____ ☐ Other: _____
☐ Play; How often? _____ ☐ Other: _____

Does your child have any other co-occurring diagnosis/es?
☐ ADHD ☐ Intellectually Disability ☐ N/A
☐ Seizure Disorder ☐ Down Syndrome ☐ Fragile X ☐ Asthma
☐ Speech Delay ☐ Seizure Disorder ☐ Other Genetic Disorder: _____
☐ Epilepsy ☐ Developmental Delay ☐ Hypersensitivity/allergy-food
☐ Other _____ **Mental Health Disorder:** ☐ Hypersensitivity-medications
☐ Depression ☐ Bipolar ☐ Anxiety

Is your child currently taking any medications? ☐ Yes ☐ No

If yes, please list the medications here: _____

Has your child ever visited the dentist? ☐ Yes ☐ No
 If yes, write age of first visit _____ Describe: _____

Which type of toothbrush does your child use? ☐ Manual ☐ Electric

Does your child use toothpaste with fluoride? ☐ Yes ☐ No

Do you floss your child(ren)'s teeth at home? ☐ Yes ☐ No

Please describe your child's at-home dental care: _____

Does your child drink water? ☐ Yes ☐ No If yes, how much? _____

What is your child's diet (servings)? Vegetable: _____ servings Fruit: _____ servings

Carbohydrates: _____ servings Sweets: _____ servings Sweets types: _____

How many servings of sugar sweetened juice or milk does your child drink each day? Milk _____ Juice _____

See reverse side

ADDITIONAL INFORMATION

The Patient needs *(check all that apply)* :

- | | | | |
|---------------------------------------|--|-------------------------------------|--------------------------------------|
| <input type="checkbox"/> Routine Exam | <input type="checkbox"/> Orthodontic Treatment | <input type="checkbox"/> Extraction | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Filling(s) | <input type="checkbox"/> Multiple Treatments | <input type="checkbox"/> Cleaning | <input type="checkbox"/> Don't Know |

The Patient's level of cooperation is likely to be *(check only one)* :

- | | | | |
|--|---|--------------------------------------|--------------------------------------|
| <input type="checkbox"/> Age Appropriate | <input type="checkbox"/> Aggressive | <input type="checkbox"/> Non-Focused | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Playful | <input type="checkbox"/> Short Attention Span | <input type="checkbox"/> Don't Know | |

Management techniques I would like the dentist to use on my child *(Check all that apply)* :

- | | | |
|------------------------------------|---|--------------------------------------|
| <input type="checkbox"/> Sedation | <input type="checkbox"/> Operating Room/ General Anesthesia | <input type="checkbox"/> Don't Know |
| <input type="checkbox"/> Restraint | <input type="checkbox"/> Short, Multiple Visits | <input type="checkbox"/> Other _____ |

How would you describe your child's level of challenging behaviors?

- | | | |
|--|--|--|
| <input type="checkbox"/> Minimal (Low) | <input type="checkbox"/> Disruptive (Moderate) | <input type="checkbox"/> Severe (High) |
|--|--|--|

What are your sources of support for coping with the diagnosis? _____

How would you rate the level of support you receive from others?

- | | | | |
|------------------------------|-----------------------------------|-------------------------------|-------------------------------------|
| <input type="checkbox"/> Low | <input type="checkbox"/> Moderate | <input type="checkbox"/> High | <input type="checkbox"/> No Support |
|------------------------------|-----------------------------------|-------------------------------|-------------------------------------|

How often does your child engage in challenging behaviors?

- | | | | |
|--------------------------------------|--------------------------------------|---|--------------------------------|
| <input type="checkbox"/> < 1 per day | <input type="checkbox"/> 1-2 per day | <input type="checkbox"/> 3+ times per day | <input type="checkbox"/> Never |
|--------------------------------------|--------------------------------------|---|--------------------------------|

The following statements are about the opinions you have about staying or not staying with the child in the dental treatment room when the child is being treated by the dentist. *(Please circle)*

- | | | | |
|---|-------|----------|------------|
| It is best if I stay with the child because the child needs me to be there. | Agree | Disagree | Don't Know |
| It is best if I stay with the child because I can help the Doctor and Staff. | Agree | Disagree | Don't Know |
| It is best if I stay with the child because I need to be there. | Agree | Disagree | Don't Know |
| It is best if I wait in the waiting room because dentists make me nervous, and that won't help the situation. | Agree | Disagree | Don't Know |
| It is best if I wait in the waiting room because the dentist knows best how to handle the child's behavior. | Agree | Disagree | Don't Know |

Things that I know will motivate the patient to try harder (i.e. computer time, DVD, iPad, video games, movies etc.) _____

Has your child ever had their haircut? ☐ Yes ☐ No If yes, what was the haircut experience like? _____

Does your child have any other physical challenges that the dental team should be aware of? _____

Is there any other information that the staff should know prior to working with this patient? _____

Is your child able to communicate verbally?

- ☐ Yes ☐ No

Does your child use non-verbal communication?

- ☐ Yes ☐ No

Please check any of the following that the child uses:

- | | |
|---|---|
| <input type="checkbox"/> Mayer Johnson Symbols | <input type="checkbox"/> Sign Language |
| <input type="checkbox"/> Sentence board or gestures | <input type="checkbox"/> Picture Exchange Communication Systems |

Please list any and all factors that contributed to you choosing our clinic (i.e. insurance, proximity to home, services offered, other)? _____

Appendix B: Transition Letter

[Insert Date]

Re: Transitioning of Patients from Mailman Segal Center (MSC) to other Nova Southeastern University (NSU) Sites

Dear Parents/Caregivers/Families:

According to our records, your child is seven years old. Due to age restrictions for patients seen at the MSC pediatric dental clinic, children ages eight and older will be referred and transitioned to other NSU pediatric dental clinics in Broward County. The dental team will work closely with you over the upcoming year to prepare your child to transition to another clinic. Our other sites include:

1. Joe DiMaggio's Children Hospital (Memorial HealthCare System): located at the Medical Office Center:
954-262-2187
1150 North 35th Avenue, Suite #220
Hollywood, Florida 33021
2. KID Clinic: located in Wilton Manors (Fort Lauderdale):
954-567-5650
819 NE 26th Street
Wilton Manors, FL 33305

Note that dental services will **not** be covered by the grant, which funds services at the Mailman Segal Center clinic, at the other dental clinic sites. Therefore, insurance and dental coverage information was collected by the clinics' Patient Navigators.

The clinical staff realizes this is an adjustment for the patient and families and wants to make the transition process as smooth as possible for everyone involved. A behavior plan will be created to outline treatment and behavior goals for their last visits at MSC, and for future use at other NSU pediatric dental clinics. This will be discussed with you at your child's next appointment. Once the transition happens, efforts will be made to transition families to providers that work at MSC and the other clinic sites listed above. It is the clinical staff's strong commitment that patients remain supported in clinical sessions using ABA techniques and a caring patient-centered approach.

For any questions please contact Stephanie Hall at 954-262-1817 or email us at mscdentalclinic@nova.edu, or ask during your next appointment.

Thank you for your attention,

Mailman Segal Center Dental Team

Nova Southeastern University

College of Dental Medicine

Appendix C: Raw Data

Frequency Tables

| Pt. Sex | | | | | |
|---------|-----------|---------|---------------|--------------------|-------|
| | Frequency | Percent | Valid Percent | Cumulative Percent | |
| Valid | Male | 90 | 89.1 | 89.1 | 89.1 |
| | Female | 11 | 10.9 | 10.9 | 100.0 |
| | Total | 101 | 100.0 | 100.0 | |

| Insurance Type | | | | | |
|----------------|-----------|---------|---------------|--------------|-------|
| | Frequency | Percent | Valid Percent | Cumulative F | |
| Valid | None | 1 | 1.0 | 1.7 | 1.7 |
| | Medicaid | 40 | 39.6 | 66.7 | 68.3 |
| | Private | 19 | 18.8 | 31.7 | 100.0 |
| | Total | 60 | 59.4 | 100.0 | |
| Missing | System | 41 | 40.6 | | |
| Total | 101 | 100.0 | | | |

| Ethnicity: Hispanic | | | | | |
|---------------------|-----------|---------|---------------|--------------------|-------|
| | Frequency | Percent | Valid Percent | Cumulative Percent | |
| Valid | No | 15 | 14.9 | 39.5 | 39.5 |
| | Yes | 23 | 22.8 | 60.5 | 100.0 |
| | Total | 38 | 37.6 | 100.0 | |
| Missing | System | 63 | 62.4 | | |
| Total | 101 | 100.0 | | | |

| Race | | | | | |
|--------------------------------|-----------------|---------|---------------|---------------|-------|
| | Frequency | Percent | Valid Percent | Cumulative Pe | |
| Valid | AA | 5 | 5.0 | 13.2 | 13.2 |
| | American Indian | 1 | 1.0 | 2.6 | 15.8 |
| | Mixed race | 1 | 1.0 | 2.6 | 18.4 |
| | More than one | 5 | 5.0 | 13.2 | 31.6 |
| | White | 26 | 25.7 | 68.4 | 100.0 |
| | Total | 38 | 37.6 | 100.0 | |
| Missing | System | 63 | 62.4 | | |
| Total | 101 | 100.0 | | | |
| | | | | | |
| Annual Household Income | | | | | |
| | Frequency | Percent | Valid Percent | Cumulative Pe | |
| Valid | Missing data | 99 | 98.0 | 98.0 | 98.0 |
| | 70,000 or more | 1 | 1.0 | 1.0 | 99.0 |
| | Prefer not | 1 | 1.0 | 1.0 | 100.0 |
| | Total | 101 | 100.0 | 100.0 | |

| BM: TSD | | | | | |
|----------------|-----------|---------|---------------|--------------------|-------|
| | Frequency | Percent | Valid Percent | Cumulative Percent | |
| Valid | Yes | 101 | 100.0 | 100.0 | 100.0 |

| BM: Sedation | | | | | |
|---------------------|-----------|---------|---------------|--------------------|-------|
| | Frequency | Percent | Valid Percent | Cumulative Percent | |
| Valid | Yes | 35 | 34.7 | 100.0 | 100.0 |
| | No | 66 | 65.3 | | |
| Total | 101 | 100.0 | | | |

| BM: Nitrous | | | | | |
|------------------------|-----------|---------|--------------|-----------------------|-------|
| | Frequency | Percent | Valid Percer | Cumulative Percent | |
| Valid | Yes | 36 | 35.6 | 100.0 | 100.0 |
| | No | 65 | 64.4 | | |
| Total | 101 | 100.0 | | | |

| BM: Papoose | | | | | |
|------------------------|-----------|---------|--------------|-----------------------|-------|
| | Frequency | Percent | Valid Percer | Cumulative Percent | |
| Valid | Yes | 37 | 36.6 | 100.0 | 100.0 |
| Missing | No | 64 | 63.4 | | |
| Total | 101 | 100.0 | | | |

| BM: OR | | | | | |
|---------------|-----------|---------|--------------|-----------------------|-------|
| | Frequency | Percent | Valid Percer | Cumulative Percent | |
| Valid | Yes | 10 | 9.9 | 100.0 | 100.0 |
| | No | 91 | 90.1 | | |
| Total | 101 | 100.0 | | | |

Bibliography and References Cited

1. Cruz S, Neff J, Chi DL. Transitioning from Pediatric to Adult Dental Care for Adolescents with Special Health Care Needs: Adolescent and Parent Perspectives--Part One. *Pediatr Dent*. 2015;37:442-446.
2. Policy on Transitioning from a Pediatric-centered to an Adult-centered Dental Home for Individuals with Special Health Care Needs. *Pediatr Dent*. 2017;39:129-132.
3. Definition of Dental Home. *Pediatr Dent*. 2017;39:12.
4. Bayarsaikhan Z, Cruz S, Neff J, Chi DL. Transitioning from Pediatric to Adult Dental Care for Adolescents with Special Health Care Needs: Dentist Perspectives--Part Two. *Pediatr Dent*. 2015;37:447-451.
5. Girish Babu KL, Doddamani GM. Dental home: Patient centered dentistry. *J Int Soc Prev Community Dent*. 2012;2:8-12.
6. Davis AM, Brown RF, Taylor JL, Epstein RA, McPheeters ML. Transition care for children with special health care needs. *Pediatrics*. 2014;134:900-908.
7. Association AP. Diagnostic and statistical manual of mental disorders: Washington, D.C.: American Psychiatric Press, Inc; 2013.
8. Maenner MJ, Shaw KA, Baio J, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. *MMWR Surveill Summ*. 2020;69:1-12.
9. Control CfD. Autism Spectrum Disorder. Vol 2020. <https://www.cdc.gov/ncbddd/autism/facts.html>: Center for Disease Control; 2019.
10. Christensen DL, Bilder DA, Zahorodny W, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among 4-Year-Old Children in the Autism and Developmental Disabilities Monitoring Network. *J Dev Behav Pediatr*. 2016;37:1-8.
11. Cagetti MG, Mastroberardino S, Campus G, et al. Dental care protocol based on visual supports for children with autism spectrum disorders. *Med. Oral Patol. Oral Cir. Bucal*. 2015;20:e598.
12. Roane HS, Fisher WW, Carr JE. Applied behavior analysis as treatment for autism spectrum disorder. *The Journal of pediatrics*. 2016;175:27-32.
13. Tiura M, Kim J, Detmers D, Baldi H. Predictors of longitudinal ABA treatment outcomes for children with autism: A growth curve analysis. *Res. Dev. Disabil*. 2017;70:185-197.
14. Tounsi A. Children With Autism Spectrum Disorders can be Successfully Examined Using Dental Desensitization. *Journal of Evidence Based Dental Practice*. 2017;17:414-415.

15. Turk N. Characteristics associated with successful dental treatment in children with Autism spectrum Disorder. Fort Lauderdale, FL: College of Dental Medicine, Department of Pediatric Dentistry, Nova Southeastern University; 2017.
16. Treating Children with Autism Spectrum Disorders: A Tool Kit for Dental Professionals. Vol 2018.
17. Medicaid.gov. Autism Services. Vol 20202014:<https://www.medicaid.gov/medicaid/benefits/autism-services/index.html>.
18. L&M Policy Research L. Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD. Medicaid.gov2014.
19. Ocanto R, Levi-Minzi M, Chung J, Sheehan T, Padilla O, Brimlow D. The development and implementation of a training program for pediatric dentistry residents working with patients diagnosed with ASD in a special needs dental clinic. *J Dent Educ.* 2020;1-12.
20. Orellana LM, Martínez-Sanchis S, Silvestre FJ. Training adults and children with an autism spectrum disorder to be compliant with a clinical dental assessment using a TEACCH-based approach. *J Autism Dev Disord.* 2014;44:776-785.
21. Mah JW, Tsang P. Visual Schedule System in Dental Care for Patients with Autism: A Pilot Study. *J Clin Pediatr Dent.* 2016;40:393-399.
22. Nowak AJ, Casamassimo PS, Slayton RL. Facilitating the transition of patients with special health care needs from pediatric to adult oral health care. *J Am Dent Assoc.* 2010;141:1351-1356.
23. Jager J, Putnick DL, Bornstein MH. II. MORE THAN JUST CONVENIENT: THE SCIENTIFIC MERITS OF HOMOGENEOUS CONVENIENCE SAMPLES. *Monogr Soc Res Child Dev.* 2017;82:13-30.
24. Serna CA, Arevalo O, Tomar SL. Dental-Related Use of Hospital Emergency Departments by Hispanics and Non-Hispanics in Florida. *Am J Public Health.* 2017;107:S88-S93.
25. Association AD. Dentist Participation in Medicaid or CHIP. Vol 2020. https://www.ada.org/~media/ADA/Science%20and%20Research/HPI/Files/HPIGraphic_0318_1.pdf; American Dental Association; 2015.
26. Hergenroeder AC, Wiemann CM, Cohen MB. Current Issues in Transitioning from Pediatric to Adult-Based Care for Youth with Chronic Health Care Needs. *J Pediatr.* 2015;167:1196-1201.
27. Barry S, O'Sullivan EA, Toumba KJ. Barriers to dental care for children with autism spectrum disorder. *Eur Arch Paediatr Dent.* 2014;15:127-134.
28. Du RY, Yiu CKY, King NM. Oral Health Behaviours of Preschool Children with Autism Spectrum Disorders and Their Barriers to Dental Care. *J Autism Dev Disord.* 2019;49:453-459.

29. Brickhouse TH, Farrington FH, Best AM, Ellsworth CW. Barriers to dental care for children in Virginia with autism spectrum disorders. *J Dent Child (Chic)*. 2009;76:188-193.