

Evaluating the effectiveness of a behaviour guidance intervention on tolerance for dental treatment in autistic children from a Johannesburg School

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Declaration:

I, Stephanus Crous, declare that research report is my original work. It is submitted in partial fulfilment of the requirements for the degree of Master of Dentistry, in the field of Community Dentistry. This thesis has not been submitted before for any degree or examination at this or any other university.

Signed

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Abstract

Introduction: The prevalence of Autism Spectrum Disorder is increasing exponentially with most affected individuals coming from middle and low-income countries. Managing this condition throughout a lifetime is costly and therefore the World Health Organization (WHO) has called for cost-effective behavior management solutions that can be used by non-professionals in lower resource settings. Dental care is the highest unmet health care need in individuals with special health care needs, autism being the most prominent. The objective of this study was to investigate the effectiveness of two behaviour guidance techniques, a visual schedule and social story, in facilitating successful dental treatment and to describe the relationship between oral health status and level of functioning.

Materials and Methods: A cluster randomised controlled trial (CRCT) was implemented to evaluate the effectiveness of a specific combination of behavioural interventions: a social story and visual schedule on oral health examination and treatment outcomes. Twenty-five classes were randomized from the low, middle and high support levels to the control or intervention arms. The primary outcomes of interest were: sitting in the dental chair, cooperative behavior as rated by the Frankl scale and the number of fissure sealants placed. In addition, the oral health status was measured for the high, middle and low support groups. The intervention was administered by classroom teachers daily for two weeks prior to the dental visit. Intention-to- treat analysis was conducted. Data were analyzed using t-tests, ANOVA and chi-squared tests to compare the intervention and control groups. Multivariate models were built to test the hypothesis that the oral health status differed by level of support while controlling for age.

Results: One-hundred and sixty-five children from the 25 classes obtained parental consent to participate in the study. There were no differences between the study arms for the outcome of sitting in the dental chair ($p=0.6$) or the number of fissure sealants placed ('Fisher's exact' $p = 0.24$). However, the evidence suggests that the intervention group performed marginally better and more dental treatment was possible over a longer period of time, ('Fisher's Exact' $p = 0.057$). There was a significant difference between the treatment and control arms in behavior as measured by the Frankl scale where the control groups displayed more cooperative behavior ('Fisher's exact'; $p=0.014$). When analyzing

these outcomes against the level of support, significant differences was found showing that as the level of support needed to function increases, children became increasingly more uncooperative during sitting in the dental chair, behavior was more uncooperative ($p < 0.001$) and fewer fissure sealants could be placed ($p < 0.001$). Logistic regression analysis showed that level of support was the strongest predictor for sitting, behavior and fissure sealant placement while controlling for socio-demographic characteristics and treatment arm.

More caries was observed in the primary teeth with caries prevalence of 42.7% and mean decayed, missing, filled teeth (dmft) of 2.01 (Std Dev.=3.07; 95% CI: 1.34; 2.69) compared to the secondary teeth 28% of children had caries and the mean DMFT was 0.9 (Std Dev = 1.91; 95% CI: 0.54; 1.25). Higher mean DMFT score were associated with increased level of support ($p = 0.001$) and children with a DMFT score of 3 and more, required the highest level of support (level 3) and experienced the highest burden of decay while controlling for age. (aOR = 4.6; $p < 0.006$)

Conclusion: Level of support required by children with ASD was the strongest predictor of ability to sit in the dental chair, behave in a cooperative way and placement of fissure sealants and none of the primary outcomes were associated with the intervention. The severity of caries observed in the permanent dentition was positively associated with higher levels of support required to function. The social story was ineffective in improving the primary outcomes in the less structured environment of the classroom and administered by non-professionals.

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Abbreviations and Acronyms

ADDM	Autism and Developmental Disabilities Monitoring Network
ANOVA	analysis of variance statistical test
ASD	Autism Spectrum Disorder
CDC	Centers for Disease Control and Prevention
CONSORT	Consolidated Standards of Reporting Trials
CRCT	cluster randomised controlled trial
dmft	decayed, missing and filled tooth score in primary teeth
DMFT	decayed, missing and filled tooth score in secondary teeth
DSM- 5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
ECD	early childhood development phase
FS	fissure Sealant
GA	general anaesthesia
JHS	Johannesburg Hospital School
OT	occupational therapists
SES	socio economic status
TEACCH	Treatment and Education of Autistic and Communication related handicapped Children
US	United States of America
VAS	visual activity schedule
VEC	vocational phase
WHO	World Health Organization

Chapter 1: Introduction, Aim and Objectives, and Literature Review

1.1 Introduction:

Autism is a neurodevelopmental disease that is increasing rapidly not only worldwide but also in South Africa.^{1,2} This makes children with autism part of a group with special needs because they require assistance for disabilities that are physical, mental, psychological and possibly medical.^{3,4}

A study by Yengopal and colleagues (2014) showed that although autistic children in a Johannesburg school had similar oral health status when compared to the general population, they had high unmet treatment needs that require urgent attention.⁵ Nqobo and colleagues (2012) also found a high unmet treatment need in children living with cerebral palsy, hearing, learning and mental disabilities in South Africa.⁶ Moreover these children also had poorer oral health than the general South African population.⁶ It was found that they had high levels of tooth decay with a 41% prevalence in the primary dentition.⁶

People with special needs often have a greater level of fear and anxiety during the process of acquiring dental treatment compared to the general population.⁷ They often exhibit disruptive behaviours due to their conditions which hinders dental treatment.^{7,8} Dentists on the other hand may not have enough training or the desire to mediate the behaviour of special needs patients creating a further barrier to access for this group.^{3,8}

The published literature shows that there is a lack of trained dentists who are willing to care for people with special needs.^{3,9} Reasons for this include: inadequate undergraduate training in the management of special needs children,¹⁰ fear of people with special needs, inadequate incentives because treating these patients require more time and resources and provide less income, and property damage due to physical resistance of patients and patient behaviour.^{3,9} If standard procedures for dental examination are not possible, the next strategy is to use general anaesthesia but this too has emerging biological dangers and long waiting lists.⁸

Due to the challenges with general anaesthetics, alternative strategies for behaviour guidance need to be explored for this group. We conducted a randomised controlled trial to evaluate the effectiveness of methods used in behavioural guidance already well established and implemented in autistic schools to see if these could facilitate successful dental treatment in children with autism.

1.1.1 Background:

The Department of Community Dentistry of the Wits Oral Health Centre has been involved in the treatment of special needs children since 2010. These included children with cerebral palsy, hearing and visually impairment, learning disabilities as well as intellectual disabilities. The department was approached by the Johannesburg Hospital School for autistic children who expressed a need for increased dental care. The department started a dental outreach program at the school in March of 2013.

The initial strategy was to try the technique of desensitization of these children to the dental environment by rotating them through the Community Outreach dental mobile unit/truck class by class. The first visit allowed the child to enter the truck and sit in the chair for about five minutes, giving the child time to look around and take in the environment and to observe the equipment. The second visit allowed for the same but then an effort was made to let the child ride on the dental chair and lie back completely. The third visit allowed for an attempt to perform an oral examination.

After two to three rotations of each class, we attempted simple cleanings, the placement of fissure sealants and fillings but with limited success. It was evident that a more 'specialized' approach in behaviour management of these children would be needed. This led to many discussions with the speech and occupational therapists about the way forward. We then came up with the idea of using the established social story and visual schedule techniques in combination and already in use at the school, to try and prepare the children to receive dental treatment.

1.1.2 Autism Spectrum Disorder: magnitude and patterns

Autistic disorder is now one of five conditions included in Autism spectrum disorder group.¹¹ Autism Spectrum Disorder (ASD) is a lifelong neurodevelopment condition accompanied by atypical development of brain maturation¹² leading to differences in the brain anatomy and functions. Although the exact cause of autism remains unknown,^{13, 14} gene alleles contributing to ASD have been identified and environmental causes are suspected calling for a renewed focus on the complex interaction between these genes and environmental triggers.¹³ This disorder has an early onset¹¹ and symptoms are typically present within the first two years of life.^{15, 16}

The global increase in ASD has been described as an epidemic.^{2, 17} In 2013 the World Health Organization (WHO) estimated the global prevalence of ASD's to be 1 in 160 children but noted that there were sound epidemiological studies reporting higher figures as well as a consensus that autism is increasing globally.¹⁴ In 2014 the Centre for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Monitoring Network (ADDM), the largest global organisation to monitor neurodevelopmental disabilities, established that 1 out of 68 children in the USA had autism, boys being almost five times more likely to be affected than girls.¹⁸ In the US there was a 123% increase in prevalence between 2002 and 2010.¹⁹

By the end of 2015, the National Institute for Health Statistics, a department of the CDC, released results from 2014 National Health Institute Survey which indicated that 1 in 45 children in the US have ASD.²⁰ This amounted to 2.24% of children between the ages of 3 and 17 and was considerably higher than the previous government statistics because the survey included all children, not just children aged eight years, and it surveyed 12 000 parents whereas the previous figure came from treatment facilities with registered autism patients, which excludes children with ASD not on treatment.²⁰ It is thought that the trend may continue and the prevalence will continue to increase.²¹ In South Africa there are few accurate statistics on the extent of autism and the trend is to make use of international statistics.

The reasons for the dramatic increase in the prevalence of ASD's include increased awareness, improved reporting, expansion of diagnostic criteria and better diagnostic tools. There has also been changes in diagnostic practices, including expansion of developmental screening and increased diagnostic diagnosis and diagnostic substitution where individuals previously diagnosed with an intellectual disability is now being diagnosed with ASD thus contributing to this rise in prevalence.¹⁴ It is not clear though if these factors alone contribute to the increases in prevalence, especially in view of the greater suspicion of environment and/ or chemical triggers.^{13, 21, 22}

Children affected by ASD are characterized by impairments in social interaction and communication as well as restricted, repetitive patterns of behavior or interests.¹¹ They form part of the special needs group because they require assistance for disabilities that are physical, mental, psychological and medical.^{3, 4} Furthermore members of this group are also vulnerable to discrimination and often have limited access to services.¹⁴

The core deficits can further be described using the American Psychiatric Association's fifth edition of the Diagnostic and Statistical Manual for Mental disorders:¹¹

A). "Deficits in communication and social interaction: i) impairment in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions; ii) deficits in nonverbal communication used in social interactions for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication; iii) deficits in developing, maintaining, and understanding relationships, therefore making friends, ranging, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers."¹¹

B). "Deficits in restricted, repetitive patterns of behaviour, interests or activities as manifested by at least two of the following: i) Stereotyped or repetitive motor movements (e.g. flapping or twisting of the hands or rocking back and forth), use of objects (lining up toys or flipping objects) or speech (e.g. sound, for example immediate echolalia which is

parrot-like copying of other people's utterances, or delayed echolalia which is repetition of words or phrases in a stereotyped way, both of which can be meaningless or used as a request; ii) Insistence on sameness represented by inflexible adherence to routines or ritualized patterns (e.g. taking the same route to a certain destination, keeping to the same meal times) or verbal and nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals; need to take the same route or eat food everyday); iii) unusual fixation or interests that are abnormal in intensity or focus (e.g. strong attachment to or preoccupation with unusual objects; excessively circumscribed or perseverative interest); iv) Hyper- or hypo- reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement)".^{4,11}

The severity of ASD can be sub classified into levels of severity based on the social communication impairments and restricted repetitive patterns of behaviour.¹¹ This results in three levels of support for the categories of severity: i) Level 3, (high support) "requiring very substantial support" to function, ii) Level 2, (medium support), children are more developed than those categorised as functioning at level 3, but still require "substantial support", iii) Level 1 (low support), typically composed of more developed and high functioning children "requiring support" for everyday functioning.¹¹

Persons with ASD will be affected in different ways. Even within the diagnostic criteria, each child is said to be different and unique.^{2,23} Symptoms will generally vary on a continuum, some being mildly and others more severely affected.²³ Some individuals can be profoundly disabled having little or no verbal ability and only able to perform gross motor skills while others are able to integrate and function in society.^{4,23} Autism is usually accompanied by other medical, psychological or psychiatric conditions.⁴

Medical comorbidities commonly associated with ASD are: seizure disorders (e.g. epilepsy) are common followed by gastro intestinal disorders (e.g. reflux, sensitivities, food selectivity), obesity, auditory disorders and infections, visual impairment; obesity, cerebral palsy, Tuber Sclerosis, Fragile X syndrome and Down syndrome.^{1,24,25} Several studies have also described various strengths of immune abnormalities associated with ASD.^{22,26,27}

Psychiatric conditions associated with ASD include the following: social anxiety disorder, depressive disorder, behavioural intellectual disability, attention-deficit/hyperactivity disorders, bipolar disorder, externalising behaviours (e.g. aggression and disruption), enuresis, encopresis, trichotillomania (compulsive disorder with the urge to pull out one's hair), sleep disruption and sensory processing difficulties and self-injurious behaviour (e.g. self-hitting, head banging, eye-poking, hand-biting, self-scratching), schizophrenia, .^{1, 2, 25, 28-30} Smirnov and colleagues described psychiatric conditions as "frequently multiple" in these individuals with 70% of their cohort having one psychiatric comorbidity while 41% had two, thus concluding that psychiatric conditions are common.²⁹ Severe autism is also associated with higher frequencies of seizures and intellectual disability.²⁵

1.1.3 Oral health and ASD

Oral health is a very important contributor to quality of life in that it enables us to speak, taste, chew, swallow, breathe, touch, kiss and smile and it safeguards us against microbial infections and environmental threats.^{31, 32} Poor oral health and oral disease, for example caries, can lead to pain and discomfort, acute and chronic infections that can become life-threatening; disfiguring; cause eating and sleep disruption; result in hospitalization; high treatment costs; loss of schooldays and diminished capacity to learn.³³ Oral diseases can also further affect general health in that it affects dietary intake and nutrition, weight gain and growth.³³ Oral health may be even more important in children with ASD where gastrointestinal symptoms like reflux, food sensitivities and preferences are common.¹

For children living with ASD acute illness or discomfort, including oral sources of pain and discomfort, can result in sudden behaviour change or bring about new behaviour.^{4, 24}

Behaviour changes may be observed because the affected child cannot express themselves verbally, and especially in times of discomfort and pain, might find other ways to do so. It has been recorded that parents of children with a cognitive or neurological deficit with resultant impaired communication would rely on non-verbal behaviour to determine if their child is in pain.^{34, 35} Nader and colleagues (2004) found that children with autism display a significant behavioural reaction in response to a painful stimulus.³⁶ Therefore being able to closely monitor their oral health and intervene when necessary is of the utmost importance

for optimizing general well-being. Given the common symptoms of ASD, sitting in a dental chair, understanding what is going to happen and then cooperating during dental examination and treatment is very difficult to the point of impossible depending on the severity of the diagnosis and the level of functioning.

Common approaches in the management of the autistic dental patient include basic and advanced behaviour guidance techniques.^{7, 24} When the use of behaviour guidance fails, the use of more advanced techniques are needed for example pharmacological, medical stabilization or general anaesthesia (GA).³ At the Wits Oral Health Centre, GA is the next available option if behavioural guidance approaches fail. GA entails the use of more personnel, like an anaesthetist, and materials resulting in far greater costs involved with providing dental treatment³⁷ and is almost always associated with long waiting periods before an appointment for GA is secured creating a barrier to access for these children. Cost and additional resources are important considerations in low resource settings like South Africa where dentistry is one of the most expensive medical services to render,³⁸⁻⁴⁰ and there is a shortage of oral health workers.⁴¹

GA has thus far not been associated with adverse neurocognitive or behavioural deficits in children^{42, 43} but there are additional concerns for children with ASD, including associations of higher autistic prevalence seen with the use of GA during childbirth.⁴⁴ Furthermore GA for an autistic patient is complex. There is substantial pre-operative preparation that is needed since children with ASD have an increased of adverse events during hospitalization.⁴⁵ The interaction with ASD medication with anaesthetics can cause a myriad of complications during GA needing special care by anaesthetists and psychiatrist.⁴⁵

Healthcare costs involved in providing care for children with ASD are exponentially higher than other children because of the need for a multi-disciplinary team needed for their primary care while education usually takes place at specialized schools.⁴⁶ The condition often necessitates a family member to stop work or disrupt employment periodically leading to loss of income for the parent or caregiver.⁴⁶ The lifetime cost of caring for a person with ASD is estimated at over two million US dollars, excluding collateral costs such as the effects of stress on the families and caregivers.⁴⁶ Therefore in view of rising prevalence, escalating healthcare costs, limited access to services and possible risks to GA, a less invasive, and economically viable solution is needed to treat children with disabilities

especially in school settings.^{14, 47} Behavioural guidance interventions could be part of the answer.

1.2 Aims and Objectives

Aim

To determine the effectiveness of a behavior guidance intervention on the tolerance for dental treatment among children with autism at the Johannesburg Hospital School in 2015.

Objectives:

1. To determine whether there were differences in the uptake of a simple dental examination between an intervention and control group of autistic children from the same school.
2. To determine whether there is a difference in the uptake of fissure sealant placement in a group of autistic children who have received a behavior guidance intervention and a control group.
3. To determine whether there is a difference in the level of cooperation for dental treatment using the Frankl Scale in the intervention and control groups among a group of autistic children who have had behavior guidance intervention and control group of children from the same school.
4. To compare the oral health status, decayed, missing, and filled teeth (dmft/DMFT) index scores obtained from oral examination and the different levels of functioning within the autistic cohort and with the national average for children in South Africa.

Null Hypothesis:

The use of the social story and visual schedule techniques has no effect on the tolerance for dental treatment in children with autism.

1.3 Literature review:

1.3.1 General approaches to the management of children with ASD:

There is no specific treatment for ASD but there does exist a diverse range of interventions aimed at improving the core deficits.⁴⁸ Considering the core deficits of autism, management of ASD's are primarily focused on improving communication and social skills resulting in enhancement of learning and development, promoting socialization, and decreasing maladaptive behaviour.⁴⁹ This helps the individual with the acquisition of skills in the core deficit areas which will maximize functional independence thus enabling better integration into society through enhanced social responsibility as well as improve quality of life and alleviate family distress.^{1, 49}

The primary approach to treatment centre around psychological and educational interventions but often this will be complimented by medical interventions to manage behaviours that interfere with education, socialization, health and safety as well as quality of life.⁴⁹ However medical treatment has not been proven to cure the core deficits and cannot serve as a primary approach.⁴⁹

Education for autistic children have been described as fostering of acquisition of skills and knowledge to assist a child to develop independence and personal responsibility, encompassing not only academic learning but also socialization, adaptive skills, communication, amelioration of interfering behaviours, and generalization of abilities across multiple environments.⁴⁹ The management of an individual with ASD would include educating the parents or caregivers about characteristics and approaches.⁵⁰ The consensus is that where possible, management of individuals with ASD should be as comprehensive possible targeting multiple core deficits.⁴⁹⁻⁵¹

Childhood educational programs are often categorized as behaviour analytic, developmental or structured teaching based on the primary philosophical origin.⁴⁹ The educational models have important differences but share areas that overlap. Within these educational models there exist specific strategies or tools for education. Some examples of these include: Applied Behaviour Analysis, Structured Teaching (TEACCH), Developmental Models, Speech and Language Therapy (e.g. Picture Exchange Communication System; sign language), and

Social Skills instruction.⁴⁹ Among the educational tools for social skills instruction is the social story.

1.3.2 Evidence for effectiveness of social skills instruction on modifying behaviour

Although interventions may vary considerably regarding their underlying theory, mode of delivery, intensity, degree of parental or teacher involvement and comprehensiveness, Seida and colleagues (2009) in their review still found positive results for the effectiveness of psychosocial interventions aimed at improving core deficits.⁴⁸ This finding is further supported by a systematic review by Maglione and colleagues (2012) who also site social skills programs as part of their recommended interventions for management of children with ASD, drafted for a technical expert panel tasked to draft guidelines for the nonmedical management of ASD's.⁵¹ Social skills programs focus on establishing particular skills to facilitate social functioning and interaction. One of their recommendations was social skills programs, with moderate strength of evidence, and social stories are included among these.⁵¹

A social story makes use of pictures and simple language to accurately describe a situation, a skill or a concept.^{33, 52} In essence "it is a short story written for an individual that describes a specific activity and the behaviour expectations associated with that activity".⁵³ Therefore it describes to the autistic child the details of an upcoming event, what they will experience, especially regarding senses, and what is expected of them. This helps the child to understand and know what to expect in events that will occur.^{33, 52} It's goal is therefore to share accurate social information with a patient in a reassuring manner that can be easily understood.⁵⁴

Social stories can be an efficient tool to use as an adjunct in the clinical setting not only because of its proven efficacy in various other environments⁵¹, but because it does not require extensive training to become competent in its use.⁵⁵ This could be a great advantage in resource limited environments.

A systematic review by Karkhaneh and colleagues (2010) found social stories as beneficial in modifying target behaviours of high functioning autistic children to improve their social

interaction with others.⁵³ This review produced evidence that social stories are effective in improving social interactions such as game playing skills, reading comprehension and social skills comprehension (e.g. greeting skills), facial emotion learning and labelling, social skills, aggressive behaviour and communication skills.⁵³ As part of this process, monitoring of an individual's progress is advised once the social story is introduced, focussing on the frequency and intensity of targeted behaviour.⁵⁴

Although there is no sufficient evidence to recommend one behavioural approach to another evidence has shown that greater intensity of treatment (hours per week) as well as longer duration (in days/months) produces better outcomes.⁵¹

1.3.3 Value of other psychosocial interventions

A visual schedule, also known as Visual Activity Schedule (VAS), is another psychosocial intervention for use in the management of children with ASD. It can help a child to understand the sequence of events and what will come next. The child can then see what steps have been completed and what still remains.^{33, 56} It also helps the child to anticipate changes in their routines and to raise awareness for the expectations within different environments.⁵⁷ This technique was developed because children with ASD often are visual learners^{33, 56} and information presented visually allows prolonged attention to symbols for information recall.⁵⁷ Examples would be a daily activity schedule which has a sequence of pictures showing the order and activities of the day for example: greetings, breakfast, toilet break, etc.⁵⁸ Another would be a sequence of pictures that describe how to build a train out of Lego blocks.⁵⁶

VAS can help children transition from one activity to another, or within an activity, increase activity engagement and decrease aberrant behaviours such as verbal and physical aggression and non-compliance.⁵⁶ Knight and colleagues (2015) described VAS's efficacy as moderate to highly effective for the majority of outcome variables in the studies investigated in their systematic review and recommended as evidence based practice to be used in working with children with ASD.⁵⁶ Therefore VAS is often used in conjunction with other techniques such as differential reinforcement and extinction.^{33, 56} A further advantage

for our proposal for future use by dentists is its user -friendliness and accessibility by all stakeholders.⁵⁶

1.3.4 Dental management of children with ASD:

1.3.4.1 Oral health status of autistic children

There have been mixed reports about the oral health status of autistic children compared to typical children. Several authors have found no difference in the decayed, missing and filled (dmft/DMFT) status of teeth in autistic individuals when compared to a control group^{59, 60} or the national or regional averages^{61, 62}. Various investigators found the dmft/DMFT status of autistic individuals to be lower than a typical cohort^{63, 64} or regional/national averages,^{65, 66} while other authors found the dmft/DMFT status to be higher than a control group^{67, 68} or regional/national averages^{69, 70}. Autistic children are considered to be of a high caries risk due to a diagnosis of ASD⁷¹ and they should be closely monitored for preventive and restorative management. Only Blomqvist and colleagues (2015) have compared caries severity to the severity of ASD diagnosis in a cohort of 47 adults with in Sweden and found no association.⁶⁰

Oral hygiene of individuals with ASD compared to control groups, as measured by the plaque and gingival indices, have been found to be worse by some authors^{64, 72} while other authors found it to be similar or better than control groups.^{60, 73} Marshall and colleagues (2010) found oral hygiene to be the most influential risk factor for new caries in children with autism,⁷¹ and therefore the oral hygiene status of autistic children should be known and improved at all times.

1.3.4.2 Current strategies for the management of children with ASD in the dental setting

Behavioural guidance in the dental setting describes a “continuum of individualized interaction”³ involving the dentist and the patient directed toward communication and education to increase trust and minimize fear and anxiety.³ This philosophy tries to mediate behaviour by improving communication and eliminating unwanted behaviours.^{3, 74}

Behavioural guidance is also recommended for management of children with special needs.^{3, 74}

There is a perceived hierarchy of several treatment strategies available starting with the least restrictive being the basic behavioural techniques and progress to include the more advanced techniques like pharmacologic, medical stabilization, sedation and general anaesthesia.^{3, 7, 74}

Basic techniques include: positive pre-visit imagery, direct observation, voice control, ask-tell-ask, tell-show-do, non-verbal communication, positive reinforcement and descriptive praise, distraction, memory restructuring, parental absence/ presence, communication techniques for parents, contingent and non-contingent escape, modelling, shaping, consistency, flexibility, desensitization, repetitive tasking, hypnosis and escape extinction, nitrous oxide/oxygen inhalation, and sensory techniques.^{3, 7, 74} The skilful use of these techniques are described as: “somewhat intuitive and empirical, as much an art form as it is a science”³ and therefore is largely dependent on the clinicians skill and experience.^{3, 7, 74}

The advanced behaviour guidance techniques include medical stabilization, conscious sedation and general anaesthesia (GA) and are used where basic behavioural guidance cannot secure the safety of the patient and dental team and especially where treatment is extensive.^{3, 7, 74} Limitations on the use of these two techniques are often practical for example great cost and large number of staff required, competition over the use of theatres from medical specialities and the fact that medical procedures generate more income for a hospital than dental procedures.³ Possibly the greatest setback is that the potential for a patient to learn and grow in coping skills is lost.³ The clinical risks for general anaesthesia during the perioperative period are considered as similar in children with ASD’s and those without.^{3, 8}

Still of major concern is the possibility that exposure of the developing brain to general anaesthetics could lead to adverse neurodevelopmental effects.^{42, 43, 75} There is definitive evidence in animal studies of the neurotoxic effects of anaesthetics causing long-term cognitive deficits.^{42, 43} There is also a frequency and dose-dependent element to toxicity.⁴³

Until recently, clinical studies that investigated anaesthetic neurotoxicity in humans have not been able to provide significant evidence that anaesthesia given up to three to four

years of age will result in neurodevelopmental deficits.⁴³ Often the evidence was insignificant because of the limitations of the study design.⁴² There have been evidence for an increased risk of learning disabilities after cumulative exposure to GA⁷⁵ but contradicting evidence for learning disabilities after a single exposure.⁷⁶

In 2014 Chien and colleagues demonstrated an association between the mode of delivery during childbirth and autism.⁴⁴ They found that neonates delivered by Caesarean section with GA had a 1.52 increased risk of developing autism compared to neonates delivered vaginally, while there was a non-significant difference between neonates delivered vaginally and those delivered via C- section with regional anaesthesia.⁴⁴ Currently there are large scale clinical studies (GAS, PANDA, MASK) currently underway to answer the question whether GA during early childhood can adversely influence neurocognitive development.^{42,}

43

The inability to select a behaviour guidance strategy and apply some of the techniques to modify behaviour and improve treatment outcomes, creates a barrier to access of dental care to the special needs patient, and a tendency to resort to general anaesthetic. It is recommended that GA be kept as short as possible, to use short acting drugs and to use regional anaesthesia where possible.⁴³ Therefore given the possibility that there could be serious health risks to GA and the fact that the waiting period for children needing dental treatment under GA at the Wits Oral health Centre is close to a year, it is imperative to find an alternative means to facilitate dental treatment.

1.3.5 Efficacy of behavioural guidance techniques in dentistry

Recommendations for the dental treatment of children with ASD commonly include some of the basic and advanced behavioural guidance techniques named previously.^{3, 7, 10, 24, 74, 77-82}

There are fewer studies exploring the use of the social story or visual preparation as an addition to behaviour guidance in dentistry but with no empirical evidence for efficacy.^{7, 24,}

83-86

Given the diverse nature of this disease, the common suggestion is to tailor approaches to perioperative dental management to the individual's needs.^{7, 10, 24, 79, 80, 82} However, there

are no empirical data to substantiate efficacy of these techniques in the dental setting possibly adding to the already established reservations in the use of behaviour guidance of the general dentist when treating children with special health care needs.³

Bäckman and Pilebro (1998) conducted a trial investigating the use of visual pedagogy to prepare autistic children for dental treatment and found the intervention group to have superior capacity to cooperate during the dental visit compared to the controls.⁸³ The preparation consisted of parents and children at home, working through a book with colour prints depicting the dental surgery, personnel, instruments and procedure. In 2005 they successfully used the same format of visual pedagogy to improve the oral hygiene of children with autism.⁸⁵

Bäckman and Pilebro (1999) used a tailored social story, read at home, to perform two extractions in a nine- year old boy with Asperger syndrome. Initially, the social story was written in the first person and on the day of the dental visit the boy refused treatment. Thereafter the social story was written in the third person and treatment was successfully completed.⁸⁴ The author speculates that the initial non-compliance could have been the result of the boy needing more time to reflect on the procedure and establish willingness which is likely since children with autism are known for slower and or impaired cognition⁸³; or that more reinforcement was needed through the second social story; or the possibility of the effect of changing the social story from the first to third person. Reflecting on this case report it is important to take into consideration that he was a high functioning ASD individual, used to routine dental visits including fissure sealant placements and cleanings, done in an established dental practice with a well-controlled environment, therefore much different to the Wits mobile dental truck parked in a noisy environment.

Marion and colleagues (2016) described the use of different types of social stories for preparation of children for upcoming dental treatment but had no actual objective patient behaviour measurement at the dental visit.⁸⁶ There was also no recording of the frequency of social story use leading up to the dental visit and focussed on the use of social stories at home and had a small and diverse sample size (n=16).

Given the common scenario of an untrained oral health care professional regarding behaviour guidance, there is a need to explore the efficacy of behaviour guidance

techniques which could help ease the selection of appropriate techniques. The decision was made to investigate the efficacy of these two techniques in enabling dental treatment because they were already commonly used by the school's occupational and speech therapist as well as teachers. This is a valid goal supported by an umbrella systematic review by Seida and colleagues (2009) investigating behavioural theory and communication-focussed therapies, concluding that some treatment is favourable over no treatment and that very little evidence exist for the relative effectiveness of treatment options.⁴⁸

Although there are many techniques listed under the behaviour guidance section, using ones that are well practiced and have proven success is a good start.

Chapter 2: Methodology

The format of this research report was prepared using the CONSORT 2010 guidelines for clinical trials.⁸⁷

2.1 Trial design:

A cluster randomised controlled trial (CRCT) was implemented to evaluate the effectiveness of a specific combination of behavioural interventions, that of a social story and visual schedule on oral health examination and treatment outcomes. Classes were randomised to receive a behavioural intervention or the standard preparation before receiving dental treatment.

2.2 Study site

The Johannesburg Hospital School's (JHS) autistic unit is the largest autism specific school in South Africa.⁸⁸ The JHS is a public school and was chosen because the Wits department of Community Dentistry was already involved in outreach activities to provide oral health care to the school for two years prior to the initiation of the study. The outreach service is provided every Friday morning from 9:00 -12:00 when the mobile dental truck which is fully equipped to provide basic dental services, is parked at the same designated area outside the school building.

The children include boys and girls between the ages of 3 and 20 years. Children are further classified into the following five phases: i) Early childhood development (ECD): equates to preschool; ii) Foundation: equates to grade 1-3; iii) Middle: grade 4 – 7; iv) Senior: high school; v) Vocational (VEC): 16+ years of age. Within these phases, classes are still formed based on the level of support needed, rather than the age of the learners.

High support is defined as requiring substantial assistance to follow a routine and support to engage and completes activities. Children requiring high support may have co-morbidities including intellectual disability. The focus of these classes is to acquire life and independent skills for example brushing hair, toilet training and brushing teeth. In the medium support groups, most children can follow routine with minimal support although they do require some support to engage and complete activities; includes acquiring life skills and early

learning activities. Low support groups are able to follow the class routine and can actively engage in activities and are starting to work independently in some tasks; their learning starts at grade one level and can progress to functional academics as age in school increases.

Virtually all the children are from a lower socio-economic background when considering the following: 30% of learners are exempt from school fees because of a lack of finances. Of these, most are on social grants. Of the remaining 70%, an estimated 60% are late with fees and/or cannot pay but have not applied for school fees exemption. School fees are R1430 per month. Between 50 - 60% of the learners receive the Care Dependency Grant. This grant is R 1500 pm and is based on the severity of the learner's diagnosis as well as on the income bracket of their parents. With regards to the feeding scheme, the school only receives enough funds to cover meals for 60 learners (from a possible 235 learners). About 30% of the learners receive hampers every year. Again, the need is much greater, however this is based on the funds raised by the school's social worker. The JHS's statistics estimate that 15% of the learners come from granny headed households while 40% come from a single parent household.⁸⁹ None of the children are from a group home and the school offers no boarding facility.

2.3 Study population and sample:

The study population included all classes and children attending the Johannesburg Hospital School's (JHS) autistic unit in Braamfontein, Johannesburg.

The trial was conducted from September to early December 2015. There were 267 children in the school, divided into 32 classes. The five visually impaired children without autism were excluded from the study. Except for the new intake of children in 2015 amounting to four classes (34 children), all remaining children in the school had received three desensitizing visits to the dental truck before the study commenced which was part of their oral health orientation. For this reason, these four new classes were excluded from the study. All remaining classes were eligible for randomisation into the intervention or control groups.

At the JHS children are placed into a class based upon the level of support (High, medium or low support) that they require within the various age groups (phases). There were 14 high-, 10 middle- and 8 low support classes.

A power calculation was carried out with 10, 12 and 14 clusters per arm and with a coefficient of variance that ranged between 5% and 50%. Since no previous studies had been conducted to our knowledge, the level of intra-cluster correlation was not known. As a result the power estimate included a sensitivity analysis where a range of possible intra-cluster correlation was included. The estimated number of eligible children in the school after exclusion was 228. The power calculation was based on a number of 192 as it was anticipated that about 20% of parents would not grant consent for participation in the study. Figure 1 shows that the study with 12 clusters in each arm is powered at 90% with the coefficient of variance (k) =0.45. The effect size was calculated as an increase from 20% to 40% in the proportion of children who could tolerate dental treatment. There was no prior study testing efficacy of behavioural modification intervention to increase tolerance to oral examination and treatment.

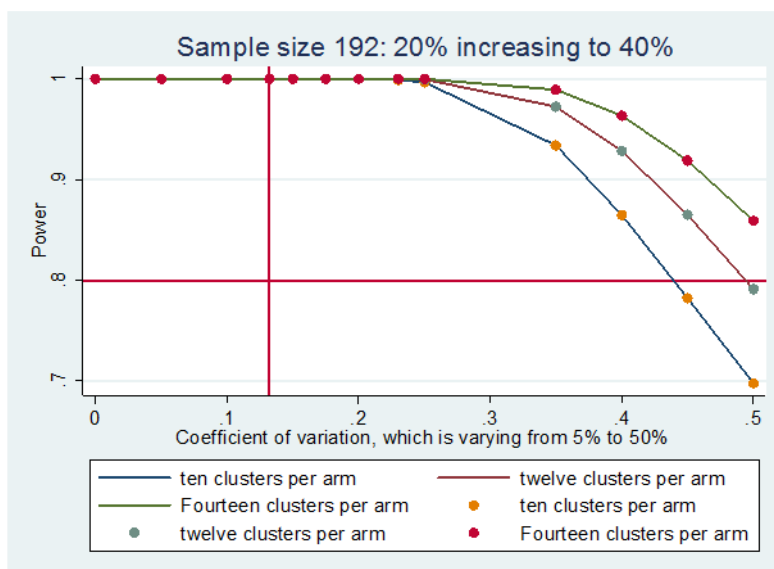


Figure 1: A graphic depiction of the power effect investigation for the study.

When excluding the four new classes and the five visually impaired children, there were 28 classes left amounting to 228 children. Of the 28 classes that could be randomised to the

control or intervention arms, 11 classes received high support, 9 medium support, and 8 low support.

Inclusion criteria:

Only children with a positive diagnosis of autism and attending the JHS, and who had a signed consent form from the parent or legal guardian were included.

Exclusion criteria:

Children who were absent on the day of treatment, as well as the four new classes. The five children attending the school with visual impairments were also excluded from the study.

2.4 Randomization Procedure and Allocation Concealment:

We randomised eight classes in each stratum which resulted in four classes from each stratum receiving the intervention and four classes receiving the standard care. For the randomization procedure, the primary researcher transferred the names of all the eligible classes onto strips of paper in the presence of the principal of the JHS and one of their residential occupational therapists (OT). The classes were then grouped into the three respective strata (high, middle or low support) and placed in three separate envelopes. The principal and OT were then asked to take turns and draw names from each stratum, finishing one stratum at a time, until all three were covered (25 classes selected). All the selected names were placed in a single container. The principal and OT were then asked to draw again, this time to select classes to either the control or intervention groups. Again they took turns until there were 13 classes selected to the intervention group and 12 classes to the control group (diagram 2).

The selected intervention and control groups were placed in an envelope and given to a resident speech therapist to keep. She was responsible for notifying the teachers of the intervention groups and giving them the social stories with instructions two weeks prior to the dental visit as well as any other logistical preparations needed.

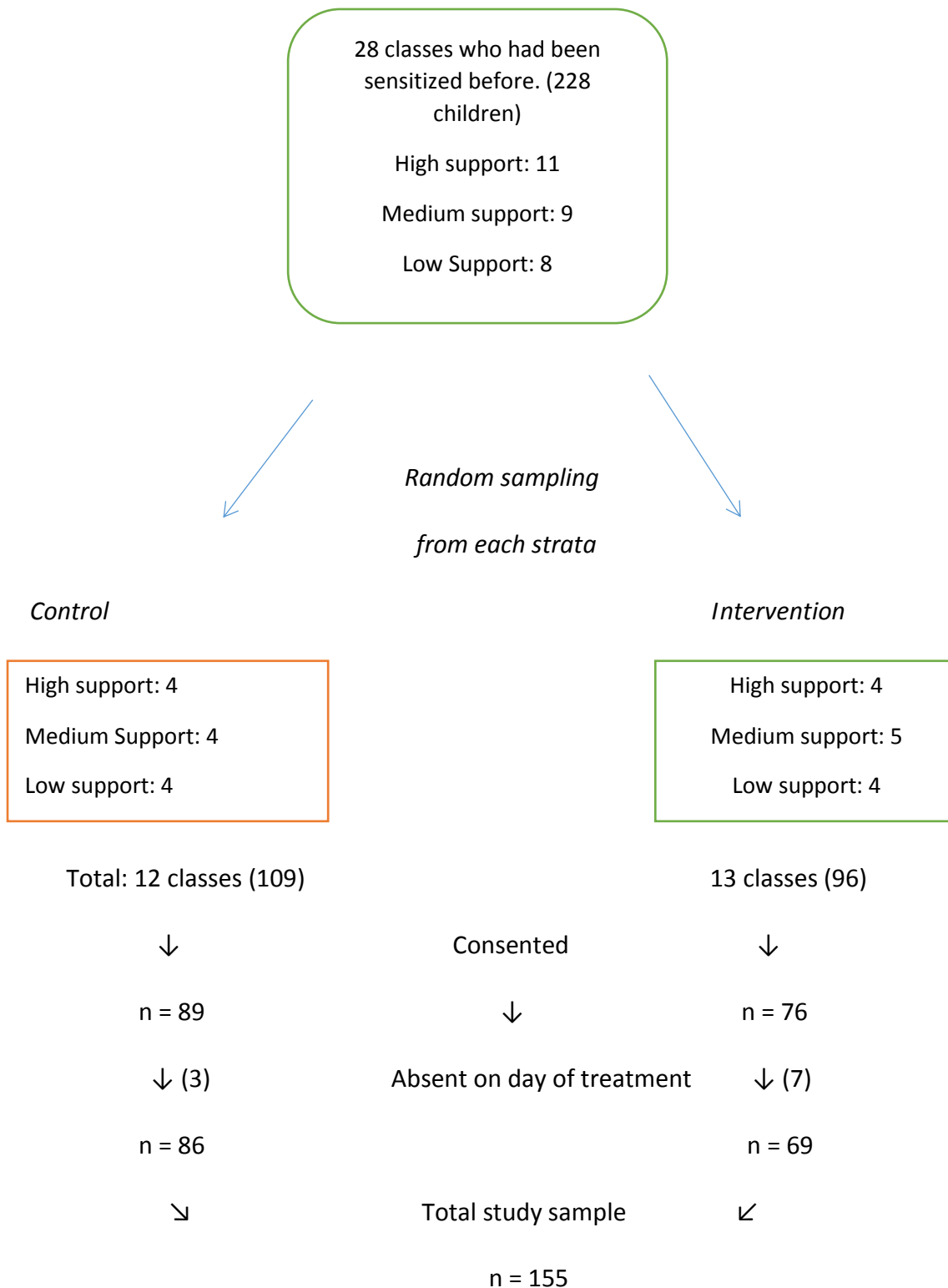


Figure 2: A diagrammatic representation of the actual sampling and randomization process.

2.5 Interventions:

There were two parts to the intervention:

A) Social story: At the JHS, the therapists will prepare a social story to be read for at least a week before the event and more than once per day. Therefore, it was decided to give our social story for two weeks at school. The decision was made to let the teachers read it at school because the majority of parents are often not compliant with instructions from the teachers.

The clusters (classes) in the intervention arm received a social story twice a day, read by the teacher. This time period was chosen because the creator of the social story, Carol Grey, indicated that success can be achieved by application in this timeframe.⁵³ Furthermore the therapists at the JHS read social stories for a minimum of one week and more than once a day. Although Grey intended the social story to be designed on an individual basis personalized to specific situations, Kharkhaneh and colleagues found that the same story targeting specific skill or behavior can be used effectively among different children.⁵³ Thus it was decided to give the same social story to a class because they are grouped into the same level of support. The speech therapist notified and gave the respective teachers the social story two weeks before the day of dental treatment and instructed them to read it in the mornings after breakfast and in the afternoons before school closes. This would amount to nine days of the story given twice daily.

A standardized story was used for all the classes. The researcher designed the content of the social story and it was written with the 'Widget talking in print' program with added Makaton sign language configured by one of the resident occupational therapists (Appendix E). The format of this program combine words and pictures with sign language and is routinely used by the occupational and speech therapists of the school when preparing the children for activities. The day of the dental visit was posted on their weekly planning calendar.

B) Visual schedule: On the day of the dental visit, a velcro board was placed on an assistant's chair next to the dental chair, in view of the patient. Six pictures (Appendix F) were positioned on the board, in sequence of treatment. As a 'phase' in the treatment was completed, the assistant removed the corresponding picture and 'posted' it into a plastic

box representing the end of the phase, until all relevant dental care was completed. This would mimic the participation of the child in an activity and the visual schedule technique is also routinely used in managing the daily activities of children at the JHS.

Control condition

The control condition is the standard of care that is provided for children going for routine dental treatment. Therefore classes in the control group did not receive the social story or visual schedule but were only told that they were going to the dentist on the Friday by means of their weekly planning calendar.

Dental treatment:

Rationale for placement of fissure sealants: Most caries lesions (80-90%) in adult molar teeth develop in the pits and fissures of these teeth, found predominantly on the occlusal aspect (top part of the tooth), while these pit and fissure caries amount to 44% of caries lesions in the primary molars.⁹⁰ A fissure sealant is a liquid material that is placed into the pits and fissures of caries-susceptible teeth that micromechanically bonds to the tooth preventing access by cariogenic bacteria to their source of nutrients⁹¹ and so reduces the risk of a cavity forming in the pits and fissures.⁹² They have been proven to successfully prevent and reduce caries from developing in pits and fissures of molar teeth for periods between 2 – 10 years depending on retention.^{92, 93} Fissure sealants are recommended for use in children that are at risk to develop caries.⁹² Children with special health care needs (ASD included) and children having parents or guardians being of a low socio-economic status are considered at high risk for developing caries.⁹⁴ Therefore it was decided to try and seal the first and second permanent molars, or the primary molars if permanent molars were absent.

Children with autism are at the JHS are at high risk for caries due to their medical condition, socio- economic status and their dietary habits.^{71, 94} The scheduled dental visit consisted of an attempted oral health examination and fissure sealant placement. The oral health examination was conducted according to WHO recommendations⁹⁵ but with the following

exceptions: if the child became too anxious as the dental chair was reclined to a horizontal position, the semi supine or supine position was maintained. For children too sensitive (anxious) to the standard dental chair light, the interior light of the mobile dental truck was used. Some children were too sensitive for the normal dental (metal) mirror and a wooden tongue depressor was used.

The hard tissues were evaluated using Klein and colleagues' decayed, missing and filled tooth index (DMFT/dmft)⁹⁶ while the plaque was scored using a modified plaque index with three options: i) no visible plaque, ii) 'visible plaque' (defined as the presence of visible plaque covering the cervical third of a tooth), iii) 'abundant visible plaque' (defined as visible plaque covering more than a third of the tooth surface). Both these indices were scored based only on visual inspection by the dentist. Gingivitis was scored as being present ('yes') when there were any signs of colour change and or oedema or alternatively then 'no', when these signs were not present.

The aim was to place fissure sealants on the first permanent molars or primary molars as indicated for the sealing of teeth in individuals classified as being of a high caries risk.^{92, 94} An attempt was made to try and place at least one fissure sealant initially on the day of the dental visit, but placing as many as the child allowed. Part of the study plan included scheduling follow up visits after the study to seal remaining teeth.

The fissure sealants were placed by the same dentist every week using the same technique. The material used was Clinpro™ (3M ESPE) resin based fissure sealant which is the standard fissure sealant used at the Wits Oral Health Centre. The recommended manufacturer's instructions for placement was followed. Summary of application sequence: i) clean the enamel surface with a rotary bristle brush; ii) dry the tooth and isolate with cotton rolls; iii) etch enamel for 15seconds and rinse afterwards; iv) dry etched enamel; v) apply sealant; vi) light cure for 20 seconds; vii) evaluate sealant and check occlusion; viii) dismissal.

Blinding:

The people involved in the randomisation of allocation into the control and intervention groups were the principal and an occupational therapist and not the primary researcher.

However, once randomization was complete, the operator (dentist), who in this case is also the primary researcher, could not be blinded because the intervention groups had a visual schedule in the truck, next to the dental chair while the control groups did not, leading to an obvious difference which cannot be concealed. The parents and children did not know if they were part of the control or intervention groups. Teachers were also not informed of the study so that they saw the visits as part of the 'normal' dental visits which would minimize suspicion or discussion of the interventions. Adding to this, all the control groups were seen during the first part of the study so that their teachers could not discuss the interventions and thus affect the intervention groups.

A teacher's assistant from the school was asked to administer the Frankl scale and complete the data collection sheet.

2.6 Study procedures

A letter explaining the study (Appendix B) was sent to all parents or legal guardians of children who were eligible to participate in the study. An additional consent form (Appendix C) accompanied the information form. If parents consented to their children participating in the study they provided written consent which was returned to the class teacher. Only children whose parents consented were included in the study. An assent form was developed for the children (Appendix D); however, due to the cognitive impairments of the children it was eventually not systematically implemented.

Children from a class were always accompanied by their teacher to provide comfort and assistance. One child was seen at a time while the remaining learners waited outside the truck supervised by the teacher's assistant. The teacher was seated or standing next to the dental chair and helped with communication and comforting the child. Once the child was seated in the dental chair, he or she is literally given a minute to just sit and absorb the environment. During this minute, no attempt was made to approach the child and all personnel inside the vehicle remained still and quiet. The mobile dental unit has LED lights on the walls which are used to light the room. The tell-show-do method was used to introduce the fissure sealant procedure. Commands were kept short and clear,

accompanied by voice control. Voice control is a deliberate alteration of voice volume, tone, or pace to influence and direct the patient's behavior as described by the American Academy of Pediatric Dentistry.⁷⁴ When the oral examination started, the dentist would count the teeth out loud as a means of distraction. Positive behavior during the visit were always rewarded with excessive praise by the dentist and teacher (differential reinforcement). Once the visit was completed, a child received a polystyrene cup full of salted popcorn as a reward.

2.7 Measurement

Outcome Measures:

Primary Outcome:

i) Success of dental treatment i.e., placement of a fissure sealant on the 1st permanent molar or primary molar, performed by the dentist. This was evaluated by whether the dentist could complete the placement of the fissure sealant according to the manufacturer's instructions or not (section B of appendix G). Thus, could a fissure sealant be placed: "no" or if "yes", number of fissure sealants.

ii) Behavior assessment:

a) This was done using the Frankl Scale. This scale is described as "one of the more reliable and frequently used behavior rating systems in both clinical dentistry and research".⁷⁴

Observed behavior is categorized into four groups ranging from definitely negative to definitely positive. The rating was done by a teacher's assistant from the JHS. The scale can be viewed on the data collection form (section C of appendix G). This is then treated as a categorical variable.

b) The ability of the child to sit in the dental chair was created as a categorical variable. The data form included if the child could sit in the dental chair and if a dental examination could be done or not (section A of appendix G). It was recorded as follows: i) 'unable to sit in the chair'; ii) Sitting in chair – uncooperative (operator unable to do oral exam); iii) Sitting in dental chair – cooperative (operator able to do oral exam); iv) Sitting on chair + able to carry

out treatment. The presence of oral defensiveness, defined as a child that seated in the dental chair but not allowing an instrument into the mouth or frequently objects to an instrument in the mouth, it was recorded as being oral defensive, was noted and also recorded by the assistant. Furthermore, tongue thrusting by the patient inhibiting examination and treatment was also recorded as being present (“yes”) or not (“no”) and treated as binary variables.

Secondary outcome: (section A of appendix G)

DMFT/dmft index score for all children who could undergo a dental examination. The measurement was performed via an oral examination by the researcher using a dental mirror and overhead light. No x-rays were taken as part of the examination. The dmft index evaluates each tooth to see if there is decay or a filling or if the tooth is missing due to the consequence of decay. The score represents the sum of affected teeth according to these criteria. The continuous variable was used in analysis. There are international cut-points for DMFT/dmft scores where 1-2.6 is considered low, 2.7-4.4 is considered moderate and 4.5 - 6.6 is considered high and a score above 6.7 is considered very high. A categorical variable was used for some analyses.

Novel Measures:

- i) Oral health data including presence of plaque was a categorical variable with three levels of severity (none, moderate and severe, as explained on page 24 under dental treatment) and gingivitis was a dichotomous variable: present or absent according to clinical observation.
- ii) Oral defensiveness (present or absent) and tongue thrusting (present or absent) during dental examination and treatment and treated as binary variables.

Covariates:

Level of support: A categorical variable with three levels. Level 1=least support required to function and can be equated to the highest functional status of the children; Level 2=moderate support required which indicates that the children had moderate functional status and Level 3=high level of support required. Children categorized in Level 3 required

substantive support and this could be equated to the lowest functional status. This was analyzed as a categorical variable.

2.8 Data analysis

Data entry was recorded using a data sheet with the following three categories (see Appendix E) i) Oral examination, ii) Success of dental treatment (yes or no answer provided by the dentist) and iii) Behaviour, as rated by the assistant by means of the Frankl scale. The observer was calibrated once by a resident clinical psychologist from the Ernie Else Foundation. All data recording was performed by this assistant. The form also included demographic data which was coded to conceal the identity and class of each child.

Data was cleaned through 10% random checks as well as using Stata 13.0 software functions.

The main analysis was on an Intention- to-treat basis and limited to the individual level. Learners were analysed according to their assignment to intervention or control arm. For continuous variables, means with standard deviation were used. For categorical variables, chi squared test was done to determine any statistical differences between the outcomes of interest in the intervention and control groups. Statistical significance was set at 0.05. Analysis started by comparing characteristics of learners who consented against those who did. Thereafter the study arms were compared to make sure the control and intervention arms equivalent on all key sociodemographic characteristics, for example, age, gender, race and level of support. The three outcomes: sitting, Frankl scale and fissure sealant placement were then compared for the intervention and the control arm. Thereafter associations between the main outcomes by level of support were tested.

Initial comparisons were based on observed outcomes comparing between groups and included t-tests, oneway ANOVA and chi-squared or Fisher's Exact tests (where there were small numbers) for categorical data.

Logistic regression was used to test the hypothesis that children with higher support needs have poorer oral health status while controlling for the possible confounding effects of age, gender and study arms. Models were built for four outcomes: sitting, Frankl, placement of

fissure sealants and DMFT. A binary variable was created for all the variables with 0=none/not able to sit and 1=any / able to sit.

2.9 Ethics

Ethical approval for the trial was obtained from the University of the Witwatersrand's Human Research Ethics Committee. (Appendix A) The ethics clearance number is M150749. Children only participated in this trial if their parents or legal guardians granted consent (Appendix C) after they were well informed (Appendix B).

The paper data forms were stored in the researcher's office in a lock cabinet. To ensure anonymity participants were assigned study numbers and analyses was done according to these unique identifiers. Data analysis was done by the researcher and supervisor after the data set was cleaned and de-identified. The dataset was stored in the researcher's laptop which is password protected. The data will be retained for a period of two years after completion of the study. Only the researcher had access to the dataset.

Chapter 3: Results

3.1 Children with consent and those without

As indicated by the flow diagram (figure 2), there were 40 learners without consent, nearly twenty percent (19.5%) of the total study population. A further ten learners were absent on the day of examination and treatment.

3.2 Comparison of study arms for sociodemographic data

Table 1: Demographic data of control and intervention groups

	Control		Intervention		Total		p value
	n	%	n	%	n	%	
Age (yrs.)	8.57	SD=2.66	11.51	SD=3.54			< 0.001
Gender							
Male	75	53.96	64	46.04	139	100	
Female	11	68.75	5	31.25	16	100	*0.30
Race recoded							
African	83	56.85	63	43.15	146	100	
Combined/ other	3	33.33	6	66.67	9	100	*0.19
Phase							
1	26	100	0	0	26	100	
2	27	48.21	29	51.79	56	100	
3	23	67.65	11	32.35	34	100	
4	10	35.71	18	64.29	28	100	
5	0	0	11	100	11	100	
Support							
1 (Low)	33	60.0	22	40.0	55	100	0.069
2 (Medium)	18	40.91	26	59.09	44	100	
3 (High)	35	62.5	21	37.5	56	100	

* Fischer's exact test

Table 1 shows the results for the comparison between the intervention and control arms and sociodemographic characteristics. There was no statistically significant difference between the two arms for gender, race or level of support of learners. Significant differences were detected in age. The mean age of the study population was 9.88 years (Std.

Dev. = 3.4) ranging from 4 to 19 years. Children in the control group had a mean age of 8.57 years while those from the intervention arm were almost three years older with a mean age of 11.51 years. ($p < 0.001$)

3.3 Oral Health Status

Table 2: Oral health status data of children in the study

Plaque	n	%			
None visible	13	10.32			
Visible plaque	65	51.59			
Abundant visible plaque	48	38.10			
Total	126				
Gingivitis					
Absent	31	24.60			
Present	95	75.40			
Total	126				
dmft/DMFT	n	mean	Std Dev.	Min	Max
Dmft	82	2.01	3.07	0	17
DMFT	116	0.90	1.91	0	12

Table 2 portrays the oral health status of the study population (n= 126) was as follows: 10.3% had no visible plaque, 51.6% had visible plaque while 38.1% had abundant visible plaque. There was no significant association between level of support and plaque. Regarding gingivitis, 75% of children had visible signs of gingival inflammation again with no significant association between gingivitis and level of support. Of these children, 18.7% (29) could not be examined.

The prevalence of dental caries in the primary dentition was calculated as 42.7% and the mean dmft score was 2.01 (Std Dev. = 3.07; 95% CI: 1.34; 2.69) while the dental caries prevalence in the secondary dentition was 28.4% with the mean DMFT score being 0.90 (Std Dev. = 1.91; 95% CI: 0.54; 1.25).

3.4 Main outcomes: Sitting, Frankl scale and Fissure sealant

This section describes the outcomes for Objectives 1, 2 and 3 as described in section 1.2.

Table 3: Main outcomes by intervention and control arms

	Control		Intervention		Total		p value
	n	%	n	%	n	%	
Sitting							
1. Could not sit at all	12	63.16	7	36.84	19	100	0.60
2. Sitting but no exam	11	44.0	14	56.0	25	100	
3. Sitting for exam	45	56.25	35	43.75	80	100	
4. Sitting with FS placement	18	58.06	13	41.94	31	100	
Frankl Score of behaviour							
1. --	13	52.0	12	48.0	25	100	0.015
2. -	26	41.94	36	58.06	62	100	*0.014
3. +	36	72.0	14	28.0	50	100	
4. ++	11	61.11	7	38.89	18	100	
Total Fissure sealants placed							
0	68	55.28	55	44.72	123	100	*0.057
1	10	83.33	2	16.67	12	100	
2 - 4	8	40.0	12	60.0	20	100	
Tongue thrusting							
no	18	58.06	13	41.94	31	100	0.86
yes	45	56.25	35	43.75	80	100	
Oral defensive							
no	19	54.29	16	45.71	35	100	0.89
yes	54	55.67	43	44.33	97	100	
Self-Injurious Behaviour (SIB)							
no	71	56.8	54	43.2	125	100	0.008
yes	0	0	6	100	6	100	

* Fischer's exact test

Table 3 shows that there was no significant difference between the control and intervention groups regarding the ability to sit in the dental chair (Fisher's exact= 0.60). Nearly 52% of the children (80) could sit for a dental examination with an additional 20% (31) who could receive treatment. It was possible to collapse the four levels of sitting in the dental chair

into two categories: 'negative sitting' (unable to sit long enough for examination and treatment) and 'positive sitting'. We found that three-quarters of the children in the negative sitting category required the highest level of support to function.

Using the Frankl scale for analysis of behaviour (Table 3) showed significant differences between the two groups (Fischer's exact= 0.014). The number of children displaying behaviour which is definitely negative (category 1) was similar for both groups but differences were evident for categories 2, (41.9% vs. 58.1%), 3 (72% vs.28%) and 4 (61.11% vs. 38.89%). When combining the negative behaviour (categories 1 and 2) into one variable as well as the positive behaviour (categories 3 and 4), significantly (p=0.003) more children from the intervention group (55%) behaved in a negative way compared to the control group (45%).

Fissure sealant placement was only possible for 20% of the study population amounting to a total of 63 fissure sealants. The number of fissure sealants placed per child ranged between zero and four. When keeping the number continuous there was no statistically significant difference between the control and intervention groups (p = 0.24). However, the data were skewed due to the high number of zeros. When combining the children into three groups or categories: no fissure sealants placed (80%), one fissure sealant (7.74%) and two or more fissure sealants (12.26%) placed, the difference neared significance (Fisher's = 0.057). Double the number of children had two or more fissure sealants placed in the intervention group compared to the control group (n=6 vs. n=12) suggesting that the intervention group had a higher number of children who could tolerate more dental work, meaning they could be more cooperative for longer.

Table 4: Sub-group analysis showing the number of fissure sealants placed among children requiring the least support

Number of FS placed	Control		Intervention		Total		P-value
	n	%	n	%	n	%	
0	18	54.55	8	36.36	26	47.27	0.057*
1	9	27.27	2	9.09	11	20.0	
2	6	18.18	12	54.55	18	32.73	
Total	33	100	22	100	55	100	

*Fisher's exact = 0.016

The results from table 4 show that significantly more fissure sealants could be placed in the intervention group compared to the controls. ($p=0.016$) Only 36% of the intervention group could not receive any fissure sealants compared to the 55% of the control group, while 55% of children in the intervention arm could receive two or more fissure sealants compared to the 19% from the control groups. When a test was performed to compare the mean number of fissure sealants placed among the study arms of children from support level 1, there were almost twice as many fissure sealants placed in the intervention groups (mean = 1.41; 95% CI: 0.79; 2.03) compared to the controls (mean 0.79; 95% CI: 0.38; 1.91). Although this finding was not statistically significant ($p=0.076$), the marginal finding suggests that the intervention may enable a longer dental treatment. Results from this sub analysis need to be interpreted with caution since it was not part of the intention- to- treat and has a small sample size ($n=55$). A properly designed study with sufficient power should be utilized to substantiate this finding.

No statistical difference was found between the groups for tongue trusting ($p=0.86$) and oral defensiveness ($p=0.89$) but significantly more children from the intervention group displayed self- injurious behaviour as reported by their teachers. (Fisher's exact = 0.008)

3.5 Oral health status and severity of caries by level of support

This section describes the results for Objective 4 of the study.

Table 5: Analysis of outcomes according to level of support

	Support level								p value
	Low		Medium		High		total		
	n	%	n	%	n	%	n	%	
Plaque									
None	3	23.08	6	46.15	4	30.77	13	100	* 0.26
Some	32	49.23	16	24.62	17	26.15	65	100	
Abundant	18	37.5	19	39.58	11	22.92	48	100	
Gingivitis									
no	13	41.94	10	32.26	8	25.81	31	100	0.99
yes	40	42.11	31	32.63	24	25.26	95	100	
	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)	p value
dmft	37	2.19 (3.45)	30	1.8 (2.94)	15	2 (2.36)	82	2.01 (3.07)	0.25
DMFT	51	0.55 (1.32)	40	0.75 (2.15)	25	1.84 (2.29)	116	0.90 (1.91)	0.001
DMFT recoded	n	%	n	%	n	%	n	%	
0	40	48.78	30	36.59	12	14.63	82	100	0.041
1	4	36.36	5	45.45	2	18.18	11	100	* 0.055
2	3	37.5	2	25.0	3	37.5	8	100	
3	4	26.67	3	20.0	8	53.33	15	100	
Sitting									
1	2	10.53	2	10.53	15	78.95	19	100	*<0.001
2	3	12.0	4	16.0	18	72.0	25	100	
3	22	27.5	35	43.75	23	28.75	80	100	
4	28	90.32	3	9.68	0	0	31	100	
Sitting recoded									
Not able to sit	5	11.36	6	13.64	33	75.0	44	100	*<0.001
Able to sit	50	45.05	38	34.23	23	20.72	111	100	
Frankl									
1	1	4.0	3	12.0	21	84.0	25	100	*<0.001
2	17	27.42	24	38.71	21	33.87	62	100	
3	21	42.0	15	30.0	14	28.0	50	100	
4	16	88.89	2	11.11	0	0	18	100	
Frankl recoded									
0	18	20.69	27	31.03	42	48.28	87	100	< 0.001
1	37	54.41	17	25.0	14	20.59	68	100	
FS total									
0	27	21.77	41	33.06	56	45.16	124	100	*<0.001
1	11	91.67	1	8.33	0	0	12	100	
2	9	90.0	1	10.0	0	0	10	100	
3	4	80.0	1	20.0	0	0	5	100	
4	4	100	0	0	0	0	4	100	

FS recoded									
0	26	21.14	41	33.33	56	45.53	123	100	*<0.001
1	11	91.67	1	8.33	0	0	12	100	
2 or more	18	90.0	2	10.0	0	0	20	100	

* Fischer's exact test

There was no difference between the amount of plaque ($p=0.26$) and gingivitis ($p=0.99$) between the three levels of support. (Table 5) However, for dental caries a different phenomenon was seen. Although there was no difference in the dmft score for the deciduous teeth ($p=0.25$), there was a linear increase in caries severity in the DMFT according to the level of support. The low support group had the lowest DMFT score at 0.55, middle support DMFT = 0.75 and high support DMFT= 1.84. ($p=0.001$ during ANOVA test). When analysing the DMFT score according to the following categories: a score of zero, one, two and three or more, there was a significant difference ($p=0.04$) among the categories. The high support group was twice as likely to have a DMFT of three or more compared to the low support (26%) and more than twice that of the middle support (20%). Therefore, there was a linear increase in the DMFT score as the amount of support needed for normal functioning increased. The logistic regression model showed that the high support group had a significantly poorer ($p=0.006$) DMFT score (1 or more) while controlling for age, gender and control/intervention status.

The ability to sit in the dental chair was also significantly associated the level of support (Fisher's < 0.001). (Table 5) Most of the children (78%) in category 1 of sitting (not able to sit on the dental chair at all) was from the high support group and for category 2 (able to sit but too uncooperative for dental examination), 72% of the children was also from the high support group. In category three (able to sit in the dental chair and receive a dental examination) most children (43%) was from the middle support group, followed by the high support (28%) and low support (27%) groups. Category four of sitting (able to sit for dental examination and treatment) was dominated by children from the low support group (90%) with a small contribution from the middle support group (10%). There were no children from the high support group that could sit for a dental examination and fissure sealant treatment.

When combining sitting levels one and two into one level, and sitting three and four into one level to create a dichotomous variable, comparing this to the level of support while

controlling for age, gender and study arm, the level of support was associated with the ability to sit ($p < 0.001$) while controlling for covariates. None of the children with a high support status was able to sit for a dental examination and or dental treatment. (Table 5)

The Frankl scale had highly significant (Fischer's < 0.001) findings. The results for negative behaviour were as follows: the overwhelming majority (84%) of children scored as level one were from the high support group, followed by the middle support (12%) and low support (4%). For level two score, the majority of children was from middle support (38%), followed by the high support (33%) and the low support (27%). Overall, the majority of children displaying negative behaviour were from the high support group (48.3%) followed by the middle support (31%) and lastly the low support group (20.7%). (Table 5)

The majority of children displaying positive behaviour was from the low support group (54.4%), followed by the middle support (25%) and the high support group with 20.6%. Specifically, in level three, (positive), 42% of children were from the low support group, 30% from the middle support and 28% from the high support group. (Table 5) In level four, 89% of children were from the low support group and the remaining 11% were from the middle support group. There were no children from the high support group displaying definitely positive behaviour. Therefore, there is a clear linear correlation between behaviour and the level of support. Behaviour becomes increasingly negative as support needed to function increases.

In table 6, logistic regression again showed that high support status was the strongest catalyst for negative behaviour ($p < 0.001$) when controlling for covariates while the same model indicated that age also significantly affected behaviour showing that for every 1 unit increase in age, behaviour improved by 27% ($p < 0.001$).

Fissure sealant placement was also highly dependent (Fischer's < 0.000) on the level of support. (Table 5) Categories are based on the total amount of fissure sealants placed and range from zero to four. Where no fissure sealants have been placed, the majority of children (45%) are from the high support group, followed by the middle support (33%) and low support group (22%), indicating a linear decline. Therefore, there is a linear decline in the amount of fissure sealants placed as the need for support increases. There were no fissure sealants placed in children from the high support group. For one fissure sealant

placed, the majority of children (92%) were from low support and eight percent from the middle support. This is virtually repeated for two and three fissure sealants, and it was only possible to place four fissure sealants in the low support group. When grouping the amount of fissure sealants placed into zero, one and two or more (FS Recoded, table 5), the association becomes even stronger showing that the lower the level of support, the greater the number of fissure sealants placed.

The use of logistic regression to control for age, gender and control/intervention status showed that level of support is independently associated with the ability to place a fissure sealant. (Table 7) No fissure sealant was possible for the high support group and there was a significant difference ($p < 0.001$) between medium and low support. Therefore, the lower the support provided to an autistic child, the more likely it becomes to place a fissure sealant and to do more fissure sealants. Age was marginally significant ($p = 0.049$; aOR 1.19) indicating that for every one year increase in age, there is a 19% increase in the ability to place a fissure sealant.

Table 6: Oral defensiveness, tongue trusting and SIB analysed by levels of support

		Support level				p value
		1	2	3	total	
Oral defensive						
no	n	27	4	4	35	* <0.001
	%	50.94	9.76	10.53	26.52	
yes	n	26	37	34	97	
	%	49.06	90.24	89.47	73.48	
total	n	53	41	38	132	
	%	100	100	100	100	
Tongue thrusting						
no	n	25	4	2	31	* <0.001
	%	50.0	10.53	8.7	27.93	
yes	n	25	34	21	80	
	%	50.0	89.47	91.3	72.07	
total	n	50	38	23	111	
	%	100	100	100	100	

SIB						
no	n	52	40	33	125	*0.15
	%	98.11	97.56	89.19	95.42	
yes	n	1	1	4	6	
	%	1.89	2.44	10.81	4.58	
total	n	53	41	37	131	
	%	100	100	100	100	

* Fischer's exact test

In the low support group, 50% of children displayed tongue thrusting which increased exponentially as the amount of support increased with the medium support at 89% while 91% of the high support group displayed tongue thrusting. (Table 6) This depicts a significant (Fischer's < 0.001) exponential increase in tongue thrusting as the level of support increases with support level two and three being virtually equal.

Oral defensiveness had a similar trend (Fischer's < 0.000) with 49% of children from the low support group while 90% and 89% were from the medium and high support respectively. (Table 6)

Self-injurious behaviour was not statistically significant (Fisher's exact= 0.15) but it is clear from table 6 that most of the children displaying this were from the high support group.

Table 7: Logistic regression analysis for the main outcomes against functional status

	Model 1			Model 2			Model 3			Model 4		
	Sitting			Frankl			FS (none vs. any)			DMFT (None vs. any)		
	aOR	95% CI	p value	aOR	95% CI	p value	aOR	95% CI	p value	aOR	95% CI	p value
Level of support												
Low	Reference			Ref								
Med	0.7	0.2 - 2.7	0.65	0.4	0.1 - 0.9	0.03	0.06	0.02 - 0.24	<0.001	1.4	0.5 - 3.7	0.58
High	0.07	0.02 - 0.2	< 0.001	0.1	0.04 - 0.26	<0.001	not possible			4.6	1.6 - 13.3	0.006
Age	1.1	0.9 - 1.2	0.45	1.3	1.1 - 1.5	0.001	1.2	1.0 - 1.4	0.049	1.1	0.97 - 1.3	0.11
Study arm												
Control	Reference											
Intervention	0.5	0.2 - 1.2	0.13	0.1	0.05 - 0.3	<0.001	0.7	0.2 - 2.3	0.58			
Gender												
Male	Reference											
Female	0.8	0.2 - 2.9	0.75	1.2	0.4 - 4.1	0.78	1.6	0.2 - 12.2	0.64	0.2	0.02 - 1.84	0.16

Chapter 4: Discussion

4.1 Synthesis of main findings

The study set out to investigate the effectiveness of a social story and visual schedule techniques in modifying the behaviour of a cohort of autistic children during dental examination and fissure sealant placement. No differences were found between the intervention and control groups on the three primary outcomes for the study (sitting, Frankl scale or fissure sealant placement) supporting the stated null hypothesis.

When comparing the oral health of children at the three levels of functioning, there was a difference with children from the lowest level of functioning having significantly worse DMFT scores.

Although there were no significant differences between the intervention and control clusters in the three outcomes pertaining to dental treatment, there was a promising trend that among the children who were able to sit in the dental chair there was cooperation for a longer period of time. When the number of fissure sealants placed was combined into three categories and compared between the study arms, the difference between study arms neared statistical significance ($p=0.057$) suggesting that children exposed to the intervention could tolerate more dental work and were cooperative for longer. This implies a greater ability to cope with the sensory overload. However, this was only evident among the children who were able to sit in the dental chair. There was no difference between the two groups in the ability to sit in the chair.

The reasons for the no significant findings could be related to the implementation of the intervention, the intervention itself, or the environment of the mobile dental clinic. While a formal process evaluation was not conducted alongside the implementation of the intervention during the trial, there were several discussions with teachers and therapists that suggest that the intervention was not implemented in the same way in every class. Teachers were expected to read the social story at least twice daily for the two weeks preceding the visit to the mobile dental clinic. It is unclear whether there was fidelity to the intervention.

A workgroup on treatment fidelity from the National Institute of Health Behavior Change Consortium describe fidelity as “the use of methodological strategies to monitor and enhance the reliability (i.e., the consistency) and validity (i.e., the appropriateness) of behavioural programmes”.⁹⁷ Concerning implementation, fidelity is the degree to which an intervention is delivered as intended.⁹⁸ Therefore the degree to which there was fidelity in the implementation of the intervention will directly influence the validity of the study outcomes. The current study could be suffering from a type two error due to either an ineffective intervention or inadequate administration of the intervention.

Due to the suspected lack of fidelity of the implementation of the intervention in the current study it is difficult to judge whether the current intervention alone could improve behaviour in the dental environment or if multiple interventions are needed and if indeed whether the intensity of implementing the intervention for two weeks before a dental appointment is sufficient preparation. Karkhaneh and colleagues (2010) reported that there is a degree of uncertainty about the true effect of social stories among children with ASD.⁵³ In addition, confounding factors, inadequate participation, co-interventions, and poor study design and implementation have made it difficult to conclude that social stories alone can result in behaviour change among children with ASD. They further conclude that effectiveness of this intervention in less- controlled settings as well as the optimal dose/ frequency is unknown and requires further research.⁵³

The analysis of the three outcomes pertaining to dental treatment: sitting in a dental chair, cooperation according to the Frankl scale and application of fissure sealants, by the level of support that the child requires produced significant findings. We found that there were associations between level of functioning of the autistic child and the outcomes.

The aim of management of the child with ASD is to improve functioning and it has been shown that results are better when interventions are implemented with greater intensity and over a longer period of time.⁵¹ This study highlighted the fact that the group requiring the least support (also known as the highest functioning group) consistently performed better in the three objectives pertaining to dental treatment compared to the groups that required considerable and high levels of support. This finding suggests that future interventions need to be tailored to the functional status of the child with ASD. The social

story in particular, may have the potential to positively affect the groups that require less support.

Although level of support was the strongest indicator of compliance with activities surrounding the dental visit, age of the child was also significantly associated with positive behaviour although was only marginally significant in facilitating fissure sealant placement and was not associated with the ability of the autistic child to sit in the dental chair. Loo and colleagues (2009) found that for every one year of life, there is an 8% decrease in negative behaviour and that the younger autistic patients were less cooperative.⁷⁷

4.2 Demographics

At the time of calculating a sample size, it was estimated that twenty percent of the parents would not consent to the study. In the end this figure was 19.5 percent amounting to 40 children. The number of children who needed to be excluded from the study as they had no consent was large enough to influence the statistical power of the study, therefore we compared the social demographics of the children who consented and those who did not to identify possible differences between the groups that might influence the study. After analysis it was clear that the children whose parents consented and those who did not were the same for every variable except race.

The ratio of males to females in the study population was 8.7 : 1, higher than the average of 3 – 4.5 :1 often quoted in the literature^{77, 99-101} and is close to the ratio found in Klein and Nowak's study (1999) which had 9.75 : 1¹⁰² and Morinushi's 9.25: 1.⁶¹

4.3 Oral health status

The fact that 90% of the study population had visible or abundant visible plaque is similar to findings of other authors in developed⁵⁹ as well as developing countries^{72, 103} who found that autistic children have low levels of oral hygiene. Three quarters (75%) of the children had gingivitis ranging from mild to severe as the amount of plaque increased. Therefore only 25% of the children had healthy gingivae which was less than the 39.5% recorded by Klein

and Nowak (1999) in the United States.¹⁰² Still it was less than the 97% recorded by Jaber (2011) in the United Arab Emirates⁶⁸ and 100% recorded by Murshid (2005) in Saudi Arabia.⁶⁵ There was no significant difference in the distribution of plaque (Fisher's = 0.26) or gingivitis ($p=0.99$) by level of support required by the child with ASD. This finding is surprising as it could be expected that the oral hygiene would be poorer among children with lower functional status because of the high level of support needed for everyday activities. The reasons for the high levels of plaque and gingivitis may be the absence of oral hygiene routine in the home and the fact that there is no brushing program currently at the school. Poor oral hygiene can also be ascribed to impaired motor function and or the inability to understand and follow instructions as well as grasping the importance of oral hygiene procedures due to the nature of the disability.^{59, 85} Marshall and colleagues (2008) found that poor oral hygiene were associated with caries in their autistic cohort of 99 children in the US.⁷¹ These findings suggest a need to improve oral hygiene amongst children with ASD.

Socio economic status might also contribute to high levels of plaque and gingivitis since virtually all of the children in the Johannesburg School are from low income households. Many are from households where the primary caregiver is a grandmother.⁸⁹ A substantial number rely on government grants and are exempt from school fees due to lack of income of parents and caregivers,⁸⁹ therefore having a toothbrush and tooth paste might not be possible.

The dental caries prevalence of 42.7% in the primary dentition of the autistic cohort who participated in this study is significantly lower than the South African national prevalence of 60.3% for six year olds as recorded by the National Children's Oral Health Survey 1999/2002¹⁰⁴ and is higher than the prevalence of 27.6% for other special needs children in South Africa as recorded by Nqobco.⁶ Furthermore it is comparable to the 50% prevalence found by Subramaniam and Gupta (2011) in India with a sample of 106 autistic children⁶⁶ but lower than the 77% recorded by Jaber (2011) in the United Arab Emirates with a sample of 61 autistic children.⁶⁸ The dmft of 2.01 is also significantly lower than the SA national average of 3.13 for 6 year olds recorded by the same survey.¹⁰⁴ The dmft of the autistic cohort is comparable to the 1.8 of the 1995 autistic cohort recorded by Morinushi in Japan⁶¹

whose cohort also had a lower caries prevalence than the national mean, as well as Subramaniam's (2011) study done in India with a score of 1.89.⁶⁶

The caries prevalence of 28.4% in the secondary dentition of the autistic cohort was lower than the national average of 41.7% for 12 year old children as recorded by the National Children's Oral Health Survey 1999/2002¹⁰⁴ and somewhat higher than the 16.9% found by Subramaniam⁶⁶ and the Furthermore the DMFT of 0.9 is also significantly lower than the national average of 1.17 for 12 year olds recorded by the same survey, and comparable to other international findings from developed¹⁰⁵ and developing countries.⁶⁵

The prevalence and severity of caries in the study population followed the same trend as seen in typical South African children in that the primary dentition was more affected by the disease than the secondary dentition.¹⁰⁶ When comparing the burden of dental disease in this autistic cohort to other special needs children in South Africa, the caries prevalence in the primary dentition (dmft) was much higher than recorded by Nqco and colleagues (2012), while the autistic cohort's DMFT score was lower than the 33.6% recorded by Nqco and colleagues.⁶

This study is the first to investigate the caries experience of the secondary teeth of autistic children against the level of support as defined by the Diagnostic and Statistical Manual of mental disorders 5th edition.¹¹ Of great importance is the finding that the severity of caries in the secondary dentition of autistic children increase as the level of support needed to function increases. This finding is partially similar to with Desai and colleagues (1999) but they reported multiple disabilities and their level of functioning was expressed using a six-point scale based on the ability to perform self-care activities.¹⁰⁷ This finding contradicts those of with Blomqvist (2015) who investigated a group of autistic adults who lived independently and found no difference in DMFT and severity of autism but severity was determined by the participants completing an Autism Spectrum Quotient rating scale, thus implying a higher level of functioning.⁶⁰ Loo and colleagues (2009) could also find no association between caries prevalence and severity between three ASD diagnosis groups: autistic disorder, pervasive developmental disorder not otherwise specified and Asperger syndrome.¹⁰⁵ The reasons for this trend can be the inability to perform basic functions, like brushing teeth, flossing and visiting the dentist, which is due to the nature of the Autism Spectrum Disorder in that the child has difficulty to understand and follow instructions as

well as the possibility of impaired motor function with increased sensory sensitivities.^{77, 85}

The ability to participate and perform these tasks will reduce as the level of support needed to function increases.

The literature does not provide a clear picture of the associations between SES and caries status among children with ASD. Marshall and colleagues (2010) did not find an association between SES and caries status in their study of autistic children.⁷¹ However, Watt (2007) contradicts this by stating that there is sufficient evidence from several countries that people with lower socioeconomic status have poorer oral health than people from a higher SES.¹⁰⁸ A review by Bagramian and colleagues (2009) investigating the global situation regarding caries showed that caries is increasing in developed and developing countries and that socioeconomic status is still an important risk factor for caries.¹⁰⁹ Furthermore the WHO has included socioeconomic status in their risk factor model for oral diseases.¹¹⁰ Most children with ASD and other developmental disorders live in low- and middle income countries¹⁴ which may mean that there is a higher burden of oral disease such as caries among this group.

4.4 Tolerance for dental examination and treatment:

The ability to sit in the dental chair and undergo a dental examination was possible for half of the study population and is far less than the 85% achieved by Lowe and Lindeman (1985) albeit their sample comprised of only 20 children.⁵⁹ Although there was no difference in the ability to sit in the dental chair between the study arms, analysis by level of support showed a very strong inverse association between sitting and higher levels of support in that three-quarters of the children in the negative sitting category required the highest level of support to function. Therefore, sitting in the dental chair is considerably easier for the higher functioning autistic children. When evaluating the four levels of sitting level three and four of sitting is most desirable for a dentist as it indicates that the child is able to sit and receive a dental examination and also whatever else is needed in terms of treatment and can be seen as 'positive sitting'.

The behaviour of the autistic cohort categorised using the Frankl scale, found that 56.1% (87) behaved in a negative way and 43.9% in a positive way. Our cohort exhibited the same

behaviour as found by Loo (2009) when 55.2% of their patients behaved in a negative way and 44.8% in a positive way.¹⁰⁵ Subramaniam (2011) found a higher percentage of negative behaviour (65.1%) versus positive (34.9%).⁶⁶ Murshid (2005) reported 85% of the study sample (n=20) who behaved in a negative .⁶⁵ The behaviour as rated by the Frankl was also associated with the level of support that a child required. As the level of support required increases, so does negative behaviour with 75% of children requiring the highest level of support behaving in a negative way. Inversely, as the level of support decreases, positive behaviour increases with 67% of children requiring the lowest level of support behaving in a positive way.

The ability to sit in the dental chair and endure a dental exam and a form of dental treatment seems to be entirely dependent on the level of functioning which is based on the severity of the autism diagnosis. The sub analysis of the low support group indeed further supports this notion that the social story enabled the intervention groups to perform better. This finding similar to Feinberg (2002) who found autism severity to be the strongest predictor of social skills score in the activities of game playing, greeting behaviour and asking one another what they want to play.¹¹¹ Regarding the outcomes of sitting, behaviour and fissure sealant placement, children requiring minimal support consistently performed best although support those requiring moderate was not far behind. Therefore, when planning dental treatment for autistic children, selection of behaviour guidance should be based on interventions relevant to the level of support of the autistic child rather than what is most comfortable or works best for the practitioner.

Oral defensiveness and tongue trusting were significantly worse in the support level two and three which is to be expected since these are part of defensive or negative behaviour which we have seen increases as the severity of the autism diagnosis increases.¹⁰⁷

4.5 Reflections on the social story as an intervention

When evaluating the specific social story used as a means to modify behaviour of the autistic child to accommodate dental treatment, it is clear that the social story was not effective for those requiring high levels of support. This is understandable since it is said that in addition to visual cues, social stories do rely on reading skills and the presence of

basic auditory processing skills⁹⁹ and seems to be naturally more suited for children requiring low and moderate support.⁵³ Video modelling can serve as an alternative method of preparation for children who have limited reading and auditory skills.⁹⁹

Aberrant behaviour in the autistic child can stem from what immediately precedes a given activity.³⁰ When evaluating the social story it is therefore necessary to take into consideration all events leading up to the dental visit, but also all events during the visit that could influence behaviour. With this in mind, the following need to be mentioned:

The mobile dental unit was parked next to the school building. As such there are numerous sensory inputs that could possibly interfere with treatment. These include: periodic noise as waste is dumped in two dumpsters about 15 meters away from the truck; periodic noise from a generator of the school about 15 metres from the truck; construction noise (grinders, hammering) from routine maintenance of the school building as well as construction of a new building about 50 metres away. There was also the periodic noise and rumble from the surgeries' compressor situated underneath the truck. Some of the children waiting their turn outside the truck would sometimes cry, scream, wail or become more playful or restless. These factors could all contribute to sensory overload in the autistic child.

Sensory sensitivities are common in individuals with ASD¹¹²⁻¹¹⁴ and are more frequent compared to than those of typical children.^{113, 114} Individuals with ASD are strongly influenced by the physical environment.¹¹⁵ The autistic child has difficulty in processing and managing sensory input from the environment¹¹⁴ and this often lead to unusual responses, including meltdowns and tantrums.²⁴ Lane and colleagues found a clear predictive association between sensory processing patterns, communication performance and maladaptive behaviours in children with ASD.¹¹⁴

This is also true for sensory sensitivities related to oral care.^{24, 116} The dental environment is recognized for multiple unpleasant stimuli affecting auditory, taste, tactile, olfactory and visual senses.^{10, 101, 117, 118} Stein and colleagues (2011) found that children with ASD had greater behavioural difficulties and sensory sensitivities to oral care at home and in the dental office compared to other disabilities.¹¹⁹ This is because they experience higher physiological stress during oral care in the dental surgery.¹⁰¹ Furthermore they found that children with ASD who are more physiologically stressed, exhibit greater uncooperative

distress behaviour during oral care.¹⁰¹ They concluded that sensory sensitivities were directly related to difficulty in oral care at home and in the dental office, including behavioural difficulty in the dental office.¹¹⁹ Therefore the sensory inputs from directly outside the truck combined with the sensory input from the dental environment inside the truck is likely to escalate into a sensory overload leading to increasing uncooperative behaviour which may override the effect of the social story.

In view of this evidence for the significant relationship between physiological and behavioural distress,¹⁰¹ and the fact that children with ASD have greater sensory sensitivities than children with other disabilities,¹¹⁹ it indeed then necessitates the adaptation of the dental environment to minimize arousal and so optimize the behaviour of the autistic child.¹⁰¹ This is supported by Shapiro and colleagues (2009) who found that a dental environment with adapted (decreased) sensory stimulation creates a significant calming effect in both typical children and those with developmental disabilities during a high anxiety procedure.¹¹⁷

Children attending the dental appointment were brought by class as selected. Only one child entered the truck at a time accompanied by the teacher. The rest of the children would be seated outside awaiting their turn. Simply waiting with no structured activity can also agitate the autistic child and increase their anxiety.¹²⁰ It was observed that children waiting outside would frequently become more restless waiting their turn which can account for increasing anxiety levels and disruptive behaviour once in the surgery. An alternative could be to bring the children one at a time with the teacher but this leaves the teacher's assistant who is still in training, to manage the remainder of the class.

One can also not be sure if there were events in the classroom preceding the dental visit that could have affected the mood and behaviour of the child. If this is known, one might consider postponing the dental visit to a more appropriate time. These circumstances are a further indication of the importance of appropriate and increased human resources needed in the management of children with ASD. For the average public autistic school in the province resources are scarce and the health sector needs to find ways to overcome these difficulties.

4.6 Limitations:

The findings of the study need to be interpreted in the light of the following limitations:

The sample size was limited by the number of classes in the school and the number of children in each class. While the sample size calculation suggested that there was sufficient power to detect a difference between arms if the intra-cluster correlation was less than 0.35. However, it is possible that the study was not sufficiently powered to detect small differences between study arms as indicated in the finding related to the fissure sealant placement in the group that required the least support.

Children from the JHS are classified into high, medium or low support classes by the occupational and speech therapists. According to international standards, this classification should be done by a psychiatrist, psychologist, developmental paediatrician or neurologist once a positive diagnosis of autism is made.¹⁹ There is a possibility that some children could be misclassified; however the misclassification would be systematic. The learner's classification is based on their initial screening by either a speech therapist or an occupational therapist at the school and is based on the classification on the DSM- 5 levels of support. Once a child starts in a class, he or she will be monitored for the first term and may be re-assigned to another level of support if need be.

Differences were observed for age with the intervention group on average being three years older which is also due to chance. Regarding phase, there was a significant difference most notably in phase 1, where no learners were selected into the intervention group and for phase 5, where no learners were selected to the control group. This can be explained by the random allocation of classes within the low, medium and high support strata. The aim of the study was to test the same interventions against the three levels of functioning of autistic children and therefore sampling of clusters was done within the levels of support as strata and not within phase. Phase is structured by age and the significant difference in the distribution of learners according to this variable between the control and intervention groups can further be seen in the significant difference in the mean age between the groups.

The data collector, who was also the rater of the Frankl scale, was a teacher's assistant at the JHS and not schooled in dentistry. This had two major implications for the study: firstly, it complicated the data entry, specifically the DMFT/dmft index, as communicating the information needed continuous clarification and diverted attention from the patient, causing interruptions in the procedure.

The Frankl Scale is a Likert-Scale measure with broadly defined items and as such is subject to observer bias and open to interpretation.¹⁰¹ The advantage in this study is that only one rater was used meaning if bias was introduced, it is systematic. The rater was blinded to the study arms therefore if this bias was introduced, it would most likely be toward the null hypothesis. In this study, the 'rating of 1' (Definitely negative – Refusal of treatment, fearful, or any other evidence of extreme negativism) was assigned to children who did not want to enter the dental truck or sit in the dental chair along with negative behaviour of crying/screaming etc. Rating 2 was given to children who sat in the dental chair, even if only for a short duration, and on some an oral examination was possible. Rating 3 was mostly given to children who allowed an oral examination to be done while seated in the dental chair; of these, a proportion of these refused FS placement. Rating 4 was given mostly to individuals with complete compliance and willingness, even though due to the nature of behaviour linked to autistic spectrum disorder (sudden withdrawal) a FS could not be placed. This is important because sudden withdrawal does not necessarily represent a negative attitude in an autistic child, while a very friendly disposition in an autistic child does not guarantee full cooperation again having no bearing on an 'active' deliberate attitude.

Therefore, this author feels that a qualified independent occupational- or speech therapist or clinical psychologist familiar with autism should make these judgements as to secure the most appropriate assignment of attitude to these patients in the dental setting.

The visual schedule had virtually no effect. In the class setup, they work very well at the JHS as each child has his/her own schedule on their locker inside the classroom. As an activity is completed, the child will go and personally remove the picture of the activity and 'post' it into a box (a rectangular plastic two litre container). During our study, it was difficult to manoeuvre the visual schedule in the confined space of the dental truck. The children hardly focussed on it to the point where it was set aside. A possible explanation might be the distraction of the many sensory inputs from the dental surgery as well as its physical

position next to the dental chair and therefore not in direct line of sight when the child is seated on the dental chair, especially in the supine position. A possible solution will be to fix the visual schedule to the ceiling of the mobile dental truck, but it will need to be manned by a separate individual or presenting it electronically. A pilot study using this intervention on middle and high support children would have revealed this problem.

A further limitation was possible inadequacies in implementation of the intervention (fidelity). After completion of the study it was discovered that not all teachers read the social story twice daily and one reported reading it only once in the prescribed two weeks. Due to the workload of the therapists at the school, the designated speech therapist coordinating the classes, could not check on the teachers on a daily basis. Therefore, this intervention was not consistently applied and there was no monitoring of teachers to see how the story was read. Therefore, one can surmise that the intervention was not effectively applied which could lead to a false result.

According to the review conducted by Kharkaneh and colleagues (2010) there is consensus in the literature about the social story's ability to facilitate the uptake of social skills in autistic children. Although there was not a significant result when the social story was evaluated between the study arms, the question remains about its effect on the high functioning (level 1) support group. Therefore exploratory analysis was done to ascertain the possible effect of the social story on the high functioning children, indicating that within the low support group, almost twice as many fissure sealants could be placed in the intervention arm, this result being beyond chance ($P=0.016$), thus supporting Kharkaneh's (2010) Evidence to support our result as due to the intervention and not from chance, is from Maglione and colleagues (2012) who clearly showed that greater intensity of treatment (according to amount of hours per week spent on facilitating behaviour guidance) and greater duration (in weeks or months) lead to better outcomes.⁵¹ With appropriate funding, a designated person could be appointed to supervise and manage this on a daily basis for the duration of such a study.

Another possible explanation for the non-significant result could be the fact that there were 13 different teachers who read the social story. Each class has a principle teacher supported by an assistant, who in this case could also have helped the teachers read the social story, producing possibly 26 different readers. None of these personnel were calibrated which was

an error on the researcher's side. Therefore, there was a lot of room for variability in the application of the intervention. A possible solution would be to calibrate all the teachers and assistants in the use of the social story. Most of the teachers are trained for normal children and receive training courses in autism and its management as they integrate into the school. One can then further surmise that not all the teachers will have the same exposure and have acquired the same skill in managing children with autism which will further mean that not every teacher and teacher's assistant will be able to administer the social story with the same proficiency. This may shed light on the question of whether a social story applied in a less structured environment by non-professionals could indeed be effective. A follow up study with the same methodology and strictly managed intervention will provide an answer.

Furthermore, the intervention was administered by non- professionals (public school teachers and teacher assistants for the social story; dental assistant for the VAS) which can shed light on the process of application. This paper does answer the need expressed by Karkhaneh and colleagues (2010) for research to investigate to what extent benefits can be achieved in other less structured environment and with the administration of the intervention by non- professionals.

The analysis did not account for possible correlated data due to similarities of children in a class. This could have affected the precision of the estimates presented.

Chapter 5: Conclusion and recommendations

5.1 Conclusion

The social story used in this study was not effective in modifying the behaviour of the intervention groups compared to the control clusters when evaluating the ability to sit in the dental chair, behave in a positive way and allow dental treatment in the form of fissure sealant placement. The main results suggest that the intervention groups can cooperate for longer when more fissure sealants are placed, therefore the social story seems to have an effect when longer treatments consisting of more procedures are performed.

Even though this trial could not produce significant evidence for the benefit of using a social story in a dental environment, it is imperative to ascribe scientific empirical value to behaviour guidance interventions. Important reasons to do so would be to inform not only general dental practitioners but any health care professional about the possible efficacy of behaviour guidance techniques in clinical settings therefore aiding appropriate selection. Although this trial was testing the efficacy of a behaviour guidance technique in the dental setting, these and future results could be beneficial to any clinical healthcare professional since the dental surgery is renowned for its sensory overload and anxiolytic stimuli.¹¹⁸ This could help healthcare professionals inexperienced in behaviour guidance techniques to select more appropriate techniques based on evidence until they grow in this field and have mastered or found approaches they are comfortable in administering.

Furthermore this study possibly sheds light on the question raised by Kharkaneh and colleagues (2010) to what extent the characteristics of a less- structured environment can influence behaviour guidance techniques usually applied in a structured environment and if non-professionals should really implement these without formal training.⁵³ To answer these two questions, this study will have to be repeated with the proper implementation of the social story, perhaps read by the same person to all the classes while possibly administering the Frankl scale by a professional in the field of psychology. It will further shed light on the effectiveness of a social story applied to groups of children.

The sub analysis showed that the social story is effective for improving cooperation of the high functioning children (support level 1) during dental treatment but these results need to be powered by a follow up study.

Caries experience in the secondary teeth of children with ASD, is directly proportional to the level of support needed to function. This means that the low support children are least affected by caries and the DMFT score increases as the level of support increases which highlight the importance of finding a solution that can make dental treatment of high support (low functioning) autistic children possible.

5.2 Recommendations

5.2.1 The importance of approaching behaviour guidance according to severity of diagnosis

This study showed that behaviour in the dental mobile truck, ability to sit in the dental chair and allow dental treatment is associated with the level of support of the autistic child which is determined by the severity of the autism diagnosis. It is therefore important to use the level of support as the primary filter for selection of appropriate behaviour guidance techniques in the dental environment as opposed to selecting a treatment based on what is most comfortable for the operator which is currently advocated. The fact remains that the prevalence of ASD is rising and most of these children are from middle- and low- income countries necessitating resource effective solutions to manage these children, especially in the dental environment.

5.2.2 The future of oral health for children living with ASD

The number of people with ASD and other developmental disabilities are increasing for various reasons which will cause an increase in demand for all services, including oral health care.¹²¹ Dental care is the highest unmet health care need in these individuals.^{122, 123}

Furthermore there is a higher unmet need for 'other' dental procedure like restorations, than preventative care among children with special health care needs. This has significant implications in that the 'other' dental needs, compared to preventative needs, are more

complex, require more time and are more expensive.¹²² Loo and colleagues (2009) in an analysis of autistic behaviour in response to dental procedures, found that there was an increased need for GA when treating autistic children with greater restorative need, thus further increasing cost and possible complications.⁷⁷

Treating individuals with ASD in ideal dental environments that is sensory optimized and aided by all necessary aids and personnel like, occupational and speech therapists, will become the exception, dare one say even in developing countries. Autism spectrum Disorder leads the way as developmental disabilities opens up a new frontier of demand on the medical care fraternity, where the general practitioner needs to acquire skills that science is still exploring. Be that as it may, as health care practitioners we determine to first do no harm as we try to find the best ways to improve the health of our patients.

All oral health care practitioners will need to upskill their ability to use behaviour guidance techniques and partner with the behavioural sciences to improve personal and professional abilities in order to meet this increasing demand for treating children with developmental disabilities in a primary care setting. Future research must focus on testing the true efficacy of various behaviour guidance interventions in the dental setting so that we can establish a more probable suggestion of interventions for use to oral health care professionals, thus removing 'best guess' in selecting behaviour intervention options. Future research will need to answer the question asked by this study in a proper way. A possible question for the future research would be if general anaesthesia could further impair the atypical brain maturation described in autistic children.

Since the three main outcomes are directly dependant on the level of support of the autistic child which is determined by the severity of autism at the time and the general management of children with ASD is to start any intervention and education as early as possible once diagnosis is confirmed,¹²⁰ this author believes that the dental management of autistic children should adopt the same approach when preparing for a life of good oral health. This means preparation for oral health, which includes dental visits, should start as early as possible and should include multiple interventions for example: brushing at home, brushing as part of daily activities at school, using a modified toothbrush when motor function is impaired, changing or replacing toothbrush bristles to an sensory acceptable material to use as a carrier of fluoride toothpaste because it is the presence of fluoride

toothpaste that decreases the incidence of caries,¹²⁴ sensory adaptation of the dental environment, oral health education to children with ASD through social stories, visual schedules, books and video modelling at home and at school, training (through modelling) of the autistic child for dental visits, better education in special needs children and their management for oral healthcare personnel, appropriate training of parents, caretakers and teachers in the use of social stories and other visual pedagogy.

This trial is but a small step to the goal of creating better access to healthcare for individuals living with ASD's as we strive to make health a right and resource for living to every human being.

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Appendices

Appendix A: HREC ethics clearance certificate



R14/49 Dr Stephanus Crous

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M150749

NAME: Dr Stephanus Crous
(Principal Investigator)

DEPARTMENT: Community of Dentistry
Oral Health Sciences
Johannesburg Hospital School's Autism Unit at the
Braamfontein Campus

PROJECT TITLE: Evaluating the Effectiveness of Behaviour Guidance
Intervention on Tolerance for Dental Treatment.

DATE CONSIDERED: 07/09/2015

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Prof V Yengopal

APPROVED BY: 

Professor P Cleaton-Jones, Chairperson, HREC (Medical)

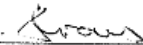
DATE OF APPROVAL: 09/09/2015

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**



Principal Investigator Signature

Date 16/09/2015

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B: Parent/Guardian information form

Dear parent/Guardian,

Good day to you,

My name is Dr Stephanus Crous; I am a dentist in the Department of Community Dentistry at the University of the Witwatersrand. We want to conduct a study at the Johannesburg Hospital School's Autism unit. We want to see if the 'social story' and 'visual schedule' techniques used by the teachers in the school of your child, can also help us do better dentistry for your child.

Study Title: Evaluating the effectiveness of a behaviour guidance intervention on tolerance for dental treatment in autistic children from a Johannesburg School.

What is involved in the study?

Participation in the study is voluntary. Your child will have an equal chance of being part of the intervention or control group. If a child is in the intervention group, he/she will receive a social story about the dentist, being read by the teacher to your child, twice a day for a week before their dental visit. They will also use the visual schedule to explain the dental visit. The control group will not receive this preparation. The dental visit for both groups will consist of an examination of the mouth as we have done before and then to place a sealant on the tooth to protect it against a cavity (hole). This only takes about 10 minutes and it does not cause pain. The assistant will manage a visual schedule for the child to help him/her understand what we do.

Risks of being involved in the study:

We do not foresee any risks. The examination is pain free and the sealant is placed without an injection and with no drilling of the tooth. The dental sealant is good for the tooth and the health of the mouth and do not cause harm to the teeth.

Benefits of participating in the study:

The learner will receive a dental examination which will be able to diagnose any dental problems which will be treated by the Community Oral Health Outreach Program's team

from the Department of Community Dentistry, regardless of which group he/she is in. The learner will be referred for treatment at the Wits Oral Health Centre when treatment cannot be provided at the outreach clinic.

Participation in the study is voluntary:

The learner may refuse to participate in the study without any penalty or loss of benefits at the school. The learner may also withdraw from the study at any time.

Study results: All results of this study will be made available to all parents and caregivers as it is for the benefit of autistic children.

Reimbursements:

There will be no compensation for participating in the study.

Confidentiality:

The information we record is kept confidential in a secure locked office and all effort is made to keep personal information personal. Absolute confidentiality cannot be guaranteed. Personal information may be disclosed if required by law.

Contact details of researcher:

If you have any queries or would like more information on the study please feel free to contact: Dr S Crous at the Department of Community Dentistry, University of the Witwatersrand, Johannesburg on 011 717 2241.

StephanusCorneliusVanAardt.Crous@Wits.ac.za

For reporting problems or complaints, you are welcome to contact the Chairperson of the Wits Human Research Ethics Committee:

Prof P. Cleaton-Jones, telephone 011 717 2301.

email: peter.cleaton-jones1@wits.ac.za

Our sincere thanks

Dr S Crous.

Appendix C: Parent/Guardian consent form



Department of Community Dentistry,
School of Oral Health Sciences,
Wits Medical School,
4th Floor, Room 4B15,
Johannesburg

✉ 7 York Road, Parktown
2193, South Africa
☎ 011 717-2593/4
Fax: 011 717-2625

Dear parent/Guardian,

Re: Participation of children in study to improve dentistry for children with autism:

My name is Dr Stephanus Crous, I am a dentist in the Department of Community Dentistry at Wits. I want to conduct a study to see if the ‘social story’ and ‘visual schedule’ techniques used by the teachers in the school for your child, can also help us do better dentistry for your child.

The study will consist of a social story about the dentist being read to your child twice a day for a week before they come for their dental visit. On the day we will examine the mouth and put a sealant on the tooth to protect it against cavity (hole) in the tooth. The assistant will manage a visual schedule for the child to help him/her understand what we do. This is a simple procedure without injection which can make the teeth stronger.

If you agree for your child to participate, you also have the right to withdraw him/her from the study at any time without consequence.

Should you have any queries about the above, you may contact Dr Crous at 011 7172241 or Prof V Yengopal at the Department of Community Dentistry, Wits on 011 – 717 2593/4

Yours sincerely
Dr S Crous
Community Oral Health Outreach Programmes.

I, (Full name and surname).....Parent/Guardian of
.....(Full name and surname of child) do
hereby give permission for my child to receive a social story about the dentist and a dental
examination and fissure sealant from staff attached to University of Witwatersrand
Community Oral Health Outreach Programmes.

Signature:_____

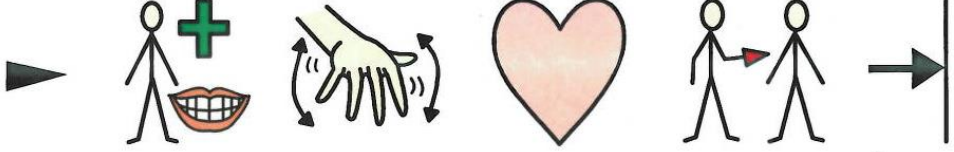
Are there any health concerns (allergies, medications, operations, health condition) that your
child may have or previously have experienced in the last 5 years?

None: Yes:.....

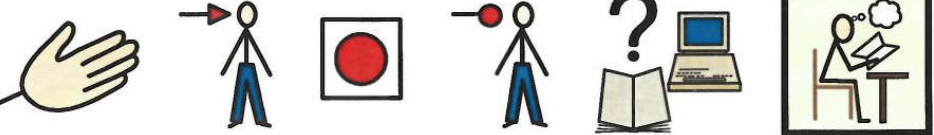
If yes, please provide details

.....
.....
.....(use the reverse side of the page if necessary).

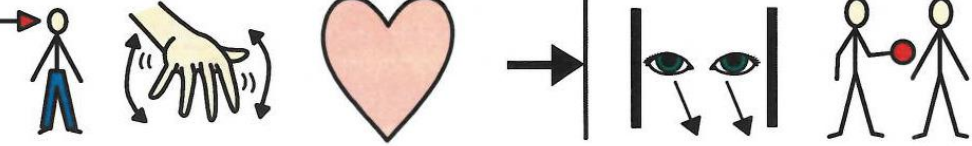
Appendix D: Child assent form




 The dentist would like you to



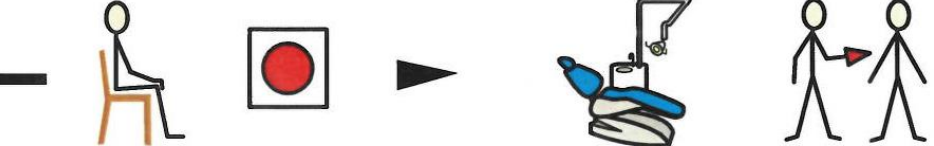
 help him in his research study.



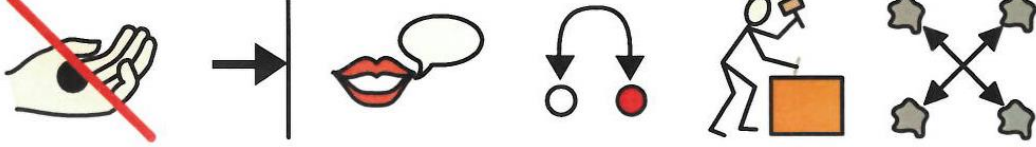
 He would like to look at your



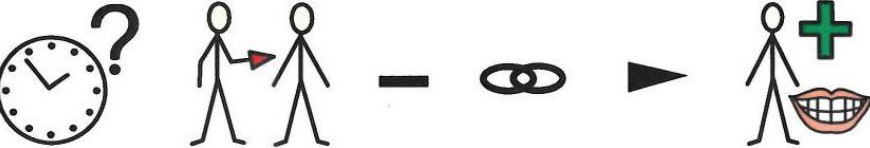
 teeth and clean your teeth too when you



 are sitting in the dentists chair. You



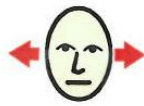
 do not have to say or do anything



 when you are with the dentist.



You can



say no



to



helping



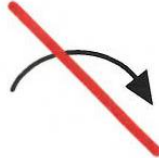
the



dentist.



You



will not



be



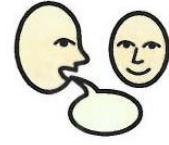
in



trouble



for



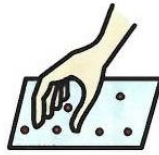
saying



no



or



choosing



to



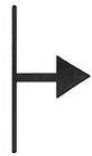
stop



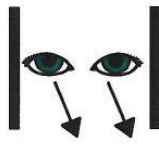
the



dentist



from



looking at



your



teeth.



Thank you



for



helping



the



dentist.



Please



tick



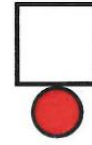
the



correct



square



below:



-



Yes,



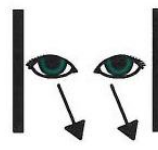
the



dentist



can



look at



my



teeth



and



clean my teeth.



-



No,



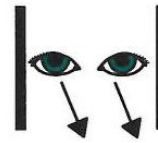
the



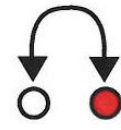
dentist



cannot



look at



or

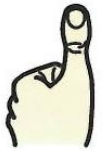


clean my teeth





Name:



Thumb

















print:























Date:















Appendix E: The Social Story













 Going to the dentist












 On  Friday  I  am going  to  the dentist.  I  am going  to  the dentist  with  my  teacher.












 I  am going  to  the dentist  to  have  my  teeth  cleaned.











 At  the dentist  I  will  sit  on  a special  chair.  The chair  will  move.














 The dentist  will  turn on  the light  and  I  will  try  to  open my  mouth  and  sit  still.

 I  will  try  to open  my  mouth  when  the dentist  asks  me  to.












 The dentist  will  count  my  teeth.  The dentist  will  use  funny  tasting  toothpaste.

 The dentist  will  use  a special  brush  that  tickles  my  mouth.  It  will












 smell  different.  it  will  taste  different.  it  will not  hurt  me.













I will try to keep my mouth open. I will try to keep still.








The dentist will dry my tooth with wind. It will feel funny.














The dentist will put cotton wool in my mouth. It will feel different.













The dentist will put some paint in my mouth. It may taste different.














The dentist will shine a light in my mouth.















The dentist will ask me to bite a piece of paper. I will try to listen.

I will try to bite the piece of paper when he tells me to.

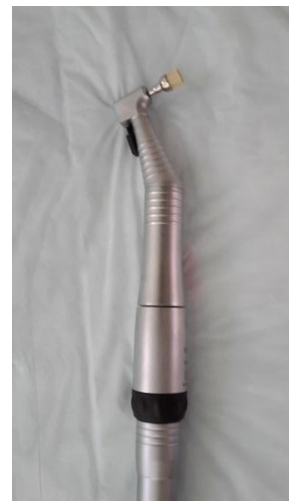














The dentist will use the funny toothpaste in my mouth again. It will taste different.

I will try to sit still. I will try to keep my mouth open.

Appendix F: The visual schedule photos



Appendix G: Data collection form

Child ID:

Age:

Class code:

Date of Treatment:DD/MM/YY)

Sex: M/F

Medications:.....

Population group:

Parental consent: YES/NO.....

Section A: CLINICAL ASSESSEMENT

Tick:

Unable to sit in the dental chair	
Sitting in chair – uncooperative (operator unable to do oral exam)	
Sitting in dental chair – cooperative (operator able to do oral exam)	
Sitting on chair + able to carry out treatment	

Extra-oral assessment	YES	NO
Normal appearance		
Ulceration, sores, erosions (head and neck)		
Cancrum oris		
Abnormalities of upper and lower lips		
Swellings of the face		
Other (specify)		

Intra-oral assessment	YES	NO
No abnormal condition		
Ulceration (Apthous, Herpetic, Traumatic)		
Candidiasis		
Abscess		
Other (specify)		
Plaque accumulation		
Bruxism		
Lip/ cheek biting		
Tongue thrusting		

Oral defensiveness		
Malocclusion; specify:		
Developmental anomalies		
Mouth breather		
Delayed eruption; which teeth?		

DENTITION STATUS AND TREATMENT NEEDED

Primary teeth

	55	54	53	52	51	61	62	63	64	65
Status										
Treatment										
	85	84	83	82	81	71	72	73	74	75
Status										
Treatment										

Permanent teeth

	18	17	16	15	14	13	12	11	21	22	23	24	25	26	27	28
Status																
Treatment																
	48	47	46	45	44	43	42	41	31	32	33	34	35	36	37	38
Status																
Treatment																

STATUS:

- 0 = Sound
- 1 = Decayed
- 2 = Filled and Decayed
- 3 = Filled, no decay
- 4 = Missing due to caries
- 5 = Missing for other reasons
- 6 = Sealant/varnish
- 7 = Bridge abutment/ special crown
- 8 = Un-erupted tooth
- 9 = Excluded tooth

TREATMENT:

- 0 = None
- 1 = Caries arresting or sealant care
- 2 = One surface filling
- 3 = Two or more surface filling
- 4 = Crown and bridge abutment
- 5 = Bridge element
- 6 = Pulp care
- 7 = Extraction
- 8 = Need for other care

Summary of dental status:

D/d	
M/m	
F/f	
DMFT/dmft	

D/d – decayed, M/m – missing, F/f - filled

Additional notes:

Section B: Placement of fissure sealant:

- 1) Was placement possible? Y/N: _____
- 2) Which Teeth: _____

Section C: Frankl Behavioral Rating Scale - pls circle relevant number:

1. “Definitely negative. Refusal of treatment; crying forcefully, fearful, or any other evidence of extreme negativism.”
2. “Negative. Reluctance to accept treatment; uncooperative; some evidence of negative attitude but not pronounced, i.e., sudden withdrawal.”
3. “Positive. Acceptance of treatment; at time of cautious; willingness to comply with the dentist, at time with reservation, but patient follows the dentist’s directions cooperatively.”
4. “Definitely positive. Good rapport with dentist; interested in the dental procedures; laughing and enjoying the situation.”



PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Dr Stephanus Crous (Student number: 625840) am a student registered for the degree of M Dent (Community Dent) in the academic year 5.

I hereby declare the following:

- ❖ I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- ❖ I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- ❖ I have followed the required conventions in referencing the thoughts and ideas of others.
- ❖ I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

Signature: S. Crous Date: 20 February 2017.